



Office of the
Privacy Commissioner
of Canada

The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance

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March 2012

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Summary

Perspectives on whether insurers should have access to individuals' genetic information (i.e., genetic test results) vary greatly. Life insurers, for example, wish to treat such information as any other medical information in order to more accurately assign individuals into risk classes. Citing concerns over privacy and unfair discrimination, many individuals and interest groups think this is one type of information to which insurers should not have access.

Conflicts over the appropriateness of a regulation that would ban insurers from having access to the genetic test results of individuals who apply for insurance are the result of differences in values and beliefs about the practical implications of such a ban. Members of the general public and related interest groups often support such a regulation in order to protect against invasion of privacy and unfair discrimination. Insurers, on the other hand, feel such information should be treated no differently than other medical information that helps them to assess health and mortality risk. They believe that if consumers can hide actuarially relevant information then insurers will be placed at a disadvantage, and be at risk of unexpected losses. They also express concern that such a regulation will lead to higher overall prices for insurance and a restriction in the amount of insurance purchased in the market. This phenomenon is referred to by economists and actuaries as adverse selection.

From the insurers' perspective, the use of actuarial principles to estimate the loss distribution of insureds, and hence the firms' portfolio of risks, is viewed as critical to ensure prices are set at a level to provide an adequate solvency position for the firms and hence protection for clients who file claims. Insurance companies also need to provide a reasonable financial return to stockholders.

It seems clear, however, that insurers needn't use all known (or potentially known) characteristics of individuals in order to establish the most finely grained (detailed) risk classification scheme possible. In many cases perfect classification of individuals is not possible as it is too complicated, too costly, or simply impossible to know everything about each individual's risk characteristics known to the individual. That is, many pricing or classification schemes used by insurers are not based on exact risk-type specific actuarially fair prices but rather on pooled actuarially fair prices. In some markets, insurers use more of such information than in others while all markets appear to be viable. For example, UK annuity providers use more personal information to classify risks than do North American firms. Also, life insurers in many European countries are not allowed access to privately held genetic test results of their clients and no apparent negative results of any consequence appear to have arisen.

The key features required for a risk classification system to work for individual firms as well as for at least a reasonably strong performance of the market as a whole is that (a) firms within a specific market use similar classification schemes (categories) and (b) applicants of insurance do not hold substantial amounts of private information that is actuarially relevant to the insurance contract. For example, when private health insurers in Australia could not assign higher prices to older clients, those who found the terms of the insurance attractive were disproportionately older, higher risk individuals. The result was that younger and healthier individuals opted for public insurance and the private plan was no longer viable. This occurred due to the substantial difference in risk levels (frequency of claims) of older people. In other words, the adverse selection effect was strong. In the context of genetic test results, it currently appears that the number of individuals holding information of sufficient actuarial relevance in terms of health or mortality risk is not so great that prohibiting firms from using such information in their pricing decisions would lead to serious or even perceptible market consequences. Of course, one must be cautious and not discount the possibility that significant adverse selection effects may arise over time as more genetic information becomes available.

Even if one accepts the prediction that a regulatory ban on the use of genetic test results by insurers will not create significant difficulties for the operation of the market in terms of industry profitability and price levels for consumers, it does not necessarily answer the broader question of whether or not such a ban is economically or socially desirable. In this report we consider the likely economic consequences of such a ban and assess the implications of such a ban from a number of alternative values and pragmatic perspectives. In so doing, we adopt a welfare economics approach, which incorporates broader social considerations into the economic analysis.

We conclude that for the present and near-term future, a ban on such information would likely have no significant negative implications for insurers or for the efficient operation of markets such as life insurance. Although we do not consider it our purview to make a recommendation one way or the other on such a regulation, a ban would provide comfort to individuals regarding protection of privacy and reduce concern about potential future problems with buying life insurance should a genetic test reveal "bad news". The institution of such a ban would seem not only unproblematic for the insurance market but even economically and socially desirable. Over time, however, new scientific developments in the predictive value of genetic information and reliability of genetic testing; increased access to the so-called \$1000 genome and the expanding market in direct-to-consumer genetic testing services and potential market responses to a regulatory ban by insurance providers, consumers and/or financial intermediaries (e.g. evolution of viatical and life settlement markets) may suggest the need to review such a conclusion in the future.

1. Introduction

In this report, we consider the possible economic and social welfare implications of prohibiting health and life insurers from using any genetic information that clients may hold in setting prices for new insurance contracts. We look carefully into many of the various perspectives on the thorny question of whether insurers should be allowed to set prices (or any other contract terms) based on results of individuals' genetic test results. The report by Macdonald (2012) demonstrates convincingly that there is currently not a sufficient amount of information derived from genetic tests that, if held privately by individuals, would *at this time* be cause for concern for the financial viability of insurance companies. Nor would one expect that allowing individuals to keep such information private would cause a significant impact on the average price of insurance or the effectiveness of insurance markets to perform their role of protecting individuals and families from financial risk due to illness or death.

However, such an actuarial assessment based on the current state of availability of genetic information within the population and the financial viability of the insurance market to make do without it at this time, does not by itself allow us to conclude whether a regulatory ban on the use of genetic test results by insurers is economically and socially desirable. In this report, we consider the likely economic and social implications of such a ban from a number of alternative values and pragmatic perspectives. For example: the economic outcomes both in terms of the prices that people pay for insurance as well as the amount of coverage that individuals and families will want to purchase; potential exposure to unfair discrimination or loss of privacy should insurers have access to such information; the potential effect on people's willingness to obtain genetic tests which may prove helpful in healthcare decisions, etc. Ultimately, having considered these and other broader social and economic considerations, we ultimately conclude that a regulatory ban on the use of genetic information for health and life insurance purposes is not only financially viable (confirming Macdonald's position), but also economically and socially desirable in the short to mid-term future for a number of reasons.

This being said, we go on to consider potential changes that may require revisiting these conclusions in the longer term. Individual access to genetic information is increasing over time. The cost of many genetic tests is

falling rapidly. Many “inside observers” believe that it will soon be possible to map an individual’s entire genome for \$1000 or less. The direct-to-consumer market for genetic testing services is growing rapidly with claims to being able to provide clients with important information about their genetic background and its possible implications on the relationship between lifestyle and health outcomes. This increased access to genetic information about oneself may, over time, significantly tip the informational asymmetry between buyers and sellers leading to a higher potential for adverse selection.

Moreover, it is difficult to assess the future significance of information from genetic testing and its predictive value. No doubt there will be more links made between so-called disease genes and the likelihood of various health and mortality risks that individuals with these genes will face. Such links could prove increasingly important as the medical community develops a better understanding of the relationship between genetic predispositions toward various diseases and possible preventive measures such as lifestyle choices and health monitoring decisions (e.g., frequency of colonoscopies or mammograms). Once a better understanding between genes and disease is developed and the predictive value of genetic information is enhanced, the current assessment of the effects of a regulatory ban on insurers’ access and use of genetic test results may have to be revisited.

Finally, the insurance industry itself may alter the types of contracts it offers (e.g., the balance between short-term and long-term life insurance contracts) and third-party financial intermediaries, such as viatical companies, may develop to offer those who find themselves to be “bad risks” an option to cash-in life insurance policies for an immediate financial return. These future developments may exacerbate some of the negative economic implications of such a ban.

In the following section we describe the basic positions that consumers and insurers have taken regarding the merits of a regulatory ban. In section 3 we outline the basic reactions that one can expect insurers to take if a ban were placed on their ability to access genetic test results of applicants for insurance. This is followed in section 4 by a short discussion about the current state of genetic information and its relevance in terms of the types of economic implications that would arise from a ban. The assessment of the market implications of a ban are then discussed in section 5 in terms of various values and pragmatic considerations, including concerns about privacy and discrimination, economic efficiency, and notions of overall societal welfare. Potential future developments in the state of genetic information, the cost of genetic tests, and the manner in which insurance markets may respond to such changes are discussed in section 6. Conclusions are provided in the final section.

2. Staking out Positions

From the Consumers’ Side:

In order to anticipate the various concerns about use of genetic information, it is helpful to start with the arguments outlined by the umbrella organization representing those groups which directly oppose the use of genetic testing by insurers. The Canadian Coalition for Genetic Fairness/Coalition Canadienne pour L’Equité Génétique, <http://www.ccgf-cccg.ca/en/about-ccgf>, presents a united stance on behalf of many Canadian associations such as:

- ALS Society of Canada
- Alzheimer Society of Canada
- Cystic Fibrosis Canada

- Centre for Molecular Medicine, UBC
- CORD (Canadian Organization for Rare Disorders)
- Foundation Fighting Blindness
- Huntington Society of Canada
- Kidney Foundation
- Muscular Dystrophy Canada
- NF Canada
- Ovarian Cancer Canada
- Osteoporosis Canada
- Parkinson Society of Canada
- Spina Bifida and Hydrocephalus Association of Canada
- Tourette Syndrome Foundation of Canada

The coalition argues that genetic testing leads to unjust genetic discrimination. Citing UNESCO proclamations on human rights, they maintain that genetic information is “unique, personal and private” and should not be used for purposes that “discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity...” (UNESCO Int. Declaration on Human Genetic Data 2003) While they affirm that Canada’s Personal Information Protection and Electronic Documents Act (PIPEDA) protects the personal information of individuals, they go on to assert that Canada still needs to “create a level playing field, within which all insurance companies can continue to operate and serve Canadians in a fair and equitable way”, concluding that “For the foreseeable future, preventing genetic discrimination would not hurt the insurance companies or penalize individual policy holders.”

In fact, most European countries have already declared moratoria on genetic testing for life and health insurance purposes. (The European Union will ban the use of sex as a risk classification for insurance in 2012 and may soon include age to the banned considerations for risk evaluation.) These legislative bodies are reacting to their assessment of public opinion. The perception is that the general public is strongly against any requirement of genetic testing by insurance companies. Philosophers describe this reticence on the part of individuals to have their DNA “discovered” as a wish to protect the privacy of one most basic self. Paul Root Wolpe (1997, p.218) declares, “Genes are, in a sense, more truly us than we ourselves are: they are us condensed, boiled down, reduced to essence.” He quotes Dorothy Nelkin in *The DNA Mystique*, “We have biologized the idea of the soul, the essence of each person, that which can recreate us and which encapsulates all that we are.” (1997 p. 216) The popular press has joined the discussion of these ideas, frequently publishing articles that claim to alert the public to possible negative outcomes from the use of genetic testing. A lead article from The Globe and Mail of January 1, 2012 is titled: Health insurance and ‘genetic’ testing: Are rules needed? Carly Weeks writes:

“Advances in medical science are bringing us closer toward understanding the genetic underpinnings of disease, which could pave the way for new treatments or therapies. But a growing number of experts fear this

progress could have serious unintended consequences for the public, allowing insurers and employers to use that information to deny coverage and benefits.”

In fact, a study by Hall and Rich (2007) conducted with genetic counselling professionals finds that 84% of counsellors bring up and discuss the potential for insurance discrimination as a risk of genetic testing.

Although the Privacy Rights Clearing House, <https://www.privacyrights.org/why-privacy>, is an American based non-profit organization, its mission, simply stated, is to help consumers protect and control their personal information which is frequently in electronic form. One of their tasks is to post lists of significant breaches in data confidentiality including that from health care organizations. They also operate a hotline to field consumer questions and complaints. According to a speech given by the Director of PRC, Beth Givens, at a conference on keeping electronic patient records,

“Many of the worst cases of privacy abuse we have heard on the hotline are the result of errors, carelessness and poor judgement by those who handle personal information. And some are the result of inadequate security in the handling of personal information.”¹

The PRC considers the medical coding done by the Medical Information Bureau (MIB), an organization which keeps coded medical information for insurance purposes on 15 million Americans and Canadians, to be a significant potential offender in the misuse of medical information. Given all this input on the possible concerns about use and misuse of genetic testing, it is not surprising that “reasonable” consumers are expressing reticence to accept genetic testing. Future concerns may also include the increase in direct-to-consumer genetic tests the results of which will not be contained in medical record files but in the companies’ own data bases, another potential risk for breach of confidentiality.

From the Insurers’ Side:

Some of the opposing arguments are presented by the Canadian Life and Health Insurance Association Inc. and the Canadian Institute of Actuaries (CIA). Insurers do not currently require genetic testing to assess risk. They do, however, request access to any genetic information already in existence as well as family medical history information which can arguably be considered genetic information. According to CLHIA, it is “extremely important that life and health insurers have access to and be able to utilize all relevant health information in order for the risk classification and underwriting process to function correctly.” They refer to insurance contracts as “good faith” agreements which by their very nature require transparency in any area which may be relevant to the contract so that both parties enter into the agreement on an “equal information” footing. The association quotes the Industry’s Code of Ethics which promises to “respect the privacy of individuals by using personal information only for the purposes authorized and not revealing it to any unauthorized person.”

The association goes on to say that PIPEDA enforces this ethical stance. In their 2010 review of their position on the use of genetic testing, (CLHIA Reference Doc. April 2010) the CLHIA remarks on the association’s thoughts on the future of genetic testing in insurance markets as follows: “The industry believes that continuing attention to the need for confidentiality is very important with respect to genetic information. The industry also will continue to assess emerging information from genetic research (and other research) on an

¹ From a speech given by Beth Givens, PRC Director, at the Toward Electronic Patient Records copyright 1996-2012. <http://www.privacyrights.org/ar/speech2.htm>

ongoing basis to ensure that its knowledge base is complete and current, including the potential benefits of genetic information on the effectiveness of health care and on longevity. Such emerging information must be assessed carefully to ensure that any information used by the industry is sound and relevant to the purposes for which it may be used. Close attention is essential to ensure that industry practices remain sound and acceptable, and that any proposals for change (especially for any limitations) are based on realities, not on assumptions.”

The Canadian Institute of Actuaries (CIA), the group which advises insurance companies on risk and uncertainty, asserts that one of their roles is to inform public debate on the relationship between genetics and insurance. Using their skills in financial analysis based on reliable and sufficient data and following strict professional standards of practice, they profess to assess risk classification and determine premiums “on a well-reasoned basis”. (Statement on genetic testing and insurance CIA November 2000, www.actuaries.ca) They reiterate that privacy issues are paramount and that any information obtained by insurers would only be used for the stated purpose and only be disclosed with the applicant’s written permission. They continue by saying, “applicants should also have the ability to choose to participate in genetic testing if they desire and not be forced.” The Institute insists that genetic testing must be rigorously proven to be reliable and relevant. Although in their discussion on privacy they predict that the industry’s future use of genetic data will need to carefully balance “societal equity needs” with “risk classification needs”, they conclude by taking a position identical to that of the CLHIA; that is,

The CIA does not support mandatory genetic testing for insurance, nor the disclosure of test results without an individual’s authorization. However, the CIA believes that should genetic test results be available, the results should be shared between both parties of an insurance contract (policyholder and insurer)... (CIA, Statement on Genetic Testing and Insurance, Nov. 13, 2000, www.actuaries.ca)

An interesting development in genetic testing reported in The Wall Street Journal of January 10, 2012 is the Life Technologies Corp. claim that within the year they will introduce a machine that will completely map an individual’s genome. The results will be available in a day for a cost of \$1000.00. Previously the cost has been about \$3000.00 and taken about a week to complete. This is being touted as a great boon to medical research and progress but as the cost to the individual of having a complete genetic map produced is reduced to where it is very accessible, insurance companies’ concerns about asymmetric information may become much more founded.

3. Potential Market Implications of a Regulatory Ban: The Basics

It is important to understand more generally how insurers might react to a regulatory ban on using relevant information for the purpose of assessing risk. Given that insurers compete with each other for clients, it is in each of their interests to attract the best composition of risks that they can. If they are not allowed to use actuarially relevant information to set different prices for different classes of risks (as reflected by different genetic risks), then they may resort to more indirect and subtle means to obtain the best group of consumers possible (i.e., from the perspective of the expected claims cost faced by the insurer). Those who do a better job will earn higher profits. Those who do a bad job will end up with so many costly “bad risks” that they could incur financial losses and even insolvency. This would not be good for any of the insurance company workforce, the investors (stock owners), or the consumers. In this section, we describe how such a ban may play out in the market place.

A ban on insurers using actuarially relevant information for pricing insurance contracts creates a situation of asymmetric information that economists and actuaries predict may in some cases lead to adverse selection.² Asymmetric information means simply that one party to a contract (the insurance buyer) has information relevant to the outcomes of the contract (expected claims) that the other party (the insurer) either can't access or isn't allowed to use. Adverse selection arises because, if insurance is offered at the same price to all, higher risk types are more likely to purchase a particular insurance contract or product than are low risk individuals and/or are more likely to purchase a higher level of coverage. This is expected to occur if all clients are charged the same price when some insurance buyers know they are of higher risk than the average. Higher risk clients find the product more valuable or desirable than lower risk clients since they are more likely to benefit from the contract (i.e., make a financial claim). This scenario has been referred to as regulatory adverse selection when insurance buyers have actuarially relevant information that insurers are, by law, not allowed to access. In this section, we consider two potential strategies that insurance providers might adopt to compensate for this inability to use this information.

a. Simple Pooling

One strategy that may be adopted by insurers in such a scenario we will call simple pooling. An insurer that cannot identify who are the good (low) risks and who are the bad (high) risks may simply pool the consumers together and charge a price high enough to cover the expected costs. Consider the following example that illustrates the implications of adverse selection when insurers put individuals who know they are of different risk levels into the same risk pool and charge everyone the same per unit price for insurance coverage:

Suppose the potential market for life insurance is made up of high-risk types and low-risk types in equal proportion. For simplicity, suppose we are considering 10-year term life insurance for individuals who at the time of making decisions to buy insurance are 40 years of age. Suppose high-risk types have a probability of dying over this ten year period equal to 0.05 (a five percent chance) while for low-risk types the risk is 0.03 (a three percent chance).³ If equal numbers of high and low-risk types purchase the same level of coverage, say \$200,000, then the expected cost of claims overall will be the average probability of loss 0.04 (i.e., $(0.05+0.03) / 2$) times the level of coverage, which equals \$8,000 (i.e., $0.04 \times \$200,000$). This calculation gives the actuarially fair price of insurance based on the population weighted average of the two risk types' probabilities of making a claim.

If insurers were allowed to charge high and low-risk types differential prices, they would presumably charge high-risk types an amount based on their higher loss probability and vice versa for low-risk types. This would imply that the cost of \$200,000 coverage would be \$10,000 (i.e., $0.05 \times \$200,000$) for high-risk types and \$6,000 (i.e., $0.03 \times \$200,000$) for low-risk types. This approach is referred to as risk-type specific actuarially fair pricing. Note that if there were no restrictions on charging different prices to high-risk and low-risk types, then one would expect such differential pricing to occur. In fact, if a firm did not do so and assessed both high and low-risk types the same cost of \$8,000, then any other firm could offer low-risk types the same coverage at a lower price, say \$7,000, and still earn a nice profit. Such a strategy would attract all the good risks. The firm charging a single price would end up losing money since it would be left with only high-risk clients and having an expected cost of \$10,000 for every contract sold for a price of only \$8,000.

² For details of how economic models predict how such a ban can affect the markets for health, life and other forms of insurance, see Hoy and Ruse (2005).

³ Please note that this example is entirely hypothetical and the numbers chosen are to make calculations simple.

Now suppose a law were put in place forbidding all insurers from charging different prices to high and low-risk types. This might be expected to lead to all insurers charging the same price of \$8,000 for \$200,000 coverage to all clients (i.e., the population weighted actuarially fair price) and that this price would cover the expected claims costs. However, given that high-risk types have a higher probability of death, the contract is in fact more valuable to them. Thus, one would expect more high-risk types to purchase such a contract and even to purchase a higher level of coverage. Suppose it turns out that high-risk types purchase a level of coverage of \$300,000 while low-risk types purchase only \$100,000 when the price is the same to both at \$4,000 per \$100,000 coverage (i.e., \$8,000 for \$200,000 coverage). In this circumstance the total amount of insurance is weighted more to the higher-risk clients. The appropriate single price that will cover expected costs should have a weight of $\frac{3}{4}$ for high-risk types and $\frac{1}{4}$ for low-risk types since that represents the relative weights of the amounts of insurance purchased. This means the pooled actuarially fair price should not be the population weighted expected cost ratio of 50:50 for high-risk: low-risk but rather a ratio of 75:25 (more heavily weighted to high-risk types). Hence, the per dollar price of insurance required to meet the expected claims cost is $(0.75 \times 0.05) + (0.25 \times 0.03) = 0.045$ or \$4,500 per \$100,000 coverage, as opposed to \$4,000 per \$100,000 coverage. The price of insurance has to be higher than the population weighted actuarially fair price of insurance because the higher-risk types buy more insurance than the lower-risk types.

The above example illustrates two outcomes related to the adverse selection phenomena that concern actuaries, insurers, and economists. Firstly, the fact that higher risk types buy more insurance than lower risk types when they face the same price leads to an increase in the average price of insurance. In this example, when the two risk types are charged different prices reflecting their different risk levels, the average price of insurance is \$4,000 per \$100,000 of coverage, while under a regulation requiring uniform pricing, the average price of insurance may rise to say \$4,500 per \$100,000 of coverage. The second concern is that the lower-risk types purchase less insurance when there is a uniform (higher) price, than they otherwise would in a scenario of risk-type specific pricing where the costs of coverage would be lower reflecting their lower likelihood of making a claim. As a result, lower-risk types may be less inclined to obtain adequate coverage for themselves and their dependants in a scenario of uniform pricing. This is the sense in which adverse selection compromises the effectiveness of the insurance market as a means for individuals to manage their risks.

If, however, insurers all follow the same strategy of simple pooling and “get the price right”, then they will not be faced with financial ruin. In fact, they could end up doing more or less just as well when forced to charge the same price to all consumers as they would if they were allowed to charge different prices that reflect different risk levels. They do, however, face the challenge of determining just what single price is required to cover the expected cost of claims when people with different risk levels are likely to purchase different amounts of insurance coverage. Moreover, there is a possibility that the overall size of the market may contract if enough low risk types exit the market or significantly reduce the amount of coverage they purchase. In the context of our hypothetical example, this would be a realistic concern if the pooling price is substantially higher than the price that would be actuarially fair for these lower-risk individuals. In the hypothetical example, the price difference was indeed substantial (\$4500, as opposed to \$4000, or 12.5% higher). The important characteristic of genetic information – at least at the present time – is that only a small fraction of the population has knowledge from genetic testing that implies that they are a “bad” or “high” risk. Therefore, the relative weights to apply to the pricing formula to compute the pooled price will be heavily skewed towards the low or “typical” risk type in the population. This is made clear in the contribution of Macdonald (2012). Nonetheless, one can expect at least a small effect on price from adverse selection caused by a ban on insurers having access to any individual’s genetic test results as well as some very modest reduction in insurance purchases by low risk types.

b. Separating Contracts

There is a second type of strategy that firms may take if their potential clients have information about their risk levels that insurers are not allowed to access. Given that high risk types value insurance coverage more than low risk types, the insurer could develop a menu of contracts that vary according to both the level of coverage and the price. In the case of just two risk types, such a menu need only involve two contracts. One contract, designed for high risk types, would offer a large amount of coverage and be priced at the actuarially fair price for high risks. The other contract, designed with low risk types in mind, would have a lower level of coverage and be priced at the actuarially fair price for low risks. It is possible to entice each risk type to purchase the “appropriate” policy. The higher risks have a stronger preference for a high level of coverage and so are willing to “pay to get it”.

Using the assumptions made in our hypothetical example above, suppose an insurer could offer two contracts. The first, designed with the high risk consumer in mind having a high level of coverage, such as the \$200,000 policy that was presumed above, at their risk-type specific actuarially fair cost of \$10,000 and the second with the low risk in mind having a low level of coverage, say \$100,000 which is priced at the low risk type specific cost of \$4,000. It is quite reasonable to expect the high risk type will prefer the first policy while the low risk type will prefer the second policy. This means that each type pays the actuarial cost based on his/her type even though the insurer can't access their hidden knowledge (genetic test result).⁴ Since both policies are available to all consumers, it seems that discrimination is not being practised. However, in the end, the high risk type ends up paying a higher price and so it may be argued is “effectively” discriminated against in the price aspect of the contract while the low risk type ends up paying a lower price but receiving a lower quantity of insurance and so is “effectively” discriminated against in terms of the quantity of coverage.

For the separating contracts strategy above to be successful, the insurer must be able to enforce exclusivity; that is, the insured individuals can purchase only a single contract from a single insurer. This is a common practice in many areas of insurance, including auto and most types of health and disability insurance. It is not, however, typically practised in life insurance. Moreover, the low risk type receives a rather limited amount of insurance in the separating contracts case compared to the pooling scenario and so the former is preferred only if the price reduction that is associated with the contract designed for the low risk consumer is sufficiently lower so as to compensate for the restricted level of coverage received. Again, in the current state of genetic information, the price in the pooling contract would not be significantly higher than the low risk types' actuarially fair price and so the sort of competition associated with firms developing a menu of contracts that leads to separating or self-selection of risk types is not at this time a likely phenomenon.

As for coverage, even though low risk individuals might end up with less insurance coverage than they would if insurers were charging risk-type specific prices (i.e., based on genetic test results), the extent of the reduced coverage is likely to be very modest and not a significant concern.

4. Current State of Genetic Information and its Relevance to Insurance Market Outcomes

Currently only a small fraction of individuals have precise information from genetic tests and this only provides information about part of their genomes and usually a small subset of health and mortality risks. For example, a person who has had a genetic test for one of the BRCA genes (breast cancer genes) will not know about

⁴ Just such a strategy was initially shown to be a possible economic equilibrium in Rothschild and Stiglitz (1976) and Wilson (1977).

other genetic risks (e.g., predisposition to colon cancer, etc.). As explained in Macdonald (2012, section 3.1), genetic disorders that are relevant for insurance fall into two basic groups – single-gene disorders (sometimes referred to monogenic diseases) and multifactorial (complex) genetic diseases which involve possibly more than one gene and/or environmental factors. An example of monogenic disorders would be Huntington disease (HD). Such disorders typically affect very few people in the population, although obviously in total this number may not be entirely unimportant in an insurance context. The multifactorial disease genes typically imply an increased risk – but not to such a significant degree – as the monogenic disease genes. There is a large number of such multi-factorial disease genes and current knowledge and understanding of these is still in its infancy (see Antonarakis and Bechmann, 2006). Knowing about having a multifactorial disease gene is often thought to be useful from a medical perspective since the onset of disease can often be affected by changing one’s lifestyle or through medical treatments (e.g., if one has a gene implying a predisposition to type-2 diabetes, one can forestall or even avoid onset of diabetes through dietary and lifestyle choices).

So, how do these different classes of disease genes relate to the economic analysis described in this report? If one has the HD gene then one is very likely not to survive past 60 years of age. Thus, a person who is in good health at age 50 but possesses this gene will have a much higher probability of dying during the span of a ten year term life insurance contract bought at age 50. One may think, then, that restricting insurers’ access to such information would cause serious problems for the effectiveness of the insurance market. Those with the HD gene could buy large amounts of insurance and this would drive up the price to everyone. However, such genes are rare. Macdonald (2012, section 3.2) refers to simulation results suggesting an increase in about 3% as a likely upper bound on the price of insurance resulting from a ban due to people being able to hide their genetic type from all those with monogenic disorders – not just the HD gene. This sort of price increase would not lead to substantial changes in the amount of insurance the “low risk types” (i.e., those without such genes) would purchase.

In the context of multifactorial or complex disorders, high risk types are composed of all those persons who have so-called predisposition genes to common diseases such as heart disease, diabetes, etc. Any one of these high risk genes may imply a modest increase in mortality risk and over time such genetic information may accumulate in the population. However, as noted by Macdonald, in the current state of knowledge and the likely short to medium term future, the extent of available genetic information for these types of genes is unlikely to create serious adverse selection problems for the insurance industry. Although many people may hold one or two such genes while others will hold several, each such gene has a much more modest impact on mortality risk than would a gene like that for Huntington’s Chorea. Therefore, even if individuals are allowed to hold such information privately, it would not lead them to purchase huge amounts of insurance relative to those who do not possess such genes. It would seem then that banning insurers from using individuals’ genetic test results to assess risk would not adversely affect the financial viability of insurance markets at this time. The remainder of this paper will go on to examine the broader economic and social implications of a ban from a number of different perspectives and then explore how these may evolve over time.

5. Economic Evaluation of a Regulatory Ban

5.1 Privacy Perspectives

There are many benefits from privacy protection – both intrinsic and instrumental – that would be enhanced by prohibiting insurers from accessing individuals’ genetic test results. One’s genome or set of genes represents, in an important way, one’s very identity. The possibility of others gaining access to this information is to many deeply worrying and the more places such information is stored the greater is one’s intrinsic sense of privacy vulnerability. A ban on insurers collecting and using genetic information would

certainly help to allay such concerns and restore an individual's state of wellbeing associated with the direct or intrinsic value of privacy (i.e., privacy being valued for its own sake – see Rosenberg, 2000).

In addition, there are important instrumental benefits from privacy that would be enhanced by such a ban. Individuals often express concern that genetic tests obtained for the purpose of improving healthcare decisions could, if available to insurers, lead to future problems when applying for insurance either through higher prices or outright denial of coverage. With no ban in place, people may decide not to obtain an otherwise useful genetic test due to fears of being assessed a higher price for insurance, or being denied insurance altogether. A ban on insurers using such information could help alleviate these concerns and thereby reduce disincentives for individuals to obtain such information when it would be valuable to them for important healthcare decisions (e.g., such as increased frequency of mammograms should someone possess one of the BRCA1/2 genes). These sorts of benefits are typical for many multifactorial disease genes. Not only does such information have the potential to improve an individual's wellbeing, it is also possible that the overall health care system could be made more efficient and less costly (see Filipova and Hoy, 2009).

On the other hand there is also the case where, for emotional reasons, an individual has no desire to learn of possible negative outcomes of a genetic test. Such a reaction is more common for monogenic disease genes (i.e., diseases for which genes are essentially the only determinant of disease and no effective prevention is available to the individual). Studies demonstrate that the individual's right *not to know* the results of genetic tests is important to many. As noted in Lemmens et al. (2008):

There is substantial evidence that troubling psychological effects can result from obtaining such information. For example, in various clinical testing environments, when anonymous genetic tests were offered at zero cost, Meiser and Dunn (2000) found that the percentage at risk who requested testing varied from 9% to 20% in various centers in UK cities and Vancouver. ... Obtaining information about a serious future illness that cannot be avoided has been compared to learning about a death sentence. People may also often simply prefer not to know information which may negatively impact on their life choices. Although it may seem rational to want to have information about how an important life activity will be affected in the future, people may prefer to leave their future more open-ended.

Outside the need to qualify for insurance, many people don't want to be tested in this manner. Not having a regulation banning insurers from insisting on genetic testing means another right will be placed at risk; namely, the right not to know about one's genetic status.

5.2 Discrimination Concerns

There are two predominant and opposing ways to view genetic discrimination in the context of pricing insurance contracts: a moral or ethical view and an economic or cost-based perspective. What we will call a moral concern with unfair discrimination is well described by the following statement:

It is morally wrong to discriminate against a moral being (or class of moral beings) unless that being (or class of moral beings) possesses a morally relevant differentiating property. ... (Pargetter and Prior, 1987, p. 129)

If the focus of potential discrimination is the price of insurance, then restricting the use of genetic test results to set differential prices based on risk type will be an effective means of avoiding price discrimination. Indeed, if insurers who are restricted from using genetic test results to set differential prices simply pool different risk types, then all insurance buyers would be charged the same uniform population weighted or demand weighted actuarially fair pooled price. However, one could argue that, in this scenario, low-risk types are unfairly treated since they must pay more per unit price of coverage than they would otherwise have to in the

absence of a ban. Or, because they experience less incentive to obtain adequate coverage for themselves and their dependants, they face unfair “quantity discrimination”. However, given the insignificant price differential that can be expected based on known genetic information at this time, this is not likely to be a concern.

There is a diametrically opposed view of discrimination often expressed (at least implicitly) by spokespersons within the insurance industry, actuaries, and economists. This is typified by the following statement:

An insurance rate structure will be considered to be unfairly discriminatory... if, allowing for practical limitations, there are premium differences that do not correspond to expected losses and average expenses ***or if there are expected average cost differences that are not reflected in premium differences.*** (Williams 1969, 211-212, bold/italics our own)

If one accepts this view of what is discriminatory, then one will believe that a ban leads to price discrimination while allowing insurers access to genetic test results will help to avoid price discrimination; that is, the price to cost ratio under a ban will differ between the two risk types. This view may seem harsh to some but is really quite understandable. For example, suppose two people hire a cleaning service for their respective houses. One person has a house that is easy to clean but the other has a number of cats and dogs and so this second house requires twice as much time to clean. Presumably it would not appear unfair to most people that the person cleaning the two houses would charge the second person more since the cost of cleaning would be higher. However, one need not accept this same stance across all suppliers, products or services. One could still take the reasonable position that insurers should nonetheless be restricted from charging different prices to individuals of different risk types if that were viewed as socially desirable in the specific context of life and health insurance.⁵ Also, the nature of insurance means that prices may in fact not always reflect expected costs in a precise manner and so the *appropriate* degree of differentiation that prices *should* embody is not so straightforward as in other markets. This is especially the case given that information that insurers often use to assign individuals to risk classes is imperfect – especially when one considers multifactorial genetic diseases where unobserved lifestyle choices also affect risk.

5.3 The Business/Actuarial and Economic Efficiency Perspectives

The insurance industry argues that insurance companies should be allowed to use actuarially relevant genetic test results held by insureds. Contracts in private sector relations typically are expected to be entered into in good faith; that is, any relevant information that either party holds should not be kept hidden. On the face of it at least, this is a reasonable position. As noted earlier, if sufficient numbers of individuals who are high risk can hide this information from insureds, then market outcomes may jeopardize the efficiency of the insurance market as a means to protect people from financial risk. Thus, efficiency concerns also tend to favour that insurers have access to such information. The reasoning is that if individuals can hide their risk type, then those who know themselves to be of higher risk will wish to purchase greater amounts of insurance and the resulting price increase will lead to lower amounts of insurance being purchased by low-risk types. So, in the context of life insurance this means that some families will have an incentive to hold inefficiently low levels of

⁵ A Canadian poll by Pollara-Earnscliffe (2003) found 91 percent of respondents believe insurance companies should not be allowed to use genetic test results in pricing contracts. Of this group, 86 percent continued to hold this view when asked if they would object to insurers’ use of genetic test results even if it meant the price of insurance would rise as a result. This may reflect both an altruistic concern for others (i.e., those unlucky in the “gene pool”) but may also reflect self-interest (i.e., concern about one’s own future premium).

coverage and place potential dependents in greater financial risk. However, this does not appear to be a serious concern at the present time.

Moreover, private sector interactions are often subject to regulations that are deemed to be in the public interest. What is more, it is generally the case that insurers do not have perfect information about each individual and so all individuals are placed into groups across which some differences in risk levels are present. Introducing additional information such as the result of a genetic test is also likely to be merely an imperfect indication of an individual's overall *true* risk type and so use of genetic tests enhances information but does not lead to perfect risk-type specific categorization. As long as all insurance companies are "playing under the same rules", not being allowed access to genetic tests, at least in the current state of information, will not lead to serious financial concerns for the industry.

Insurance companies typically compete not just over price but also over quality of their product, types of restrictions on claims, and on what variables or characteristics of individuals to use in forming their risk classes. These can change quickly over time. As an example, in the case of automobile insurance, credit scores were recently determined to have significant predictive power for placing drivers into different risk classes. Shaver (2011) points out (using US data) that, although credit scores have been shown to be a powerful rating variable, it had been adopted by only 31% of automobile insurers by 1999 and 63% by 2006. Thus, many insurers did not categorize risks to the full extent possible yet survived in the marketplace. But once enough firms use a new rating variable, others are pressured to follow suit or else face attracting a disproportionate share of the higher risks. This example suggests that if all firms are restricted in using a rating variable – genetic tests being the example of interest in our case – they can all survive quite well financially.

5.4 Social Welfare Perspective

Besides addressing efficiency considerations of market performance, economic analysis can also offer an assessment based on the perspective of the interpersonal distribution of economic well-being. This involves making trade-offs between those persons whose incomes are enhanced and those whose incomes are restricted by a given regulation and how different people perceive such implications. In the context of the phenomena we are addressing – the use or (not) of genetic information in the context of insurance markets – this is a rather complicated exercise. We need to compare the situation of individuals at the point in time when insurance contracts are purchased as well as after time has passed and some insurance buyers (or the surviving family members in the case of life insurance) have made claims while others have not.

Before such information becomes available, individuals don't know what genetic test results they may receive in the future. They recognize that there are risks associated with the premium they will face should they wish to buy insurance in the future, a phenomenon often referred to as premium risk. This is naturally undesirable and so, from this perspective, a regulation banning insurers from using such information accords with individuals' private interests as well as concerns about fairness. From the point in time when individuals purchase insurance contracts, the implication of a ban that leads to a single price being charged to all is that the "few unlucky" (high risk types) are implicitly subsidized by the "many lucky" (low risk types) and so the ban improves the overall distribution of well-being from an equity perspective. Some would even say it would be cruel to charge high-risk types, who are unlucky in the context of their health and mortality prospects, a higher price for insurance than low-risk types.

Once time has passed and claims have been submitted for those who die, the survivor families of low-risk types who purchased less insurance than they might otherwise have in the absence of a ban end up worse off due to lower levels of insurance coverage. However, based on what is known to date, the reduction in coverage by low-risk types induced by the higher uniform price per unit of insurance coverage is not

significant. From a social welfare perspective, it seems convincing that, in the context of the current state of genetic information, a ban would be justified, and even desirable.

6. How Conditions/Working Assumptions Might Evolve Over Time

Based on currently available evidence, we have concluded that the use of genetic information will have only very modest quantitative significance for actuarial purposes. Moreover, for all the pragmatic reasons canvassed above, our view is that a ban on the use of genetic information for insurance purposes may in fact be economically and socially desirable at this time. However, these conclusions will have to be revisited in the longer term in light of future developments.

Key factors in determining the potential social value of a regulatory ban on insurers having access to individuals' genetic test results is the fraction of the population that has such information and the magnitude of the enhanced mortality or health risk that is implied by positive genetic test results. Future scientific developments influencing the practice of genetic testing and the predictive value of genetic information will have to be continually monitored. Also, as the state of genetic information at the population level evolves, markets may respond in ways that imply the need for reassessment vis-à-vis how genetic information should be regulated.

6.1 Increased Availability and Decreased Cost of Genetic Testing

Only a small fraction of individuals currently hold actuarially relevant genetic test results. As noted earlier in this paper, however, it may well happen in the not too distant future that an individual's complete genome will be determined (sequenced) at a cost of no more than \$1000. Direct-to-consumer genetic testing services are also growing at a rapid rate. As more information becomes available to consumers, the information asymmetry between buyers and sellers of insurance may begin to tip more significantly, influencing purchasers' behavior (high-risk types buying more insurance coverage; low-risk types buying less), and leading towards greater potential for adverse selection.

Moreover, with greater accessibility to affordable genetic testing and the added protection of a ban in place, more purchasers may be incentivized to undergo genetic testing than may have otherwise been the case. Some individuals may be more willing to undergo genetic testing in order to make strategic decisions about how much insurance to buy given that, in the presence of a ban, they cannot be penalized if they turn out to be of a high risk type. If sufficient numbers do this, then with high risk types buying more coverage and low risk types buying less coverage the price of insurance will rise in a manner described in the hypothetical example presented in section 3. This creates a feedback effect since in order to know whether insurance is worthwhile to some people, they will want to find out whether they are of a high risk type. Again, the more people who do so, the more others will have an incentive to obtain genetic information even if they would rather not know about their genetic type except for making a better informed decision about purchasing insurance. Therefore, in terms of the effect of either instituting a ban or not having a ban, it is not clear what sort of implications will follow regarding the evolution of genetic information and whether the effects are on balance good or bad for individuals. Thus, it is important that the industry and policy makers remain vigilant and reassess the implications of any ban in the future.

6.2 Improved Understanding of the Relationship Between Genes and Disease and Potential Treatments

Apart from the identification of more disease genes and associated inferences about risk, there will be increased understanding about the relationship between genes and disease and how specific variants of genes (alleles) interact with medications and environmental influences, including lifestyle choices that individuals make. It is quite possible that initially we will see greater predictability of health and mortality risks based on the growing number of genetic tests and the understanding of what specific genes mean in terms of health risks. The scientific community's understanding of the relationships between genes and health will undoubtedly continue to develop. Gene therapy may even improve to the extent that for many genetic diseases, treatment will be "complete" and those with so-called bad genes will not face greater health risks. These sorts of developments should mitigate the effects of increasing genetic information discussed in the previous section (6.1) and so lend support to continuance of a regulatory ban.

6.3 Potential Future Market Responses to a Regulatory Ban

With a continuing ban on the use of genetic test results, insurers may find other ways to try to avoid "high risk clients". Insurance companies restricted from using genetic test results to price their product may, if adverse selection becomes sufficiently strong, include restrictions such as to exclude those who get Huntington's disease from making claims on a long-term care policy. This observation suggests that, in addition to a ban, one may have to enforce a form of comprehensive coverage for insurance contracts. These are referred to as mandates in the case of private health insurance contracts. Firms tend to innovate in uneven ways and the implications of one firm or a few firms introducing a new characteristic of individuals upon which to base the price of insurance may spread slowly or quickly across the industry. This means it is not easy to predict what the future holds in terms of how insurance firms will develop the way they price their products or other characteristics of their policies.

It is also possible that increasing amounts of genetic information could lead to changes in the ways consumers make strategic use of such information. People with extremely high mortality risk may purchase very large quantities of insurance especially if they can leverage large amounts of money immediately through viatical transactions. A viatical or life settlement refers to a transaction in which a life insurance policy holder who is at substantially higher than average mortality risk sells his policy at a percentage of its face value to a company or any third party who then becomes the beneficiary of the policy.⁶ Suppose, for example, that a person with a disease gene has an 80% chance of dying during the period of the policy. If he decides his current financial needs are more important than those of beneficiaries, then he can sell the policy to a viatical company for say 50 to 80 percent of the face value. This may be an attractive proposition for both parties. Moreover, if this person can purchase any number of life insurance policies at the same price as everyone else (i.e., if insurers are banned from using genetic information), then he can leverage his position almost without limit. Although a single insurer would likely be suspicious of selling huge quantities of insurance to a single individual knowing this circumstance could be the reason for such a high demand for insurance, a person can purchase many insurance contracts from many different providers. If several people do this then insurers will see their losses

⁶ Viatical settlements refer to transactions for people with less than two years expected lifetime while life settlements refer to transactions involving people with more than two years expected lifetime. They have operated in Ontario, for example, only for about 10 years. As of 2006, viaticals have been deemed securities and, therefore, companies trading in them must comply with the registration and prospectus requirements of the Ontario Securities Act.

climb higher since more policies in aggregate will be sold to high risk types who are then selling them off (immediately) at a profit to viatical companies.

This type of behaviour was a concern in the early period of the HIV/AIDS experience as some individuals who discovered adverse news about their life expectancy through an anonymous AIDS test would then purchase several insurance policies at less than their true actuarially fair rate. Such individuals would then immediately engage in a profitable arbitrage opportunity by selling the policy on the secondary market (e.g., to a company specializing in viatical or life settlements). If the insurer simply asked the individual if he/she had any knowledge of HIV status and the person hid such information, the contract would be null and void. However, proof was not generally easy to obtain given the anonymous nature of the tests. In the context of a regulation banning insurers from using such information, hiding the information would clearly not be illegal and so this issue may become a concern.

7. Conclusions

There is a growing debate in Canada about whether there should be a regulation banning insurers from using information resulting from genetic tests of applicants in order to assign different prices for insurance. The views of the merits of such a regulation depend both on what values are important to individuals and what outcomes are likely to result from a ban.

Throughout this paper, the quantity of relevant genetic information that is held by the insurance buying public is the most crucial feature of the contracting environment and it can tip the balance on just how adverse selection will be realized in the market place. This in turn affects, in a fundamental way, how any of the criteria considered in this paper performs as a useful framework for deciding on the merits of a regulatory ban. In a review of the current actuarial (academic) literature Macdonald (2009, p. 4) concludes that “little, if any strong empirical evidence has been found for the presence of adverse selection (although it is admittedly hard to study).” Simulation exercises based on population genetics and epidemiological data (see Hoy, et al. 2003 and Hoy and Witt 2007) also find, for the most part, little impact is likely to occur from a ban on insurers using genetic test results for health and life insurance markets, respectively. Oster, et al. (2010), however, report strong evidence of adverse selection in the long-term care insurance market due to individuals holding private information about HD (Huntington disease) carrier status. It seems safe to say that the future holds uncertainty in this regard and continued empirical research will be necessary in order to help resolve the debate about the use of genetic information in insurance markets.

There are some potential developments that could shift the debate. Suppose the so-called “\$1000 genome” becomes a reality and the market for direct-to-consumer genetic testing (DTC-GT) continues to expand. The potential for substantially more private information to be held by insurance buyers may increase and adverse selection may end up making a ban harmful to the efficient functioning of insurance markets. However, it is not only knowledge about the sequence of an individual’s DNA that is relevant from an actuarial perspective, but also an understanding of the associations between this information and different levels of health and mortality risk across the population. That level of understanding will likely require a great deal more medical research. Therefore, even in the medium term future it may well be that a ban will not lead to even moderate problems with insurance markets from an efficiency perspective. Long term predictions, however, are much more difficult to make in this area.

Moreover, over time, and with increased access to, and predictive value of, genetic information, insurance buyers and sellers may begin to alter their purchasing and selling behaviour in response to a ban. Viatical markets may develop such that people at higher risk will leverage their ability to purchase insurance at less than the actuarial value of the contract and sell them at a profit. For their part, insurance companies may, for

example, begin to restrict certain high-risk categories or persons – such as those who end up succumbing to Huntington disease - from making claims on any long-term care policy and deny them coverage when the specific risk materializes.

Thus, if a ban were created, there should be periodic reviews of how the insurance market is performing.

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