



Office of the  
Privacy Commissioner  
of Canada

# The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context

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# Table of Contents

1. Executive Summary.....	1
2. Principles of Insurance.....	2
2.1 Life and Health Insurance .....	2
2.2 Pooling of Risk.....	2
2.3 Insurance Premiums .....	3
2.4 Insurance Payment Schemes .....	5
2.5 Adverse Selection.....	6
2.6 Adverse Selection: How Likely? .....	8
2.7 Summary .....	9
3. Genetics and Insurance Markets .....	10
3.1 Genetic Risk in Insurance Contracts .....	10
3.2 Single-Gene Disorders.....	11
3.3 Complex Disorders .....	13
4. Further Reading .....	13
References .....	14

# 1. Executive Summary

Insurance is based on pooling of risks that are independent of one another. Not all risks are equal. For example, life insurance pays out on the death of the insured person. An old person is much more likely to die, during any given period, than is a young person, all else being equal. The private insurance market uses price to share the risk equitably, thus an old person will pay higher life insurance premiums than a young person. Premiums can be equalized for all individuals, for example, through the compulsory purchase of insurance, but this results in some individuals paying premiums that appear expensive relative to the risk they bring to the pool.

Underwriting is the process of assessing individual risk, based on probabilities of adverse events occurring, and thereby setting insurance premiums. It is not, as sometimes thought, an attempt to predict the future of any individual person, rather it predicts the likely outcomes given a large number of individuals. It may be possible to say, quite accurately, how many people we expect to die next year, out of a large population, but be impossible to identify exactly who will die.

Many factors that influence the risks of ill health or death may be used in underwriting, based on statistical evidence. Such risk factors may include age, sex, medical history, smoking habits, blood pressure, cholesterol levels and so on. Recently, genotype has appeared to be a candidate as a risk factor in insurance pricing.

Concerns have been expressed about genotype as a risk factor, from two directions. From the consumer's point of view, genotype appears to be so strongly predictive of future illness and mortality as to greatly dilute the randomness that currently underlies insurance underwriting. If insurers can accurately predict future health outcomes based on genotype, those with 'poor' genes will be unable to obtain insurance, except perhaps at prohibitive cost. From the insurer's point of view, if they are barred from knowing about a genetic risk factor known to the customer (for example, someone who knows they are at increased risk because they have taken a predictive genetic test) then the insurer is exposed to adverse selection; those at higher risk being more likely to choose to buy insurance, below its true cost.

This report discusses the evidence for both points of view above. There is a crucial distinction between two kinds of risk to life and health mediated by genes.

- First, a small number of mutations in single genes lead to high risks of severe disease and premature death in mature adults (old enough to have bought insurance). Examples are Huntington's disease, and certain hereditary cancers. Life and health insurance, priced according to the risks presented by the known presence of one of these mutations, or even the possible presence based on the chance of inheriting the mutation from a parent, can in many cases be prohibitively expensive. In this case there is substance to both concerns above; consumers carrying such a mutation may be substantially disadvantaged, but for the very same reasons an insurer barred from knowing about the risk may face adverse selection. However, such mutations are rare: so rare, that in reasonably large and well-established markets, the cost imposed on insurers by any likely adverse selection is very small. Insurers have, in many jurisdictions, accepted this cost.
- Second, the genetic contribution to most common, complex disorders, where research is still at a relatively early stage, is in most cases likely to involve networks of variations in multiple genes, each alone of modest effect, in combination with environment and lifestyle. It is plausible that such genetic

risks as are identified may take their place alongside commonly accepted health indicators, like blood pressure, cholesterol level and diet. As such, they will not affect the insurance market, either for individuals or insurers, any more than current clinical medicine does.

The severe single-gene disorders described above tend to provide our canonical models of how genes influence disease. Were they commonplace, life and health insurance would indeed become a minefield, for individuals and for insurers. But they are in fact rare enough that no such disruption is apparent in well-established insurance markets, whatever approach is adopted by policymakers. The vast majority of the genetic contribution to health and mortality, on the other hand, looks nothing like the canonical idea provided by the single-gene disorders, and for that reason is equally unlikely to introduce new or unmanageable disruption to well-established insurance markets.

## 2. Principles of Insurance

### 2.1 Life and Health Insurance

Our concern is with various forms of insurance depending on the contingencies of life, death, health and disability, in particular as those chances may be affected by a person's genetic endowment, or genotype. The chief examples of such insurances are the following.

- Life insurance, which pays a lump sum called the sum assured on the insured person's death. Premiums are usually paid monthly.
- An annuity or pension, which pays a regular income to the policyholder for life, most commonly during retirement.
- Critical illness or dread disease insurance, which pays a sum assured on the occurrence or diagnosis of one of a specified list of serious illnesses, such as cancer, heart attack or stroke.
- Disability insurance, which pays a proportion of income lost during periods of sickness and inability to work.

This list is not exhaustive. Collectively, we will call all such insurance contracts life and health insurance.

### 2.2 Pooling of Risk

The basic idea of insurance is simple, and well-understood by anyone who has taken out an insurance policy. Individuals, each at risk of some rare but potentially ruinous event, band together to pool their risks. Entry into the 'risk pool' is at the cost of an affordable fee, or premium, and the premiums in total constitute a collective fund. The small proportion of unlucky persons who suffer the event are compensated out of the resources of the collective fund, and so saved from ruin.<sup>1</sup>

We may say that any kind of insurance scheme is financially viable if, over the intended period of its operation, the premiums received are at least equal to the claims paid in compensation to the unlucky few. This is to

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<sup>1</sup> Under life insurance, the insured person's dependents or estate may be saved from ruin, not the insured person themselves, but the principle is the same.

ignore a long list of other considerations important in practice but that do not bear essentially on the underlying principle of risk pooling, such as:

1. the expenses of running any kind of insurance scheme;
2. the ability of an insurer to invest premiums to earn interest;
3. the need to establish sufficient reserves to be able to meet future claims with near certainty;
4. the need to raise and to deploy economic capital and to earn a reasonable return on it;
5. the need, sometimes, to compete in a commercial insurance market.

A fundamental problem for any manager of an insurance scheme is, therefore, the calculation of premiums sufficient to make the scheme viable.

## 2.3 Insurance Premiums

The calculation of the insurance premium lies at the heart of any system of insurance. Although some mathematical intricacies arise in practice, the process is entirely intuitive, as the following example shows.

A householder owns a property valued at \$500,000 and wishes to insure it against total destruction during the next year. An insurer knows, from past experience, that on average, the chance of a property being totally destroyed during a single calendar year is 1 in 1,000. Ignoring all the other factors, such as expenses and profit, mentioned in Section 2.2, the insurance premium can be calculated as:

Amount of Loss × Chance of Loss = 500,000 / 1,000 = \$500.

Were an insurer to write just one such contract, it would simply have assumed, very nearly, the ruinous hazard formerly faced by the householder. With large probability (999 in 1,000, or 99.9%) the insurer would pocket the premium, face no loss and profit by \$500, but with small probability (0.1%) the insurer would have to pay out \$500,000, offset by the premium received, a net loss of \$499,500. But by writing a very large number of such contracts, charging the same premium of \$500 under each contract, and pooling the individual risks, the laws of statistics ensure that the aggregated premiums can, with near certainty, cover the losses of the unlucky few.

This simple example ignores many practical aspects of carrying out an insurance scheme, in addition to those mentioned in Section 2.2, such as: (a) the exact amount of damages need not be fixed in advance; (b) things change, and the future may not resemble the past; and (c) past experience can be quantified only by imperfect statistical models. Nevertheless, if the average chance that a property should be totally destroyed is 1 in 1,000 then \$500 is clearly in some sense a 'fair' premium to insure a property worth \$500,000. An insurance scheme run along these lines, therefore, ought to be perfectly viable.

However, let us look more closely at the term 'average chance' used innocently above. In fact, not all properties worth \$500,000 are the same, and neither are their respective chances of total destruction all the same. In reality, these chances are affected by many factors such as construction (stone or wood?), proximity to regular violent weather events (hurricane, tornado, flooding?), the owner's qualities (careful or careless?) and many others. An insurer would call these risk factors.

To extend the example, suppose that the information available shows how the chance of total destruction is influenced by the first two of these risk factors, as follows.

Category	Construction	Exposed to Violent Weather Events?	Chance of Total Destruction	Premium
1	Stone	No	1 in 10,000	\$50
2	Wood	No	1 in 5,000	\$100
3	Stone	Yes	1 in 500	\$1,000
4	Wood	Yes	1 in 200	\$2,500

It can be seen that the average chance of total destruction quoted at the start of this section, 1 in 1,000, lies somewhere in the middle of the range, as we would expect.

The table above also shows what premiums would be calculated for each category of property, were the risk factors taken into account by the insurer. Gathering information about risk factors, and using them in the calculation of premiums, is called underwriting. The range is wide, from \$50 to \$2,500, and the premium calculated using the 'average' chance of total destruction, \$500, lies somewhere in the middle.

On the face of it, we are presented with two or more ways in which the insurer could conduct this insurance scheme.

1. They could charge everyone a premium of \$500, calculated using the overall average risk of total destruction. This has the merit of simplicity.
2. They could charge each owner a premium taking the risk factors into account. The premiums would range from \$50 to \$2,500.
3. They could choose which risk factors to take into account and which to ignore. For example, they could ignore construction but still allow for the risk of violent weather events. Then a householder whose property was so at risk would pay a premium of somewhere between \$1,000 and \$2,500, while a householder whose property was not so at risk would pay a premium of somewhere between \$50 and \$100.

In principle, any and all of these may be viable ways to arrange for premiums to be paid. This is one of the fundamental choices of setting up an insurance scheme: how fine-grained, or otherwise, should the risk assessment be in calculating premiums?

## 2.4 Insurance Payment Schemes

Motivated by the example above, we look more closely at different methods of collecting the premiums needed in aggregate. Two systems often cited, at opposite extremes, are mutuality and solidarity (for example, see Wilkie (1997)).

- Under mutuality, in its purest form, each individual admitted to the risk pool pays the premium calculated in respect of their individual risk. In the example above, calculating premiums using all available risk factors would express mutuality.
- Under solidarity, the total of premiums needed to insure everyone, or everyone in some coarse sub-grouping of individuals, is spread equally over the individuals concerned. In the example above, charging everyone \$500 based on the average chance of total destruction would express solidarity.
- Many payment schemes express a mixture of mutuality and solidarity, such as when some risk factors are used and others are ignored. In the example above, ignoring construction means that there is solidarity between the owners of stone-built and wood-built houses, but mutuality in respect of violent weather risks.

Perhaps the most familiar example of solidarity is the provision of universal health care, whether paid for through taxation (as in the United Kingdom) or through some compulsory (and regulated) insurance scheme (as in several other European countries).

Solidarity tends to be associated with compulsory insurance, from which there is no opt-out for those who will be forced to pay most, for example wealthy individuals paying high taxes who could easily purchase their own personal cover at lower cost. Mutuality tends to be associated with insurance that is largely or wholly voluntary, so that individuals at greatest risk can only join the risk pool at a cost that reflects the risk of loss that they, personally, contribute to the collective.

If insurance is compulsory then, clearly, no question of access to insurance arises, similarly there is no question about access to services provided *via* compulsory insurance schemes. Such questions do arise if insurance may be purchased voluntarily, because price is then a factor — one of many — that may be expected to influence the decision to purchase insurance. Voluntary insurance purchase and mutuality immediately raises questions about an individual's decision to purchase insurance or not, faced with the trade-off between price and their desire for insurance cover. This is the province of microeconomics.

In the remainder of this report, we mainly focus on mutuality, as this is where the relevant questions arise, but we note that pure mutuality is an abstraction that is not attained in reality. For practical reasons, any 'mutual' insurance scheme is really a patchwork of micro-solidarity schemes, because the subdivision of risk can be taken only so far. The possibility of choosing to ignore construction as a risk factor in the example in Section 2.3 is a case in point, and an insurer might quite often choose to ignore a risk factor if the cost of collecting and using the information appears to outweigh the benefits.

So, the association of solidarity with compulsory insurance, and of mutuality with voluntary insurance, is simple and intuitive. What may happen, however, if we disrupt this 'natural' state of affairs, and insist that solidarity be associated with voluntary insurance? For example, what if the use of a particular risk factor was denied to insurers in a voluntary insurance market?



## 2.5 Adverse Selection

Suppose life insurers were barred from asking anything at all about an applicant's state of health. For all kinds of reasons, people might have an incentive to buy life insurance at any stage of their lives (for example, to protect dependents when raising a family). But a person whose death is imminent, say in the terminal stages of a disease, might have an overpowering incentive to buy life insurance. If such a person could secure life cover of \$100,000, pay the first monthly premium of \$20 (quite reasonable at some ages) and should then die during the next month, on immediate receipt of the sum assured their estate would have secured an annual rate of return of about 2,440,000,000,000,000,000,000,000,000,000,000,000,000,000,000,000,000,000,000% on the transaction (Macdonald, 2004). Even if the estate had to wait until the end of the year to receive the sum assured, the annual rate of return would be about 500,000%. The example is extreme<sup>2</sup> but it makes the point that an insurer who insures an event believed to be rare, and hence charges a modest premium, when in fact the event is rather likely, could make large losses.

The first salient feature of this example is that the insured person knew about the imminent risk while the insurer did not. Economists call this asymmetric information: two parties enter into a transaction with unequal knowledge about the risks. The second salient feature is that it could only arise under a mutual system of insurance. If everyone had to have \$100,000 of life insurance in force, the insurer could calculate the premiums needed in aggregate based on reasonable information about the health of the whole population.

Our earlier example about insuring properties can also be used to illustrate the point. We may suppose that all householders know the risk factors relevant to their properties. The question is, what may happen if the insurer does not?

1. To begin with, a mutual insurance system is in place, and each householder is charged the appropriate premium based on the risk factors (as in the table in Section 2.3). Presented with these premiums, some householders will choose to buy insurance, and others will choose not to.
2. Then, the mutual life insurance system is ended and replaced by a solidarity system, under which all householders must be charged the same premium. This might arise, for example, because the government comes to view residence in areas at risk of violent weather events as being a misfortune that ought not to be made the basis for 'unfair' discrimination. If all remained as it had been, everyone would pay a premium of \$500, based on the average chance of total destruction.
3. However, one might expect incentives to change under the new system. Persons who had previously paid \$50 or \$100 might balk at paying \$500, and cease to buy insurance. Persons who had previously refused (or were unable) to pay premiums of \$1,000 or \$2,500 might be quite happy to pay \$500, and would start to buy insurance.
4. But this changes the composition of the population who actually buy insurance. Instead of the average chance of total destruction *in the insured population* being 1 in 1,000, it must have increased, because some low-risk householders have stopped buying insurance, and some high-risk householders have started to buy insurance. Suppose that this shift has changed the average chance of total

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<sup>2</sup> Although it is not wholly far-fetched. In the UK in the 1980s, life insurance policies were popular as savings vehicles in connection with house purchase. Some insurers began to sell such policies with no medical underwriting at all. It became known that some insurance agents were arranging house purchases by terminally ill people in order to obtain the life insurance, and the practice ceased.

destruction, *of houses actually insured*, from 1 in 1,000 to 1 in 500. Then the level premium that everyone should pay, in solidarity, is no longer \$500 but is \$1,000. The insurer has to raise the premium to this level, or make a large loss and face insolvency.

5. However, at a premium of \$1,000, perhaps even more low-risk householders would decide not to buy insurance, so the mix of the insured population shifts even further towards higher risks. Then the premium of \$1,000 would no longer be sufficient, the premium would have to be increased again, and so on.

The phenomenon outlined in points 4 and 5 above is the appearance of adverse selection and an adverse selection spiral. Adverse selection arises when the applicant has information relevant to the risk that is not or need not be disclosed to the insurer; in other words, asymmetric information to the benefit of the applicant. As a result, the insurer is pricing under solidarity in respect of that item of information. If the insurer misjudges the characteristics of those who purchase insurance, the calculation of the premium will be wrong. If, as above, the circumstances are such that persons at higher risk are offered insurance priced below its true cost, the insurer's error will be on the loss-making side. The insurer will discover this position in due course, when the loss is realized, and can respond by increasing the premium to compensate, but if that deters even more individuals at lower risk from buying insurance, the process can repeat with no guarantee of reaching a stable position: an adverse selection spiral. In the extreme case, everyone at lower risk may be deterred by higher premiums and only those at higher risk buy insurance at all.

As with the mathematical premium and the pure mutual insurance system, the description of adverse selection given above is idealised. In particular, the imagined behaviour of individuals faced with different premiums for insurance is strongly influenced by basic ideas of supply, demand, utility and equilibrium taken from microeconomics. That does not make the concept empty or mean that real insurance companies need not worry about adverse selection.

A further consequence of the sequence of events described above is that it can be difficult for any insurer not to use a risk factor in underwriting, if just one other insurer is using it. An example arose in the UK in the early 1980s. Until then, no major insurer used smoking habits as a risk factor, except for underwriting persons in ill health possibly caused by smoking. The premium rates charged by each life insurer were (it was presumed) somewhere in between those appropriate for non-smokers and those appropriate for smokers. Then one company began to charge lower premiums for non-smokers of cigarettes, and commensurately higher premiums for smokers of cigarettes. The immediate effect ought to have been that every non-smoker seeking life cover should have been directed to the innovative company, while every cigarette smoker seeking life cover should have contracted with a competitor still charging the 'averaged' premiums. The latter companies, no longer getting the mix of smokers and non-smokers they were expecting (even if just implicitly) would now be charging inadequate premiums in aggregate and would make losses. In practice, during the next few years, almost all UK life insurers switched to offering separate rates to smokers and non-smokers.<sup>3</sup> An analogous shift seems now to be taking place in the annuity market, with one company having introduced postcode as a risk factor, and others following suit.

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<sup>3</sup> The author at the time worked for a life insurer that had not yet switched to offering smoker and non-smoker premium rates, and was charged with surveying applications for term assurances to see if the proportion of smokers was excessive. If the market had been efficient, the proportion should have been close to 100%. Instead, it was practically indistinguishable from the proportion of smokers in the population. This particular market, it seems, was almost completely inefficient.

In general, any risk factor that separates the population into those at greater risk and those at less risk of the event insured against, leads to different premiums being calculated. If the insurer is free to use a mutuality principle and can actually charge different premiums, the correct premiums will be collected regardless of who does or does not buy insurance. If, however, the risk factor is ignored, and different premiums are not charged, the cost of insurance depends on the mix of risks admitted to the risk pool. Being ignorant of that mix, the insurer is in peril of charging inadequate premiums.

## 2.6 Adverse Selection: How Likely?

Adverse selection is a consequence of human behavior — the decision to buy or not to buy insurance, influenced by price among other things. A purely economic model based on rational actors in a market will always suggest some change in behavior in response to any change in circumstances, however small. Reality might be different, and we ought to consider whether adverse selection is likely to be material, or not.

One of the oldest risk factors in use in life insurance — with overwhelming statistical evidence of its validity — is gender. In the European Union, a recent court judgement has upheld an interpretation of a directive banning sex discrimination, that denies insurance companies any exemption. As a result, from late 2012, insurers in the E.U. may not charge different premiums to males and females for any kind of insurance.

It is not yet known how insurers will adjust their premiums in this new unisex market. Take term assurance as an example,<sup>4</sup> generally the cheapest form of life cover. Females pay lower premiums than males just now, as males have markedly worse mortality. In the unisex environment, insurers might just charge everyone the higher premiums appropriate for males, although over time one might expect competition to bring premiums down to a level corresponding to some representative mix of males and females.

On the face of it, this is a classic adverse selection opportunity. If males are offered term assurance below its true cost, they ought to buy more of it. And, if females are offered term assurance above its true cost, they ought to buy less of it. If economic models are correct, some of this may happen at the margin. However, no-one, not even the insurance industry, has presented a serious case that this move will lead to adverse selection that will disrupt the market. So many other factors affect the decision to buy term assurance, that the opportunity for males to buy it slightly too cheaply, and the necessity for females to pay slightly too much, is likely to have a minor impact, if any. The connection between opportunity and incentive appears to be too slight.

Similarly, if the current practice of charging smokers higher life insurance premiums than non-smokers were to be banned<sup>5</sup> (however unlikely), it is hard to imagine adverse selection becoming a problem, even though the possibility exists in economic models. The market functioned without trouble before this distinction was introduced to insurance pricing, and there is no reason to suppose it would not do so again.

We can, however, imagine other circumstances in which the connection between opportunity and incentive may be strong, and adverse selection may pose a real threat. We take an example from the E.U. again, where similar anti-discrimination directives cover gender, age, disability and other characteristics. If the European Court of Justice were to affirm the same interpretation of age discrimination law, as it did of sex discrimination

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<sup>4</sup> Term assurance pays a sum assured on death within a specified limited term, often up to age 60 or 65.

<sup>5</sup> The difference in mortality between smokers and non-smokers is of a similar magnitude to the difference in mortality between males and females.

law, European insurers would be unable to use age as a risk factor. Rates of mortality and of disease onset (the latter relevant for critical illness insurance) typically rise steeply with age, and most insurers decline to issue new life or critical illness insurance policies to the very old. Growing old brings with it intimations of mortality, even among those who keep in good health, hence incentive is added to opportunity. The prospect of having to offer the same terms to a healthy 80-year old as to a healthy 20-year old might present a combination of opportunity and incentive that the insurance industry really could not handle.

## 2.7 Summary

We have deliberately introduced the background to insurance and premium calculations in this section without mentioning genetics, to emphasise that these issues affect all kinds of insurance, life and non-life. Genetics may present special difficulties from a legal or ethical point of view, but as far as the mechanics of insurance is concerned, genetic information is a potentially quantifiable risk factor just like any other.

We summarise the points emerging from the above discussion, and the implications for any purported *need* for an insurance company to charge individuals different premiums.

1. The basis of insurance is the pooling of a large number of individual risks. It rests on statistical laws in which the mathematical chance of loss plays a key role, determining the correct premium as follows:  $\text{Mathematical Premium} = \text{Amount of Loss} \times \text{Chance of Loss}$ . It follows that the financial management of an insurance scheme, in which the setting of adequate premiums is fundamental, is not arbitrary.
2. The chance of loss may be influenced by many risk factors, some more significant than others, and may vary from individual to individual.
3. Under mutuality, the insurer charges each insured individual according to their individual risk. Under this payment scheme, the insurer need have no regard to the mix of greater or lesser risks admitted into the risk pool.
4. Under solidarity, the insurer charges premiums not related to the individual risks. Payment of the same premium irrespective of the value of a relevant risk factor is an example, which may exist within a system that is, in principle, mutual. Cross subsidy from lower risks to higher risks is inherent in a solidarity system.
5. Under solidarity, the insurer charges premiums not related to the individual risks. Payment of the same premium irrespective of the value of a relevant risk factor is an example, which may exist within a system that is, in principle, mutual. Cross subsidy from lower risks to higher risks is inherent in a solidarity system.
6. The extent to which adverse selection introduced by limiting the use of a risk factor may cause serious disruption is unclear. We can cite realistic examples in which serious disruption seems unlikely (risk factors: sex and smoking status) and others in which it seems highly likely (risk factor: age). A relevant factor may be the extent to which risks of grossly different magnitudes are forced together by the removal of a risk factor.

We may draw from the above certain conclusions about an insurer's *need* to charge different premiums for different levels of risk. These conclusions depend on how essential or desirable we believe a private insurance market to be, in the absence of compulsory insurance cover. If we strongly wish a private insurance market to

be viable, we should protect it from adverse selection so extreme as to threaten its existence. Then age, for example, should be a permitted risk factor even if age discrimination is deprecated; it is arguable that insurers really *needed* to charge different premiums depending on age. Below that level of existential threat, it is harder to argue that insurers *need* to charge different premiums; it is rather a question of what ends we wish to achieve. If we strongly believe that each individual should be able to buy insurance at the best price for their circumstances then we should allow insurers to use any risk factors they wish. We may argue that insurers *need* to charge different premiums if this aim is to be achieved. If we have aims (for example, concerning discrimination) that stand above the maximisation of economic efficiency at the level of the individual, then the insurer's *need* to charge different premiums is surely disputable.

The next step, therefore, is to examine these general considerations in the specific cases of risk factors relating to genetic information.<sup>6</sup>

### 3. Genetics and Insurance Markets

#### 3.1 Genetic Risk in Insurance Contracts

The common perception of a genetic disorder is that a person has a faulty gene, and therefore inevitably will suffer the associated disease. Some such disorders actually do exist, for example a person with a deleterious mutation in the Huntingtin gene will contract Huntington's disease with virtually 100% certainty. However, the vast majority of the genetic contribution to disease is nothing like as extreme or as clear-cut as this.

If the risk of a genetic disorder is to affect life and related insurances, some quite restrictive conditions have to be met.

1. The person must be free of the disease when they apply for insurance, otherwise it would simply be a pre-existing medical condition. People tend to buy life and related insurances at ages when they are economically active, so onset must be delayed until after these ages.
2. The disease must appear, or have a significant risk of appearing, while the insurance contract is in force, which again most often means at an age when the insured person is economically active.

Disorders meeting these conditions fall, more or less, into two groups.

First, there are some disorders caused by a fault in a single gene, where onset is delayed until middle age or later. These are called late-onset disorders. They tend to be dominantly inherited. Disorders that are recessively inherited tend to display their symptoms from birth or quite early in life, so are rarely relevant for insurance.<sup>7</sup> Late-onset single-gene disorders often present an exceptionally high risk of premature disease or death, but they are comparatively rare.

Second, there are common disorders such as heart attack, stroke, cancer and so on, which begin to take their toll from middle age onwards. All are likely to be influenced by genetic factors, though in complicated ways rather than *via* the canonical gene-to-disease link seen in the single-gene disorders.

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<sup>6</sup> Note that we have already dealt with one such risk factor, namely gender.

<sup>7</sup> An unusual exception exists in Sweden, where there is a market for private health insurance for children, to supplement the state's provision.

Broadly speaking, quite a lot is known about the single-gene disorders, because their presence was revealed by their striking pattern of inheritance in large families long before DNA-based genetic testing became available in the 1990s. The epidemiology of these diseases (which is what matters for insurance risk) is fairly mature. In contrast, the study of the genetic contribution to common, complex diseases is only beginning. We consider in turn the likely consequences for insurance, of each type of disorder.

### 3.2 Single-Gene Disorders

This section is based on Macdonald & Yu (2011).

There are about two hundred dominantly inherited single-gene disorders (Pasternak, 2000), but most are extremely rare and not all have late onset. In 1996, the genetics advisor of the Association of British Insurers (ABI), Professor A J Raeburn, drew up a list of eight disorders that, at the time, seemed to cover those most relevant to insurance. They were:

1. two untreatable brain disorders, Huntington's disease (HD) and early-onset Alzheimer's disease (EOAD);
2. a degenerative disorder of the motor system, hereditary motor and sensory neuropathy (HMSN);
3. three rare inherited variants of cancers; breast/ovarian cancer (BC/OC), a colonic cancer, familial adenomatous polyposis (FAP), and a cancer of the endocrine system, multiple endocrine neoplasia type 2 (MEN2);
4. a degenerative muscular disorder, myotonic dystrophy (MD); and
5. a degenerative kidney disorder, adult polycystic kidney disease (APKD).

Subsequently APKD was dropped from the list, because of its method of diagnosis, and hereditary non-polyposis colorectal cancer (HNPCC) was, by implication, added (see Professor Raeburn's evidence in response to a discussion paper from the Human Genetics Commission (HGC, 2000; Raeburn, 2000).

Several of the disorders listed above had, by 2000 or soon afterwards, good enough epidemiology to allow actuarial models to be developed, in order to address two questions. First, if insurers could use presymptomatic genetic tests for these disorders, what would be the cost to applicants in terms of increased premiums? Second, if insurers could not use presymptomatic genetic tests for these disorders, what possible costs might arise from adverse selection? Table 1 (below) summarises the extent of this modelling, as it was described in Macdonald & Yu (2011). These authors concluded that the models between them captured enough of the variety and extent of late-onset single gene disorders that robust conclusions could be drawn about the implications for life and critical illness insurance. Those conclusions are summarised below.

**Table 1: Actuarial models of six major single-gene late-onset genetic disorders, the genes implicated and references (source: Macdonald & Yu (2011)).**

Genetic Disorders	Mutations	Reference
APKD	APKD1 and APKD2	Gutiérrez & Macdonald (2003, 2007)
EOAD	PSEN-1	Gui & Macdonald (2002) Espinosa & Macdonald (2007) Gui (2003)
HD	Huntingtin gene (HTT)	Gutiérrez & Macdonald (2004)
MD	DMPK gene	Macdonald & Yu (2011)
HNPCC	MLH1 & MSH2	Lu <i>et al.</i> (2007)
BC & OC	BRCA1 & BRCA2	Macdonald, Waters & Wekwete (2003), Gui <i>et al.</i> (2006)

1. If insurers could use genetic test results to set premium rates, then some individual carriers of known deleterious mutations would be charged extremely high, possibly unaffordable, premiums. Insurers are accustomed to quoting increased premiums as a percentage of the premium charged to a healthy applicant subject to no known exceptional risks (known as the 'Ordinary premium rate'). In many cases the increased premium would be many hundred percent of the Ordinary premium rate, in some cases well over one thousand percent. Such high increases are greater than many insurers would be willing to quote in practice, so in many countries the mutation-carrying applicant would simply be refused cover at any price. Limiting the insurer to using the family history of one of these disorders, disallowing genetic test results, would reduce the level of premium increases, but often the disease risk is so severe that there would be no difference in outcome. It most certainly is the case, therefore, that persons who carry or are at risk of carrying deleterious mutations have their access to life and critical illness insurance severely curtailed.
2. If insurers could not use genetic test results, and were possibly barred from using a family history of a genetic disorder too (as is the case in Sweden, for example) then adverse selection becomes a possibility. However, the disorders in question are sufficiently rare, that in an insurance market of reasonable size, even if the adverse selection was as bad as it might possibly be, the cost would be extremely limited. The authors tested several scenarios and in the worst of these, when many factors conspired against the insurer, the cost of adverse selection amounted to about 3% of total premiums. This may be taken as an extreme upper limit, with the realistic costs being very much less. If the scope for adverse selection of this kind were more widespread, it would probably threaten the viability of insurance (just as being unable to allow for age in the E.U. might do). However, purely because of the rarity of these disorders, the adverse selection has quite small costs. This is the reason why insurers in various countries have been able to accept limitations being placed on their use of genetic information, without necessarily conceding that arbitrary limits on what risk factors may be used do no harm.

### 3.3 Complex Disorders

The effect of genetic information relating to more complex and common disorders, such as heart disease, is harder to assess. Epidemiology is rarely as clear-cut as in the case of single-gene disorders. However, it is possible to draw some plausible conclusions, based on general considerations rather than hard empirical evidence.

1. The genetic contribution to common disorders is likely, in many cases, to involve variations in multiple genes, interacting in biological pathways with many other relevant factors such as diet, environment and lifestyle. It is possible that some combinations of variants in genes will turn out to be relatively more common than others, but the randomness inherent in parents passing their genes on to children means that the numbers of possible combinations may be vast, and each individual combination relatively rare.
2. Single-gene disorders tend to have a straightforwardly adverse effect. Mutations lead to some critical process failing and disease results; the benefit of carrying 'normal' genes is simply absence of disease. Networks of genes contributing to complex disorders may not be unambiguously adverse; some combinations of gene variants may confer relative benefits (indeed, this is the engine that powers evolution). So the effects on health may tend to lie somewhere in a range from 'good' to 'bad', perhaps with rather few individuals at either extreme.
3. Many complex diseases are themselves the outcome of processes. For example, many forms of heart disease arise through cumulative changes such as raised blood pressure, raised cholesterol or onset of diabetes, as well as environmental factors such as smoking. Genes that affect the underlying processes may have an effect much less dramatic than if they affected the disease end-point directly (there is evidence for this in at least one modelling study, see Macdonald *et al.* (2005a, 2005b)).

For these reasons, the likelihood of genes related to common disorders causing major changes to underwriting practices, or major problems for insurers or for individuals, seems to be quite small. As epidemiology advances, no doubt genetic variation will begin to improve clinical medicine, in the sense that a physician's advice can be better tailored to the individual patient. But it seems plausible that this will not be very different from, for example, advising someone about their diet on the basis of a cholesterol measurement. No doubt also some individual exceptions will arise, just in the process of acquiring new knowledge, but more than that would probably be a surprise.

## 4. Further Reading

Apart from the small number of technical papers cited in the examples above, the reader may find further information in many sources. For a wide-ranging discussion of social and ethical issues raised by genetics, the various reports of the Australian Law Reform Commission are useful (ALRC, 2001; 2002; 2003). For different viewpoints on genetics and insurance specifically, see Daykin *et al.* (2003), Doble (2001), Moultrie & Thomas (1997) which have an actuarial flavour, or Radetzki *et al.* (2003), Rothstein (2004) or Sorell (1998) which consider more the legal and ethical background. Wilkie (1997) gave one of the first accounts of mutuality and solidarity in this context. Adverse selection, an important part of the discussion on genetics and insurance, is rather hard to study empirically; Pauly *et al.* (2003) and Viswanathan *et al.* (2007) are rare exceptions. More theoretical approaches from an economic perspective are available; see Doherty & Thistle (1996), Hoy & Polborn (2000) or Hoy & Witt (2007) for examples.



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