

*Genetic Discrimination and Beyond -  
A Proposal for Ethical Life Insurance*

by

Ozan Gurcan

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*To Boomer*

*Early one morning, an old man was walking along the shore after a big storm had passed and found the vast beach littered with starfish as far as the eye could see, stretching in both directions.*

*Off in the distance, the old man noticed a small boy approaching. As the boy walked, he paused every so often and as he grew closer, the man could see that he was occasionally bending down to pick up an object and throw it into the sea. The boy came closer still and the man called out, "Good morning! May I ask what it is that you are doing?"*

*The young boy paused, looked up, and replied "Throwing starfish into the ocean. The tide has washed them up onto the beach and they can't return to the sea by themselves," the youth replied. "When the sun gets high, they will die, unless I throw them back into the water."*

*The old man replied, "But there must be tens of thousands of starfish on this beach. I'm afraid you won't really be able to make much of a difference."*

*The boy bent down, picked up yet another starfish and threw it as far as he could into the ocean. Then he turned, smiled and said,*

*"It made a difference to that one." <sup>1</sup>*

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<sup>1</sup> Short story by Loren Einseley (Starfish Story from 1969)

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# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	7
ABSTRACT .....	9
SUMMARY.....	10
<b>CHAPTER 1. INTRODUCTION: GENETIC DISCRIMINATION AND LIFE INSURANCE .....</b>	<b>15</b>
1.1 OPPONENTS OF THE GENETIC NON-DISCRIMINATION ACT .....	15
1.2 PROPONENTS OF THE GENETIC NON-DISCRIMINATION ACT .....	18
1.3 RELATIONSHIP BETWEEN GENES AND INSURANCE .....	20
1.4 HOW PREVALENT IS GENETIC DISCRIMINATION IN LIFE INSURANCE? .....	22
1.5 INTERNATIONAL PERSPECTIVES ON GENETIC DISCRIMINATION .....	24
1.6 HISTORY OF LIFE INSURANCE .....	27
1.7 LIFE INSURANCE IN CANADA: STRUCTURE, FUNCTION AND VALUE.....	29
<b>CHAPTER 2. ETHICAL CONSIDERATIONS, AND GENERAL MOTIVATIONS AND FRAMEWORK .....</b>	<b>43</b>
2.1 GENETIC DISCRIMINATION IN THE POLITICAL PHILOSOPHY LITERATURE.....	43
2.2 CONTROVERSIAL FEATURES OF GENETIC DISCRIMINATION .....	45
2.3 MAIN RESEARCH QUESTIONS.....	48
2.4 GENERAL MOTIVATIONS AND FRAMEWORK: PUBLIC REASON .....	50
2.5 DUTY BEARERS .....	52
2.6 CRITICISM OF PUBLIC REASON .....	54
<b>CHAPTER 3. GENETIC EXCEPTIONALISM IN LIFE INSURANCE?.....</b>	<b>57</b>
PART 1. GENETIC EXCEPTIONALISM .....	57
PART 2. GENETIC TEST EXCEPTIONALISM.....	64
<b>CHAPTER 4. LUCK AND LIFE INSURANCE IN A PLURALISTIC SOCIETY: ETHICAL LIFE INSURANCE .....</b>	<b>74</b>
4.1 THE NO-DENIAL RULE.....	79
4.2 THE PRIVACY RULE: BASIC, NO-QUESTIONS-ASKED LIFE INSURANCE COVERAGE.....	81
4.3 THE INFORMATION RULE.....	87
4.4 THE GUIDING RULE ON APPROPRIATE STATE RESPONSE TO (GENETIC) DISCRIMINATION .....	89
4.4a <i>Insurer profit rule: financial responsibility of life insurers.....</i>	<i>94</i>
4.4b <i>Immutability and responsibility .....</i>	<i>97</i>
4.4b i The clear immutability rule: Huntington's + .....	99
4.4b ii The addiction rule (complex immutability rule).....	103
4.4b iii The mutable lifestyle rule: breast cancer + .....	107
4.4b iii a. Uncertainty and tracking lifestyle.....	111
4.4b iii b. Ignorance towards genetic predispositions .....	114
4.4b iii c. Some recommendations for the mutable lifestyle rule .....	115
4.4b iv Obesity.....	116
4.4b v Biomarkers of behavior.....	120
4.4b vi Epigenetics and the Guiding Rule.....	122
4.4b vii Practical considerations.....	128

4.4b viii Justification of my Guiding Rule continued .....	130
4.4b viii a. Affordable discrimination and expressions: limits of luck egalitarianism? .....	130
4.4b viii b. The expressivist account of discrimination .....	139
4.4b viii c. Genetic discrimination and expression.....	140
<b>4.5 CRITICISMS FROM FREEDOM .....</b>	<b>146</b>
<b>4.6 SECONDARY MARKETS: THE STANDING OF THE EMERGING LIFE SETTLEMENTS INDUSTRY .....</b>	<b>149</b>
<b>CHAPTER 5. CONCLUSION .....</b>	<b>157</b>
<b>APPENDIX 1. LIFE INSURANCE INDUSTRY IN CANADA .....</b>	<b>163</b>
<b>APPENDIX 2- COST OF WHOLE LIFE INSURANCE .....</b>	<b>166</b>
<b>WORKS CITED .....</b>	<b>168</b>

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## Abstract

The Canadian Genetic Non-discrimination Act prohibits service providers such as life insurance companies from using genetic test results in their risk assessment procedures. From a practical standpoint, however, this law does not change much for those seeking life insurance. The law does not change much for these individuals because it is reflective of what I call a '*genetic test exceptionalism*' policy rather than the broader '*genetic exceptionalism*' policy. What this means is that insurers are still free to request other sources of genetic information such as those from family history of genetic disease and the results of non-genetic tests that, nonetheless, reveal genetic information. These may similarly render genetically disadvantaged persons ineligible for insurance and/or increase their premiums, which are outcomes that the law is attempting to reduce.

In this thesis, I critique both genetic exceptionalism and genetic test exceptionalism as ways to protect genetically disadvantaged persons and defend an alternative response to the problem of unjustified discrimination in life insurance. Without equating all genetic discrimination to "unjustified discrimination", I argue that every life insurance customer ought to be offered two options: (1) a substantive no-questions-asked guaranteed insurance; and (2) insurance based on full disclosure of information. When a person seeks insurance coverage above the no-questions-asked limit but below a maximum limit, the premium cost ought to be shared between the insured (who pays for what is controllable) and the state (who pays for what is based on "bad luck" and leads to disadvantage/expresses a negative message).

## Summary

My dissertation, *Genetic Discrimination and Beyond*, aims to make a contribution to the literature on genetic inequality and to improve Canada's genetic non-discrimination laws. *Genetic Discrimination and Beyond* is an interdisciplinary project between philosophy and public policy, hosted by the Ethics and Public Affairs program at Carleton University. It is intended to be read by philosophers, ethicists and policymakers who are interested in the ethics of discrimination policies. The two main research questions that are addressed in this dissertation are the following: (1) is the practice of genetic exceptionalism justified as a form of protecting genetically disadvantaged persons, and (2) if not through genetic exceptionalism, how *should* the state in a pluralistic society respond to (genetic) discrimination in life insurance? The 2017 Canadian Genetic Non-discrimination Act prohibits life insurers from using genetic test results to determine eligibility and the pricing of premiums of potential clients. This policy is called "genetic (test) exceptionalism" and it is based on the idea that genetic (test) information is so special that it is deserving of special protection/treatment. What I do in this thesis is to critique this policy and provide a unique, multi-faceted solution to the problem of (genetic) discrimination in life insurance. Below is the structure of this thesis.

In **Chapter 1**, I introduce genetic discrimination and life insurance in Canada. To this end, I highlight the different positions of opponents and proponents of the Canadian Genetic Non-discrimination Act; explain the relationship between genes and insurance; provide insights regarding the prevalence of genetic discrimination in life insurance; and outline several international perspectives on genetic discrimination. I end the chapter by giving an

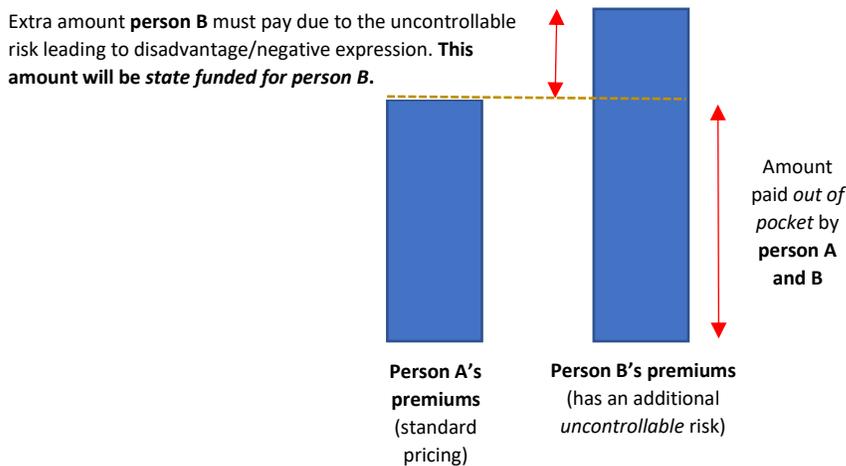
overview of the history of life insurance and provide my take on the structure, function and value of life insurance in Canada.

In **Chapter 2**, I explain the main ethical considerations in the genetic discrimination literature; state and explain my research questions; and outline my general motivations and public reason and feminist framework.

**Chapter 3** addresses the first research question of this thesis, which is on whether the practice of “genetic exceptionalism” is justified as way to protect genetically disadvantaged persons. I aim to argue against genetic exceptionalism, as well as what I call ‘genetic test exceptionalism’, which is a narrower form of genetic exceptionalism that is practiced in the Canadian context. The main rationalization for the Genetic Non-discrimination Act in Canada is that without such a law, persons are afraid to make use of genetic tests and to participate in genetic research studies. I refer to this fear as the ‘science and public health problem’. I argue that the ‘science and public health problem’ does not constitute a good reason, overall, for why *only* genetic test results should be prohibited from use by insurers or for why they should be treated differently in any other way. One of my intentions, then, is to shift the focus from “genetic” to “all relevant health and life related” information of a person. In other words, I broaden the focus from ‘genetic discrimination in life insurance’ to ‘discrimination in life insurance in general’. So, if not through genetic exceptionalism, how should the state respond to (genetic) discrimination in life insurance?

**Chapter 4** addresses the second (and main) research question of this thesis, which is on *how* the state ought to respond to (genetic) discrimination in life insurance. Among other things, the main task I accomplish here is to propose and defend a combined luck egalitarian

and expressivist position, claiming that (genetic) discrimination deserves a response from the state when it is (a) based on *bad luck* and *leads to disadvantage*, and (b) when it is based on *bad luck* and *expresses something negative*. This position, which I call the ‘guiding rule’, places a strong emphasis on immutability and recognizes that not all outcomes of genetic characteristics are immutable, yet many outcomes arising from non-genetic features of persons are immutable. I then demonstrate how this combined account plays out in a variety of cases of (genetic) discrimination such as those based on Huntington's disease, breast cancer, addictions, and obesity, etc. At the same time, I argue that the response from the state ought to take the form of *compensating* deserving individuals, instead of banning private insurers from using particular health-relevant information. So, when a sought policy is above a basic amount but below a maximum amount, the premium cost of deserving persons should be shared between the insured (who pays for what is controllable) and the state (who pays for what is based on “bad luck” *and* leads to disadvantage/expresses a negative message). This proposal is part of a larger scheme of life insurance where every customer is to be offered a no-questions-asked guaranteed insurance product as well.



The reason why compensation is better than prohibition (of insurers from discriminating based on certain health-relevant information), I argue, is that such information is necessary for the healthy functioning of the private life insurance industry.

### **What makes my project unique?**

- I combine literature from the life sciences with that of political philosophy and ethics to apply them within the context of life insurance.
- I offer a critique of the 2017 Canadian Genetic Non-discrimination Act.
- I generate a pluralistic account for the wrongness of discrimination and apply it to demonstrate how the state should respond to different cases of discrimination in life insurance.
- My account for the wrongness of discrimination leads to the generation of useful, *prima facie* rules of (genetic) non-discrimination that policymakers in the government and within the insurance industry can (and should) consult in reviewing and devising their policies.
- I indirectly provide a critique of the idea of *genetic determinism*, especially with respect to health outcomes. Genetic determinism is the idea that our phenotype (e.g., behaviour) is exclusively determined by our genotype.
- I contribute to the genetic exceptionalism literature by particularly examining the justifiability of “genetic test exceptionalism”.

- I contribute to the ethics of genetic discrimination literature by broadening the debate, based on logical reasons, to say that many other types of information are also implicated in the debate.
- Overall, I generate a pluralistic, compensation-based solution to the problem of unjustified discrimination in life insurance by taking account of, and balancing the interests of all stakeholders including insurers, individuals, and public-at-large.

## **Chapter 1. Introduction: Genetic Discrimination and Life Insurance**

On May 2017 Canada passed the Genetic Non-discrimination Act, Bill S-210, amending the Canadian Human Rights Act by adding “genetic characteristics” to the list of traits that are barred from being the basis of differential treatment (Government of Canada, 2017). The Genetic Non-discrimination Act also prohibits service providers such as life insurance companies from using genetic test results in their risk assessment procedures (Government of Canada, 2017). In other words, it is now a “criminal offence for a service provider or anyone entering into a contract with a person to require that person to take or disclose the results of a genetic test or collect, use or disclose a person’s genetic test results without written consent” (Government of Canada, 2017; Canadian Coalition for Genetic Fairness, 2019). Those who violate the law may be fined up to CAD 1,000,000 or imprisoned for up to 5 years (Government of Canada, 2017).

While Bill S-201 was being discussed in Canada’s government in 2016, proponents and opponents of the legislation made their voices heard on radio shows and newspaper articles. In the next few pages, I will refer to a key a discussion that took place on CBC’s *The Current*.

### **1.1 Opponents of the Genetic Non-discrimination Act**

Those opposing the Bill, such as Frank Swedlove, then president and CEO of the Canadian Life and Health Insurance Association, claimed that if genetic non-discrimination were to become law in Canada, it would unfairly allow individuals to withhold critical information from insurers (CBC, 2016). As others working on this topic have also pointed

out, this group holds that genetic information is just another factor to be evaluated, on top of, *inter alia*, age, family history, and health status in the underwriting process (Rothstein & Anderlik, 2001, p. 356). Underwriting is known as the “...process of assessing individual risk, based on probabilities of adverse events occurring, and thereby setting insurance premiums.” (MacDonald, 2011, p. 1). It was claimed on *The Current* that life insurance is a contract whereby there is supposed to be equal knowledge of information by the involved parties (CBC, 2016). If the state of equal knowledge is disturbed, as it is when individuals withhold genetic test information, insurers argue that this would lead to adverse selection (CBC, 2016). Adverse selection is the “... disproportionately heavy purchase of insurance by high-risk individuals when rates are not adjusted for risk” (Rothstein and Anderlik, 2001, p. 356). Adverse selection is claimed to violate the principle of actuarial fairness, where everyone is to pay according to the risk they bring to the insurance pool. Thus, insurers are worried that people with genetic test results indicating relevant risk information will take out large sums of policies that will not be correctly price adjusted for risk.

During the radio show, Swedlove stated that in order to respond to this problem and make up for the risk of financial loss, insurance companies would now have to increase prices for all others, which would be unfair, and as a further outcome, could be a barrier for persons to purchase life insurance when it is warranted (CBC, 2016). Increased prices can also lead to insurance companies losing their clients to international competitors, as well as to the collapse of the insurance market altogether (O'Neill, 2006). For insurers, then, the key moral principle is the following: “groups with equal morbidity and mortality risk should be treated equally.” (Rothstein & Anderlik, 2001, p. 356).

Although there seems to be a tension between discrimination and human rights, it is important to note that Canadian Human Rights legislation does not prevent discrimination in insurance (Oscapella, 2012, p. 43). In fact, “most human rights statutes explicitly recognize the validity of this practice by providing an exception to the prohibition against discrimination for insurance purposes” (Lemmens, 2000, p. 405). Moreover, it may be said that there can be no ill-will on the part of insurance companies when they discriminate because they are not looking for causal relations between personal/risk information and health/life outcomes but rather interested in statistical correlations (Radetzki, Radetzki, & Juth, 2003, p. 120). This is referred to as *indirect discrimination*. In indirect discrimination there is no intent to exclude persons. However, due to the way certain rules and policies have been designed (to serve the interests of a particular group) the outcome is the same in that persons do end up being excluded (Lippert-Rasmussen, 2018, p. 3).

In a court case regarding auto insurance in 1992, for example, the Supreme Court of Canada ruled that “...a discriminatory practice is reasonable, if, first, it is based on a sound and accepted insurance practice and, second, there is no practical alternative.” (Lemmens, 2000, p. 406). The details of this ruling are as follows:

The first condition allows practices that are desirable ‘for the purpose of achieving the legitimate business objective of charging premiums that are commensurate with risk’. With the second condition, the Supreme Court rejects the argument put forward by the Human Rights Commission, which suggested that an insurance company must demonstrate that the very essence of its business would be undermined if it could no longer rely on discriminatory group characteristics to determine premiums. The

Supreme Court sets a less stringent standard, namely that it is sufficient to show that an alternative approach would be 'impractical'. (Lemmens, 2000, p. 406)

## **1.2 Proponents of the Genetic Non-discrimination Act**

On the other hand, those supporting the legislation such as Francoise Baylis, then Canada Research Chair in Bioethics at Dalhousie University, argued that the claim that contracting parties have equal knowledge is a false claim (CBC, 2016). She said that insurers have access to the demographic, health, lifestyle, and family history of persons who are similarly situated which reveals information about the potential client which the client themselves do not know (CBC, 2016). Thus, it was concluded that there is already an information asymmetry between the potential client and insurer. Moreover, Baylis stated that insurers can access and interpret new scientific research, and assess risk in a systematic way, which are things that ordinary individuals cannot necessarily do (CBC, 2016). With these points, Baylis is highlighting the relevant power differential that is present between an insurance company and an individual insurance seeker.

Another commenter on the radio show, Yvonne Bombard, Associate Professor in the Institute of Health Policy Management and Evaluation at the University of Toronto, argued that due to the absence of such genetic non discrimination laws in Canada, people were less likely to participate in genetic research and genetic testing in fear of discrimination in the future, and that this impeded knowledge generation and the ability to take preventative health measures, respectively (CBC, 2016).<sup>2</sup> Moreover, it is possible that many deaths or

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<sup>2</sup> For example, geneticists have reported that "...parents were choosing not to have genetic tests done for fear of future repercussions for employment and insurance eligibility." (Stefanovich, 2020, p. 1)

injuries from drug intolerance may be avoided or minimized if more persons took certain genetic tests. With persons' pharmacogenetic information available, the healthcare system could save lots of time and money in the long run by avoiding treatments/prescriptions that are not likely to work or likely be harmful towards patients.<sup>3</sup> As Rothstein has also pointed out, early intervention is likely to increase persons' life expectancies (2018). Swedlove responded to such points by explaining that life insurance companies did not increase insurance rates if persons took a genetic test *after* they had purchased insurance (CBC, 2016). Since life insurance is voluntary, he claimed, persons could choose to purchase insurance and then take a genetic test if they wish to later (CBC, 2016).<sup>4</sup>

Along with Baylis and Bombard, Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness and CEO of the Huntington Society of Canada, is another proponent of the new law. Although she was not present at the radio show, she has indirectly responded to Swedlove's aforementioned point elsewhere stating that "genetic information can help individuals make informed decisions. It is unacceptable that Canadians risk discrimination by insurance companies if they wish to obtain their personal genetic information. This ... stands in the way of Canadians being proactive about their own health." (Canadian Coalition for Genetic Fairness, 2014, p. 1). The informed decisions she is talking about range from being more careful about following a healthy lifestyle to deciding whether to purchase life insurance or not, *etc.*

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<sup>3</sup> This point was brought to my attention by Bev Heim Myers.

<sup>4</sup> I suspect that he was most likely referring to the purchase of Guaranteed Insurance which is a modest level of no-questions-asked coverage at a standard rate. Much more will be said about this product in Chapter 4.

Regarding the concern over adverse selection, many, including Rothstein and Brothers, believe that genetic tests “...have little proven value in underwriting...” (Banning Genetic Discrimination in Life Insurance, 2021, p. 1). As MacDonald writes, “... [single gene disorders] ... 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.” (MacDonald, 2011, p. 12).<sup>5</sup> When it comes to multifactorial conditions, Macdonald says that any relevant genetic test information is not likely to bring about new/unmanageable disruptions to the market (MacDonald, 2011, p. 2).

In March 2017, months before the Genetic Non-discrimination Act had passed, Canada’s life insurance industry announced, on a voluntary basis, that insurance companies would no longer request genetic testing information from persons applying for coverage below CAD 250,000 (Weeks, 2017). This did not stop the Bill from becoming law, however, and in May 2017 the Genetic Non-discrimination Act received royal ascent.<sup>6 7</sup>

### **1.3 Relationship between genes and insurance**

Genetic discrimination is concerned with genes, so it is important to know what genes are and how they are related to discrimination in insurance. Genes are the DNA codes found in the cells of living beings that instruct the living being on how to make/control proteins (National Institutes of Health, What is a Gene, 2020). Proteins make up the structural and functional components of cells, tissues, organs, and organ systems. Through the analysis of

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<sup>5</sup> MacDonald states that in one study, the cost of adverse selection was calculated to be about 3% of total premiums (MacDonald, 2011, p. 12).

<sup>6</sup> The law was appealed to the Supreme Court of Canada for supposed unconstitutionality after it passed, but, in 2020, the Supreme Court ruled that the law was constitutional. More will be said on this later in this chapter.

<sup>7</sup> I suspect that one reason why proponents of the law did not push too hard for all genetic information to be banned, but only for genetic *test* information to be banned, is that this would be a barrier for the passing of the law. Thanks to Bev Heim-Myers for bringing this to my attention.

one's genes, one can determine whether persons are biologically male or female or whether they are prone to certain ailments, among other things. It is an uncontroversial claim, for example, that many anthropometric traits (e.g., height and weight), psychological traits, and personality traits (e.g., introvert, extrovert) have a partial genetic basis (Kandler, Richter, & Zapko-Willmes, 2017). With the advancement of human knowledge on genes, corporations and other institutions have had a greater interest in using the genetic information of human persons in order to achieve their ends better. In the context of private life insurance, this end is accurate risk-grouping and pricing.

Genetic discrimination can take place not only in the context of insurance, but also in employment, immigration, and adoption, among others, as these institutions have an interest in the health and life outcomes of persons.<sup>8</sup> The differential treatment (i.e., discrimination) in the case of insurance is generally characterized by charging higher-risk clients more or outright denying them coverage. As Per Sandberg indicates, however, insurers can also "...write exclusion clauses, ...exclude entire industries or groups, introduce waiting periods, and use other indirect ways to discriminate according to their assessment of the risks involved." (1995, p. 1553).

Researchers have found that genetic discrimination has led to psychological distress and loss of social opportunities for persons (Joly, Ngueng Feze and Song & Knoppers, 2017; Bombard, Veenstra, *et al.*, 2009). For instance, high-level executive positions generally require that persons take out life insurance, and those who cannot acquire it are thereby

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<sup>8</sup> Most recently, potential for genetic discrimination has been linked to the idea of immunity passports. With the aim to track who has recovered from and has presumed immunity against COVID-19, companies and states have begun considering or began issuing immunity passports/certification to persons. As Natalie Kofler and Francoise Baylis have stated, however, with such platforms in place, it would be easy to expand to include other personal health information such as mental health records and genetic test results, which could introduce new problems (2020).

barred from taking up such positions, which is a clear limitation of freedom (equal opportunity), a sort of harm. There have also been reports in Canada indicating how a person (whose father has Huntington's) faced difficulties acquiring life insurance that was required in order for her to start a chiropractic practice (Boyle, 2011). As Heim-Myers states, "...protection against genetic discrimination is necessary so that people can get the insurance they need to start health-care practices, buy homes and 'lead the best lives that they can live.'" (Boyle, 2011, p. 1). There are other potential consequential worries as well. For example, in the near future, with the advancement of artificial intelligence and machine learning, certain decision-algorithms may unjustifiably prevent persons who have been denied life insurance from purchasing other forms of insurance as well (*e.g.*, auto insurance).<sup>9</sup> It may one day be the case that persons who have not purchased life insurance will be discriminated against in society.

#### **1.4 How prevalent is genetic discrimination in life insurance?**

Before the Genetic Non-discrimination Act had passed, and now as well, the majority of those with life insurance were/are included in the "common pool" and pay premiums at the *standard* rate (Joly, Ngueng Feze, & Simard, 2013).<sup>10</sup> However, one must interpret such a statement in a context where many people who would like insurance are outright denied coverage for posing too high a risk, meaning that their situation is not represented by the aforementioned statement. Huntington's is one of the more common conditions that is difficult to insure. In 2009, Bombard *et al.* conducted a cross-sectional, self-reported survey

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<sup>9</sup> I thank Marc Saner for pointing out these possibilities to me.

<sup>10</sup> Appendix 2 shows these rates for Whole Life Insurance. Whole Life Insurance, as opposed to Term Life Insurance, remains in effect for the entire duration of one's life.

to “assess the nature and prevalence of genetic discrimination experienced by persons at risk for Huntington’s disease who had undergone genetic testing or remained untested.” (Bombard, et al., 2009, p. 1431). Their survey results revealed that discrimination was reported by 93 respondents (39.9%) (Bombard, et al., 2009, p. 1431). Insurance (29.2%), family (15.5%), and social (12.4%) settings were the top 3 contexts in which persons reported facing discrimination (Bombard, et al., 2009, p. 1431). Among the 71 respondents who had undergone genetic testing and reported facing genetic discrimination, “...41 attributed their experiences to their family history, whereas only 13 believed that their genetic test results were the main reason for their discriminatory experiences. Seventeen tested respondents attributed their experiences to both family history and genetic test results” (Bombard, et al., 2009, p. 1435).

Joly and colleagues also investigated the prevalence of genetic discrimination but with an exclusive focus on life insurance (Joly, Ngueng Feze, & Simard, 2013). They conducted a systematic, critical review of around 20 years of genetic discrimination studies, and found that due to the methodological limitations among the studies, it was very difficult to justify policy action on genetic discrimination taken on the basis of evidence of genetic discrimination alone (Joly, Ngueng Feze, & Simard, 2013). Regardless, Joly, Ngeung Feze and Simard imply in their paper that other empirical and theoretical factors can, nonetheless, at least partially justify certain policy actions (2013). Among the stated empirical and theoretical factors are the “prevalence and impact of the fear of genetic discrimination among patients and research participants, the (un)importance of genetic information for the commercial viability of the private life insurance industry, and the need to develop more equitable schemes of access to life insurance” (Joly, Ngueng Feze, & Simard, 2013, p. 1).

Taking policy action despite the potentially low prevalence of genetic discrimination can be interpreted as a pre-emptive measure taken against the speculation that genetic knowledge, and its use in society, will increase over time.

In order to systematically record and track cases of genetic discrimination, different stakeholders have now established the online Genetic Discrimination Observatory. The organization “...aims to better understand discriminatory events and compile information on the incidence and consequences of genetic discrimination in order to advance the debate on this issue.” (Genetic Discrimination Observatory, 2020, p. 1). Persons from Canada and the US who would like to share their experiences with genetic discrimination are encouraged to fill out a report through the Observatory website.

### **1.5 International perspectives on genetic discrimination**

Canada’s legislation is viewed as one of the stricter laws on genetic discrimination; it “...is much more protective of patient rights than insurer interests.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). For example, Belisle-Pipon *et al.* state that “if the US insurance industry or the law imposed a rule similar to the one Canadian insurers self-imposed [no genetic test information requested unless asking for a policy above CAD 250,000]...[it] would be a major step forward in protecting patients willing to engage in genetic testing for the sake of the public good or research.” (2019, p. 1200).

There have been many authors who have written on the international perspectives on genetic discrimination (Bélisle-Pipon, *et al.*, 2019; Prince, 2019; Joly, Ngueng Feze and Song & Knoppers, 2017; Adjin-Tettey, 2013; Otlowski, Taylor and Bombard, 2012; Joly, Braker and Le Huynh, 2010; Malpas, 2008). There are different strategies that have been

adopted in different countries. As identified by Joly, Braker and Huynh, these strategies, which are not mutually exclusive, include the fair limits approach, human rights approach, prohibitive approach, moratorium approach, rational discrimination approach, and the status-quo approach (wait and see approach) (2010, pp. 355-356). I will now briefly explain the different approaches that have been taken in the United States, UK, Australia, and France, Switzerland, and the Council of Europe.

There has been a genetic non-discrimination law in the **United States** since 2008 called the *Genetic Information Nondiscrimination Act*. One of the strengths of the law is that the term “genetic information” encompasses not only genetic test results, but also family history of genetic diseases (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1999). This law, however, only applies to health insurance. Persons seeking to take out life insurance may still have to hand over genetic information to life insurers (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1199). Thus, the United States has adopted a lenient approach, with respect to life insurer interests, to regulating genetic discrimination.

The **UK** has adopted a more complex strategy, establishing a *Code on Genetic Testing and Insurance* in 2018. It is a non-legislative approach to genetic discrimination, seen as a hybrid of government regulation and industry self-regulation (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). Insurers are “...prevented from requiring the disclosure of predictive test results unless they are pre-approved by the government after consultation with independent experts according to the use of ‘higher standards of evidence’.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). To be eligible for this pre-approval, “the tests may apply only to monogenic (single-gene) disorders and late-onset and high-penetrance

conditions [i.e., with a high probability that a specific gene is expressed].” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). As of now, it is only Huntington’s disease that must be disclosed (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). Moreover, “...for requiring the disclosure of a patient’s predictive genetic test results: 1) the applicant (that is, the patient) must be seeking coverage for life insurance above £500,000 [approximately CAD 840,000], and 2) the insurer must ask the applicant for the results.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). This approach aims to “...balance consumers’ need for fair access to insurance with the sustainability and profitability of the insurance industry.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200).<sup>11</sup>

In **Australia**, a moratorium has been established preventing the use of genetic test results for insurance (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1201). It is effective from mid 2019 to 2024, upon which it will be reviewed for its different impacts. Showing their appreciation of genetic inclusion, this approach by the Financial Services Council of Australia “...will enable Australians to get insurance, without the need for disclosing adverse test results, for up to AUD\$500,000 [approximately CAD 480,000] for death and permanent disability...” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1201). This policy “...still allows the insured to choose to disclose favorable genetic test results to prove that they do not possess an illness-associated gene pattern that may run in their family.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1201).

In **France**, genetic test information of persons is strictly protected under the prohibitive approach; life insurers are barred from accessing genetic test results and

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<sup>11</sup> The Code is to be reviewed “...every 3 years to keep it up to date and to ensure that its provisions remain relevant and efficient.” (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, pp. 1200-1201).

violation can lead to 1 year of imprisonment and a €15,000 fine (approximately CAD 24,000) (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1199). As with most countries, other sources of genetic information such as family history of genetic disease must still be provided to life insurers (Joly, Dupras, Ngueng Feze, & Song, 2017, p. 8).

In **Switzerland**, life insurers can only make use of genetic test results if persons request to buy a policy greater than CHF400,000 (approximately CAD 580,000) (Bélisle-Pipon, Vayena, Green, & Cohen, 2019, p. 1200). This is another example of the fair limits approach.

The **Council of Europe** has also adopted recommendations on genetic testing in insurance. They state that insurers should not request genetic tests from persons, and that predictive tests already at hand may be used by insurers only where the law allows it (Joly, Dupras, Pinkesz, Tovino, & Rothstein, 2020, pp. 2.7-2.8). These recommendations state that “existing genetic data from family members of insureds may not be processed for insurance purposes” (Joly, Dupras, Pinkesz, Tovino, & Rothstein, 2020, pp. 2.7-2.8).

Thus far I have explained how the issue of genetic discrimination has played out in Canada, made some remarks on the prevalence of genetic discrimination, described several international perspectives, and briefly explained the relationship between genes and insurance. Now let's take a closer look at life insurance, which is the main site in which I will be analyzing the issue of genetic discrimination.

## **1.6 History of life insurance**

The idea of life insurance has its origins in the Roman Empire (Dahl, 2013). Caius Marius, “...a Roman military leader, created a burial club among his troops, so in the event of

the unexpected death of a club member, other members would pay for the *funeral expenses*” (Dahl, 2013, p. 1). But it was in 1688 at the Edward Lloyd’s Coffee House in London, a social gathering spot for ship captains, owners and merchants, where the modern concept of an insurance company first arose (Dahl, 2013). Lloyd’s Coffee House began as a center for marine insurance where... “some came to insure the safe return of their ships and cargo... [and] ... others came to bet on lives and events [ex. ships being lost] in which they had no stake apart from the wager itself.” (Sandel, 2013, p. 349).

However, “the rampant wagering on death in Britain prompted a growing public revulsion against the unsavory practice. ... Life insurance, increasingly seen as a prudent way for breadwinners to protect their families from destitution, had been morally tainted by its association with gambling.” (Sandel, 2013, p. 350). Soon after, the Gambling Act of 1774 “... banned gambling on the lives of strangers and restricted life insurance to those who had an “insurable interest” in the person whose life they were insuring.” (Sandel, 2013, p. 350).

Life insurance has also faced resistance in the United States since putting death on the market did not fit so well within a culture committed to the sanctity of life principle (Sandel, 2013, p. 350). By the mid 19<sup>th</sup> century, “... the life insurance business began to grow, but only by emphasizing its protective purpose and downplaying its commercial aspect. ... [but] as the industry grew, the meaning and purpose of life insurance changed.” (Sandel, 2013, p. 350). It changed from being viewed as a good that existed to protect families to a means of investing and saving, and a regular part of business, even though an “insurable interest” component was present in this context as well (Sandel, 2013, p. 350).

According to Adjin-Tettey, “widespread insurance, especially among the working class, was characterized as an important element in the rise of the welfare state given the focus on workers’ welfare in the early nineteenth century.” (2013, p. 582). Canada’s first life insurance company, *Canada Life*, was started in 1849 by Hugh C. Baker, who was then manager of the Bank of Montreal (Swiss Re, 2017). For its initial operations, *Canada Life* drew heavily on practices and standards from the UK and was issuing insurance policies to residents of the UK and Ireland on top of Canada (Swiss Re, 2017; Canada Protection Plan, 2016). In 1869, there was still only one Canadian life insurance company and thirteen British and nine American companies, making up around 80% of the whole market (Swiss Re, 2017).

### **1.7 Life insurance in Canada: structure, function and value**

In most developed countries, life insurance is provided on the private market by large insurance companies (O’Neill, 2006, p.568). The system of life insurance in Canada can be characterized as a voluntary mutual insurance market. As O’Neill describes it, “a mutual insurance market operates through the pooling of risk, with payment into the pool being in accordance with the best estimate of the level of risk brought to the pool.” (2006, pp. 568-569). The price of mutual life insurance premiums generally depends on factors such as age, sex, overall health, and the type/duration/amount of insurance one purchases. All else being the same, the younger, non-smoking woman pays less than the older, smoking man (O’Neill, 2006, p.568). Mutual insurance systems are generally private and contractual (O’Neill, 2006, p. 569). Since they are voluntary, individuals have a choice in how much cover they would like to purchase. Overall, then, O’Neill characterizes mutual insurance as a flexible, choice-sensitive free-market solution to insurance (2006, p. 578).

There are two main types of mutual life insurance products; *permanent* and *term* insurance. Permanent insurance lasts for the entire lifetime of the insured. On top of death protection, "...cash values are accumulated and can be used for financial emergencies, or to supplement retirement income." (Canadian Life and Health Insurance Association, 2016, p. 9). There are two types of permanent life insurance products; whole life insurance and universal life insurance. In whole life insurance, on top of taking the risk related to death, the insurer also takes on the underlying investment risk (Canadian Life and Health Insurance Association, 2016, p. 9). In universal life insurance, it is the insurer who takes on the risk related to death but consumers manage the investment risk themselves (Canadian Life and Health Insurance Association, 2016, p. 9).

Premiums for permanent insurance are generally five to ten times more expensive than a term insurance policy of the same size (Policy Advisor Magazine, What is life insurance?, 2020, p. 1). In general, a 30 year old with regular health will pay around CAD 100-130 per month on premiums for a CAD 250,000 of whole life insurance (Policy Advisor Magazine, 2020, p. 1). A 50 year old smoker, on the other hand, will pay much more for the same policy. An important fact about permanent insurance is that around 40 percent of such policies lapse within the first ten years due to policyholders not making their monthly payments (Policy Advisor Magazine, What is life insurance?, 2020, p. 1).

Term insurance, on the other hand, provides temporary coverage typically in 5, 10 or 20 year terms. It is the more popular product as 76% of Canadians who have life insurance, have term insurance (Policy Advisor Magazine, What is life insurance?, 2020, p. 1). This popularity may be due to the fact that it is usually possible to convert term insurance to

permanent insurance at a later time without any further underwriting, which offers flexibility to consumers (Canadian Life and Health Insurance Facts, 2016, p. 9). In general, a healthy 30 year old will pay around CAD 15-20 per month for a 20 year CAD 250,000 term policy whereas a 60 year old smoker will pay over CAD 120-190 a month for the same product (Policy Advisor Magazine, What is life insurance?, 2020, p. 1). Women will normally pay around 10-25% less than men, and smokers will normally pay around 50-100% more than non-smokers (Hands, 2020, p. 1).

### **What is required for the proper functioning of mutual insurance schemes?**

As Sandberg explains, “insurance markets exist because people are willing to pay modest premiums on a regular basis rather than great losses at unpredictable times.” (1995, p. 1554). However, there are certain conditions that must be met. For example, “there is some maximum price above which the individual will decide not to purchase insurance... [and] there is also some minimum premium that the insurer must receive in order to be willing to supply insurance.” (Sandberg, 1995, p. 1554). Consequently, “mutual insurance markets are stable only under conditions where there is no significant divergence in the level of risk-relevant information available to the insurer and insured” (O’Neill, 2006, p. 571). Thus, as long as genetic information is related to risk, it is said that “...privacy ... when relevant to risk levels, would lead to the kind of informational asymmetries that would violate the Principle of Informational Symmetry, thereby threatening the stability of the mutual ... insurance market.” (O’Neill, 2006, p. 574).

Discrimination based on health information, then, which may include genetic information, is an important part of mutual life insurance schemes. Even though family

history of genetic disease also reveals genetic information, and so it may be said that genetic test information would not be necessary, genetic tests can confirm, with the greatest precision, whether one has a genetic mutation or not. For example, even though family history of disease can show that a person has Huntington's disease in the family, only a genetic test can confirm whether one has the Huntington's gene. Similarly, even though there may be breast cancer in one's family, only a genetic test can confirm whether there is a genetic contribution involved. So, differentiating between people according to their risk status, and charging them different premiums that are commensurate with their risk status, is an essential feature of the underwriting process in private life insurance (Lemmens, 2000, p. 405).

### **Solidaristic Insurance**

Mutual insurance systems are contrasted with solidaristic insurance systems. In solidaristic insurance, the amount that one pays for coverage is not affected by their risk status, and the amount of cover one acquires is not determined by how much one pays. Rather, coverage levels are determined by the standard of "need" and payment into the risk pool is determined by standards such as ability to pay or strict equality of monetary contribution (O'Neill, 2006, p. 569). Solidaristic insurance is generally publicly operated, universal, and non-voluntary (O'Neill, 2006, p. 569). Thus, individuals do not have a say in how much cover they would like to acquire. O'Neill characterizes solidaristic insurance as a universal, compulsory, and centralized solution to insurance (2006, p. 578).<sup>12</sup> With respect to genetic discrimination in life insurance, then, a solidaristic insurance scheme would be

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<sup>12</sup> An example of solidaristic insurance is the health insurance system in Canada which covers most basic health necessities of individuals and is funded through taxation.

one where individuals could have full access to their genetic information without any worries over genetic discrimination.

### **Function and value: What kind of good is life insurance?**

It is important to know what kind of good life insurance is because this can help us determine whether the provision of life insurance should mainly be the responsibility of the state, therefore provided under a solidaristic system, or whether it should be the responsibility of the private market, therefore provided under a mutual insurance system.

Per Sandberg classifies social goods into three types:

*Primary social goods* are goods that everyone needs for leading a life under decent physical conditions. Well-ordered societies normally guarantee access to these goods for all their members. Secondly, *commodities* are goods that are sold on the 'normal' market, e.g. cars and clothes. *Non-primary social goods* fall between these types. They are not serving basic human needs, but neither are they 'just' commodities. They serve a social function, but are usually not considered so important that access to them must be guaranteed to all members of a society. (1995, p. 1554)

Sandberg thinks that it is reasonable to see life insurance in Europe as a *non-primary social good*; "it is an instrument for rational agents to secure a certain economic standard of living, above the publicly guaranteed minimum floor, for their dependents in the event they die. But dependents of people who are unable to receive private life insurance will nonetheless be guaranteed a decent minimum economical living standard, thereby securing satisfaction of primary goods." (1995, p.1554). The reason Sandberg gives as to why European life insurance is not simply a commodity is that it serves valuable social functions (1995). On the

contrary, there can also be circumstances that make life insurance a primary good rather than a non-primary one (Sandberg, 1995). One such circumstance, according to Sandberg, is if the state has a less extensive welfare system (1995, p. 1554). Another circumstance that would make life insurance a primary good is if one *needs* to have life insurance in order to take out a mortgage, for example, as in the United Kingdom, which may be necessary for people to purchase a house (Sandberg, 1995, p. 1554).

### **So what kind of good is life insurance *in Canada*?**

What is it that Canadian life insurance seekers are hoping to gain from the transaction? There are multiple functions of life insurance in Canada. According to the Canadian Life and Health Insurance Association, proceeds from a life insurance policy are generally used to replace income, pay debts, or create or add to an estate (2016, p. 8). Elizabeth Adjin-Tettey further describes life insurance in Canada as a peace-of-mind contract which allows for “...eliminating, or at least minimizing, the financial consequences of future events beyond a person’s control.” (2013, p. 582). It gives persons “...some security and a means of managing the risk of misfortune by shifting the potential financial impacts of the materialization of the risk in question, either in whole or in part, to another person or risk pool.” (Adjin-Tettey, 2013, p. 582). Life insurance can also facilitate different forms of economic and social endeavours for persons while they are alive “such as the kind of entrepreneurial activity in which individuals can engage if they have access to large and reasonably-priced bank loans; it allows access to the housing market; it facilitates stable family life; and it provides for long-term planning of a kind that would be impossible under uncontrolled levels of risk.” (O’Neill, 2006, p. 578).

Therefore, persons who would be purchasing life insurance in Canada are those that have:

- (1) some risk of premature death and/or
- (2) partaken or planning to partake in an activity that would leave potential beneficiaries (e.g., family members) in a difficult position if they were to die, such as having a baby, and buying a house and/or
- (3) planned to pursue entrepreneurial activities, take up high level executive positions, or simply to provide extra money for their family upon their death

**But is private life insurance the only way to attain the good that private life insurance currently provides in Canada?**

Does the Canadian state already have means set up to do the same thing that private life insurance does? In describing the social role of private life insurance in the United States, for example, Thomas Murray says that “...we must evaluate the role of such insurance in the context of a not particularly generous social welfare system that would otherwise leave the surviving dependents of a deceased breadwinner in very poor financial condition.” (1992, p. 15). Murray reminds us that the average insurance seeker is one who has one or more dependents who are not likely to be financially independent in the short term (1992, p. 15). In Europe, Per Sandberg describes how many states “...include all their citizens in more extensive [than the US] social security systems.” (1995, p. 1554). In most European states, when a principal earner dies, a minimum level of primary goods is provided by public systems (Sandberg, 1995).

The Canadian state does provide death benefits and survivor's pension in the event of death in a family; "As of January 1, 2019, the amount of the death benefit for all eligible contributors is a flat rate of \$2,500." (Government of Canada, 2018). With respect to survivor's pension,

if the survivor is 65 or older, the survivor's pension is 60% of the contributor's retirement pension (if the surviving spouse or common-law partner is not receiving other CPP benefits), and if the survivor is under 65, the survivor's pension is a flat rate portion plus 37.5% of the contributor's retirement pension (if the surviving spouse or common-law partner is not receiving other CPP benefits). (Government of Canada, 2019)

The Canadian state also provides social support for its citizens in more general ways. Moscovitch describes the welfare state in Canada as a "... multi-billion dollar system of government programs that transfer money and services to Canadians to deal with an array of societal needs such as poverty, homelessness, unemployment, immigration, aging, illness, workplace injury, disability, and the needs of children, women, gay, lesbian, and transgender people." (2015, p. 1). These programs include "Social Assistance, the Canada Child Tax Benefit, Old Age Security and the Guaranteed Income Supplement, Employment Insurance, the Canada and Quebec Pension Plan, Workers' Compensation, public education, medicare, social housing and social services." (Moscovitch, 2015, p. 1). The Province of Ontario, among others, also provides emergency assistance to people who have had a death in the immediate family (City of Ottawa, 2020).

It may be suggested, then, that persons would not *really* have a need for private life insurance since the state does not leave their citizens and residents socially vulnerable, whether they have lost a principal earner in their family or not. But is it enough? If it is enough, it would mean that private life insurance is a commodity or non-primary basic good. As Moscovitch points out, since 1975, due to changes in social service and income support programs, social welfare in Canada has been eroded (2015, p. 1). Social assistance and program are "... still designed to deal with unemployment as a 'contingency,' an unusual occurrence, and not as the regular feature of economic and social life that it has become" (Moscovitch, 2015, p. 1). Adjin-Tettey adds to this characterization, stating that "the picture that emerges is an increasing devolution of responsibility from governments to individuals to look after their own financial security and, to some extent, their own health care needs through the private sector by obtaining insurance or by being self-insurers." (2013, p. 584). And she believes that "this is likely to be a growing trend as governments try to eliminate their growing deficits and balance their budgets." (Adjin-Tettey, 2013, p. 584).

So, it seems as though the direct and indirect assistance provided by the state is not close to the immediate financial benefit/security one can acquire from private life insurance. In 2016, for example, it was reported that 22 million Canadians owned a total of CAD 4.3 trillion in private life insurance coverage (Canadian Life and Health Insurance Association, 2016, p. 4). These 22 million Canadians paid a total of CAD 18.5 billion in insurance premiums, and the average coverage per insured household was around CAD 388,000 (about five times the income of the average insured household) (Canadian Life and Health Insurance Association, 2016, p. 8). Given the trend of dismantling of social programs in Canada, and the benefits provided by private life insurance, there is good reason to believe that private life

insurance in Canada fits somewhere between a *non-primary social good* and a *primary social good*.<sup>13</sup> Apart from employment income and state support, some families will still be in need of additional funding to cover living expenses, mortgages or debts in the event of death in a family. Moreover, as mentioned earlier, pursuing entrepreneurial activities and acquiring high-level executive positions usually require that persons take out a life insurance policy, and these are all things that persons should be free (and able) to do. So, I am in line with O'Neill who further classifies life insurance as a 'gateway social good' (2006). He summarizes it best when he states that

Access to a full range of financial products, including the mortgage needed to buy a house, is a very basic precondition of full economic citizenship in a society such as ours. Moreover, the opportunity to create and sustain a stable family life seems also to be a very basic and fundamental social entitlement. Perhaps most significantly of all, access to life insurance is an important pre-requisite for certain kinds of long-term planning—with regard to both economic and family life— which are absolutely central aspects of living a full and successful human life. (O'Neill, 2006, p. 579)

The significance of life insurance being characterized as a gateway social good is that it becomes especially important to ensure that all who want to access it can access it. One aspect I have yet to touch upon, however, is the relevance of the dollar amount of a policy. The value of insurance is certainly also dependent on the dollar value of a policy. As Lemmens says, "a life insurance contract under which an insurer accepts to pay out three

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<sup>13</sup> Note that universal basic income could make private life insurance a commodity.

million dollars to one's spouse, for example, cannot be qualified as a social good to which all should have access. Such a contract seems to be an extravagant personal choice and as such does not merit public protection.” (2000, p. 398). On the other hand, having access to a policy worth CAD 100,000 may be a major symbol of full membership in society even if this product is not necessary for access to ownership and if the state provides resources to support surviving family members (Lemmens, 2000, p. 398).

The characterizations thus far do not say anything about whether it is preferrable to increase social welfare (perhaps through the provision of a basic public life insurance) or to ensure that everyone who wants it can access a basic amount on the private market. And what about those who want more than the basic amount? Should this be provided on the private market or directly by the state? If it is to be provided on the private market, should the state also ensure that all can access it? From a “recipient” perspective these questions lead to four distinct considerations. I lay it out as follows to make the conceptual distinctions very clear:

- 1) Basic life insurance to the average person (gateway social good)**
- 2) Basic life insurance to disadvantaged groups (gateway social good)**
- 3) More than basic life insurance to the average person (commodity)**
- 4) More than basic life insurance to disadvantaged groups (commodity)**

Each of these can be provided directly by the state, subsidized/regulated by the state or provided on the market. My thought is that the question of whether, and if so, how, the state should be involved in the provision of life insurance (basic or more than basic) only becomes an issue in circumstances where there is a disadvantaged group involved. Such

disadvantaged groups can be those who cannot afford private life insurance (basic or more than basic), and those who are routinely denied life insurance (more than basic). In general, the remainder of the population is not implicated as private life insurance (basic or more than basic) cannot be characterized as unreasonably unaffordable, and almost all persons who apply to private insurance get coverage.<sup>14</sup> Moreover, I can reasonably take it as an assumption that in a free market society, life insurance companies have a *prima facie* right to exist. In other words, there is no real difference between the average person paying premiums to a private company and the average person paying tax to the state, if both options will provide life insurance coverage. There is no good reason for the state to increase taxes to provide a public life insurance system for the *general* population.

On the contrary, there may be some benefits to not have the state directly provide life insurance to the average person. Primarily, the provision of life insurance by the private market is an established institution and, therefore, may be capable of providing life insurance more efficiently. Another benefit is that, in the private market, persons can choose how much coverage they want to acquire, and this is not likely to be the case under a solidaristic scheme. Moreover, not every average person will want life insurance, and thus we would thereby avoid the debate surrounding the (un)fairness of having one pay into taxes just so another average person can collect a sum of money upon the death of a family member. People can already do this on the private market in an affordable way.

All this does not absolve the state from being involved in life insurance. This is what I will focus on next. Disadvantaged groups cannot access private life insurance as the average

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<sup>14</sup> In order to help the public realize the potential benefits of private life insurance, states should be involved through education, promotion, etc.

person is able to. In the current context, disadvantaged groups are those who cannot afford basic insurance on the private market, and/or those who would like more but are routinely denied private life insurance. These require two different solutions. With respect to those who cannot afford basic insurance on the private market, the state can either provide a basic amount for these people directly or subsidize a part of their cost on the private market. For my purposes, I see no difference as to which method is used as long as those who want basic insurance can get insurance. Consider the following criticism. Basic life insurance is a basic right in that *everyone* should have reasonable coverage without having to “opt-in”. For the purpose of determining if and how the state should be involved, however, it is important to note that this point does not mean that life insurance must be directly provided by the state, or that it should be provided for free. Basic rights, despite being universal, come at a cost. Such is the case for housing (rent), groceries, and healthcare. When it comes to the provision of basic rights in a society, it is acceptable that the state be involved only by means of providing subsidies to all (or to only disadvantaged groups) and/or through regulation, just as is the case for healthcare in Canada. In other words, the private market, under certain conditions and safeguards, can fit within an overall system committed to upholding rights. On top of providing subsidies, such a system would have mechanisms by which persons can voice their complaints and have them addressed by the courts. So, there is no issue of injustice in the fact that persons need to make a payments, and need to make these payments to a private business, to have their lives insured at a basic amount.

The second solution that is required is the solution for when life insurance takes on the role of a commodity, where a person desires more than basic amount of life insurance but is blocked from accessing it. Someone can object at this point and make the point that it

should be illegal to purchase more than the basic amount. In other words, it can be claimed that only those who truly *need* life insurance (e.g., likely to die young and leave their family members without an income) should be able to purchase life insurance. However, this would be unjustifiably paternalistic. It is certainly reasonable for persons to want to purchase more cover to pursue entrepreneurial activities or take up high level executive positions or to make this investment decision for their families and/or charities. Consequently, it is similarly reasonable to expect persons to pay (more) for this. But is there not a problem in the fact that a certain group is directly/indirectly blocked from accessing such a product, despite their desire and ability to pay? I think there is a problem. If there is, then in addressing this ethical problem, I think it is more practical for the state to subsidize part of such disadvantaged persons' costs on the private market, up to a limit, than to create a public insurance system specifically for this case. The remainder of my thesis is going to discuss what would make it that someone would be deserving of state support.

In the next chapter I will outline the main ethical considerations involved in genetic discrimination in life insurance, my research questions, and my general motivations and framework. I will start with the question of what exactly 'genetic discrimination' is in the political philosophy literature and why it is considered important.

## Chapter 2. Ethical considerations, and general motivations and framework

### 2.1 Genetic discrimination in the political philosophy literature

The philosophical literature on genetic discrimination defines it as the differential treatment of persons based on their genetic characteristics (Lippert-Rasmussen 2015, p. 188; O'Neill 2006, p. 575; Hellman 2003, p.87).<sup>15</sup> Before I expand on “genetic discrimination”, I would like to note how the use of the term “discrimination” differs between political philosophy and law. Discrimination in the legal sense already has a normative/moralized component attached to it, meaning that the term “discrimination” is viewed as a *prima facie* wrong.

But in the philosophical sense there is a differentiation made between “discrimination” and “unjustified discrimination”. Discrimination, on its own, merely means differential treatment and there may be nothing wrong with it. Treating persons differently does not necessarily cause a disadvantage (Lippert-Rasmussen, 2018), nor is it necessarily incompatible with the moral principle of equality. Unjustified discrimination, on the other hand, is generally said to take place when there is *disadvantageous* differential treatment, where the resulting disadvantage is said to be unfair (Moreau, 2018).<sup>16</sup> As Moreau says, “sometimes this occurs intentionally or explicitly, and we call it ‘direct discrimination’ or ‘disparate treatment’; sometimes it is a side-effect of a policy adopted for quite different and

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<sup>15</sup> Philosophical discourse on genetic discrimination does not fit so neatly into the general discrimination literature because it is the case that there being a socially salient group (e.g., “protected class”) to which a person belongs to is usually necessary for an action or policy to be labelled as *discriminatory* (Lippert-Rasmussen, 2015). Nevertheless, genetic discrimination is still referred to as “discrimination”, and it has its own unique features that are debated. These are discussed below.

<sup>16</sup> One way to think about unjustified discrimination, then, is to view it as when the state or other agent is not treating persons as equals (Moreau, 2018, p. 264). This could mean that that the agent is generalizing/profiling/making assumptions about a person based on a group/trait that does not define them.

perhaps even beneficial reasons, and we call it ‘indirect discrimination’ or ‘disparate impact.’” (Moreau, 2018, p. 264).

One kind of case where the resulting disadvantage is said to be unfair is when the discrimination is based on a *morally arbitrary* trait or reason (Lippert-Rasmussen, 2015). Those who are in favour of the Canadian Genetic Non-discrimination Act, for example, could be said to be viewing certain genetic information as morally arbitrary, implying that persons ought not be disadvantaged as a result of possessing them. Recall that being *disadvantaged* in the case of life insurance mainly refers to not being able to afford insurance. On the other hand, those who argue against the Canadian Genetic Non-discrimination Act claim that requiring genetic information from persons to protect actuarial fairness is not a morally arbitrary reason, implying that genetic discrimination is justified discrimination.

There are other similar accounts of what makes discrimination unjustified. Sophia Moreau, for example, argues that discrimination is unjust if it reduces one’s deliberative freedoms (2010). Deliberative freedoms are the “freedoms to have our decisions about how to live insulated from the effects of normatively extraneous features of us, such as our skin color or gender” (2010, p. 155). All of us are entitled to certain deliberative freedoms and these freedoms depend “... not on the range of options available to a person, but on the absence of certain considerations from his deliberations.” (Moreau 2010, p. 173). Having to think about certain genetic characteristics in being able to access life insurance can be interpreted to be clashing with our deliberative freedoms.<sup>17</sup>

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<sup>17</sup> Although Moreau’s account shares similarities with the luck egalitarian approach (which also focuses on moral arbitrariness), Moreau refers to her account more so in providing a philosophical justification for anti-discrimination laws. I, on the other hand, will mostly use the luck egalitarian account because one of my aims is to criticize anti-discrimination laws, and luck egalitarianism has been (explicitly/implicitly) used to do this.

Another account for the wrongness of discrimination is Deborah Hellman's new *compounding injustice* account, which states that discrimination is unjustified if it compounds injustice (Hellman, 2018). In order for an agent to compound injustice, they must (1) "...amplify the prior injustice either by making the harm caused by the prior injustice worse or by causing it to lead to a new harm in another sphere of life" (Hellman, 2018, p. 113), and (2) "...take the prior injustice or its effects as their reason for action." (Hellman, 2018, p. 113). This account is similarly harm-based.

Deborah Hellman also has an older account for the wrongness of discrimination. This is the *expressivist account*, which says that discrimination is wrong because of the meaning that it expresses (Hellman, 2003). In other words, wrongful discrimination is discrimination that demeans a person. Demeaning is said to be wrong because it violates the moral principle of equality (Hellman, 2003). A person is demeaned "... iff (1) the act expresses the view that the person is less worthy of concern or respect, and (2) the agent discriminating is in a position of power or has superior status relative to the person being discriminated." (Hellman, 2008, p. 35). For obvious reasons, the context in which the message is expressed is key to determining whether it is demeaning or not. Note that in such a case, harm to the individual is not necessary; offense is enough. But even if the person does not feel demeaned or offended by the expression of a negative message, the expressivist account would still find it wrong because of what the action or policy *represents*.

## **2.2 Controversial features of genetic discrimination**

Persons who are genetically discriminated against in insurance are generally **asymptomatic individuals** which is one aspect of what makes genetic discrimination

controversial. If they were symptomatic at the time of application to insurance, their condition would simply be viewed as an “existing medical condition” instead of “genetic information”. What makes this aspect of genetic discrimination controversial is that genetically compromised individuals may never come to manifest the associated disease, and yet such information is used in risk calculations by insurers. However, this may be no different than discrimination based on lifestyle or environmental risk that insurers routinely engage in. Insurance is based on risk, and persons are not (and should not be) treated as though they will necessarily get the associated disease, whether it is based on environmental, lifestyle, or genetic information. Rather, pricing is (should be) calculated based on the risk that health-related information brings, with respect to the manifestation of the health outcome. Of course, such an explanation for why this aspect of genetic discrimination is not controversial is only convincing if we can be sure that insurers are, in fact, using genetic information correctly when calculating risk. If insurers are genetically profiling potential clients, without adequate attention to contextual information, for example, then the same kind of problems that arise in racial profiling are introduced.<sup>18</sup>

Another controversial aspect of genetic discrimination is that laws against genetic discrimination have generally focussed on protecting **only genetic test results**, and not other types of genetic information (Joly, Dupras, Pinkesz, Tovino, & Rothstein, 2020, p. 2.13). Family history of genetic diseases, and other non-genetic medical tests, also reveal information about one’s genes and its relationship to a disease, though not necessarily with

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<sup>18</sup> As Francoise Baylis says about race, for example, “...our racial identity is not in our genes, but in the world in which we live and in the stories we choose to construct and are able to sustain” (Baylis, 2003, p. 149). Similarly, our health is not only in our genes. I will comment much more about this aspect of genetic discrimination in Chapter 4.

as much precision or detail. Yet, these are still routinely used in insurance decisions (Joly , Dupras, Pinkesz, Tovino, & Rothstein, 2020). Thus, among other things, the Canadian law can be said to protect only those who can afford to get a genetic test label on their genetic condition while leaving those who cannot without legal protection. Moreover, most Canadians who claim to have experienced genetic discrimination state that it is because of discrimination based on their family history of genetic disease, not genetic test results (Bombard, et al., 2009, p. 1435). I will say much more about this aspect of genetic discrimination in Chapter 3, where I discuss the moral standing of *genetic test exceptionalism*.

The third controversial feature of genetic discrimination has to do with the reasonableness of the claim that it is wrong for insurers to ask persons to take a genetic test as a **condition for eligibility**, whereas it is acceptable for them to demand test results if they are already at hand (Sandberg, 1995). Is there a difference between the two cases? I will comment on this important liberty issue, along with other liberty problems associated with revealing genetic information, at the end of Chapter 4.

A fourth controversial feature, in the Canadian context, is that life insurance is under the **jurisdiction of provincial governments**, yet a federal law (sections 3-5) is now in place to regulate life insurance practices. After an appeal from the Quebec Government, Bill S-201 was reviewed by the Supreme Court of Canada for its constitutionality. On June 10, 2020 the court ruled that that the Genetic Non-discrimination Act did not constitute a violation of the constitutional exercise of federal power (Stefanovich, 2020). Despite making criticisms of the Genetic Non-discrimination Act, this is a feature I will not comment on any further in this

thesis.<sup>19</sup> Another dimension I will not discuss in this thesis is how life insurers should respond, with respect to their regulatory practices, to the legalization of medical assistance in dying in Canada.

### 2.3 Main research questions

The primary context in which genetic discrimination is analyzed in this thesis is that of life insurance in Canada. My main research question is the following. *How should the state respond to genetic discrimination in life insurance?*<sup>20</sup> Those who have worked on whether genetic discrimination is acceptable have generally analyzed whether using such information amounts to unjustified discrimination—that is, they have analyzed whether genetic characteristics is a morally arbitrary trait when it comes to insurance decisions, and/or whether it is disadvantageous/harmful/demeaning, *etc.* for these individuals when their genetic information *is* used in insurance decisions. Naturally, a familiar theory which has made a prominent mark on this question is that of luck egalitarianism. Luck egalitarianism states that persons should not be disadvantaged based on traits or circumstances over which they have no control (Lippert-Rasmussen 2015; Segall, 2010; Cappelen and Norheim 2005). The trend, then, has been to explicitly or implicitly state that genetic discrimination in life insurance amounts to unjustified discrimination on luck egalitarian grounds (Lippert-Rasmussen, 2015)<sup>21</sup>

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<sup>19</sup> Two other unique features of the Canadian law are that this Bill was introduced by a private member in the Senate, James Cowan, and that Liberal backbenchers as well as all other major party MPs voted against the current liberal government's assertion that the proposed law was unconstitutional (Akin, 2017).

<sup>20</sup> The aforementioned controversial issues will be discussed under this main research question.

<sup>21</sup> As mentioned earlier, there are other accounts of why genetic discrimination may be unjustified discrimination but most of the policy articles on the topic explicitly or implicitly highlight the *immutability* aspect and the *disadvantaging* aspect of genetic discrimination when discussing the wrongness of discrimination.

For luck egalitarian reasons, or others, many governments have created genetic non-discrimination laws prohibiting life insurers from demanding genetic test results from insurers. In a way, this is one response to the question of how the state should respond to genetic discrimination. However, given that genetic discrimination is generally viewed as unjustified discrimination based on luck egalitarian grounds, the creation of these exceptionalist laws have prompted the second fundamental research question in the genetic discrimination literature: is it acceptable for the law to *only* protect genetic information, and not other (“uncontrollable”) health related information, from being used in insurance? (Lippert-Rasmussen 2015; Lemmens 2000). The trend here has been either to argue that genetic exceptionalism is not justified because the said differences between genetic and non-genetic information do not hold (Murray, 1992; Rothstein and Anderlik, 2001) or to argue that genetic (test) exceptionalism is justified, at least as a first step towards the ultimate goal (Hellman, 2003; Rothstein and Anderlik, 2001), or because it allows persons to make use of genetic tests and participate in genetic research studies without *fear* (Bombard and Heim-Myers, 2018; Avraham, 2018; Hellman, 2003).

The arguments I will put forth and defend in this thesis are situated within this philosophical context. In light of these trends, I will begin by discussing whether genetic exceptionalism is justifiable in the context of life insurance, in Chapter 3. From here I will explain how the state should respond to genetic discrimination, if not through genetic exceptionalism, in Chapter 4.

## 2.4 General motivations and framework: Public reason

In this thesis I make arguments about how persons should be treated by life insurance companies with respect to pricing and eligibility. Since I want my conclusions to inform policy on life insurance, and since policy in a democratic society cannot be determined by the private interests of stakeholders, I ground my conclusions in reasons that could and should be accepted by all (reasonable) persons affected by the policy. This is why my research is situated within the public reason tradition in political philosophy. I will start by explaining my understanding of public reason, and then proceed to consider some implications for a society's discussions regarding policy on life insurance.

Public reason is 'public' in two ways. Primarily, it is public in the sense that it is concerned with public issues, or issues involving the exercise of power by the state in the interest of those over whom the power is exercised (Rawls, 1999). Public reason does not deal with non-public issues since the value of individual, negative freedom is clearly more fundamental in cases that do not involve the responsibility of the state. These are cases where autonomous persons have given free and informed consent, and where whatever action taking place does not have secondary negative effects (broadly construed).

Public reason is also public in the sense that it works out our views and our will *as a public*. What it means to work out our views and our will as a *public* is that, in the process of doing so, we are to refer to reasons that all reasonable persons within a public can come to understand. This is a general moral claim about whether, and if so, how, *individuals'* moral or religious doctrines are to play a role in political discourse. So, if we are to use reasons that all reasonable persons can come to understand, then public reason is said to be impartial/neutral towards persons' world-views, meaning that it is not concerned

about assessing the truth claims of such world-views. Rather, public reason is concerned about reasonableness and how we can live together. As Jonathan Quong (2010, p. 291) puts it, an unreasonable view is one that rejects one or more of the following:

(a) that political society should be a fair system of social cooperation for mutual benefit,

(b) that citizens are free and equal, and

(c) the fact of reasonable pluralism

So, the basic idea is that each person, who is aware that they are sharing the world with others, *will* come to accept that, when dealing with issues that affect us all, we should use public reasons to defend our proposals. As Mandle summarizes it, this is necessary “...in order for a decision to be truly collective and therefore legitimate” (2013, p. 133).

Given that there may be different ways to weigh and balance competing views/interests, how exactly should this this weighing and balancing take place? In this thesis, I am working under the presumption that if (1) all public reasons can be accommodated, this is what should be done; (2) public reasons themselves clash, we should once again use other public reasons to adjudicate between them. In practice, this will be done in real time in a particular society. As Mandle says, it is

... a decision that must be made by the citizens of a democratic society, presumably through their representatives. An account of public reason provides the framework to decide what kinds of considerations are relevant to that public deliberation and what kinds are not. At least in the case of ordinary political decisions, it is left to

citizens collectively to assess the strength of these considerations and make the decisions they think best from within this framework. (2013, pp. 135-136)

However, there is still something to be gained by theorizing, and so, in this thesis, I want to provide a sense of which outcomes would be *more* justifiable. The arguments I will make in the following chapters, then, should be useful for policymakers in liberal democracies. In chapter 4, I will put forth rules of (genetic) non-discrimination that are informed by the values and interests that are involved. The persons or agents who are affected by policy on life insurance, especially with respect to discrimination, are (1) clients and potential clients, (2) representatives of the insurance industry, and (3) the public-at-large. Each of these groups, which have sub-groups within them, have reasonable concerns and interests. Among others, these concerns and interests are embedded in values that include luck egalitarianism, the expressivist account of discrimination, the compounding injustice account of discrimination, humanitarianism, privacy, reasonable business profitability, actuarial fairness, the value of public health and scientific (genetic) progress, the social connection model of responsibility, the harm principle, and practicality. So, in developing and defending my rules, I account for these values by either using them to justify the rules or using them to adjudicate between the competing interests.

## **2.5 Duty bearers**

For the rules that I develop to be put into action, there needs to be certain duty bearers, and so, now I will say a little bit more about how I justify the assignment of responsibilities to different agents with respect to their role in the realization of the rules of (genetic) non-discrimination. First, it must be recognized that all persons, who have genes,

can be genetically discriminated against and that this is a strong factor for solidarity; “the issue of genetic discrimination expands from linking only with a small affected population to an issue that concerns the entire population.” (Van Hoyweghen & Rebert, 2012, p. 873). With the advancement of cheap and effective gene editing technologies such as CRISPR/cas9 this concern over genetic discrimination is further amplified; if such technologies become available for persons to make use of as they wish, not only can this exacerbate genetic discrimination, but it can subsequently widen other inequalities. As Joly *et al.* put it,

Gene editing and gene therapy may indeed lead to a novel form of GD [genetic discrimination]: discrimination based on genetic intervention rather than test results (32). Considering the possible unknown adverse effects associated with gene editing, individuals could be stigmatized or discriminated against. This would also likely be the case for those attempting cutting-edge preventive gene therapies. Conversely, should such genetic interventions become common in our societies, it may be those who do not want to be gene altered or cannot afford it who will be at risk of discrimination. These considerations indicate that forward-looking approaches to regulating GD should seriously consider genetic intervention–based discrimination scenarios in order to prevent future unfair treatment of individuals who have had genetic interventions. (Joly , Dupras, Pinkesz, Tovino, & Rothstein, 2020, p. 2.13)

To prove that we are all responsible to correct a problem, in the ways that we can, it is sufficient to show that this problem is directly or indirectly related to an injustice. Singer’s famous principle makes the point here: If it is in our power to prevent something (very) bad from happening, without thereby sacrificing anything morally significant, we ought, morally,

to do it (Singer, 1972). This principle is not inconsistent with the idea that first and foremost, it is the state's responsibility to set up just institutions. When it comes to citizens, as Rawls says, "... the most important natural duty is that to support and to further just institutions." (1999, pp. 293-294). There are two parts to this: "...first, we are to comply with and to do our share in just institutions when they exist and apply to us; and second, we are to assist in the establishment of just arrangements when they do not exist, at least when this can be done with little cost to ourselves." (Rawls, 1999, pp. 293-294). So, it is the responsibility of all relevant agents to help set up conditions where the rules of (genetic) non-discrimination are applicable. This does not mean that all agents will have the same responsibility; relative power and ease are two important considerations in assigning responsibility. Since a system of life insurance is already set up, the actions that will be required will mainly be compartmental changes and additions and/or financial assistance. More details about the particular tasks and subsequent responsibility-holder(s) of each task will be addressed after each rule of (genetic) non-discrimination is laid out and discussed in Chapter 4.

## **2.6 Criticism of public reason**

My main objective in this thesis is to explain how the state in a pluralistic society ought to respond to discrimination in life insurance. To this end, I outlined my understanding of public reason in this chapter and explained how it is to be used. Even though I believe that the public reason framework has valuable contributions to make to this issue, and is sufficient to provide a legitimate answer, I am, nonetheless, cognisant of some of the shortcomings that public reason may have as a framework. I will briefly explain them below, including my response to how I have taken these considerations seriously.

The term 'public', for example, assumes a clear dichotomy between 'public' and 'private' spheres, which is both gendered and hierarchized (Tronto, 1993). Feminism is interested in the implications of this dichotomy, to the exclusion of women and other oppressed groups. It analyzes how this dichotomy leads to the construction of social roles, norms, and categories that are associated with sex, gender, race, class, ethnicity, species, etc. For example, as Baier puts it, traditionally men's moral theories' version of obligation does not include some sort of obligation to ensure that there be adequate care of the young, which then unequally falls on the shoulders of women (Baier, 1995, p. 6). She says that "these theories...exploit the culturally encouraged maternal instinct and/or culturally encouraged docility of women." (Baier, 1995, p. 7).

Moreover, classical theories have disproportionately focused on values such as autonomy, individuality and abstract rationality, and they take the attention away from the value of *care* in our lives (Tronto, 1993, p. 179). They have focused on abstracting away, where morality is appropriate only from a "the moral point of view." This, however, runs contrary to an ethic that begins from people's connection to others (including non-human animals) and makes care either an expectation or voluntary. So, feminists have critiqued the supposed priority given to 'reason' understood in this way, and its ability to generate abstract principles. I agree with Baier and Tronto that care (a felt concern for the good of others) deserves moral recognition, and that it is a virtue that ought to co-exist with the virtue of justice in governing our relations. Ethics of care, for example, is a legitimate and alternative model of reasoning that has much value to add. And, to an extent, I have (purposely) taken these considerations into account within my arguments.

When adjudicating between different interests, for example, I pay close attention to the lived experiences and epistemic privilege of these groups.<sup>22</sup> As Tronto says, thinking about care forces us to think concretely about people's real needs, and how we can meet them (1993, p. 124). I have also chosen not to use the Kantian overtone of distance and rather focused on the helping and nurturing tone of care, where appropriate. For example, when I discuss the social connection model of responsibility as well as when I theorize about luck in Chapter 4, I pay very close attention to context and social relationships.<sup>23</sup> I have, as much as I can, taken these concerns about the public reason framework seriously, and worked to incorporate them into my argumentation.

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<sup>22</sup> In the ways Maria Lugones (1987) Uma Narayan (1988) advocate. Lugones' "World"-travelling, for example, is a great way to concretely learn about others' lives.

<sup>23</sup> Moreover, I do not necessarily contend that public reason only applies to 'constitutional essentials and matters of basic justice'.

## **Chapter 3. Genetic exceptionalism in life insurance?**

The question this chapter answers is whether it is acceptable for the law to only protect genetic information, and not other health related information, from being used in life insurance. As the way things stand now, the law in Canada specifically protects *certain forms* of genetic information but not other types of health-related information, such as those relating to lifestyle and environment. This position is known as *genetic exceptionalism*. But what exactly is the difference between having the breast cancer gene and having a pre-existing condition, say from growing up under second-hand smoking, that makes it acceptable to discriminate based on the risks associated with the damages of second-hand smoking but not on the risks associated with the presence of the breast cancer gene? Many authors have addressed this sort of question concluding that genetic exceptionalism does not hold (Malpas, 2008; Lemke, 2005; Launis, 2003; Lemmens, 2000). In this chapter, I also intend to conclude that genetic exceptionalism does not hold.

### **Part 1. Genetic exceptionalism**

I will first state the arguments that have been put forth to defend genetic exceptionalism, and then explain the responses that they have received. The general way that critics have shown that the arguments in support genetic exceptionalism do not hold has simply been to provide other types of health-related information that are also covered by the said arguments. The top four arguments from the genetic discrimination literature in support of genetic exceptionalism are the following: (1) genetic information is very precise about its predictive value; (2) genetic information is “other”-regarding; (3) genetic

information is fundamentally personal; and (4) genetic information is beyond one's control (Launis, 2003; Lemmens, 2000).

### **The predictive value of genetic information**

The first argument in support of genetic exceptionalism is that genetic information is very predictive about one's future health. It is true that genetic information reveals how much one's genes can contribute to their risk of developing a health condition. However, genes are not the only determinant of future health; generally speaking, one's environment and lifestyle work together with one's genes to determine a health outcome. Only information regarding high-penetrant, single-gene disorders are very predictive in this regard. One such disease is Huntington's disease. If one has a mutation in the Huntington gene, it is almost certain that they will begin to show the symptoms of Huntington's around the age of 40 (National Institutes of Health, Huntington Disease, 2020).<sup>24</sup> With respect to Huntington's, then, the precision of the genetic information may warrant it to be deserving of special treatment, whatever this treatment may be. But this is only one of thousands of genetic markers. When it comes to the majority of genetic conditions, the genetic information is no more predictive of future health risk than information from non-genetic sources. Such information includes lifestyle information such as eating habits, exercising, skydiving and parasailing, and medical information such as having an HIV or Hepatitis B infection (Lemmens, 2000). Thus, this argument does not give reason as to why genetic knowledge in general should be dealt with differently than other health-related information.

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<sup>24</sup> Huntington's will be discussed in some detail in chapter 4.

## **Genetic information is other-regarding**

The second argument in support of genetic exceptionalism is that genetic information is other-regarding (Factum of the Intervener- The Privacy Commissioner of Canada, 2019, p. 8). Genetic information may be other-regarding with respect to family-members/sexual-partners, as well as with respect to populations-at-large (ethnic, racial, local) (Lemmens, 2000). I will consider family-members/sexual-partners first. Genetic information has relevance to family members because there are similarities in the genetic constitution of family members. If one family member has a genetic condition, this will say something about whether another family member also has the genetic potential to develop this condition. Ilklic writes that “due to this aspect and the consequences which it implies for example with regard to the autonomy of family members, informed consent or the right not to know, many authors advocate special treatment of genetic information.” (2009, p. 133).<sup>25</sup> Being other-regarding, however, is not a feature that is unique to genetic tests. Non-genetic health information such as positive tuberculosis, gonorrhea or HIV tests are also other-regarding for family members and sexual partners in much the same way (Ilklic 2009, 133; Lemmens 2000, 372).

Genetic information is also other-regarding with respect to what it means for populations-at-large (Lemmens, 2000, p. 373). For example, sickle cell anemia is much more common in the African-American population, which is a group that is already stigmatized. Lemmens notes how

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<sup>25</sup> As addressed in the beginning, this special treatment usually comes in the form of legally prohibiting insurers from having access to genetic test information.

...in the 1970s in the United States, massive sickle-cell screening, which was introduced as a health care program, led to [further] discrimination against African-Americans. Many African-Americans identified as carrying the sickle-cell trait were excluded from a variety of occupational settings as a result of protective measures that were based on what later appeared to be erroneous scientific grounds-the theory that carriers of the genetic trait are at risk for losing consciousness as a result of exposure to low oxygen levels. (2000, p. 373)

Commenting on the same issue, Lemke states that as a result “there is ... the danger that there will be a disparity in resource allocation and in the public attention on these diseases.” (2005, p. 26). For example, even though Sickle cell anemia is much more widespread across the whole United States population as compared to Cystic fibrosis, which mainly affects White people, there is much more funding allocated to research into Cystic fibrosis (Lemke, 2005, p. 26)

So, the argument that results is that genetic information should be treated differently in order to protect certain groups and populations. Admitting that these are serious concerns, Lemmens says that they are not unique to genetic sources of information (2000). For example, “statistics indicate differences in the [1] incidence of cancers among local communities, [2] the lower incidence of high cholesterol levels among certain ethnic groups, and the fact that HIV/AIDS is more prevalent among gays and intravenous drug users and specific ethnic communities.” (Lemmens, 2000, p. 374). Another example is postal codes. Where someone lives can provide statistical information about one’s chances of having an HIV/AIDS infection, as well as information about their housing and living conditions

(Lemmens, 2000). This can then then provide further statistical data about one's life expectancy (Lemmens, 2000, p. 374). As Lemmens stated 20 years ago, but is equally representative today, "in general, rates of poverty in America are much higher among certain ethnic group. ... [and] in Canada, some Inuit communities have very high rates of youth suicide and lower average life expectancy than elsewhere in the country." (2000, p. 375). Therefore, it is clear that if something being other-regarding is the reason as to why it deserves special treatment or protection, then not only genetic information, but such non-genetic information discussed by Lemmens should also be treated in the same way by life insurance.

### **Genetic information is fundamentally personal**

The third argument in favor of genetic exceptionalism is that genetic information is fundamentally personal (Factum of the Intervener- The Privacy Commissioner of Canada, 2019; Launis, 2003). The claim is that our DNA is representative of our fundamental characteristics and is therefore more essential to our existence than other types of information. Launis responds to this by saying that "it seems ... incontestable that which characteristics are essential to our being will depend, at least to some extent, on us. In the final analysis, we are the only ones who can decide whether the fact that we have some genetic or genetically determined characteristics has some special meaning for us..." (2003, pp. 91-92). Just as some persons may view having the Huntington's gene or HIV as having a special meaning for themselves, others may consider their internet search history, monthly subscriptions and how much they exercise just as special or personal. Objectively speaking, given that genes do not mean much by themselves (and require environments and lifestyles

to have a certain meaning), there is no reason as to why genes should be viewed as more fundamentally personal. What if one claims that genes are personal because they are literally inside of us? Well, our blood is similarly inside of us, but blood tests are nonetheless routine parts of acquiring insurance.

### **Genetic information is beyond one's control**

The fourth argument in support of genetic exceptionalism is that one's genetic predispositions are beyond one's control (Lemmens, 2000; Lippert-Rasmussen, 2015). It is true that one's genetic predispositions may be beyond one's control but one's genetic predispositions generally do not have much meaning without context, where something relevant may be under the control of the individual (Lippert-Rasmussen, 2015). As mentioned earlier, Huntington's is an important exception. Regardless of the controllability of the potential consequences of genetic predispositions, however, it turns out that many non-genetic sources of health information are beyond individual control to the same extent. For example, being exposed to air pollution or second-hand smoking as a child, being born into poverty, and not having access to required nutrients, being abused and bullied are similarly beyond individual control, yet society has not chosen to interfere with life insurance to prohibit such information, or information that can be derived from them, from being used in insurance. So, this luck egalitarian defence of genetic exceptionalism only directly covers the Huntington gene, and those like it, but it also *directly* covers other non-genetic information about persons. Thus, this argument also fails to defend genetic exceptionalism.

While these four arguments do not press in favour of genetic *exceptionalism*, I do acknowledge that they may press in favour of restricting a wider range of information from life insurance. For example, it may be said that the arguments from privacy and uncontrollability are strong arguments that prescribe not only the special treatment of “genetic information” but of all “private” and “uncontrollable” information. This may include some genetic information, some epigenetic information, some environmental information, and some lifestyle information, among others. In this case, the “special treatment” or “protection” is in the form of legal prohibition. But does it have to be that way? Earlier I explained why life insurance for the average person is best provided on the private market on a mutual insurance scheme, and how it is essential for all relevant information to be provided to insurers for this insurance scheme to function. Apart from this practical point, in the next chapter, I will further explain why a luck-based account of discrimination (my favoured account) in a value-pluralist society does not necessarily require legal prohibition, while still maintaining that a wider range of information ought to be “protected”. In other words, I suggest that there are better ways to ensure that persons are not disadvantaged/demeaned due to uncontrollable information, and/or to ensure that their privacy is not infringed. The more plausible solution, I will suggest, is for (1) there to be a no-questioned-asked, basic, guaranteed life insurance coverage available to all; and, for anyone who reasonably demands more than the basic amount, (2) genetic and non-genetic discrimination to take place at the level of insurance, but then (3) for the state to offer compensation when such discrimination is based on bad luck and leads to disadvantage/expression of a negative message. This will be the topic of Chapter 4.

## Part 2. Genetic test exceptionalism

Although genetic exceptionalism in general does not hold, Canadian law nonetheless upholds an *exceptionalist*, prohibitionist policy. The Canadian law upholds a narrower form of genetic exceptionalism policy that I call *genetic test exceptionalism* (or genetic test-result/information exceptionalism). In other words, Canada has only banned the use of *genetic test* results, and not the use of *all* genetic information in insurance. Genetic information from family history of disease, and genetic information gathered from non-genetic medical tests are still routinely used in pricing and eligibility decisions. Whether an individual with cysts on the kidney, liver and spleen, has polycystic kidney disease (a genetic disease) can almost certainly be determined through an ultrasonography (Malpas, 2008, p. 549). Similarly, “other non-genetic forms of clinical testing, for instance, blood pressure measurement, studying familial patterns of disease (family pedigrees), chloride tests on perspiration to test for cystic fibrosis and cholesterol tests can also be highly predictive of genetically based disease.” (Malpas, 2008, p. 549). All data gathered through these means are still legally permissible to be requested by life insurers in Canada. What justifies this? Why is it only genetic test results, and not other types of genetic and non-genetic health information, that deserves a state response?

Perhaps genetic test result exceptionalism is justified because genetic tests are more precise than non-genetic tests in confirming that a condition is, in fact, caused by a genetic mutation. However, we already established that precision does not justify genetic exceptionalism since non-genetic tests are just as precise in detecting non-genetic diseases. Having said this, although genetic test information is a sub-part of genetic information at large, and I concluded that genetic exceptionalism does not hold, there is still another reason

why this sub-part may require special treatment. One possible justification is that there is too much data, including information that may be unknown at the time of genetic testing, that can come be extrapolated from one's genetic tests (Factum of the Intervener- The Privacy Commissioner of Canada, 2019, p. 7). The worry is that this may cause potential clients to be uncomfortable with this uncertainty in the long term. For example, they may worry that new information that can come to be discovered from their DNA will affect their policies.

The response, however, is that insurers will probably not be requesting whole genome sequences from potential insureds but rather ask for more targeted testing. This would be a self-interested motive (to not drive consumers away) that would also work positively for insureds. Moreover, to comfort potential clients, insurers will likely explicitly state and emphasize that they will set premiums based solely on what is known at the time of contract. In any case, this is how it *should* be. If it is the case that insurers are not doing this, then this would be a sufficient reason to not allow insurers to request genetic test information. Having said this, there is no reason to assume that insurers will make this mistake.

Another reason in support of genetic test exceptionalism is that prior to the establishment of this policy in Canada, persons were afraid to make use of genetic tests for health purposes, and were deterred from participating in genetic research studies in fear of discrimination in other contexts (Bombard and Heim-Myers, 2018; Joly, Ngueng Feze, Song, & Knoppers, 2017). So, the argument goes, genetic test exceptionalism is justified because of the important value we place on promoting public health and scientific progress. I will make

a brief qualification about this particular argument before looking at criticisms. The point of this argument is that due to its relative newness, it is only genetic tests that lead persons to be afraid to make use of them, thereby missing out on opportunities to take preventative health measures, and/or halting society from making progress with respect to genetic sciences. If chloride tests, for example, also caused this fear, the argument would apply to chloride tests as well. An understanding of the historical use of the term “exceptionalism” can help to clarify this argument further. Ilkilic concisely summarizes the history of “exceptionalism” as follows:

The concept of exceptionalism was introduced in the early 1990s in the context of discussions on how to deal with HIV infections and HIV patients (Bayer, 1991). In order to guarantee more effective prevention and treatment, the aim was to test as many infected persons as possible. Due to society’s perception of this disease, additional measures not taken in the case of other infectious and sexually transmitted diseases were required to increase people’s willingness to undergo testing. In the context of this special treatment, demands were made for better counseling offers and increased efforts to gain the persons’ trust regarding the handling of test results, for example by ensuring anonymity. Such measures were discussed in reference to the concept of HIV exceptionalism. This exceptional approach to an otherwise normal problem of an infectious disease was not based primarily on scientific facts, but rather on societal perceptions and apprehensions. Thus exceptionalism of this kind is pragmatic rather than epistemological. In the course of time, society’s attitude towards this disease and towards HIV patients has undergone a major transformation

so that one can now speak of a major shift ‘from exceptionalism to normalisation’.  
(2009, p. 138)

Similarly, the general perspective towards genetic tests now is based on fear of disadvantageous treatment. So, a pragmatic solution that the Canadian government has instituted is that of banning the use of genetic test results in life insurance. As Avraham puts it, even though we may conclude that genetic discrimination is actuarially fair, and that it helps to avoid adverse selection, the resulting behaviour of insureds must also be considered by such policies (Avraham, 2018, p. 344). If genetic discrimination was permitted, persons may be deterred from taking genetic tests, and this may mean that persons will not have make any pre-emptive changes in their lives, and that genetic sciences will not be able to improve as well as it could (Avraham, 2018, p. 344). And according to Avraham, “these costs might justify prohibiting genetic discrimination, at least in lines of insurance where people might be deterred from taking the tests, despite such discrimination being fair and despite the costs associated with the risk of adverse selection.” (2018, p. 344)

There are three potential criticisms that can be made of this pragmatic argument for genetic test exceptionalism. First is that this position is classist. Second is that the justification of genetic test exceptionalism—that people fear unjustified discrimination in other contexts—is an irrational fear. Third is that even if it was a rational fear, the only or best way to deal with this fear is not through genetic test exceptionalism.

Primarily, there is the argument that genetic test exceptionalism is somewhat classist; this law only protects those who can afford genetic tests. Regardless of the merits of this criticism, however, it would only apply to those tests that persons can purchase online

through companies such as 23andMe. This is because within the institutional healthcare context in Ontario, for example, genetic tests are already covered if a medical doctor requests such testing (Grand River Hospital, 2020), and if a genetic disease is suspected, then a medical doctor will most likely directly or indirectly request such testing. Thus, the relative necessity of personal tests from companies like 23andMe may be questioned so as to undermine the classist label. Regardless, for the sake of argument I will accept that these tests currently are or one day can be interpreted to be a necessity. And since we established that genetic tests *are* unique in that they cause fear of discrimination, I believe that instead of responding by saying that all other genetic information revealing methods should also be protected, we can rather respond by saying that genetic tests should be more widely available and accessible to the public—that is, the government should subsidize such personal/commercial tests or offer such services directly for free. So, if anything, this criticism merely shows that genetic test exceptionalism is incomplete. If we accept genetic test exceptionalism in principle, it should be coupled by the public funding of genetic tests. Since this is conceivable, the argument from classism is not final, and so I will proceed to the second criticism.

The second criticism of genetic test exceptionalism is that the fear that persons have about genetic tests may be an irrational fear.<sup>26</sup> It may be said that this reaction from

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<sup>26</sup> Note here that I am initially assuming that there is good security of information in that there are no unordinary chances of genetic test information leaking, or of intentional, malicious information transfer to other organizations, etc. It is true, however, that this may not always be the case in the real world. Privacy breaches *do* happen. Now in response to this criticism, it is easy to point out that perhaps this issue should be dealt with separately, since there is no good argument for why there should *not* be good security of private information. So, the counter argument is that since things *should* be a certain way, it is irrelevant to the topic at hand (whether genetic test results should be disclosed to insurers) that things, in fact, are not as they should be. Rather, the focus should be on changing the way things are to match how they should be, the argument goes. Same is true in other circumstances. For example, it is a possibility that a Canadian life insurance company may be purchased by a foreign company and suddenly there may be new rules of access to data by government. To this important issue, again, it may be said that if an individual's fear is a result of this particular worry, this would be an argument for improved rules, instead of an argument against providing genetic information to insurers. Even though some may be convinced by such points, I am not. If privacy breaches and rules changing is a possibility, why shouldn't the potential victim be concerned? Here is my response and point. It is rational for them to be concerned, but it is irrational for this concern to only be present when it comes to genetic test information. There

individuals is an irrational one because it is actually to the benefit of the client for insurers to have genetic test information of persons, most of the time. As the way things stand now, family history of disease must already be made available to life insurers. This means that if a genetic condition is present in the family, insurers are already going to charge persons higher than if they did not have this genetic condition in the family. Same is true of a non-genetic medical test result found in one's medical history that reveals that there is a genetic mutation present; insurers are already going to charge persons higher than if they did not have this information. All that a genetic test does is to *confirm* fully whether there is a genetic mutation. With more precise information, insurers are only going to make a more precise calculation of an actuarially fair premium price. Certainly, this is to the benefit of persons in the insurance pool in general.

Moreover, from the perspective of the genetically "disadvantaged" individual, if a genetic test confirms that they *do not* have the genetic mutation, the premium price will be lower than when insurers only use family history of disease or other medical tests. If you do have the mutated gene, on the other hand, the price and outcome will oftentimes be similar (*i.e.*, access to life insurance will be restricted or more expensive), all else being the same (MacDonald, 2011, p. 12). The irrational fear, therefore, comes from thinking that genetic tests alone are able to make the price of premiums go so much higher than otherwise, that insurance becomes unaffordable. As it will be discussed in the next chapter, if insurers did

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is nothing in the essence of genetic test information that makes it more likely to be leaked, and there is no reason why other sources of information cannot be as damaging, objectively speaking. So, I think that it is still an irrational fear to fear that genetic test information may be breached, and to then use this as a reason for not having to provide genetic information to insurers.

this, it would be considered a breach of actuarial fairness. Assuming that insurers are engaging in *proper* actuarial fairness, this fear is unfounded.

Regardless, this fear exists. So how should we proceed? If we do not take any action, which is one response to this criticism, genetic tests will not be taken up and persons will not want to participate in genetic research projects. This is an outcome we want to avoid. Something that can be done is for insurers and/or public health and research bodies to offer counselling services to inform persons that these fears are irrational, or provide them with concrete, convincing information so that they can reach this conclusion on their own. I will say more about *fear* when discussing the next criticism. Before proceeding, however, note that one may say that family history of disease should not have to be provided to insurers either. But, as we said, access to health information is important in order to protect actuarial fairness in mutual insurance schemes. If the law does not allow access to genetic information, from whatever source, insurers will not be able to know a piece of the risk profile, and will not be able to charge accordingly. The provision of a no-questions asked, guaranteed insurance should help to satisfy persons who are against the provision of family history of disease to insurers. I will expand on this in the next chapter as well.

The third criticism against genetic test exceptionalism is that even if this policy was justified in order to promote public health and genetic science, it is not the best overall policy to achieve this end. I agree that the value we place on public health and scientific research is a good *prima facie* reason as to why genetic test results should be specially protected by law. But genetic test results being specifically protected by law is only one way to protect the value of public health and scientific research. A world where public health and scientific

research is protected, and where genetic test results are still disclosed to insurers is a conceivable and more reasonable world. This would be the case if the state supported individuals who were disadvantaged or demeaned as a result of having to pay more for possessing an *uncontrollable* characteristic.

So, we could say that the fear for these individuals exists not because insurers request genetic test information but because there is no state support *yet* for the people who need and deserve state support. Thus, as I will explain soon, there should be (1) a law making it illegal to deny persons insurance; (2) universal, no-questions asked, guaranteed insurance available to all at a standard rate, which would already decrease the fear; and (3) for those seeking more coverage, a means set up by the state to support people who must pay more due to bad luck, when paying more disadvantages them and/or expresses a negative message. This is the best balance of all the relevant values and interests involved, which also takes account of the value of actuarial fairness.<sup>27</sup>

### **A comparison to internet search history**

In order to further demonstrate my main point, observe the following. Currently, information such as internet search history and magazine subscriptions are not requested by life insurers. For the sake of argument, assume that this information is now being requested and that there is sound evidence indicating that there is a statistical correlation, however indirect, between a consistent search item and premature death. Also assume that in light of this, persons are now self-censoring, which is leading to several other unwanted

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<sup>27</sup> In the case of persons who are not deserving of state interference, as per the conditions mentioned above, the fear they may experience is, unfortunately, justified. This will also be expanded on in the next chapter.

outcomes. Under these circumstances, would I similarly recommend that such information should be made available to insurers, and that those whose searches or subscriptions are the result of bad luck (or for which it would be unreasonable to hold them accountable) should be compensated by the state, assuming that having to pay more would be disadvantaging/demeaning?

If the aforementioned statistical correlation is correct, then I think that just like genetic test information, internet search information should also be made available to insurers. However, for the types of data that can be gathered through internet search history, which cannot or is not gathered through other means, it is not likely that there *would* be such a correlation. For example, if one is searching about anti-depressants, and they (i) have a history of depression in their medical history, then this information is not useful, (ii) do not have a history of depression in their medical history, then insurers would need research that shows that it is making such internet searches (and not that they are in fact depressed), either by itself or when combined with other information, is correlated with premature death.

Moreover, information symmetry may not be broken in many of these cases since all that searching for something may mean is that they have searched this thing. Genetic testing, on the other hand, at least confirms that a genetic mutation is present, which is more precise than the information that could be gathered from internet searches. As we have said, even in this case, genetic information alone did not mean much (most of the time). So, even precision was not a reason for special treatment. Now, assuming that there is such a correlation, persons should have the option to not present this information but in doing so must accept

premium prices that are commensurate to the associated risk (of not knowing) and/or accept potential limits on cover. After all, one may ask, if people are willing to pay, why limit what they can buy (for guaranteed insurance)? However, it is likely to turn out that the prices will be too high if there is no cover limit. It must also be remembered that these businesses have an interest in having more people take up life insurance so they may be reluctant themselves to ask for such private information, especially if there is a negative public perception over the matter.

## **Chapter 4. Luck and life insurance in a pluralistic society: Ethical life insurance**

In this chapter, I will answer how the state should respond to genetic discrimination in life insurance. I will argue that every life insurance customer should be offered two options: (1) a no-questions-asked guaranteed insurance; and (2) insurance based on full disclosure of information. What this means, first and foremost, is that no one ought to be denied life insurance coverage. Concerns over (i) privacy; (ii) why the money ought to go here and not to, say, therapies; (iii) who is to pay for this insurance scheme, and how the transaction is to look like will be discussed. Note that when I say “guaranteed insurance” or “no-questions-asked insurance” I mean the same thing.

There are several ways to move forward. The no-questions-asked insurance can be publicly funded, privately funded, or privately funded but publicly subsidized (for some). If it is publicly funded, premium prices are likely to be offered at a standard rate or a sliding scale rate with a limit on cover.<sup>28</sup> If it is privately funded (whether publicly subsidized or not) premium prices can either be set according to cover amount *or* offered at a standard rate/sliding scale rate with a limit on cover. The latter is more likely to be the case because without a limit on cover, the risk of providing life insurance to everyone, without any health info, will be too high for insurers. On the other hand, if insurers were to take account of the risk and price accordingly, the price for everyone’s premiums would be too high to be accessible.

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<sup>28</sup> The limit on cover in the case of life insurance can be interpreted as the equivalent of limit on what is offered by public health insurance in Canada.

When it comes to insurance based on full disclosure, insurance is best provided on the private market. As such, premium prices would be based on actuarial calculations. How it is to be subsidized, if at all, however, is dependent on how the no-questions-asked insurance is delivered. If there is no cover limit on the no-questions-asked insurance and it is accessible to all, then there will be no need to subsidize anyone for the full disclosure insurance. But if the no-questions-asked insurance will have a cover limit, then those who want/need more ought to be subsidized under certain conditions. It is these conditions that will be the main focus of this chapter.

Those who have worked on whether it is acceptable for insurers to use genetic information in pricing and eligibility decisions have generally analyzed whether doing so amounts to unjustified/wrongful discrimination—that is, they have analyzed whether (1) the genetic characteristics of persons is a morally arbitrary trait when it comes to insurance decisions, and (2) it is *disadvantageous*, in the broadest possible sense, for these individuals when their genetic information *is* used in insurance (Rothstein and Anderlik, 2001, p. 356; Lemke, 2005, p. 28; O'Neill, 2006, p. 586; Lippert-Rasmussen, 2015, p. 189). Naturally, a familiar theory which has made a prominent mark on this question, either explicitly or implicitly, is that of luck egalitarianism.

Luck egalitarianism is the idea that persons should not be disadvantaged based on traits or circumstances over which they have no control (Lippert-Rasmussen 2015; Segall, 2010; Cappelen and Norheim 2005). Call this the soft version of luck egalitarianism. A stronger version says that inequalities, harms, disadvantages should *only* be neutralized if they arise from traits or circumstances over which persons have no control. Having no

control over something is, at times, meant in the literal sense, and at other times, meant to say that it would be unreasonable for society to expect persons to avoid doing this thing (Segall, 2010). One way to view this description, especially with respect to personal traits, is that these would be traits that, "...whatever the nature of the trait, the burdens that result from it are not ones that we believe its possessors should have to factor into their deliberations in ... particular social contexts." (Moreau, 2010, p. 156).

Luck egalitarianism plays a central role in how I think life insurance should be devised. However, since I am not using luck egalitarianism as a world-view/all-encompassing ideology, but rather looking at how it may be useful in a value-pluralist society, I will (1) adhere to the soft version, and (2) use it along with other commensurable shared reasons and considerations. These will become obvious as I proceed. For example, there will be times when certain forms of discrimination in life insurance will (1) despite being based on controllable traits or circumstances, still be impermissible due to humanitarian concerns, and (2) despite not leading to a (tangible) disadvantage, still be impermissible, such as when the discrimination merely expresses something negative about an individual or group. More so, since luck egalitarianism seeks to neutralize inequalities from all uncontrollable factors, I will not limit the discussion to only *uncontrollable* genetic information, but to all relevantly similar uncontrollable information—hence the title of this thesis, *Genetic Discrimination and Beyond*.

As a general note, luck egalitarianism may be considered by some to lead to cruel consequences. However, the claim that luck egalitarianism is not compassionate is only possible if the 'immutability' aspect of it is not theorized about in depth, and not enriched by

empirical data. These are things I will avoid, and in the end, I intend to show how luck egalitarianism can be very compassionate. My luck-based account of discrimination will actually increase the circle of people who will have life insurance protection. That being said, the way I approach the question of this chapter is by devising rules of (genetic) non-discrimination, which emerge from the values and considerations that are involved (luck egalitarianism, privacy, etc.), and which differ based on the contexts of select cases. The table below summarizes the rules I will be discussing.

**Table 1. Rules of (genetic) discrimination in life insurance**

Rule name	Explanation	Example	Is this rule currently being followed?
The no-denial rule	<i>No one</i> should be denied life insurance coverage. Rather everyone who applies should be charged according to their risk.	A person with Huntington’s gene applies to life insurance, and is not denied coverage as a result of possessing this trait	No
The privacy rule	A basic, modest amount of no-questions asked (universal) life insurance cover should be available to <i>all persons</i> at a <i>standard or sliding scale rate</i> .	- Guaranteed insurance	Yes, but needs improvement
The information rule	<i>All health-relevant information should be provided to insurers for use under the following conditions:</i>  1. For insurers to <i>request</i> certain information, the information they are seeking must be relevant to risk of death, directly or indirectly, and requesting the information must not be indicative of <i>bad character</i> .  2. While <i>using</i> certain information, the decision to charge higher or lower must be based on scientifically sound conclusions—that is, insurers should take account of all relevant information (genetic, environmental, lifestyle, epigenetic, etc.) when making decisions.	- Age and death  - Abuse  - Internet, magazine subscriptions  - Genetic profiling, breast cancer	Yes, but can be strengthened

The guiding rule	When seeking cover above the basic amount but below a maximum amount:  If uncontrollable information (genetic or other) increases premiums (and thereby either disadvantages the individual or merely expresses a negative message), the state should subsidize the extra cost.	- The guiding rule is the rule from which all the others below arise from.	No
The insurer profit rule	In order to do their part in combatting unjustified discrimination, insurers should <i>slightly lower their profit targets</i> or <i>contribute to a fund to help subsidize the cost of select individuals</i> .	- If cost of a premiums has a profit target of $x$ , then in order to help a person with Huntington's access insurance, they should accept a new target of $< x$ .	No
The clear immutability rule	Those who have the Huntington's gene, and other high-penetrant single gene disorders, as well as those with pre-existing conditions who were not autonomous at the time of harm, should be <i>prima facie</i> financially supported by the state for the extra cost associated with possessing this trait.	- Huntington's  - Some pre-existing conditions (ex. damages from pollution, second-hand smoking)	No
The complex immutability rule	Smokers, those with alcohol addictions and others who are addicted, and persons who cannot be considered fully <i>autonomous</i> , with respect to their lifestyle deserve state support, <i>but with conditions</i> .	- Addiction  - Obesity	No
The mutable lifestyle rule	For persons who know they have a genetic predisposition for a multifactorial disease such as breast cancer and are, nonetheless, contributing to their likelihood of getting this condition through a controllable lifestyle, the extra cost they may incur is justified to them, meaning that the state is not responsible to cover the extra cost.	- Diet & breast cancer, type 2 diabetes, heart disease	No

## 4.1 The no-denial rule

Primarily, I take it that being *denied* life insurance coverage solely based on uncontrollable characteristics (including genetic ones) is necessarily *prima facie* wrong because denying persons life insurance is disadvantageous.<sup>29</sup> This claim is justified by luck egalitarianism since luck egalitarianism is interested in eliminating disadvantages based on immutable traits.

But I think that even the person in control of their risk, genetic or not, should not be *denied* life insurance. This claim is based on humanitarian grounds, much in the same way Cappelen and Norheim discuss it in their influential paper, “Responsibility in Health Care: A Liberal Egalitarian Approach” (2005). Luck egalitarianism has been criticized for leading to harsh consequences since it purportedly abandons those who are responsible for their bad life/health outcomes (Segall, 2010, p. 46). Cappelen and Norheim, however, say that luck egalitarianism is sufficient enough to address the abandonment objection because it holds that persons need not be denied healthcare services at the time of need, but rather that they ought to be taxed a reasonable amount at a prior stage, if they are willingly choosing to participate in activities that increases their chances of needing healthcare services unreasonably more than others (Cappelen & Norheim, 2005). Life insurance, despite being less obviously important than health insurance (since not everyone will want/need even the most basic life insurance coverage), can nonetheless be an important social good in the lives of persons—hence the reason I say that being denied is *disadvantageous*. Taking these

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<sup>29</sup> One may say that *age* is uncontrollable, yet it does not seem problematic to deny a 100 year old life insurance. Regardless, the principled response to this objection is to say that even the 100 year old should not be denied, but rather that they should be charged according to the risk they bring into the pool (this would be a very high price). In actuality, however, there is not much need to debate this topic because, from a practical standpoint, 100 year old persons are not likely to seek out life insurance anyway. There is also the point that since *everyone* ages, we need not focus on a specific moment of age discrimination in life insurance, so long as there are other reasons justifying it. Rather we should remember that others who reach that age will be treated in the same way, all else being the same, when the time comes.

considerations into account, then, the first rule of (genetic) non-discrimination—the **no denial rule**—, is that *no one* should be denied life insurance coverage.<sup>30</sup>

In current society, those who are most likely to be denied life insurance are persons who are deemed to be very high risk, meaning that it is very likely that a financial payout would have to be made out by the insurer either (a) within the policy timeframe, for cases of term insurance; or (b) earlier than the average time, for cases of whole life insurance. From a genetic standpoint, these would be persons who possess single gene, high penetrant conditions such as Huntington's.<sup>31</sup> There is an important further consideration here; even after such a rule is put in place, it is still the case that persons with the Huntington's gene will not be able to access insurance. This is because they will be required to pay much more for their premiums. In this way, at least from a practical standpoint, it will be as if they have been directly denied insurance. In other words, it can be said that these two options—denial and paying much more—can be categorized as one, and that the *no-denial rule* does not achieve much; it is not “paying much more” instead of “being denied” that these people want (and deserve) but rather to be able to *afford* insurance.

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<sup>30</sup> Some may attempt to explicitly distinguish between justified and unjustified disadvantaging/harm, thereby underplaying the abandonment objection—*i.e.*, that it is okay to abandon non-deserving persons. With this move the attention is shifted back to the idea that harm is not enough, and that there needs to be another factor involved. In order to demonstrate that mere harm is not enough, one may refer to the following example by Hellman: “I open a store across the street from yours and thereby diminish your profits, which harms you.” (2018, p. 108). Similarly, one can attempt to say that it is permissible for insurers to deny insuring persons who purposely choose to live a lifestyle that increases their chances of early death, even if this harms them. Even though this *would* be a justified harm, my point is that insurers would be equally well off (and with no more unjustified work being done) if they charged persons the appropriate amount as opposed to denying them. Note that in the case where an immutable trait is involved, the other factor on top of harm is immutability.

<sup>31</sup> Other conditions which may have a genetic component and may be relevant for life insurers include breast cancer, Parkinson's, Alpha-1 Antitrypsin Deficiency, Amyotrophic Lateral Sclerosis (ALS), Alzheimer's, congenital heart disease, Cystic Fibrosis, Phenylketonuria (PKU), blindness, addictions, kidney diseases, Multiple Sclerosis (MS), Muscular Dystrophy, Neurofibromatosis, Osteoporosis, Ovarian cancer, Tourette Syndrome, Spina Bifida and Hydrocephalus, rare disorders (Canadian Coalition for Genetic Fairness, 2019) as well as hereditary motor and sensory neuropathy (HMSN), colon cancer, familial adenomatous polyposis (FAP), cancer of the endocrine system, multiple endocrine neoplasia type 2 (MEN2), myotonic dystrophy, adult polycystic kidney disease (AKPD), Li-Fraumeni syndrome and Lynch Syndrome (MacDonald, 2011, p. 11; Rothstein, 2018, p. 796).

While I agree that what is fundamental for persons with the Huntington's gene, and others like it, is to be able to access insurance (and I will get to this soon), I do think that there is nonetheless a difference between outright denying a person insurance and charging them according to the true risk they bring into an insurance pool. This difference is found in the demeaning expression that is conveyed when a person is outright denied insurance for possessing the Huntington's gene.<sup>32</sup> This is what I refer to as the expressivist account of discrimination—*i.e.*, discrimination is wrong because of the demeaning/wrongful message it expresses. The expressivist account of discrimination is a fundamental part of my account, and I will expand on it later in the chapter.

#### **4.2 The privacy rule: basic, no-questions-asked life insurance coverage**

I argue that a basic, modest amount of no-questions-asked (universal) life insurance cover should be available to *all persons* who want it at a standard rate or a rate commensurate with their income (sliding scale). This is generally referred to as *Guaranteed Insurance*. The main justification for this proposal comes from the value of privacy.

It would not be a controversial claim to say that persons have a *prima facie* right to privacy of personal information, and that this may include genetic information. Radetzki *et al.* say that “laws of privacy are often justified with reference to the importance of respecting the feeling that this information is nobody else’s business” (2003, p. 119). In Canada, “Subsection 91(27) of the Constitution Act, 1867, the criminal law power, entitles Parliament to prohibit practices that violate individuals’ privacy and in turn, their dignity and bodily autonomy” (Factum of the Intervener- The Privacy Commissioner of Canada, 2019, p. 1).

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<sup>32</sup> Even though a negative expression may still be conveyed if insurers charge much more for premiums to these people, it is less bad with respect to degree. It is partly for this reason that I argue for the state to interfere, albeit in different ways, to respond to this problem.

Genetic privacy is said to “protect an individual’s ability to control their own genetic information, and in so doing ensure privacy, dignity and bodily autonomy.” (Factum of the Intervener- The Privacy Commissioner of Canada, 2019, p. 2).<sup>33</sup>

All rights have limits, however. The harm principle, offense principle, paternalism, and legal moralism are some potential reasons that can justify limitations to rights and liberties, including the right to privacy of personal information. The context in which this right would be limited is important, however, because it will tell us what is at stake.<sup>34</sup> Remember that in Chapter 1 I had labelled life insurance as a gateway social good. A gateway social good is a good that is necessary to pursue certain activities which to some may (reasonably) be central aspects of living a full and successful human life. But since private life insurance is a gateway social good and not a primary good, the justification for limiting this right does not *need to* appeal to some other primary good. This would be necessary if we were talking about a limitation of a right to privacy in *health* insurance.<sup>35</sup> Thus, it follows that some private information can be requested by insurers for the purposes of ensuring actuarial fairness. But since life insurance is a gateway social good and not merely a commercial good, I think that persons ought to have the option to exercise this right fully, if they wish to, but at the cost of accepting a reasonable response from the insurer. In other words, this type of insurance product should be offered by insurers, but insurers should be free to limit cover (since otherwise, the mutual insurance system would not work due information

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<sup>33</sup> According to O’Scapella, “Canadian privacy laws are much more porous than their titles might imply. Often, they are mere regulatory statutes, setting only the broadest – and often unenforceable – rules for the collection, use and disclosure of personal information. For genetic and other sensitive personal information, that may not be enough, particularly in an increasingly digital environment and one in which centrally stored personal health records is the stated goal of many health care systems.” (O’Scapella, 2012, p. 41) Of course, this should be corrected, and the Genetic Non-discrimination act may be doing just this.

<sup>34</sup> Clearly privacy is taken to be an instrumental good.

<sup>35</sup> See (Kious, Genetic Nondiscrimination and Health Care as an Entitlement, 2010) for more on this.

asymmetries) and/or charge according to the overall risk they are undertaking given the potential information asymmetries. This is the second rule—**the privacy rule**—of (genetic) non-discrimination. In other words, the privacy rule necessitates that there be a reasonable amount of Guaranteed insurance available to all those who desire it.

Joly *et al.* also suggest that “...insurers should at minimum offer life insurance policy covering a minimal (ceiling) amount at an affordable rate and with no health questions (including about genomics) asked.” (Joly, et al., 2014, p. 577). They make this suggestion under the belief that it would “...foster public trust in genomics and promote the eventual use of risk prediction and stratification models...” (Joly, et al., 2014, p. 577). This proposal would also be especially useful for persons who value their privacy as a priority. However, as I just mentioned, persons must accept that insurers would have to keep the coverage limit reasonably low (but not too low) in case there are multiple individuals who may end up being high risk.

An alternative proposal that Radetzki, Radetzki and Juth offer is for death benefits and social insurance compensation by the state to be made more extensive (2003). If this happens, then private life insurance becomes a luxury good, and so it can be left to industry self-regulation, for example, to offer such a product or not (Radetzki, Radetzki, & Juth, 2003, p. 150). Increasing social insurance compensation in the event of death achieves the same end as that of private insurers when they offer a basic, no-questions-asked life insurance product. So, the privacy rule can be fulfilled through a publicly funded basic insurance as well. Of course, here too, there would have to be cover limits.

Several companies in Canada offer a product known as Guaranteed Insurance, where insurers ask minimal to no health questions. Premium prices for Guaranteed Insurance depend on age, sex, and coverage sought (BMO Insurance, 2020). This type of product is intended for people who have been denied from other coverage plans. In a way, then, Canadian insurers, at least as an industry altogether, meet the first and second rules of genetic (non) discrimination (in principle). I say ‘in principle’ because there is a problem with it. This problem is regarding how little the coverage limit is for people seeking to get Guaranteed Insurance. The maximum amount varies between CAD 25,000 to 50,000 (Manulife, 2020; BMO Insurance, 2020). It is understandable, on the other hand, that the premium rates are higher than regular life insurance products where health information is provided. After all, the reason they keep coverage low is so that premium prices do not become too out of the reach, which would somewhat defeat the purpose of such a product. Regardless, due to the importance of the value of privacy, there should be the option to have higher coverage (perhaps \$75-100,000 or more), which would of course come with higher premium rates.

There is one more consideration. Even though persons will have opportunities to access Guaranteed Insurance one way or another, I think that ideally it should be *all life insurers* who offer this product as a matter of respecting our deliberative freedoms. Sophia Moreau has an interesting thought experiment to demonstrate this idea. She says,

Suppose that a country authorized restaurants to discriminate against clientele on the basis of religion, provided that within any particular area there were an equal number of restaurants accessible to people of any given religion— for instance, thirty

restaurants for Christians, thirty restaurants for Jews, thirty restaurants for Muslims, and so on. To take off the table the situation of people who wish to go out for dinner with friends of different religions, let us suppose there are also thirty restaurants open to everyone. Suppose further that each of these groups of thirty restaurants has the same mix of good restaurants and poorer ones, so that no religious group is left with vastly inferior dining overall. And suppose that it is equally easy for everyone to access the restaurants that are open to members of their religion. (Moreau, 2010, p. 172)

Moreau believes this situation is still discriminatory regardless of the fact that “everyone can decide which of thirty restaurants to go to, in the knowledge that they will have the same quality of food to choose from and the same ease in getting there” (Moreau, 2010, p. 172). In giving her explanation as to why this is still discriminatory, she says that we must remember what freedom is at stake; “the relevant freedom in this example is not the freedom to deliberate about which of thirty restaurants to attend. Rather, it is the freedom to make decisions about which restaurant to go to without having to think about one’s religion as a barrier to any restaurant.” (Moreau, 2010, p. 172). And according to Moreau, this freedom is not present in the restaurant scenario described above (2010). What this country has done instead is to make religion a consideration for everyone when thinking about where they can eat, thereby making it that no one’s deliberative freedom in this regard is respected (Moreau, 2010).

The same is true of insurance if it is the case that not all providers are offering Guaranteed Insurance. However, since no one would be disadvantaged in a situation where

Guaranteed Insurance is overall available and accessible, I think that the only thing that can explain the wrongness of this situation is the *negative expression* that is conveyed when it is not offered by a life insurance company; one should not have to deliberate about giving up their privacy in order to access basic life insurance coverage.

Note how luck egalitarianism may not see a problem with the aforementioned situation since persons would not necessarily be disadvantaged (so long as there are options that they can easily access). Moreau, however, says that protecting our deliberative freedoms depends on not having to consider features external to us in each circumstance where they can be considered, and not on the range of options available to us (2010, p. 173). In the restaurant example, persons have to consider their religion in deciding what restaurant they can go to. And this expresses something negative; something that is unreasonable to hold people responsible for (their religion) is being used to decide where they can eat. This is similar to persons having to consider giving up their privacy when determining where they can access Guaranteed Life Insurance from. The relationship between the expressivist account and Moreau's deliberative freedoms account will be discussed later, but for now it is sufficient to say that in this case, a negative expression is conveyed because persons' deliberative freedoms are not respected.

Overall, then, all life insurers should offer a limited no-questions-asked life insurance coverage. This is respectful of persons who especially value their privacy, and is respectful of our deliberative freedoms. It is also a great product for persons with high-penetrant genes such as Huntington's.<sup>36</sup> As Radetzki, Radetzki and Juth state, the function that no-questions-

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<sup>36</sup> Note that even though such a product is currently offered by insurers, it is clearly not substantial enough that persons with Huntington's are not pursuing it.

asked insurance serves, can also be done through the state increasing death benefits or providing more extensive social insurance coverage in the event of death (2003). Those who'd like more coverage or are required to get more coverage by secondary parties, should apply for private life insurance (full disclosure option). This is what I will discuss next, starting with the conditions that are necessary for (genetic) information to even be requested and used by insurers in the first place.

### **4.3 The information rule**

Now that I have assured that no one will be denied life insurance, and that a basic, no-questions-asked insurance will be available to all, the next problem is regarding price differentiation in cases where persons seek more than the basic amount of coverage. Price differentiation is the main form of discrimination that takes place in life insurance, so I will use these terms interchangeably. For the private life insurance industry to exist, after all, insurers must be able to charge persons according to the risk they bring to the pool. Therefore, we can initially say that all relevant information ought to be provided to insurers. All things considered, however, there may be certain circumstances when information should not be provided to insurers, even if they *are* related to risk. So, before I explain how the state should respond to price differentiation, I will first expand on the prior issue of the necessary conditions for (genetic) information to even be requested and used by insurers in the first place. The following conditions will make up the information rule.

As I just mentioned, all relevant information ought to be provided to insurers so that insurers can use the data to produce an actuarially fair price for their clients' premiums. This is true under two conditions. The first condition is regarding when it is appropriate to

*request* information, and the second is regarding when it is appropriate to *use* the relevant information. I will expand on the first condition first, which itself has two parts.

Primarily, for insurers to request certain information, the information they are seeking must be relevant to risk of death, directly or indirectly. For example, there must be research indicating that a trait is correlated to death, or at least that a trait is correlated to the development of a medical condition/health outcome, which is correlated to death, etc. One can think of age as an example; age is correlated with death either directly or indirectly due to the reality that as one ages, the more likely they are to have medical conditions. Secondly, asking for information for the purpose of pricing is only appropriate when it is not indicative of *bad character* (on the part of the insurer). An action would be a mark of bad character, for example, if it is complicit with an overall avoidable injustice in real time. An example of this is requesting information about whether one is currently or has *previously* been in an *abusive relationship*.

The second condition of the information rule has to do with the appropriate *use* of the information by insurers. Using information properly means several things. Primarily, it means that the decision to charge higher or lower must be based on scientifically sound conclusions. Insurers should take account of all relevant information (genetic, environmental, lifestyle, epigenetic, etc.) when making decisions. For example, they should not overestimate the role of genes in certain multifactorial conditions. This is already how life insurance works, or it is at least established that this is how life insurance should work. Nevertheless, there should be oversight of insurers to make sure (genetic) information is

being used in a scientifically sound manner, and that insurers are continuously incorporating new scientific research into their risk calculations/models.<sup>37</sup>

Note that the information rule is effective at the level of the insurer, and not at the later step of deciding whether one deserves state compensation or not. So, when the information rule is met, we say that the discrimination that took place is *actuarially justified*. But this does not mean it is justified to the individual, all things considered. Some persons may be deserving of state compensation. This will be the topic of the *Guiding Rule*, which I will discuss next. After all, the only reason we allow genetic discrimination to take place at the level of insurance is because we are assuming that genetic information is relevant to risk, and that it is being used correctly by insurers. Not following the information rule would classify the action as “genetic profiling”, and this should not be allowed. So, a reason why genetic information should not be provided to insurers is if it is generally known that insurers are not meeting these conditions.<sup>38 39</sup>

#### **4.4 The Guiding Rule on appropriate state response to (genetic) discrimination**

Even after the no-denial rule, privacy rule as well as the information rule are met, the problem of unlucky individuals who would like more coverage, or who are required to have more coverage in order to pursue certain social activities, remains. Such activities include starting a business, taking up an executive position in a company, making an investment

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<sup>37</sup> This would include information regarding uncertainty, *etc.*

<sup>38</sup> These conditions are also relevant to family history of genetic disease, among others. For example, just because someone has a family history of breast cancer, it does not mean that this person will thereby get breast cancer.

<sup>39</sup> Of course, the basic integrity and proper basic functioning of insurance is also assumed. This includes, among other things, that private information is kept confidential, contracts are not altered after the contract is signed (i.e., insurers should be setting premiums based only on what is known at the time of contract), and other best practises in privacy protection are respected.

decision to benefit their family, etc. Klitzman, Applebaum and Chung respond to this problem. They are in support of “...universal availability of modest amounts of life insurance ... [and] for those desiring additional coverage, insurers would be allowed access to genetic information for a limited number of clinically well characterized high-risk, high-penetrance genes and variants.” (Klitzman, Applebaum, & Chung, 2014, p. 3). Per Sandberg also advocates for a life insurance scheme where limited community-rated (i.e., solidaristic insurance) insurance is offered (i.e., where the privacy rule would be met), and where insurers are allowed to ask for existing genetic information when the sought insurance cover is of a certain size (Sandberg, 1995).<sup>40</sup> Klitzman *et al.* and Sandberg’s proposals are the same except that Sandberg does not say that insurers can only request genetic test information for high-risk, high-penetrance genes such as Huntington’s. Of course, this is under the assumption that the genetic information is relevant to risk and that the information is being used correctly by insurers. So, I think that such a limitation (only high risk, high penetrance genes) offered by Klitzman *et al.* should only be in place if life insurers are misusing genetic information.

Malpas thinks that it is a plausible suggestion for insurers to be given access to relevant genetic information (including those relevant to multifactorial conditions) (2008, p. 550). From here, he says that persons who are known to be carriers of single gene, high penetrant conditions can be offered limited coverage. This suggestion also goes in the right direction but on top of suggesting limited coverage for persons with Huntington’s, as well as everyone else (*i.e.*, no-questions-asked insurance), I would also allow them to access full

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<sup>40</sup> He says insurers should be forbidden to demand genetic tests as a condition for an insurance contract if a genetic test has not already been conducted. I will discuss this liberty problem in more detail later in this chapter.

disclosure insurance if they so choose. This will allow persons who want or need to purchase more coverage with the option to do so, and it will not express a bad message in the same way since their options will remain open.

So, while all three of the aforementioned positions get some things right, I do not think they are fully correct. I will now explain my own position. My central **Guiding Rule** for (genetic) discrimination in insurance, from which many of my specific rules of (genetic) non-discrimination will follow is that when a person seeks insurance above the basic amount, but below a set maximum:

If uncontrollable information (genetic or other) increases premiums (and thereby either disadvantages the individual or merely expresses a negative message), the state should subsidize the extra cost.<sup>41</sup>

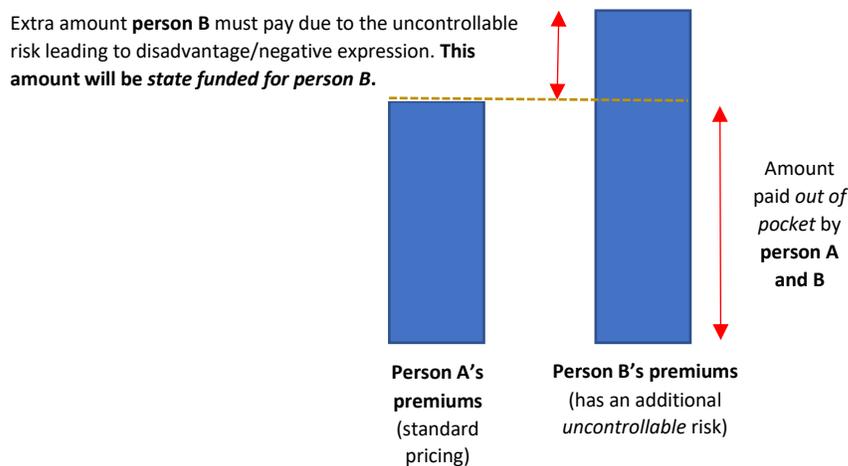
As you can notice, this guiding rule is a combination of luck egalitarianism and the expressivist account of discrimination. I will expand on both of these aspects soon but for now it is enough to know that, based on this rule, both *disadvantage* (i.e., unaffordability) as well as the expression of a negative message are enough on their own to warrant state compensation, if the said discrimination is based on an immutable feature.

The state would compensate such individuals by paying for the extra cost associated with the uncontrollable/immutable risk. *Figure 1* below represents the amount that would be paid by the state. This funding can be provided either directly to the individual or

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<sup>41</sup> This guiding rule captures the wrongness of genetic discrimination. But because I frame the problem with respect to compensation, as opposed to prohibition, it can also be said that what this guiding rule captures is the wrongness of deserving persons not being compensated for experiencing (genetic) discrimination.

indirectly, by making payments to the insurance company on behalf of the individual. The source of the funding can either be reserved state money and/or money that is collected through taxation. Of course, there would be a reasonable limit placed on the amount of cover any person, who would like, and who qualifies for state assistance, could purchase. One thing to bear in mind is that the more coverage sought, the more the “extra amount” that the state will be responsible for. As Per Sanberg says, “Limit-negotiations should refer to statistics about actual sizes of insurances that people buy today, in order to thereby reach some understanding of 'needed' and feasible limits.” (1995, 1557). It is not one of the primary objectives of this thesis to determine this limit (or the limit of Guaranteed insurance), as I think this should be the task of policymakers. However, this amount should be above the guaranteed insurance coverage already accessible to everyone.



**Figure 1. Amount to be paid by state**

It is the state that should (directly or indirectly) support individuals who must pay an extra amount due to an uncontrollable risk leading to disadvantage or the expression of a demeaning message because it is mainly the state’s responsibility to respond to (overall)

unjustified discrimination. I say “overall” because remember the discrimination may be *prima facie* justified, from the point of view of the insurer, but may not be justified, all things considered. This does not mean that the discrimination ought not take place at the level of insurance, but that the person ought to be compensated.

Even though solidarity is a foundational principle of insurance (Radetzki, Radetzki, & Juth, 2003, p. 60), it would be unreasonable, and a financial deterrent, to hold only those in the insurance pool accountable for upholding this solidarity towards high-risk individuals. This is because purchasing life insurance above the basic amount is not something that persons should not be doing in the first place.<sup>42</sup> The scope of solidarity, therefore, should expand from only those who purchase life insurance above the basic amount to all tax paying persons of a country. Solidarity, after all, is an even greater foundation for democracy, states, and human rights. As Francoise Baylis points out in her opinion piece, “Canadians understand the concept of shared risk; in large measure, this explains our public health care system.” (Baylis, 2016, p. 1). A practical benefit of following the guiding rule is that it would significantly decrease the amount that each person would be responsible for providing.

The main objection to this line of argument is regarding why the state should not allocate more funding to increase the basic insurance coverage limit rather than to subsidize those who want more but cannot access it. I think there is merit in doing both, but I do not intend to make a final decision on this matter here. One important consideration, however, would be that if the funding provided to subsidize high risk individuals can increase the basic

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<sup>42</sup> Note that, on the contrary, we say that it is permissible for something like a meat tax to only be paid by those who purchase meat (as opposed to everyone) because it is reasonable to expect persons not to buy meat in 2021.

amount limit to a level that would also satisfy disadvantaged persons' concerns, then increasing the basic coverage limit should have priority.<sup>43</sup>

This state responsibility to respond to (overall) unjustified discrimination certainly includes regulating what insurance companies are allowed to do. How much profit insurers may take, for example, may be limited by concerns over overall unjustified genetic discrimination. This will be discussed in the next sub-section.

#### 4.4a Insurer profit rule: financial responsibility of life insurers

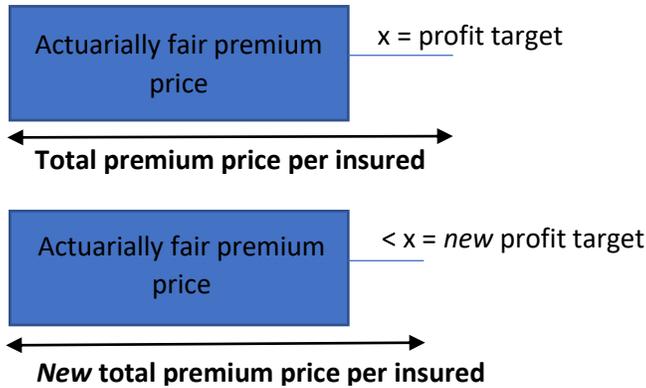
Before applying the guiding rule to different cases, I will explain what it says about the financial responsibility of life insurers, and briefly respond to a libertarian criticism of my responsibility justification. As I mentioned in the 'duty-bearers' section earlier, I think that everyone is responsible to do their part in order to respond to the problem of (overall) wrongful discrimination. In other words, all those who are implicated by the guiding rule should do their part to address it. This will undoubtedly include financial assistance from the state and citizens. But what about insurers? I argue that the equivalent of citizens paying slightly higher taxes and/or the government using reserved money to pay for the extra costs of deserving persons (those who are subjects of wrongful discrimination) is for insurers to contribute funds to a pool that is used to pay these subsidies, or to slightly lower their profit targets.

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<sup>43</sup> Even though I began writing this thesis in early 2019, I am finalizing it in 2021, which corresponds to the time of the COVID-19 pandemic. During this time many states, including Canada, provided a significant amount of financial aid to their citizens and residents. This changes the landscape of state assistance programs in the short term as government will have to balance their budgets. This may change the urgency at which this proposal would be taken up. In the meantime, however, private investors could see an opportunity to make profit. Investors could choose to pay for the extra cost, post disclosure of information, and then reap a part of the payout. For this to work for both parties, the resulting payout to the individual's beneficiaries (i.e., the amount after the investor takes part of it) must be more than the payout from Guaranteed Insurance. I thank Marc Saner for bringing this to my attention.

First, note that insurer profits (revenue-cost) come from the premiums that don't go to cover contract claims (underwriting income) plus the money they generate from investing some of the premiums, *minus* costs which include claims paid out, operating costs, and taxes. So, one way for insurers to lower their profits is by increasing the tax that they pay. This amount would be combined with the taxes paid out by citizens, or would be added to the state reserved money that would be used to meet the rules of (genetic) non-discrimination. And this would be seen as a cost of doing business. The cost is incurred directly by the businesses, not by those they insure. Insofar as costs are passed down directly to the insured, this can be viewed as a transactional cost for the buyers. The surcharge, then, happens outside the realm of actuarial fairness.

Another way for insurers to lower their profits, especially if the costs are stable, is to adjust the premium prices that all insured persons need to pay, by lowering the profit target amount that is added to (or included in) the actuarially fair premium cost for each individual. The actuarially fair premium cost also includes costs related to persons' relative risk, which also includes things like their risk of dropping out of the pool, etc. In this way, insurers' ability to pay out contract claims is not compromised because only the profit target amount is lowered. This final detail is meant to signify the point that this responsibility could be met by insurers without a great cost to themselves. See figure below for a representation of this strategy.



**Figure 2. Financial responsibility of insurers in meeting the Guiding Rule**

Agents such as average citizens or insurers may not be convinced. They may ask how they can be responsible for unlucky individuals when they did nothing to contribute to disadvantaged persons' condition(s), and so their need to be higher-cost to insure. My response is that, since we are dealing with an issue of justice, we ought to view the issue from the perspective of the *social connection model of responsibility* rather than from the perspective of the *liability model of responsibility*; persons may not be responsible in the sense advocated by the liability model, but they are responsible in the way described by social connection model.<sup>44</sup> The liability model of responsibility says that "to be responsible is to be guilty or at fault for having caused a harm and without valid excuses." (Young, 2006, p. 119). It "...relies on a fairly direct interaction between the wrongdoer and the wronged party." (Young, 2006, p. 118). This model is not well placed to deal with unjustified discrimination because any wrongdoing that may be done unto someone in this case would not be a wrongdoing committed by an agent who is doing something *out of the ordinary*. For example, insurance companies do not intend to exclude or make life insurance more difficult to acquire for those with the Huntington's gene. Rather, they are only trying to serve others

<sup>44</sup> Singer's famous principle from *Famine, Affluence, and Morality*, which was referred to earlier is commensurable with the social connection model of responsibility.

fairly and make a profit. It just happens that they do not serve others *as fairly* and make *as much profit* when genetically disadvantaged persons are included in insurance.

The social connection model of responsibility does not accept the “it just so happens” argument and rather focuses on those who are wronged. In other words, the social connection model of responsibility questions the background conditions that the liability model takes as given. Accordingly, regardless of an agent’s absence of intent in causing a direct harm to another, if they are a part of the process that keeps such persons excluded and disadvantaged, they are responsible to play a part in correcting it. Reasonable investors should be okay with this suggestion since they would/should also have an interest in supporting just institutions and socially responsible businesses.

It is also important to note that there is no issue of incompatibility between luck egalitarianism, which is an important part of my guiding rule, and the social connection model of responsibility. This is because luck egalitarianism is a distributive theory of justice, whereas the social connection model of responsibility merely theorizes about the responsibility of moral agents in making such distributive arrangement possible. Since there is no concern that moral agents would be disadvantaged as a result of aiding in making such distributive arrangements possible, luck egalitarianism is not implicated.

#### 4.4b Immutability and responsibility

I will now begin to explain how I determine who is responsible (and therefore not deserving of state support) and who isn’t (therefore deserving of state support) for the risk they bring to an insurance pool. Note that it is assumed in this section that persons would be disadvantaged by the discrimination taking place since it would make premiums

unaffordable. Some cases, such as Huntington's will be straightforward, given what we know about how this disease works, and others will be more complicated. It is here that I will provide specific rules of (genetic) non-discrimination, which emerge from the application of my guiding rule to the conditions I consider.

I will be considering the following cases: Huntington's disease, breast cancer, obesity, and behavioral genetics. The reason why these are selected in particular is because they come with their own set of unique moral challenges. Moreover, these cases are the ones that insurers often deal with today or will likely deal with in the future (especially behavioral genetics). That being said, my discussion will expand from these particular cases as I, implicitly or explicitly, draw certain comparisons to other conditions and circumstances, for which people are equally responsible or not responsible for in the same way. These comparisons include addictions such smoking and alcoholism, epigenetics, and one's sex and home address, among others.<sup>45</sup> Note once again that unless specified otherwise, the rules assume that when insurers charge more, the extra amount clients must pay is enough that it causes a disadvantage. Even though my focus below will be on how the state should respond in each case, I will also mention instances, relevant to the case I am discussing, where the *information rule* is implicated.

Before I begin with the task of assigning responsibility, it must be said that the main criticism of attempting to theorize about holding people responsible for their risks/conditions is that they too often do not take into account the social, cultural and environmental contexts of these persons (Sandberg, 1995). A common instance of this grave

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<sup>45</sup> Note that issues surrounding internet search history and subscriptions were discussed in the previous chapter.

mistake, for example, is to hold all women similarly responsible for not leaving an abusive relationship, or to hold all factory workers responsible for their injuries and/or deaths after not leaving a building that is on the brinks of collapse. I will, therefore, continue only by taking account of the contexts of persons when concluding who can be reasonably held responsible or not for their risk.<sup>46</sup>

#### *4.4b i The clear immutability rule: Huntington's +*

Around 1 in 7000 people in Canada have Huntington's disease (Huntington Society of Canada, 2017). It "...is a progressive brain disorder that causes uncontrolled movements, emotional problems, and loss of thinking ability (cognition)." (National Institutes of Health, Huntington Disease, 2020). Huntington's is a single gene (*HTT gene*), high penetrant disorder meaning that a mutation in this gene almost always causes the disease (National Institutes of Health, Huntington Disease, 2020). As the disease progresses, affected persons struggle to walk, speak and swallow (National Institutes of Health, Huntington Disease, 2020, p. 1). It is "...inherited in an autosomal dominant pattern, which means one copy of the altered gene in each cell is sufficient to cause the disorder." (National Institutes of Health, Huntington Disease, 2020, p. 1). So, an affected person generally inherits the mutated gene from one parent who is affected (National Institutes of Health, Huntington Disease, 2020, p. 1).

Given this, I argue that those who have the Huntington's gene, and other high-penetrant single gene disorders, as well as those with pre-existing conditions who were not autonomous at the time of harm, should be financially supported by the state for the extra cost associated with possessing this trait. This is the *clear immutability rule*. There are two

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<sup>46</sup> Note that I am assuming that in ideal conditions, persons have free will, or at least that compatibilism is true. Also note that when I say "responsible for one's risk", I mean "responsible for one's risk in having a disease/condition manifest".

forms of Huntington disease; the adult onset and the juvenile form, with the former being the most common form (National Institutes of Health, Huntington Disease, 2020). What is unique to adult-onset Huntington's disease is that despite possessing the gene, symptoms of this disease do not manifest until persons reach their 30s or 40s (National Institutes of Health, Huntington Disease, 2020). However, in Juvenile Huntington's disease, which makes up about 5-10% of all Huntington's cases, symptoms begin to appear in childhood or adolescence (before age 20) (National Institutes of Health: National Center for Advancing Translational Sciences, 2016). This unique feature of Huntington's has implications for life insurance. In particular, regardless of the clear immutability rule just mentioned, it would seem to follow that persons who would like to purchase *term* insurance, with a start date of when one turns 21 and a termination date of before one turns 30, should have no problems acquiring life insurance in the same way, and at the same rate (or very close) as those without the Huntington's gene, all else being the same. Creating problems for these individuals is a clear case of actuarially unjustified discrimination and a breach of the information rule.

Pre-existing conditions that would be implicated by the clear immutability rule are those that were the result of having grown up under second-hand smoking, or air and water pollution, physical and emotional abuse, etc. What about domestic abuse? Whether an applicant is a victim of domestic abuse is relevant for insurers because it provides information about one's current and future health and life status. As Hellman notes, "battered women are likely to die earlier than the average women of the same age... [and] this is true whether the woman stays with or leaves the batterer." (2018, p. 110). But what is different between battered women and someone who grew up under second-hand smoking is that "if the insurer charges the battered woman a higher rate, it uses the fact that

domestic abuse victims are likely to be attacked in the future in making its pricing decisions.” (Hellman, 2018, p. 110). And this is the reason why insurers should not be allowed to request information about domestic abuse in pricing in the first place, instead of being provided with this information, followed by the state compensating these individuals. The latter response is how things should be done for other pre-existing conditions. In other words, insurers should not be allowed to request information about domestic abuse in the first place because doing so would be a mark of bad character on insurers’ part, in the way using other pre-existing ‘conditions’ would not be.

Hellman, however, would argue that all pre-existing conditions for which the person was not autonomous at the time of harm should not be allowed to be used by insurers for the purpose of higher pricing. Her reason is that this action would be *compounding injustice*, as in the domestic abuse case, which she believes we have a duty not to do (Hellman, 2018). There are two requirements that must be met for an action to said to be compounding an injustice: the discriminator (1) “...exacerbates the harm caused by the prior injustice because it entrenches the harm or carries it into another domain.” (Hellman, 2018, p. 107) and (2) takes either the prior injustice or its effects as *the reason* for treating a person differently, or for doing something that will affect them (Hellman, 2018, p. 113).

In examining domestic abuse, consider Hellman’s analysis:

Should the insurance company take into account the fact that battered women are victims of wrongdoing when determining whether to include this relevant risk factor? The insurer, in the normal case, is permitted to consider the likelihood that an insured will die early when offering or pricing life insurance, or so I assume. But is Insuring

Battered Women different? Does the insurer wrong the battered woman if it charges her a premium for life insurance? If the insurer charges the battered woman a higher rate, it uses the fact that domestic abuse victims are likely to be attacked in the future in making its pricing decisions. ...the effects of the wrongdoing are precisely the facts that the insurer relies on in making its decision. As a result, the insurer bears some responsibility for the effects of the original injustice because the insurer takes the injustice or its effects as a reason to charge battered women higher rates. In addition, the insurer amplifies the original injustice because the harms caused by the battery now include not only the physical and mental suffering caused by domestic violence but also the economic loss of high priced insurance. For these reasons, the insurer who charges the abuse victim a premium for life insurance compounds the prior injustice. (2018, p. 110)

The same reasoning applies to growing up under second-hand smoking and the pre-existing conditions I mentioned earlier. Contrary to Hellman, however, the reason why I think that these can nonetheless be provided to insurers for pricing purposes (under the condition that they will be compensated), but domestic abuse cannot, is because even if domestic abuse victims were compensated by the state, this would not erase the negative expression that is conveyed when they are charged more. It is unreasonable to accept that victims of domestic abuse may be killed by their abusers. The particular difference is that there are currently things society can do protect this woman in real-time from potential harm or death, whereas the damage from past second-hand smoking, for example, is already done. Even if it may not be the private insurer's direct duty to protect abused women from harm, they should at least do what they can to show they are not complicit to the wrongdoing, which in this case is to

not charge her higher, should she seek insurance above the universal, no-questions-asked amount. So, an act of compounding injustice can be neutralized, therefore tolerable, so long as the state compensation can neutralize the expression of the negative message.

I would like to briefly note some important practical considerations that support this point further. Primarily, insurers for public perception purposes may already choose not to request such information. Moreover, persons may not interpret their status as a victim of domestic abuse yet or may have adapted preferences, and there may be no public record of the abuse (such as a restraining order). In other words, it may be difficult to “measure” domestic abuse for the purposes of insurance decisions.

#### *4.4b ii The addiction rule (complex immutability rule)*

The complex immutability rule is that persons who smoke, persons who live with alcohol addictions and others who have addictions and/or cannot be considered fully autonomous, with respect to their lifestyle, also deserve state support *but with conditions*. Conditions are placed because smoking (and the others) is not in the same category of immutability as having the Huntington gene. Regardless, smokers and others with addictions may not be considered fully autonomous for two reasons. The first reason is that the genes that persons are born with may make some persons much more prone to addiction than others. Ducci and Goldman state that “evidence from family, adoption, and twin studies converges on the relevance of genetic factors in the development of addictions...” (2012, p. 496). There are two variants associated with smoking that appear to act additively with respect to nicotine addiction (Ducci & Goldman, 2012, pp. 498-499). These are the *CHRNA5-CHRNA3-CHRNB4* nicotinic acetylcholine receptor subunit cluster and in the *TTC12-*

*ANKK1-DRD2* cluster (a dopamine receptor involved in nicotine reward) (Ducci & Goldman, 2012, p. 499). In one study on nicotine addiction, for example,

Adolescent carriers of three to four risk alleles at these two loci (20% of the population) had a threefold increase in odds of smoking regularly and 2.5-fold increased odds of occasionally smoking as compared to noncarriers, who constitute 9% of the population. Carriers of one or two risk alleles were at intermediate risk. A similar stepwise increase in risk with allele dosage was observed in adulthood, and again consistent with additivity. (Ducci & Goldman, 2012, p. 499)

Thus, as Norheim and Cappelen state, even those health complications that may arise from a lifestyle can be a matter of brute luck (2005). So, it is true that people may choose to smoke cigarettes and drink alcohol, but it is also true that people have different choice-making capacities (Lippert-Rasmussen, 2015). Thus, the genetic sub-basis of the capacity for choice-making challenges the principle of equalization which we have become familiar with. The principle of equalization states that people who make the same choices should bear the same costs, regardless of whether one ends up being lucky or not (Cappelen & Norheim, 2005). But if one's choices are similarly affected by something that is beyond their control, it is not rational to hold all people who make the same choice similarly accountable.

The second reason why persons with addiction cannot be considered fully autonomous is that the social environment of different people, for which they cannot be reasonably held accountable for, may make them more prone to addiction than others. Smoking rates correlate with lower income and education levels (Government of Canada, 2019; Center for Disease Control, 2019). More broadly, poor housing and living conditions

may increase one's likelihood of smoking, and negatively affect their life expectancy (Government of Canada 2019; Center for Disease Control 2019). To what extent are persons similarly responsible for being low income, uneducated or for living in poor conditions? I think it is safe to conclude that in ideal circumstances almost no one would choose to be or do these things. Therefore, I can assume that if people are low income, uneducated, and live in poor conditions, it is *probably* not due to choice. Of course, one may claim that not all people who are low income, uneducated, and live in poor conditions smoke or drink alcohol. Regardless of the truth of this, it does not mean nor is it reasonable to believe that all were affected by these social conditions equally.

Per Sandberg criticizes the task of assigning responsibility for insurance decisions because he thinks that trying to assign responsibility will turn ugly (1995). It will turn ugly in that the smoker who chose to smoke because it was popular, for example, will claim that it is unfair that another smoker has to pay less than they do, out of pocket. He will try to find reasons, genetic markers, psychological theories and other evidence to show that his smoking, which, as we first said, was due to it being popular, was in fact also not by choice.<sup>47</sup> More specifically, he could try to show that he is naturally prone to fall for peer pressure or that his social environment, which was beyond his control, made him more easily affected by the popularity of activities. For this reason, Sandberg thinks that it is simply better if what matters is only whether one smokes or not. Although what Sandberg suggests is contrary to luck egalitarianism (it is under-inclusive), it is clearly true that the sort of rule I am describing here would be a practical nightmare for many cases.

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<sup>47</sup> Similar to the smoker who became a smoker due to family distress or because he is genetically prone to addiction.

My suggestion, therefore, is that we should apply a direct luck egalitarian rule for cases that are clear cut such as Huntington's, but for cases that are not clear cut, such as addictions, we should be forward-looking instead of backward-looking. What I mean is that we should not try to assign responsibility for the past, but rather assign responsibility for future actions. For example, those who join smoking cessation groups, for free, and continually attend them should be supported by the state in paying for the extra cost associated with smoking, for the time being.

One justification for this is that even if we accept that people could not fully control their past, there is danger in accepting that they cannot control their lives, to a greater extent, in the future. In other words, while it is an extreme to conclude that all persons are personally responsible for their life outcomes, it would be another extreme to conclude that people can never be (and should not be) held responsible for their life outcomes. What makes us human is that, at least with adequate help, we can become free—*i.e.*, be held responsible for certain life outcomes.<sup>48</sup> So, if the help is *genuinely* there, and persons do not take it, it can be concluded that they were autonomous, and are (1) choosing to stick to their life outcomes, and (2) do not deserve state support to cover the extra cost of their insurance premiums. Of course, this may very well be chosen by individuals who are simply not bothered by the extra cost they must pay. And this would be unproblematic because the practice of charging

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<sup>48</sup> Note that I am aware that addiction is not a complete loss of autonomy. Rather, it is a condition characterized by diminished self-control which persists even at the risk of bringing harm to oneself or others. But even the diminishment of self-control is morally significant and so this is why I say what I say. I would like to thank Jay Drydyk for reminding me of the fine detail surrounding the *degree* of self-control.

persons more for smoking or alcoholism is not meant to be a public health measure to deter persons from smoking or drinking, though it may certainly aid in such a process.

What exactly the conditions associated with the addiction rule will look like will depend on the particular society's priorities. One important consideration will be effectiveness. Ideally, there will be evidence that a specific program has had success in the past with helping to reduce addictions within persons. A second consideration is regarding invasiveness. The monitoring of the rules should involve whether they have attended specific programs or not, but should not require receipts of purchases, for example. Finally, note that the no-questions-asked insurance will already be available as an alternative option for such persons.

#### *4.4b iii The mutable lifestyle rule: breast cancer +*

Unlike Huntington's, but like addictions, breast cancer is a multifactorial condition. In fact, the majority of medical diseases are multifactorial. Multifactorial diseases are complex because of the way genes and environmental factors may work together to manifest a disease. They may be caused by defective gene(s) working together with an environmental stimulus and/or lifestyle; or only by an environmental stimulus and/or lifestyle. *Figure 3* below shows the relationship between the relevant factors involved in the different types of multifactorial diseases.

1. Defective gene(s) + bad environmental conditions/lifestyle → multifactorial disease
2. Bad environmental conditions/lifestyle → multifactorial disease

**Figure 3. Different causes of multifactorial diseases.<sup>49</sup>**

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<sup>49</sup> A disease that is caused by mutations in more than one gene, and nothing else, can also be classified as multifactorial but this is not what I mean here.

As I mentioned, breast cancer is an example of a multifactorial disease. All else being equally bad, mutations in two breast cancer genes (*BRCA1* and *BRCA2*) increase one's chances of getting breast cancer (National Institutes of Health, 2020). However, more people who do not have mutations in the breast cancer genes get breast cancer (Cancer.net, 2019). This means that having these mutations do not lead to breast cancer, and you do not need to have the mutations to get breast cancer.<sup>50</sup> How should insurance deal with this? *The mutable lifestyle rule of (genetic) non-discrimination* is the following.

For persons who know they have a genetic predisposition for a multifactorial disease such as breast cancer and are, nonetheless, contributing to their likelihood of getting this condition through a controllable lifestyle, the extra cost they may incur is justified to them, meaning that the state is not responsible to cover the extra cost.

Lippert-Rasmussen agrees that luck egalitarianism is compatible with such a proposal. He says,

Suppose that, in a two-persons-world, Robinson and Friday each has two occupational options. These and their sets of options are equally good. Robinson's genes dispose him to have a higher risk of developing an occupational disease if he chooses the first option, whereas Friday's genes dispose him to have a higher, similar risk if he chooses the second. Luck egalitarianism is compatible with Robinson's having to pay a higher occupational disease insurance premium if he chooses option

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<sup>50</sup> Note that from this point forward I will interchangeably use the terms "mutations in the breast cancer genes" and "breast cancer genes".

one and Friday having to do the same if he chooses option two (Lippert-Rasmussen, 2015, p. 198).

However, he thinks that this kind of situation is not likely (Lippert-Rasmussen, 2015, p. 198). I disagree with Lippert-Rasmussen that this situation is unlikely. Consider the following. It is well established that a well planned, whole-food plant-based diet, which is reasonably accessible in the Western world, is a great way to achieve good health at all stages of life (Academy of Nutrition and Dietetics, 2016), and can prevent and fully reverse type-2 diabetes, and heart disease (Esselstyn Jr., 2007; McMacken and Shah, 2017), and can significantly reduce the likelihood of getting many cancers (Physicians Committee for Responsible Medicine, 2020). Persons who eat a whole-food plant-based diet are less likely to die from cardiovascular diseases, which is the top killer in North America (Kim, et al., 2019). Moreover, researchers have concluded that “Adherence to a healthy lifestyle [which includes healthy eating] at mid-life is associated with a longer life expectancy free of major chronic diseases.” (Li, et al., 2020).

It is also well established that dairy, for example, is a promoter of breast, prostate, and ovarian cancers (Greger, Dairy and Cancer, 2019). Meat consumption is also linked to many chronic diseases such as cancers, type 2 diabetes, and cardiovascular diseases (Etemadi, et al., 2017). Given this, regardless of whether one has genetic predispositions or not to heart disease, diabetes and certain cancers, if a person chooses to consume animal products, they are responsible for the risk they bring and deserve to pay for the associated risk out of pocket. Let me explain further.

The person who has the uncontrollable breast cancer genes does not get breast cancer because she has the breast cancer genes. Although she did not choose to have the breast cancer genes, I do not think we can claim that her having the breast cancer genes is bad brute luck because having these genes means nothing without context. Generally, since it is reasonable for society to expect persons to not consume animal products (harm principle, among others), which is one thing that triggers breast cancer, having the breast cancer genes is not something that requires neutralizing.<sup>51</sup>

If, on the other hand, a person does have the breast cancer genes (or a genetic predisposition for another multifactorial disease that functions in a similar way), but eats a mainly whole-food plant-based diet (or leads a lifestyle that makes the genetic predisposition insignificant) it does not make actuarial sense to have this person pay more for having this genetic predisposition. Here, once again, I am referring to the information rule. Moreover, the person who leads an unhealthy lifestyle without the genetic mutations would already be required to pay more than the person who leads a healthy lifestyle regardless of whether they have the genetic mutation or not. So, with respect to multifactorial diseases, instead of genetically profiling persons into certain risk groups, insurers should categorize them based on *all relevant health information* including ones from lifestyle and environment. And this is already how life insurance works, or it is at least established that this is how life insurance should work. For example, if a person has a genetic predisposition to breast cancer but has had their breasts removed electively, their premiums

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<sup>51</sup> Depending on other information, including how much and how often one consumes unhealthy foods, there may be no associated price increase. For argument's sake, I am assuming that there is a price difference.

will not be affected by the genetic predisposition. This is similar to eating a whole-food plant-based diet.

#### 4.4b iii a. Uncertainty and tracking lifestyle

In principle, in order to do a correct contextual analysis of risks, insurers need to be able to track the accuracy of a person's claim to mainly be eating a whole-food plant-based diet. This is because if this person does have the breast cancer genes and does not eat a mainly plant-based diet, then genetic information becomes effectively useful. As it was mentioned, all else being equally bad, the genetic defect does increase one's chances of getting breast cancer. But that is not all. It is even *more* important, for example, that insurers know that a person mainly eats animal products, if this is the case, since eating animal products increases one's chances of getting breast cancer, regardless of having a genetic predisposition or not. Of course, it is also relevant how much and how often and what type of animal body parts a person consumes. However, all else being the same, consuming animal product (especially ones derived from conventional animal farming), is worse for health (especially cardiovascular health) than consuming plant-based foods (Academy of Nutrition and Dietetics, 2016; Kim, et al., 2019; Physicians Committee for Responsible Medicine, 2020). As the mutable lifestyle rule stated about such cases, the state would not need to compensate such individuals should they seek more cover than the no-questions-asked, basic life insurance coverage.

There are a couple of criticisms that I would like to consider. Having accepted the importance of luck egalitarian fairness, it may be said that knowing about the lifestyle information of such persons may be difficult (Van Hoyweghen and Rebert 2012; Sandberg

1995, 1551), and so it may not be possible to do a fully correct contextual analysis of risk. This is true, but this difficulty is not unique to diseases that have a genetic component. For example, unhealthy eating in general, which weakens the immune system, also contributes to the manifestation of diseases that do not have a genetic component. Thus, it would not be a strong argument to claim that because lifestyle information cannot be *confirmed* by insurers, genetic information need not be provided to them. Rather insurers can merely add a reasonable amount of risk of uncertainty that comes from not being able to confirm lifestyle, if that is the case, to the premium costs.<sup>52</sup> This applies to all those who eat, and not only to those with genetic predispositions to conditions like breast cancer. So, persons with such genetic predispositions would not be subject to any unfair treatment, as compared to those who do not have genetic predispositions. Despite this potential for uncertainty, I think that those who *do* eat whole-food plant-based diets or lead a healthy lifestyle in general, would be likely to comply, within reasonable limits, to prove that they do in fact live this way. This is also true of persons who have genetic test results that indicate that they do not have a genetic predisposition to a disease.

Sure, some people may agree with me so far on the importance of luck egalitarian fairness. But this proposal may also make some others uncomfortable, and this is understandable. What we eat, after all, is an intimate part of who we are, as individuals as well as within groups. Many foods have cultural value, regardless of whether they are

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<sup>52</sup> One upcoming way of confirming lifestyle information is through epigenetic tests. For example, “DTC-ET [an epigenetic test] can reveal a person’s ‘smoke exposure’ history. Indeed, studies have shown that DNA methylation levels at three specific CpG sites in whole blood samples — cg05575921 (AHRR), cg03636183 (F2RL3) and cg19859270 (GPR15) — are strongly correlated with both active smoking (past and/or ongoing) and increased risks of developing smoking-induced diseases. In the future, DTC-ET may provide information about a wide variety of exposures such as stress, alcohol or other toxic chemicals (for example, pollutants or illicit substances), uncovering new layers of sensitive information about individuals that were not made accessible by genetic tests (Dupras, Beauchamp, & Joly, 2020, p. 1). These types of tests will be able to reveal dietary information as well.

“healthy” or not, and it is not easy to accept that the state can tell us what we can and cannot eat.<sup>53</sup> Consequently, it may be said that the public places more value on privacy (of what/how we eat) than it places on luck-egalitarian fairness; the social cost to privacy of enforcing my mutable-lifestyle rule may be excessive to the public, who might believe it better to ignore this lifestyle information when deciding to subsidize insurance for those with the such genetic predispositions.

Unfortunately, the aforementioned claim is true given that animals do not yet have their right to life recognized in society, and that attempts to address the climate crisis are not yet taken seriously by many individuals and organizations (Rueter, 2021). Moreover, change takes time. Despite all this, however, and fortunately for critics and supporters of my mutable-lifestyle rule alike, the potential problem is not a real problem and is not dependent on the rightness or wrongness of eating animals (moral patients). Here is why.

My mutable-lifestyle proposal does not call for an excessive invasion of privacy. As I noted above, it will mainly be those who consistently eat healthy that would be willing to disclose such information and take on the additional oversight measures, whatever they may be (if any). So, what will end up happening is that these people will pay lower premiums. The rest, all else being the same, will pay what they pay now (which is nonetheless relatively higher). I would presume that a part of what constitute the baseline price is the (un)health value of the foods that are generally consumed. In some places, those who eat a primarily plant-based diets, for example, already pay lower premiums (Health IQ Insurance Services,

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<sup>53</sup> Note that in this case the state would not actually be telling persons what they can eat or not but rather whether they would be compensated (or not) for what/how they eat. But because this is an emotionally charged topic, persons may interpret the policy in this way.

Inc, 2021; Chiorando, 2018). Moreover, personal and health information is already part of the underwriting process and so allowing persons who eat healthy to disclose this information is nothing out of the ordinary and supported by luck egalitarianism. The way insurers currently know how people eat is through questionnaires and initial health assessments, which provides information about how persons eat. So, how my mutable lifestyle rule is likely to play out is that, all else being the same, those who consistently eat healthy will pay lower than those who do not, and this is going to be the result of those who eat healthy providing this information to insurers (and will not require any invasion of privacy for anyone).<sup>54</sup> Also note that my privacy rule already provides the option for a no-questions-asked insurance for all.

#### 4.4b iii b. Ignorance towards genetic predispositions

Recall that the mutable lifestyle rule stated that for persons who *know* they have a genetic predisposition for a multifactorial disease and are, nonetheless, contributing to their likelihood of getting a condition through a controllable lifestyle, the extra cost they may incur is justified. But what if this person does *not know* that they have a genetic predisposition? The question of what if they don't *want to know* along with other liberty problems will be discussed later in this chapter. That being said, generally, due to the diversity in the way which people lead their lives, and the general public knowledge about conditions that may

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<sup>54</sup> I say this as opposed to explicitly saying that those who pay "normal" (*i.e.*, relatively higher compared to those who eat healthy) do not deserve compensation for paying the "normal" amount. Also note that, of course, this is all said in a context where there is evidence indicating that not eating healthy leads persons to have more chronic conditions, all else being the same. So, people can keep eating exactly what they like, even though it may be that there are very good moral and practical reasons why what we eat is not a personal choice in the way preferring soccer to basketball is. A final note is that an important part of my proposal is that eating healthy should be easy, and for most of us, it is. If it was hard to eat healthy (fruits and vegetables, grains and seeds, *etc.*), I accept that the 'personal choice' point above would be less strong (and this is why there is, nonetheless, the *Recommendations for the mutable lifestyle rule* section below). But as I explained above, regardless of these points, there is no 'out of the ordinary' "invasion" of privacy anywhere.

have a genetic influence, one does not necessarily need to take a genetic test to have some good reason to think that they may have a genetic predisposition to a genetic disease. In the case of breast cancer, for example, people would have some good reason to think that they may have a genetic predisposition to breast cancer if there are women in the family who have or had breast cancer. Of course, the reason why these women may have had breast cancer could be that they simply led unhealthy lifestyles. But given the public knowledge about the possibility of breast cancer having a genetic component, combined with the knowledge that certain family members have had breast cancer, it is reasonable to say that all the requisite information is there for persons to plan to be more cautious to lead a healthy lifestyle, if they so choose.<sup>55</sup> If a multifactorial condition has not manifested in the family or one has not grown up with their biological family in order to make an informed guess, on the other hand, then there are no problems because information symmetry between the client and insurer is not disturbed, and the insurer does not have anything proportionally significant to lose.

#### 4.4b iii c. Some recommendations for the mutable lifestyle rule <sup>56</sup>

To strengthen my position on discrimination with respect to multifactorial diseases such as breast cancer, I suggest that states should:

(1) increase their efforts to spread awareness about the health effects of animal based and plant based diets, which the WHO and many nutrition and dietetics bodies have already began doing (Academy of Nutrition and Dietetics, 2016). In Canada, “The

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<sup>55</sup> This information about family history of breast cancer will already have to be made available to insurers.

<sup>56</sup> There is a different rule for multifactorial conditions that resemble breast cancer, as opposed to addictions, because continuing to eat animal products despite knowing its health effects is not like continuing to smoke or continuing to be an alcoholic despite knowing its health effects since it is not as clear cut that people have an acceptable level of control over smoking and alcoholism.

Food Directorate is the federal health authority responsible for establishing policies, setting standards and providing advice and information on the safety and nutritional value of food” (Government of Canada, 2006). The Canadian Food Guide has removed dairy as a food group in 2019, and it was noted that this was the first time that industry was not involved in the development of the food guide (Crowe, 2019);

(2) increase consumer transparency in food production. This would be the role of the Canadian Food Inspection Agency. Policies like Bill 136, which seeks to, among other things, ban citizens from filming conditions inside factory farms, should not be permitted;

(3) stop subsidizing and instead tax animal products;

(4) make fruits and vegetables, seeds, nuts, grains, and plant-derived foods even more accessible by further subsidizing them;

(5) set up conditions where persons can *freely* access relevant genetic tests, if they wish, so that they can have this additional information to help them make decisions about their lifestyle.

#### *4.4b iv Obesity*

I will now continue by analyzing the use of another common multifactorial health outcome, obesity, and explain how the state ought to respond. Obesity is a chronic condition characterized by excessive fat accumulation that may result in many health problems (Obesity Canada, 2018). The excessive fat accumulation is the result of an “...energy imbalance between calories consumed and calories expended.” (World Health Organization,

2020). It is a "...leading cause of type 2 diabetes, high blood pressure, heart disease, stroke, arthritis, cancer and other important health problems..." (Obesity Canada, 2018). It is reported that about "...one in 10 premature deaths among Canadian adults age 20 to 64 is directly attributable to obesity." (Obesity Canada, 2018). For this reason, obesity is an important pre-health condition for insurers, and persons with obesity are charged higher premiums, all else being the same. But do all persons with obesity deserve to pay this extra cost out of pocket?

Although many people associate obesity with being lazy, and holding an uncaring attitude towards their health, this is insensitive to the objective reality of this condition. As Michael Greger puts it, "... the prime cause for obesity is neither gluttony nor sloth. Obesity may be a normal response to an abnormal environment" (Greger, 2019). This abnormal environment can refer to things such the predominantly sedentary and stressful lifestyle of modern, capitalist society (Pollan, 2006; Little, 2016). So, obesity can be categorized as a widespread social issue that "...is a product of the industrialization of the food chain, which since the 1970s has produced increasingly cheap and abundant food with significantly more calories due to processing." (Little, 2016, p. 6).

Obesity is a multifactorial condition influenced by genetics, epigenetics, lifestyle, and environment (Public Health Ontario, 2014). These factors are not only relevant to the process of becoming obese, but also to the process of *remaining* obese. In obesity, and unlike in breast cancer, the genes at play actually direct persons to display certain (feeding) behaviours (Bear, Connors, & Paradiso, 2007). These behaviours are a response to genetic errors which, among other things, make persons not feel full despite eating, and be more

attracted to high calorie foods (Bear, Connors, & Paradiso, 2007; Centers for Disease Control and Prevention, 2013). It can also lead their bodies to store excess calories rather than to burn them, as well as to the slowing down of their metabolism (Bear, Connors, & Paradiso, 2007). As Bear, Connors and Paradiso state, “It is now apparent that there are multiple regulatory mechanisms, some acting over a long period of time to maintain the body’s fat reserves, and others acting over a shorter time period to regulate meal size and frequency.” (2007, p. 512). Whereas it is normal for bodies to have a mechanism for maintaining energy homeostasis, which varies from person to person, this system is or becomes dysfunctional in people with obesity (Bear, Connors, & Paradiso, 2007, p. 513).

It is also true, however, that there may be persons who do not have such genetic errors, and still display these behaviours. This may be due to environmental stressors, epigenetic modifications or out of choice. Environmental stressors may range from social factors to exposure to chemicals (obesogens), which can change hormones and increase fatty tissue in our bodies (National Heart, Lung and Blood Institute, 2019). Epigenetic influences include “eating too much or eating too little during your pregnancy [which] can change your baby’s DNA and can affect how your child stores and uses fat later in life.” (National Heart, Lung and Blood Institute, 2019, p. 1). It has also been shown that “...obese fathers have DNA changes in their sperm that can be passed on to their children.” (National Heart, Lung and Blood Institute, 2019, p. 1).

Once in a state of obesity, persons find it very difficult to initiate and maintain a lifestyle that will help them reverse or halt their feeding behaviour; in the case of obesity, what is needed is to be in a state of calory deficit. This may be due to genes that continue to

make persons feel starving; environmental conditions that make accessing healthy foods and exercise difficult; and stigma and bullying that may make persons give up trying, directly or indirectly. Nevertheless, it is also true that some are able to overcome these obstacles. Although there is much more that the food industry and states should do to improve the social environments for obese individuals, it is also true that, generally speaking, fruits and vegetables and plant-based foods are widely available and accessible in North America and Europe.<sup>57</sup>

As I have suggested in the case of smoking and other addictions, I think here too we should be forward-looking instead of backward-looking; we should not try to assign responsibility for the past, but rather assign responsibility for future actions. In other words, if the social support is *genuinely* available, and persons take it up, then they should have state support to cover the extra cost of life insurance premiums in the meantime. The social support component, in this case, would be in the form of free medical treatment (which may include surgery, hormone therapy, gene therapy, medications) but also in the form of helping these individuals make healthy and effective lifestyle changes (Greger, 2019) and making improvements on social and environmental conditions that may make eating healthy and exercising more difficult. One particular suggestion is to tax unhealthy foods and make healthy foods even more appealing. Programs that incentivize healthy and effective weight loss through paying persons (well) may also be an effective suggestion benefitting all those who are involved. Of course, it must be ensured that any such programs do not contribute to weight stigma and weight bias.

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<sup>57</sup> Continuing to eat when obese despite knowing its health effects is not like continuing to eat when you are not obese despite knowing its health effects because it is not as clear cut that people have control over the activity of eating when they are obese.

What about persons who have certain obesity-linked genes but aren't yet obese? The answer to this question will follow the same format as those who have genes that may affect behavior in general such as impulsiveness, novelty seeking, and risk-taking. This is discussed next.

#### *4.4b v Biomarkers of behavior*

I have already discussed addictions, which may have a genetic basis in certain people. Now I will talk about biomarkers in more detail. Biomarkers include metabolites, protein levels, genetic variants and brain states that are predictive of behavior but not determinative (Savulescu & Baum, 2013). Autism Spectrum Disorder, attention-deficit/hyperactivity disorder, schizophrenia, depression, antisocial behaviour, among others, are behaviors/conditions that are thought to have a genetic component (Rutter, 2013). This is not an exhaustive list by any means, and the list is growing as we learn more about biomarkers of behaviour and behavioral genetics.<sup>58</sup>

Applying this knowledge to life insurance, Rothstein writes that “genetic predisposition to risk-taking, novelty-seeking, depression or impulsivity could be considered a risk for premature mortality (Rothstein, 2005, p. 797). Here I agree with Rothstein when he says that “policy decisions that relate to behavioural genetics and insurance should be attuned to overall policies for the use of genetic information in insurance.” (Rothstein, 2005, p. 797). This time, I will first comment on whether this type of information should be used by insurers in the first place. For such information to be used,

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<sup>58</sup>Aggression, alcoholism, anxiety and anxiety disorders, bipolar disorder, memory and intelligence, neuroticism, novelty seeking, schizophrenia, substance addiction are some other ones that have been analyzed from an ethics and philosophy perspective (Savulescu, 2001).

there must be evidence indicating the correlation between the genetic/biomarker information and behavioral predisposition. Secondly, all relevant information concerning the behavior should be accounted for altogether. If, for example, a lifestyle or environmental stimulus is *necessary* to make the genetic predisposition effective, and this lifestyle or stimulus is not present, then the risk from genetic information should be calculated accordingly, as in the case of breast cancer. In aggression, for example, there needs to be an abnormal environmental stimulus for the genetic predisposition (variant of the MAOA gene) to be effective in increasing likelihood of future aggression (Savulescu and Baum, 2013; Rothstein, 2005). If, on the other hand, all else being equal, it has been shown that a genetic predisposition is likely to increase the chances of one portraying a certain behavior by itself, then that information can be taken into account given that there is also correlation to risk of death. For example, if one has a genetic predisposition to impulsivity, and assuming that all other relevant information regarding impulsivity are also available, then there should be research indicating that being more impulsive *is* correlated with the likelihood of death, in order for that information to be allowed to be used by insurers to increase prices. In the case of behavioral genetic information about impulsivity, “properly used” would also mean that insurers would take account of the reality that it is possible that this person can nonetheless control whether they will live a risky-lifestyle or not. But since we cannot be sure of this, insurers can still take it into account. However, in taking it into account, they cannot assume that this person *will* lead a risky lifestyle.

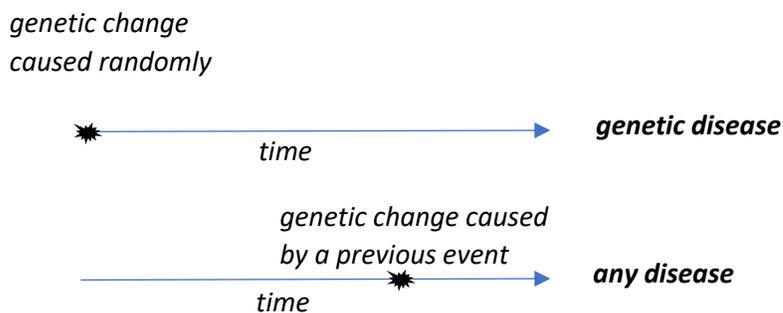
Do persons with such predispositions deserve state compensation? I will consider the case of risk-taking. I will consider two possible scenarios. In the first case imagine that there is research that indicates that a genetic modification, alone, is associated with risk taking. In

the second case, imagine that there is research that indicates that a genetic modification, when combined with other lifestyle/environmental stimuli is associated with risk taking. In both cases, imagine that risk-taking is associated with premature death. In the first case, where the genetic modification alone leads to risk taking, the state should compensate the individual who must pay more as a result of possessing this genetic characteristic. This is because the person has no control over this fact, and would otherwise be disadvantaged. This is similar to the conclusion in the Huntington's case. In the second case, we would check whether the lifestyle/environmental stimuli that is required for the gene to display risk-taking behaviour is reasonably avoidable by the individual. If it is, and persons still do not choose to avoid it, then they are not eligible for state support. If it is, and persons do avoid it, then their premiums should not be affected by this genetic predisposition. Note that persons obviously have the liberty to live a risky lifestyle. What this would simply mean is that they would not be eligible for state support if they chose to acquire life insurance. This second case is similar to the *breast cancer* case as well as the *addiction* case.

#### *4.4b vi Epigenetics and the Guiding Rule*

We know that genes can affect lifestyle, and that lifestyle and environment can affect genes. Consequently, my definition of "genetic disease", thus far, has been a disease that results in full or in part from a genetic defect that is *already present* in the human being (i.e., the zygote stage). So, when I talk about *genetic* discrimination, I am talking about cases where the genetic defect was already there, due to a random mutation as an embryo, or due to it being passed down from the family, or due to it randomly developing in a somatic cell after birth, when it by itself or through working together with an environmental/lifestyle stimulus, led to the manifestation of the disease.

This detail is important because even non-genetic diseases affect the genes of persons. But non-genetic diseases are not *caused*, in full or in part, by an already present/natural genetic defect. A non-genetic disease, rather, is caused by a foreign body such as bacteria or viruses, or only from a harmful environmental/lifestyle stimulus. Such diseases/conditions include heart disease, dementia, the cold flu, etc. But as I just mentioned, in the process, the genes of the genetically healthy individual are also changed. This change leads to problems in protein synthesis leading to disease/illness, yet this does not make it a genetic disease. So, what would make something a genetic disease is if this disease is at least in part caused by a genetic defect which was embedded into the genome of the person prior to any other foreign body or environmental stimulus. *Figure 4* below illustrates this difference. The reason I am differentiating genetic diseases from non-genetic ones is so I can provide a clearer definition of *genetic discrimination* (as opposed to discrimination based on other health-related information).



**Figure 4. One important difference between genetic and non-genetic disease**

The field of epigenetics complicates this definition. Epigenetics is “the study of changes in gene function that are mitotically and/or meiotically heritable and that do not entail a change in DNA sequence” (Wu & Morris, 2001, p. 1104). The most common types of epigenetic modification are DNA methylation and histone modifications (Dupras, Song,

Saulnier, & Joly, 2018).<sup>59</sup> These can be acquired before birth but also through lifestyle (bad diet, smoking, alcohol consumption, etc.) (Dupras, Song, Saulnier, & Joly, 2018). From the aforementioned definition of epigenetics, then, it seems as though epigenetic information may be viewed as relevant for genetic discrimination, as well as non-genetic discrimination. It would be relevant to genetic discrimination because the changes in gene function are *heritable*. It would be relevant to non-genetic discrimination because (1) the modifications may be caused by lifestyle and environmental stimuli, and (2) the modifications do not affect the DNA sequence of the genes. To make things even more complicated, however, in 2015 Lappé and Landecker, stipulated that that epigenetic modifications could “...in fact be perceived as changing DNA’s linear nucleoid sequence when transforming cytosines (C) into methylcytosines (meC)” (Dupras, Song, *et al.* 2018, p. 3; Lappé and Landecker, 2015).

On top of the difficulty in knowing whether an epigenetic modification is inherited or acquired through lifestyle/environment, there are two other important details. The first of these is that many scientists now agree that differences in epigenetic modification found between persons is attributable to the differences in persons’ genetic composition (Dupras, Song, Saulnier, & Joly, 2018). This means that having a specific genetic composition, which is inherited and immutable, affects the likelihood of what kind of epigenetic modification, and where within the genome, a modification is likely to take place. The second detail is that some epigenetic modifications last only for a few hours, whereas others can last for years (Dupras, Song, Saulnier, & Joly, 2018).

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<sup>59</sup> RNA and mRNA information of persons can also provide health information about persons.

Researchers note that, “by assessing DNA methylation levels and/or histone modifications in specific cell types ... epigenetic tests may soon provide additional layers of predictive information, complementary to genetic information, about an individual’s disease risk profile or response to specific treatments.” (Dupras, Song, Saulnier, & Joly, 2018, p. 1). Epigenetic tests could also reveal information about persons’ past exposures to physicochemical and psychosocial disruptors such as toxic pollutants/cosmetics, and familial stress/social adversity, respectively (Dupras, Song, Saulnier, & Joly, 2018).

It is stipulated that “many conditions have been associated with ‘epigenetic signatures’, such as congenital abnormalities, cardiovascular disorders, diabetes, cancer and asthma (Dupras, Joly, & Rial-Sebbag, 2020). One of these epigenetic signatures is known as an epigenetic clock. Dupras and colleagues describe the science of epigenetic clocks as follows:

Epigenetic clocks, correctly described as ‘epigenetic age and aging estimators’, function by determining the DNA methylation state of specific CpG sites (around 100–500) across the genome and analysing them with mathematical algorithms. This recent scientific progress has already led to widespread use of these clocks in many studies on exposure- or disease-associated epigenetic modifications, where its value is becoming increasingly appreciated. When DNA methylation age is higher than chronological age, it is known as ‘age acceleration’. When DNA methylation age is lower than chronological age, it is ‘age deceleration’. Age acceleration has been linked to multiple cancers, whereas age deceleration has been linked to longevity. Variability in aging rates has been associated with familial heredity, race/ethnicity, and sex, as

well as exposures to endogenous factors (e.g. HIV, menopause) and exogenous disruptors (e.g. toxic chemical products, traumatic events). (Dupras, et al., 2019)

Thus, Dupras, Song, Saulnier and Joly have stated that the line between genetics and epigenetics appears much more blurred than what is usually admitted, which means that the line between genetic and epigenetic discrimination is similarly blurred (2018). So genetic non-discrimination does not guarantee that epigenetic non-discrimination is also protected (Dupras, Song, Saulnier, & Joly, 2018).

Taking this concern seriously, the first thing to note is that the study of epigenetics certainly brings complexities with it that need further attention. How I want to start attending to these, however, is to recall that I do not claim that all genetic discrimination that takes place in life insurance is problematic and requires state compensation. Only those genetic diseases that are beyond an individual's control *and* lead to disadvantage/express a negative message are eligible to be deserving of a response. Since it is immutability that I take as fundamental, I claim that *all* relevant information that is beyond the individual's control, regardless of source, is eligible to be deserving of a response if it leads to disadvantage or the expression of a negative message. Similarly, at the prior stage, all epigenetic information that is relevant to a health outcome ought to be provided to insurers, given that they will use the information correctly and its use is not a mark of bad character. Something relevant in this regard is whether it is possible to know whether an epigenetic modification is only present for a short term or if it is more long term. Taking multiple tests across a timeline can help to get closer to an answer, but this may be invasive and there would be problems if a contract is already in place.

The way I would start addressing the appropriate state response to potential discrimination based on epigenetic information, then, is to ask whether there are any epigenetic modifications that are fully deterministic with respect to the negative outcomes they give rise to. Those that are fully deterministic, like Huntington's, should have their extra costs funded by the state. Those that are multifactorial, should be analyzed along with all of the other relevant information. *Figure 5* below show the relationship between all the relevant factors in an epigenetic modification, followed by all the relevant factors in a disease. In this analysis, one important question is whether it is possible to find out if an epigenetic modification is inherited or acquired through lifestyle. Notice, however, that even if it was inherited it does not mean that it is deterministic with respect to the negative outcome it may give rise to.

A second important question in the full analysis is whether, to what extent and how one's genetic composition affected the epigenetic modifications that took place. For example, even the time frame of an epigenetic modification may be dependent on the nature of the modification itself, lifestyle/environmental condition, or the genetic makeup of the individual. Again, notice that even if one's genetic composition was naturally prone to negative epigenetic modifications in that nothing externally unusual was necessary to acquire them, it does not mean that the resulting epigenetic modification is fully deterministic with respect to the outcome it may give rise to. I do not think that the detail about whether an epigenetic modification affects the DNA sequence or merely changes its structure is important to the analysis so long as an epigenetic test can detect that there is a change. Below is a diagram showing, first, what can cause epigenetic modifications; and second, what can cause disease.

1. Genetic composition → **epigenetic modification**
2. Lifestyle/environment → **epigenetic modification**
3. Genetic composition+ lifestyle+ environment → **epigenetic modification**
4. Epigenetic modification → **disease**
5. Defective gene → **disease**
6. Defective gene(s) + bad environmental conditions/lifestyle → **disease**
7. Bad environmental conditions/lifestyle → **disease**
8. Epigenetic modification + defective gene + bad environment conditions/lifestyle → **disease**

**Figure 5. Factors in epigenetic modifications and diseases**

#### *4.4b vii Practical considerations*

I have already discussed practical considerations such as difficulties in assigning responsibility to individuals, tracking lifestyle, and concerns over not knowing certain genetic information, but before moving on, I will comment on a few remaining practical considerations.

A practical problem with my guiding rule has to do with the compensation process. Information transfer between the government and individuals, or the government and insurers may be difficult. Apart from the administrative hassle, persons may not want the state to know of certain private information either. But recall that offering a no-questions asked line of limited insurance offsets this problem.

Secondly, there is the possibility that since insurers are profit driven, they may drive up the “extra” cost of unlucky persons knowing that the government will cover them.<sup>60</sup> However, this can be offset by government oversight over insurance practices, which may

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<sup>60</sup> Thank you to Charles Dupras for discussing this with me.

come in the form of an appointment of a scientific committee as well as independent actuaries to review such processes. This is similar to what is done in the UK.

A positive aspect of my proposal, with respect to practicality, is that genetic test information need not be removed from medical records before being sent to insurers any longer. So even though information transfer may not be too easy, it would nonetheless be more practical in this regard.

A more general practical issue is whether the state should give priority to attending to the problem of unjustified discrimination in insurance or whether they should first fund gene therapies that can be used to treat or cure diseases such as Huntington's. One potential argument for why the priority should be on therapies, for example, can be that insurers can afford to support such genetically disadvantaged persons themselves. But this argument can go the other way around as well. We can say that the biotechnology companies that develop such therapies can afford to help in the treatment of such individuals themselves. Thus, just because an agent can afford to do something, doesn't mean they need to do it. I think that both insurers and biotech companies should do what is required of them, but we must remember that there are other actors who are similarly responsible, such as states and individuals.

So, in answering the question just posed, I believe that the basic minimum for each demand should be met by the state, and the rest of the funding should be allocated by policymakers who would take account of the context of the relevant situation. Some considerations include whether the trait being treated/cured is a serious medical problem or one whose members are generally happy to live with. If it turns out that it is not a serious

medical problem, then more funding should go to eliminating unjustified discrimination in life insurance. The basic minimum in the case of life insurance could simply be for insurers to offer the no-questions asked, limited (but adequate), guaranteed insurance.

A final concern that I will only briefly mention here is that since I argue that all *uncontrollable* factors, and not only genetic information, ought to be treated in the way I describe in the guiding rule, it may be said that this significantly clashes with the way the current state-life insurance-client relationship works. Although this is no moral argument against my proposal, it makes the provision of a basic, moderate, no-questions-asked insurance product all the more important. And within the current context, we may simply view the Genetic Non-discrimination Act as a first step towards that direction.

#### *4.4b viii Justification of my Guiding Rule continued*

##### 4.4b viii a. Affordable discrimination and expressions: limits of luck egalitarianism?

In all the previous cases I considered, I had assumed that the discrimination taking place would make premiums unaffordable, *i.e.*, the discrimination would cause a disadvantage. I mainly responded to this problem through an appeal to luck egalitarianism, *i.e.*, I argued that the state should compensate individuals when the extra cost results from an immutable risk. Remember, however, that luck egalitarianism is only one part of my guiding rule. Imagine the following situation. It is calculated that someone who is not responsible for their risk is only a *little bit* more expensive to insure (than if they did not carry this risk) in that their monthly premiums are actually quite affordable to the individual (either because they are wealthy or because the price is not *that* much different from the

average cost). Call this *affordable discrimination*. Is this still unjustified discrimination, overall? In other words, would persons still be deserving of state support in such a situation?

Even though it may seem like affordable discrimination is not problematic, the position I will defend is that such discrimination could still be unjustified discrimination, but not because of luck egalitarianism. Rather, it could be unjustified discrimination if the discrimination based on the morally arbitrary trait *expresses* something negative.<sup>61</sup> This conclusion arises from the second part of my guiding rule, *i.e.*, the expressivist account of discrimination. So, as mentioned earlier, a fundamental aspect of my guiding rule is that the luck egalitarian account of discrimination and the expressivist account of discrimination can work together. Whereas luck egalitarianism would take account of situations where a clear disadvantage is present, the expressivist account would take account of situations where a clear demeaning expression is conveyed. So now my aim is to further justify my guiding rule through an ethical analysis of so-called *affordable discrimination*.

Before I begin, note that although affordable discrimination is possible, it is not likely (at least today). Since insurers have an interest in maximizing profit, and the majority of life insurance holders already pay “normal” premiums, it is assumed that any high-risk individuals will actually have to pay substantially higher, meaning that it is not likely to end up being “affordable” to an average income citizen. Regardless, it may also simply turn out that there are easy practical solutions to the problem of affordable discrimination in that there would be no need to waste any time discussing the ethical aspects of it. For example, we could simply disperse the already “affordable” amount across the insurance pool, which

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<sup>61</sup> In other words, the expressive dimension of actions and policies matter; social contexts and meanings of actions are morally relevant, independent of the subjective intentions of agents or the objective harms that may be caused.

would only make a negligible addition to everyone's premiums. Another possibility is that persons could simply choose to pay the extra "affordable" amount, instead of going through the process and hassle that would be required to receive a compensation. The reason why I nonetheless consider *affordable discrimination* is mainly to reveal a limitation of luck egalitarianism, with respect to its ability to take account of all unjustified forms of discrimination, and to thereby defend my own hybrid of luck egalitarian-expressivist account of discrimination.<sup>62</sup>

An advantage of the expressivist position is that we do not need to answer the difficult question of how we can know whether a given amount is actually affordable (or not) to an individual, or if we were to take a more theoretical approach, we would not need to come up with a theory of reasonable affordability. This is something that the luck egalitarian account would have to do. This point is not intended as a knock down argument of luck egalitarianism, since easy reliable predictions could be made, but rather to indicate that there is more detailed work for the luck egalitarian position to accomplish when it comes to the permissibility of discrimination in life insurance. The expressivist account does not need to do this because it says that even if it was affordable, whatever this means, persons should not have to pay it if the discrimination based on the morally arbitrary trait expresses something negative.

Let's begin with why luck egalitarianism alone would not find a problem with affordable discrimination. Since this person must only pay a little bit more than the person

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<sup>62</sup> Also, "affordable" price differentiation may actually become more common in the future.

who does not carry this risk, they would not actually be *disadvantaged* by the extra cost. And as you recall, luck egalitarianism is mainly concerned with neutralizing disadvantages and harms. It is not enough that a trait or circumstance is immutable. In other words, luck egalitarianism would find that it is *prima facie* acceptable to expect persons, who are not responsible for their risk, to pay more for their premiums on their own so long as the price is not so high that they can no longer afford insurance (*i.e.*, be disadvantaged). This is true regardless of whether a negative message is expressed or not. Affordable price differentiation, then, is still discrimination, but it is justified discrimination, on luck egalitarian grounds.

Lippert-Rasmussen, however, argues that it is actually contrary to luck egalitarianism for a genetically disadvantaged person to be paying more than those who are not similarly genetically disadvantaged. Assuming that he is discussing high penetrant, single gene disorders such as Huntington's, Lippert-Rasmussen says "...if individuals are charged different premiums on the basis of genetic information, then, *ceteris paribus*, the distribution of burdens and benefits is sensitive to differences in people's brute luck, that is, whether their genes dispose them to develop serious illnesses and this is unjust on a luck egalitarian account." (2015, p.197). So, according to Lippert Rasmussen, luck egalitarians would conclude that unless there is some sort of state compensation it would likely be unjust for insurers to determine premium prices based on genetic information (2015). But remember that in a case like Huntington's the discrimination is likely to lead to a disadvantage. This is not necessarily the case for genetic discrimination in general.

If it were the case for genetic discrimination in general, then, in the absence of state compensation, it would still be unjust to charge genetically disadvantaged persons even \$10 more per month. Given the subjective nature of what it means to be disadvantaged, this idea is plausible; after all, persons from all economic classes may feel the need to acquire life insurance at some point in their lives, and paying the extra \$10 per month could make insurance unaffordable for some, which would disadvantage them. Yet, as I implied above, I do not think luck egalitarianism would prohibit a policy which stated that those who can easily afford the extra cost (or not charged that much higher), ought to cover this extra cost out of pocket. It would not demand state compensation. And I think this is problematic, based on the expressivist account of discrimination.

Deborah Hellman, who is the main proponent of the expressivist account, also puts forth a criticism of luck egalitarianism but her point in doing so is different from mine. Whereas my aim is to demonstrate that there are cases of unjustified discrimination that luck egalitarianism does not recognize, and that it should be supplemented with the expressivist account, her aim is simply to criticize luck egalitarianism more generally. Hellman thinks that genetic discrimination, for example, ought to be prohibited but she disagrees that luck egalitarianism could be a reason why it should be (Hellman, 2003). Although I agree that luck egalitarianism cannot recognize all instances of unjustified discrimination (*e.g.*, affordable discrimination which expresses a demeaning message), in which case the expressivist account would do the job, luck egalitarianism can still recognize unjustified discrimination in many of the unjustified cases. And it would do it by prescribing state compensation when the discrimination is based on a morally arbitrary trait and leads to a disadvantage.

Hellman, however, does not consider the state support option, and would rather outright eliminate luck egalitarianism as a basis for dealing with genetic discrimination. She has two problems with luck egalitarianism to which I will now respond. First, she says that this principle is not one that is represented in our current laws since most goods are distributed according to different principles (Hellman, 2003). For example, the basketball player earns a very high salary only partially due to effort; his height and natural talent which are things he has no control over also contributes to him being a good basketball player (Hellman, 2003). Moreover, she says, "...while many of the traits on which discrimination is prohibited are immutable, traits such as race or sex for example, others are accorded special protection, even if they are in fact highly mutable, such as religion." (Hellman, 2003, p. 87).

Given the history and context of issues of inequality, I am more inclined to have a problem with not supporting those with bad luck, than making sure that anyone with good luck does not get ahead. If women are charged less by insurance because they are women (and, in general, live longer), value-pluralist luck egalitarianism would be fine with that outcome, due to restorative justice, and since it is neither disadvantageous for (assuming it is still affordable for men) nor does it express anything negative about men.<sup>63</sup> There is nothing negative expressed about men because men as a group have not been subject to current or historical oppression, say for example, in the way women have. On the other hand, if one is charged more because of their bad luck, such as someone who lives in a poor neighbourhood, and this makes insurance unaffordable, then this is a concern for luck

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<sup>63</sup> Sufficiencyarianism may also provide an explanation for this.

egalitarianism.<sup>64</sup> Thus, it is not a problem that the basketball player earns more money than someone who was not as lucky.

With respect to the second point Hellman makes in this quote, it must be noted that religious freedom, along with non-discrimination based on race and sex, is protected in society because these are basic rights and liberties, not because they are protected by a principle of distributive justice such as luck egalitarianism. Many basic rights and liberties can also be justified through luck egalitarianism but need not be. For example, since we do not claim that following one religion is a better way to live than following another religion, differences in the outcomes of following different religions in a society is not a matter of individual responsibility. Thus, religion is similar to race and sex in that their social consequences are beyond what we are willing to allow individuals to be responsible for, all else being the same. But if, for whatever reason, these basic rights and liberties cannot be secured to all equally in practice, then it would not be a terrible distributive policy to provide money or other resources to those who are disadvantaged because they have decided to follow the religion which has not been lucky in attaining much power in that society, which is completely arbitrary. Thus, regardless of what the moral basis of basic rights and liberties are, the social outcomes associated with being one sex, race, or a follower of one religion is

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<sup>64</sup> I think that such persons should also be covered by the state even if it is affordable to the individual. Generally speaking, people live where they can afford, and quality of life is likely to be lower in lower income neighborhoods. I think those living in poor neighbourhoods should have the extra cost covered because of the negative message it would otherwise express. But note that this case is especially likely to be one that would be covered by luck egalitarianism instead of the expressivist account because such price differentiation is more than likely to make insurance less affordable for them, thereby disadvantaging them. A practical consideration in this regard is that it is not likely for persons who are not doing financially well to consider purchasing life insurance to begin with. This consideration opens up different possibilities for research or policy action. For example, it is reported that in recent times it is more difficult for individuals to climb up the economic ladder, and especially so if they are already at the bottom (Cairns, 2017; Wilkinson & Pickett, 2011). Life insurance can be used as a tool to generate long term wealth for such persons across generations.

certainly a matter of direct or indirect (historical) luck, which is under the purview of luck egalitarianism.

The second problem Hellman identifies is that luck egalitarianism is much more conceptually complex than it appears (Hellman, 2003). She uses smoking to demonstrate her point. The practise of charging smokers more than non-smokers for health insurance, Hellman admits, is morally appealing because the smoker chooses to smoke and so is at least partially responsible for the fact that they are more likely to become ill than a non-smoker (Hellman, 2003). But, Hellman says, "... even that example is problematic because of the addictive quality of nicotine and the fact that scientists are beginning to learn that qualities outside of individual control influence the degree to which each smoker in fact endangers his or her health by smoking." (Hellman, 2003, p. 87). As researchers discover more about genetics and genetic predispositions, they learn that different human bodies can make different demands on us (Hellman, 2003). Another example Hellman refers to in order to demonstrate this idea is that of consuming a high fat diet. She says that some persons can eat very fatty foods with little health risk while others would become ill or prone to certain diseases if they were to do so (Hellman, 2003). Admitting that one's diet is generally within a person's control, Hellman says that our genetic predispositions that make us require a certain type of diet (e.g., low fat diets) are not within a person's control (Hellman, 2003). From these points, she concludes that "if we say that the second person is responsible for her poor health if she does not follow the prudent diet [low fat diet], but that the first person [the better fat metabolizer] is free to indulge, then we in fact hold the second person responsible for factors beyond his control—the fact that his genetic make-up demands an especially low fat diet (Hellman, 2003, pp. 87-88).

I have addressed such complexities earlier, for example, while discussing addictions and obesity. With respect to the diet example Hellman provides, if someone's genetic make-up demands an especially low fat diet, and they are aware of this, then there is no problem in concluding that this person is responsible for their poor health when they choose to consume high-fat foods, especially because consuming high-fat is already something we can control and something we should not be doing, if we want to contribute to our health. That one's genes make them more prone to getting a disease if they eat in the same way as someone who does not have such a genetic composition, is irrelevant to luck egalitarianism because the outcome is no longer dependent only on the so called unlucky genetic composition. It is dependent on the controllable diet. There is no issue of addiction here; it is an autonomous choice.

Luck egalitarianism in a value-plural society would not thereby conclude that this person ought to be denied life insurance (on humanitarian grounds), as this would be a disadvantageous, but that it would be acceptable to have them pay more for their insurance premiums out of pocket. Since this person does have control over what they eat, any amount they must pay as a result would be their own responsibility. Of course, this person, and all others, regardless of being responsible or not for their risk with respect to life insurance, would still have their basic rights and liberties secured and have fair equality of opportunity in society (for example, through having access to guaranteed life insurance). It must also be noted that the example provided by Hellman is not a representative one. For the general population, high fat diets are bad for health (Greger, 2020). It is a genetic anomaly that a very small percentage of the population may be better fat metabolizers. Regardless of this,

Hellman is wrong to assume that in this example the person with the genetic predisposition is being held responsible for reasons beyond their control.

#### 4.4b viii b. The expressivist account of discrimination

Now let's look at why affordable discrimination can nonetheless be unjustified discrimination. As I said, I will make use of the expressivist account of discrimination to make this point. The expressivist account is based on the claim that the expressivist dimensions of actions and policies matter; an action or policy can be impermissible if it causes reasonable offense or expresses a demeaning message, even if it may not cause direct harm or disadvantage (Hellman, 2003). For example, according to Hellman, taking account of the historical context of genetic inequality—i.e., eugenics movements—the social meaning of genetic discrimination is problematic because it violates the equal concern mandate (Hellman, 2003).

Before I expand on this position and continue with my analysis, I would like to state two differences between my expressivist account and Hellman's. The first difference is that I think the most reasonable solution to unjustified discrimination in life insurance is state compensation instead of prohibition of the said discrimination. Secondly, whereas Hellman asserts that all genetic discrimination expresses a negative message and are therefore problematic, I think that some are unproblematic. Wachbroit and Wasserman, for example, explain how "in the first half of the 20th century... combating genetic disease was regarded as a public health problem: someone who failed to promote genetic health not only risked her own well being but that of the race as well." (1995, p. 104). This perspective led to many abuses such as forced sterilizations in the United States and eugenic programs in Nazi

Germany (Wachbroit & Wasserman, 1995). While the policies mainly aimed to promote “genetic hygiene”, what they actually did is to deny persons their liberties and lives (Wachbroit & Wasserman, 1995). However, “what distinguishes modern genetic practice from eugenics is the complete rejection of coercion as a method, not the complete abandonment of genetic health [or more broadly, the use of genetic information] as an objective.” (Wachbroit & Wasserman, 1995, p. 105).

So, affordable genetic discrimination based on an immutable risk does not necessarily express a demeaning message. In this context, persons who have the breast cancer genes but continue to eat animal products do not deserve state compensation for possessing the breast cancer genes because they are choosing to create a risk unreasonably. In other words, despite giving equal weight, as Hellman does, to the importance of context, I place more importance on the control we have over the manifestation of a health outcome than Hellman does. So, I think that for discrimination to be problematic, as per the expressive account, not only must the discrimination express something negative, but it must also be based on an immutable risk.

#### 4.4b viii c. Genetic discrimination and expression

According to Hellman, genetic discrimination expresses that people are not of equal moral worth (Hellman, 2003, p. 92). In other words, the expression that is conveyed is that “...some people have intrinsic flaws that render them less good, less worthy and less fit to be a part of our community” (Hellman, 2003, p. 105). She refers to Lori Andrews, who states that the reason given by insurers in favour of genetic discrimination “is similar to that used in the earlier eugenics movement—that healthy people (that is, people with ‘good genes’)

should not have to support people who have or may develop genetic disease[s] (people with 'bad genes)' (Hellman, 2003, p. 100). Overall, although Hellman does not go as far as to say that the whole private insurance industry violates the moral principle of equality, she does say that, given the history of eugenics, the insurance industry's use of genetic information does violate the moral principle of equality (2003).

Her argument is similar to that of the US Supreme Court in *Brown v. Board of Education 1954*. In this case, the Supreme Court decided that the racial segregation of public schools at the time was unjustified discrimination, and thereby unconstitutional (Brown v. Board of Education, 1954). The opinion of the court was that regardless of the educational and psychological affects of segregation, the problem with discrimination consisted in the very act of using a morally arbitrary trait (race), with a problematic history, to treat persons differently (Brown v. Board of Education, 1954). On par with this, Hellman is claiming that regardless of the disadvantages that may or may not result from genetic discrimination, the very problem lies in separating persons into risk categories based on genetic characteristics, which has a problematic history. So, on this understanding, treating blacks differently from whites is a problem even if they receive the same quality education as whites. Analogously, treating genetically disadvantaged persons differently from those who are not genetically disadvantaged is a problem even if genetically disadvantaged persons can still easily afford, and thereby access insurance. As the court famously wrote in the Brown case, "separate educational facilities are inherently unequal" (Brown v. Board of Education, 1954). This is also the claim of Hellman who argues that genetic discrimination is inherently unequal.<sup>65</sup>

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<sup>65</sup> Hellman is making this argument in the context of health insurance but if her argument is true, it should be equally applicable in life insurance as well.

Now observe the following thought experiment by Hellman, followed by her analysis, in order to demonstrate her point:

...a decision by a District Attorney's office to hire only men on the theory that men make better prosecutors because they are more aggressive than women violates the Clause [of equality]. Yet, the decision to hire only law graduates in the top ten percent of their graduating class on the theory that they are more likely to be successful prosecutors does not. Despite the current doctrines focus on the degree of fit between the classification and its target, it does not matter whether men really are more aggressive than woman. In fact, as feminist scholars have rightly pointed out stereotypes often fit quite well because of the history of ubiquitous gender stereotyping or because of real differences between men and women. The use of sex as a proxy for lawyerly skill is not wrong because it is irrational or because it harms the group left out. After all, the use of grades as a proxy for legal ability may turn out to be equally irrational and it equally harms those not hired. The difference between these two instances of discrimination is that the first expresses that some people do not equally deserve concern and respect while the second policy does not similarly denigrate those with lower grades. The first policy expresses denigration while the second does not because it is interpreted in the context of American history, a history replete with denials of the intellectual capacity of women. (2003, p. 104)

The aforementioned "prosecutor hiring" example by Hellman is a little bit different since it involves denial, and we already said that denial would certainly be expressing a negative message. But to make it more like the case of *affordable discrimination*, we could simply ask

whether there would still be a problem if women had to pay, say, \$10 more to be considered for the job, where this money would be used to cover the losses which are “more likely” to occur now since there are more less-aggressive prosecutors. And clearly, yes, this is still problematic even if the \$10 is a small amount. Why should women have to pay this? Getting women to pay anything extra here is representative of belittlement. The same is true, I argue, when a person with the Huntington’s gene must pay even \$10 more to acquire life insurance. Contrarily, however, the expressivist account has no problems for men to pay higher than women (assuming premiums are affordable) because despite men not choosing to be born as men, there is no negative message that is expressed as a result of the differential treatment. The fact that men, as a group, are not the victims of past or current injustice may play a part in this conclusion.

There are two potential criticisms one can make against Hellman’s expressivist argument. Some may push back and claim that regardless of whether such a message is actually conveyed or not, it is not the message that matters but rather the actual disadvantage or harm caused by discrimination. For example, Moreau agrees that unjustified discrimination may express something negative, but this is only a side effect of the real wrong which, according to her, is the reduction of persons’ deliberative freedoms (Moreau, 2010, p. 178). She says that “if it is true ... that discriminatory actions prevent some people from having an equal set of deliberative freedoms, then the importance of these freedoms to us is likely to mean that any act or policy that denies some individuals these freedoms will imply that these people are second-class citizens.” (Moreau, 2010, pp. 177-178). So, according to Moreau’s account of discrimination, even though discrimination can express a

demeaning message, the reason why they do express such a message is because they deny persons something they are entitled to which is their deliberative freedoms (Moreau, 2010).

In response to this criticism, I think that just as how there being only a disadvantage based on a morally arbitrary trait is enough to make discrimination wrongful, there being only a negative message expressed based on a morally arbitrary trait is also enough to make discrimination wrongful. In other words, concern over the expression of such a negative message is a reason, in and of itself, as to why persons should be compensated by the state. Hellman thinks of a creative way to defend her point. She says,

... if harm to the person subject to discrimination were a necessary component of wrongful discrimination, then racial segregation of facilities for those in a permanent vegetative state would not be wrongful because such persons are incapable of suffering psychological or emotional hurt. As this conclusion seems untenable, the claim that wrongful discrimination requires that those affected feel stigmatized fails. (Hellman, 2003, p. 90)

Here, a negative message *is* being expressed when humans in vegetative states are racially segregated. This message is that there is a difference between (past) sentient beings of different races. Even if we were to assume that the family members of the deceased persons do not care about the segregation, and that this is an isolated incident which would have no physical effects on society, this practise is still wrongful. However, it would not be wrongful because anyone's deliberative freedoms are reduced or anyone is harmed, but because of the demeaning message it expresses.

This brings me to the second criticism that one can make about Hellman's expressivist argument. Referring to Eva Feder Kittay, Hellman writes that "... if context seems to be doing all the work, then it is hard to say that the particular practice under discussion expresses anything at all." (2003, p. 113).<sup>66</sup> What Kittay is implying is that what we should be focusing on is fixing this negative context instead of prohibiting the action from taking place. In line with Hellman, I think that contexts and actions work together. Even though we should first and foremost work on fixing unjust contexts, until this is established, the particular action should also be addressed, since it actually works against fixing the context. So, this criticism by Kittay does not challenge the wrongness of affordable discrimination.

I will now consider a criticism of my own view. I say that I care about the expressive dimension of policies, yet I still allow unjustified discrimination to take place at the level of insurance, as long as it is actuarially justified. Does the state compensation really eliminate the negative expression in the way outright prohibition of unjustified discrimination would? Going back to the prosecutor example, would it make it better, as I claim, if the \$10 was still paid to the employer, but it was paid out by the state instead of the woman? I think that the government paying the \$10 makes the situation better, even if it does not fully solve the problem. And given the money-based world we live in, this may be the best we can do. In other words, if we are to accept a free market society, the problem is not one to be completely solved, but to be reduced as far as practically possible. The government would be expressing a message back saying that this is offensive and providing a money-based solution/compensation. At the same time, it would be respecting essential insurance

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<sup>66</sup> This is similar to the point Julian Savulescu makes in "Bioethics: Why Philosophy is Essential for Progress" (2015), and Tarif Bakdash in "Is It Ethical for Patients with Renal Disease to Purchase Kidneys from the World's Poor?" (Bakdash & Scheper-Hughes, 2006)

practises. It would also be preferable if this process was automatic in that the individual would not even be part of the process of money transfer. In other words, we would be subsidizing the insurer, instead of the insured.

#### **4.5 Criticisms from freedom**

I will now refer to some liberty problems that are generally brought up against the proposal that insurers should have access and use of genetic information in insurance, and explain how they are either not problems or how my overall proposal responds to them.

##### **A. Forcing to know**

What if individuals do not want to know whether they have the Huntington's gene or the breast cancer gene? By requesting such genetic information, insurers are thereby making them know something that they do not want to. My response to this point is that although persons should certainly have the freedom to not know, it is only a *prima facie* freedom. Once this person decides to engage in an insurer-insured relationship, the context changes. As we said, any information that is relevant to risk of death is an important consideration for insurers. Assuming that a reasonable amount of no-questions-asked coverage is an available option for this person, they can have no reasonable complaint, towards insurers, about being asked to provide genetic test information for coverage sought above this limit. However, some persons may have a reasonable complaint towards the state if they are not compensated for the extra cost they may have to pay as a result of providing the genetic test results.<sup>67</sup>

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<sup>67</sup> This is also true of a family member who may not want to know. If the individual themselves want to know but a family member does not, there is no good reason why the individual should not be free to take a genetic test. What happens afterwards is something to be dealt with between the family members, and it would be wrong to be paternalistic in this regard.

## B. Forcing to take a genetic test

Another similar liberty problem is that even though it may be acceptable to demand existing genetic test information from potential clients for coverage sought above the moderate coverage, insurers should not be allowed to force persons to take genetic tests if they have not already done so, as a condition for accepting to insure them. I agree that insurers should not be allowed to deny someone for being high risk once it is established that they are high risk but it is not obvious why it would be wrong for insurers to demand genetic test information as a condition for insuring them above the moderate amount, just as they do for blood tests and other medical tests. After all, these are all sources of information that tell insurers about the risk profile of a potential client.

Sandberg points out, however, that in the case where individuals have not already taken a genetic test, there is no concern over information asymmetry since both parties have equal knowledge (none) of genetic test information. This means that the potential client does not have knowledge that would allow them to unfairly take advantage of their situation, whatever that situation is. This is a good *prima facie* reason as to why persons who have not already taken a test should not have to take one. But in such a case, the insurer should nevertheless be allowed to limit cover to a reasonable amount, albeit at a standard/sliding-scale rate, hence the reason why there should be Guaranteed Life Insurance.<sup>68</sup>

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<sup>68</sup> Since I said that the state will interfere when it is necessary, this suggestion also corresponds to the state being free to limit funding if persons choose not to undergo genetic testing and consequently release such information. Note that, with state support, persons will be less likely to be worried over genetic discrimination and so will be less hesitant to take genetic tests for reasons such as personal health. This means that the number of people who have taken genetic tests, before purchasing insurance, will probably rise.

Even though information asymmetry may not be disturbed, it is not a reasonable risk for the insurer and thereby others in the insurance pool to have to take, so long as Guaranteed Life Insurance is available.<sup>69</sup>

### **What about the following situation?**

*“I’m not sure if I want insurance, and I want to know some genetic test information”*

In this case, genetic testing plays two distinct roles and may introduce two insurance related problems for the individual. First, genetic testing will help persons in deciding whether they want insurance in the first place. Secondly, it will tell them whether it would be rational for them to seek more than the modest coverage. Let’s examine the first role and the problem it may give rise to. Commenting on the Genetic Non-discrimination Act, Frank Swedlove (past President of the Canadian Life and Health Insurance Industry) has stated that life insurance companies do not increase insurance rates if persons take a genetic test after they have purchased insurance coverage (CBC 2016). Here he must have been talking about no-questions-asked, universal coverage since genetic test information was required above a certain limit before the passing of the law. Since life insurance is voluntary, he claimed, persons could choose to purchase this option, and then take a test, if they wish to, later (CBC 2016). In this way, they could have insurance, know their genetic information, and not be penalized for it.

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<sup>69</sup> An unrelated liberty problem is about not being allowed to provide favourable genetic test results—*i.e.* the proposal that one should not be allowed to provide favourable genetic test results, if providing genetic test results is not required from *everyone*. This argument can be made by insurers, but it is not limited to them. What is important to note, however, is that the current Genetic Non-discrimination Act would not prohibit insurers from implementing a policy where they do not allow anyone, even consensually, to provide genetic test results. The charge is that this would be unfair towards those who do not have favourable results. I think that so long as people who don’t have favourable results don’t have to pay more than the standard amount, it would be an unjustifiable restriction of liberty to not allow those who have favourable results to reduce their premium costs below the standard cost, all else being the same.

As I have argued elsewhere, one problem with this proposal is that it does not take into account that, in some cases, especially those involving the Huntington's and the BRCA genes, the result of a genetic test may actually help persons in deciding whether to purchase insurance in the first place, at whatever amount, or not (Gurcan, 2018). For example, if a person who anticipates that they may develop a genetic condition in the future is informed by a genetic test that the corresponding gene(s) are not contributing to the risk, they could find this information useful in deciding whether to purchase insurance or not (Gurcan, 2018). So, it may turn out that they would not even want the basic, no-questions-asked coverage.

Secondly, it can be interpreted that having to settle for the basic, no-questions-asked coverage is also case of being penalized, if it turns out that they would have wanted more coverage after seeing the result of their genetic test. This problem can be solved simply by insurers allowing such persons to increase their coverage afterwards.

#### **4.6 Secondary markets: The standing of the emerging Life Settlements industry**

Michael Sandel thinks that "...markets in life and death have outrun the social purposes and moral norms that once constrained them (Sandel, 2013, p. 351).<sup>70</sup> His major concern is the *message* that is conveyed when life insurance (a death wager) serves *no socially useful* purpose. Here he is referring to the viaticals and life settlements industries, which I will explain shortly.

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<sup>70</sup> Thank you to Prof. Phil Ryan for telling me about this text.

Firstly, it must be recalled that private life insurance has had a history where those taking out a policy did not need to have a familial relationship or close interest in the life of the person for which they were taking out insurance on (Sandel, 2013). For example, Walmart took out life insurance on their rank-and-file workers, and if they were to die, Walmart, not their family members, would get all the benefits (Sandel, 2013, p. 343). Was this not a disincentive to continuously improve worker safety measures? Walmart did this without the consent of its workers but even if consent was given, Sandel believes that the problem remains that “creating conditions where workers are worth more dead than alive objectifies them; it treats them as commodity futures rather than employees whose value to the company lies in the work they do.” (Sandel, 2013, p. 345). Additionally, Sandel states that a further objection to what companies like Walmart were doing is that it “... distort[ed] the purpose of life insurance; what was once a source of security for families now becomes a tax break for corporations.” (Sandel, 2013, p. 345). So Sandel views the investment of companies in the life expectancy of their employees instead of the focus on the production of goods and services as an example of the shift from an economy of production to an economy of speculation (Sandel, 2013).

When life insurance serves no socially useful purpose, Sandel says, the line between insurance and gambling becomes very blurry (2013, p. 348). Although it is now necessary to have an insurable interest in the life of someone whose life you want to insure, what one does with that policy afterwards is up to them (Sandel, 2013, p. 350). For example, there is a market where rich investors buy life insurance policies from original holders who are terminally ill. This is the “viaticals” industry, and it works like this:

Suppose someone with a \$100,000 life insurance policy is told by his doctor that he has only a year to live. And suppose he needs money now for medical care, or perhaps simply to live well in the short time he has remaining. An investor offers to buy the policy from the ailing person at a discount, say \$50,000, and takes over payment of the annual premiums. When the original policyholder dies, the investor collects the \$100,000. (Sandel, 2013, p. 345)

This seems like a good deal for both parties, but it is also true that “...the investor must hope for the early demise of the person whose life insurance he buys.” (Sandel, 2013, p. 346). In fact, to deemphasize that they had an interest in the death of terminally ill individuals, viatical brokers described their mission as “... providing those with terminal illnesses the resources to live out their last days in relative comfort and dignity.” (Sandel, 2013, p. 346).<sup>71</sup>

When people began living longer, and returns were not as profitable as before, investors began buying policies from old but healthy individuals as well (Sandel, 2013). It took longer to get the benefits, but the payouts were usually larger (Sandel, 2013). This is the “life settlements” industry. Sandel describes how “hedge funds and financial institutions like Credit Suisse and Deutsche Bank were spending billions buying the life insurance policies of wealthy seniors.” (Sandel, 2013, p. 353). As the demand for such policies (called specular initiated or “spin life” policies) increased, brokers began paying aging adults to take out life insurance, and then sold them to investors who would reap the benefit once the insured died (Sandel, 2013).

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<sup>71</sup> It may be the case that one day tertiary markets will emerge on the chances of onset of genetic disease, where investors can bet on when a person (from who they have bought an insurance policy from) will begin to show symptoms of their genetic condition. It may be difficult to determine when a genetic disease officially begins, and investors may have further difficulty tracking this information, but it is nonetheless a possibility. Thanks to Marc Saner for bringing this possibility to my attention.

According to Sandel, a society that is based on an economics of speculation instead of economics of production is a way of thinking that is *morally corrosive* (2013, p. 347). He recognizes that “if death bets are objectionable, it must be for reasons that lie beyond market logic, in the dehumanizing attitudes such wagers express.” (Sandel, 2013, p. 349). He gives an example of a grim life insurance wager from the past to make this point. This particular wager involved “...eight hundred German refugees who, in 1765, were brought to England and then abandoned without food or shelter on the outskirts of London. Speculators and underwriters at Lloyd’s placed bets on how many of the refugees would die within a week.” (Sandel, 2013, p. 349). He continues stating that most people would view such a wager as “morally appalling” (Sandel, 2013, p. 350). But, he asks, from the point of view of market reasoning, what is so objectionable about the wager on how soon they will die, provided that the gamblers are not responsible for the suffering of the refugees? (Sandel, 2013). And to this he answers, ‘nothing really’ since everyone who is financially involved in the wager has made an autonomous economic choice and is under the impression that they are made better off by it (Sandel, 2013). The refugees, on the other hand, are unaware of the wager and are not harmed by it (Sandel, 2013). But, Sandel says,

For the gamblers themselves, a cavalier indifference to death and suffering is a mark of bad character. For society as whole, such attitudes, and the institutions that encourage them, are coarsening and corrupting. Notwithstanding the sense of social responsibility that underlies insurance, the actual practice of the insurance industry undermines the image of an aid institution interested in the welfare of people who experience misfortune. (Sandel, 2013, p. 350)

Adjin-Tettey also writes about the negative aspects surrounding private life insurance. Her major point is about the disconnect between the “sales” and “claims” visions of insurance. The sales vision is all about the promise to be there and highlights how important it is to protect and financially secure family members (Adjin-Tettey, 2013, p. 585). The claims vision, on the other hand, is all about tough-love, the need to protect the insurance fund, and the need to protect others against fraud and abuse (Adjin-Tettey, 2013, p. 585). She continues stating that “the insurance industry uses the phenomenon of risk segmentation to be selective in its target audience (usually those they view to be low risk and less likely to pose moral hazards) and to insure those classified as substandard risk at higher premiums.” (2013, p. 585). What is questionable, then, according to Adjin-Tettey is that the value of insurance for most insureds is not something tangible, but rather a psychological benefit from knowing that their beneficiaries would be financially secure in the event of death within the policy time-frame (Adjin-Tettey, 2013). In many cases, however, a payout will not be made because the policy will lapse (Adjin-Tettey, 2013).

I agree with most of Sandel’s points, and all of Adjin-Tettey’s. I do not think I would be misplaced, however, to suggest they are not making these points as an argument for the abolition of private life insurance, but rather for more regulation of it and activities surrounding it. Starting with Adjin-Tettey’s concern, I argued earlier in this chapter that life insurers should not deny coverage to anyone for being high risk. Rather, they should offer a no-questions asked guaranteed insurance as an option, and for those seeking further coverage, offer an actuarially fair price for their premiums. These changes would certainly soften the conflict between the sales and claims vision of insurance that Adjin-Tettey is describing. With respect to her point concerning the value of life insurance not being actually

realized most of the time, I think that since those seeking insurance do, in fact, value the psychological security it provides, there is nothing much that can be done in the meantime. But as I have iterated earlier, in order to meet their social responsibility, insurers should also accept to lower their profits to a certain degree, to support disadvantaged persons access insurance. This would mean that, regardless of there being very-high risk individuals in the insurance pool or not, insurers would be offering premiums at a lower cost overall. On this same point, I think that Adjin-Tetty would actually be in support of the resulting secondary markets that Sandel is talking about since these industries provide options for persons who own life insurance policies that they no longer want.

As Sandel thoroughly describes, there are emerging industries (viaticals and life settlements) that are looking to provide market-based options for life insurance policy holders while also looking to take a share of life insurers' profits, however indirectly it may be. As you recall, insurer profits come from (1) keeping and investing the premiums that clients pay to them, and (2) the money they get to keep when they do not need to provide a payout. There may be multiple reasons that insurers may not need to make a payout. These include cases where clients choose to no longer pay their premiums (for a variety of reasons), and where their contract lapses (in the case of term life insurance). The viatical and life settlement industries (these will be collectively referred to as the *life settlement industry*, hereafter) offer policy holders money for their policies that is more than how much they have already paid in premiums to insurers, but less than the cost of the policy. In this case, clients would no longer need to abandon their life insurance contracts at a financial loss.

This is to the disadvantage of life insurers in two ways. With respect to term life insurance policies that are convertible to whole life insurance, insurers would be making a payout that they otherwise may not have had to, since the client would simply let the contract lapse. In the case of whole life insurance, persons who may not have been originally thinking of taking out life insurance may be nudged to do so with the intention of selling to a life settlement company later, meaning that there would be more payouts to be made than otherwise. The life insurance industry calls this “financial exploitation” (McCaffery, 2018). Generally, insurers also have a buy-back option, but it seems that the benefits of selling to a life settlement company outweighs the benefits that life insurers are willing to provide, from the perspective of the seller.

What about Sandel’s criticism? Is life and death something that should not be bet on when it serves no socially useful purpose? I believe that Sandel is right to label the life settlement industry’s alleged attempts to intentionally and explicitly lure persons to take out a life insurance policy is somewhat dehumanizing. This would be a *prima facie* reasonable line to draw. But I do not think that offering this service for those who already have a policy, whether terminally ill or not, is a mark of bad character. Rather, they are offering a service for those who no longer have a beneficiary, no longer have debt, or no longer want their insurance policy for any other reason, but would not like to lose the premiums that they have already paid out. Since offering this service is not inconsistent with having the wellbeing of persons in mind, it qualifies as serving a socially useful purpose.

Although such companies will receive what they truly desire only when the person dies—money— this is not the same thing as having an interest in their death in the way those

betting on the lives of German refugees did. This is because, in the case of life settlements, there is nothing that can be done to keep such individuals alive. In other words, there are morally significant differences between the German refugee and the life settlement cases.<sup>72</sup>

Should life settlement companies be banned from asking persons without life insurance to take out life insurance with the intent of selling? I understand the initial appeal of the argument from financial exploitation and the morally corrupting expressions of such actions. These, however, are seriously challenged by arguments from autonomy, as well as fair pricing. Without attempting to provide a full answer to the question, then, I would simply like to point out that the actions of life settlement companies to get persons to take out life insurance becomes much less problematic, if at all, in a context where life insurers are already:

- Denying persons insurance
- Not offering a reasonable amount of no-questions-asked insurance
- Not doing what is required of them to help disadvantaged persons access insurance
- Possibly, engaging in actuarially unjustified discrimination processes

In other words, it is odd that the argument from financial exploitation is mainly being voiced by life insurers themselves, who, to many, are in the business of covert financial exploitation.

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<sup>72</sup> One can also claim that the idea that there is nothing to do about aging adults dying is committing the naturalistic fallacy, but, for now, I believe I would not have much opposition if I were to accept that as we age, we will die.

## Chapter 5. Conclusion

The motivation for this thesis was to do a critical reading of genetic discrimination policies in Canada as they applied to life insurance. It investigated whether it was acceptable for the law to only protect genetic information, and not other health-related information, from being used by life insurers; and, secondly, what the best way to respond to (genetic) discrimination was, if not through genetic exceptionalism.

### **So, what are some key takeaways regarding the problem of genetic discrimination and the standing of the Genetic Non-discrimination Act in Canada?**

Primarily, from a practical standpoint, it was demonstrated the Canadian Genetic Non-discrimination Act does not change much for those seeking life insurance. The law does not change much for these individuals because it reflects a *genetic test exceptionalism* policy rather than the broader *genetic exceptionalism policy*. What this means is that insurers are still free to request other sources of genetic information such as those from family history of genetic disease, and the results of non-genetic tests that, nonetheless, reveal genetic information. These may similarly lead to rendering some (e.g., genetically disadvantaged persons) ineligible for insurance and/or increasing their premiums, which are things that the law is attempting to reduce.

However, it is also true that as we learn more about behavioral genetics and human genetics in general, genetic tests are likely to become more and more useful for insurers. In the near future, for example, these tests may reveal risk information about certain conditions that other tests or sources of information cannot reveal. Thus, life insurers in Canada are not content with the standing of this law either.

But there is more; insurers and those who are genetically/medically disadvantaged are not the only ones who may not benefit from this law. If insurers choose to overplay the importance of the information that they can gather from genetic tests *today*, they will likely increase prices for *all others* in the insurance pool with the rationalization that this necessary to make up their potential financial losses.

The Genetic Non-discrimination Act of Canada commits a triple wrong with respect to what it accomplishes for life insurance: the method of illegalization (of the use of genetic test results) is wrong, its theoretical scope is wrong, and, as just outlined above, some of its intended consequences are not realized. The method of illegalization is wrong because it ignores reasonable interests from insurers; the theoretical scope is wrong because genetic exceptionalism (as an idea) does not hold and many theoretically deserving individuals are not protected; and some of its intended consequences are not realized because it does not protect people it claims to protect.

On the other hand, what this law *does* achieve is that persons wishing to make use of genetic tests and to participate in genetic research studies may do so with peace of mind (however irrational this feeling of comfort may be, for reasons discussed in Chapter 3). Having the ability to take genetic tests without fear would allow persons to take personal genetic tests from companies like *23andMe*, which they can then use to make decisions regarding their lifestyle. Such information can also provide health care professionals with a fuller picture of what kind of medications or interventions persons would best respond to, and what kind of medications or interventions would not work or be harmful towards them,

*etc.* This also has indirect benefits for society which will come from the progress that genetic sciences will thereby be able to make.

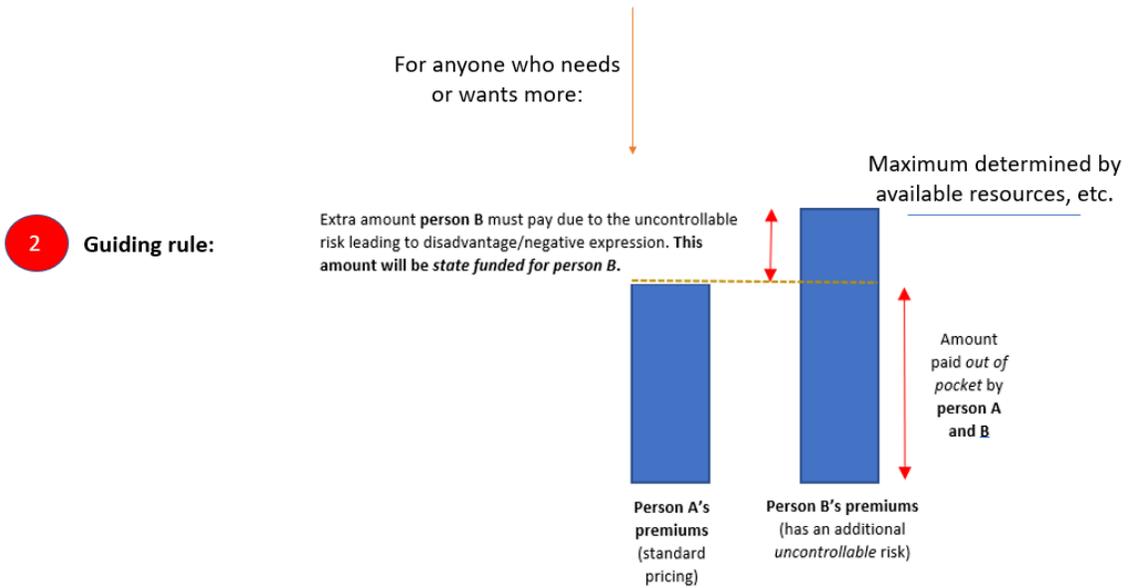
Overall, through a consideration of the interests of all those who are involved, it was concluded that the way things are done now are not satisfactory. This law (as it applies to life insurance) is a not-so-great step in the right direction. I, instead, proposed and defended a combined luck egalitarian and expressivist position, claiming that (genetic) discrimination deserves a response from the state when it is (a) based on *bad luck* and *leads to disadvantage*, and (b) when it is based on *bad luck* and *expresses something negative*. Taking the interests of insurers seriously, I argued that the response from the state ought to be in the form of *compensating* individuals who deserve it, rather than through the banning of insurers from using particular health-relevant information. So, when a sought policy is above the basic coverage limit, but below a maximum limit, the premium cost of an insured should be shared between the insured (who pays for what is controllable) and the state (who pays for what is based on “bad luck” *and* leads to disadvantage/expresses a negative message). This is part of a larger scheme of insurance where a substantive no-questions-asked guaranteed insurance is also available to everyone. In this way, what I am proposing is a way to keep and improve the positive aspects of this law while getting rid of the negatives. My solution takes account of all persons’ reasonable interests, thereby handling the science and public health problem<sup>73</sup>, without limiting all deserving/unlucky persons’ freedom to purchase more than limited insurance cover, and without compromising actuarial fairness. This is a more

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<sup>73</sup> Remember that the science and public health problem refers to the fear persons have to participate in genetic research studies and take genetic tests in fear of discrimination in other contexts such as insurance. The problem is that this fear negatively impacts public health and the development of science.

desirable system of insurance. Below is a depiction of my overall proposed insurance scheme, as well as a summary table displaying the different policies and whether they meet certain conditions.

**1** Guaranteed basic life insurance at a standard rate available to all



**2** Guiding rule:

**Figure 6. My proposed insurance scheme – “Ethical Insurance”**

**Table 2. Summary table of different policy options**

	<b>Genetic test exceptionalism</b>	<b>Genetic exceptionalism</b>	<b>My solution (Ethical insurance)</b>
<b>Meaning</b>	There is special “protection/treatment” of genetic test results meaning that life insurers cannot request the results of any genetic test for the purposes of determining eligibility or setting prices of premiums.	There is special “protection/treatment” of all genetic information meaning that life insurers cannot request any genetic information (regardless of source such as a genetic test or family history of disease) for the purposes of determining eligibility or setting prices of premiums.	When uncontrollable information (genetic or other) increases premiums (and thereby either disadvantages the individual or merely expresses a negative message), the state covers the extra cost.
<b>Does it meet genetically disadvantaged</b>	✗	✓	✓

<b>persons' interests?</b>			
<b>Does it meet generally disadvantaged persons' interests?</b>	×	×	✓
<b>Does it meet insurer interests?</b>	×	×	✓
<b>Does it meet all other insureds' interests?</b>	×	×	✓
<b>Does it meet the public's interest wrt<sup>74</sup> the science and public health problem?</b>	✓	✓	✓
<b>Theoretically strong?</b>	×	×	Yes. For example, it is sensitive to "desert"

I have left many things up to policymakers to decide. One of these is about macro-allocation in general. Surely disadvantaging/demeaning bad luck is not only involved in life insurance, but also in many other spheres of life. Should non-discrimination in life insurance have priority over non-discrimination in adoption? Why should taxpayer money go to supporting disadvantaged persons in life insurance instead of disadvantaged persons from natural disasters? Even though these hard questions should be decided by policymakers, what I have done in this thesis is to demonstrate the important role that life insurance can have, as a gateway social good, which policymakers can and should take into account while allocating resources. As I highlighted on multiple occasions, ensuring the provision of a reasonable, no-questions-asked, guaranteed insurance at a standard rate could be a first step towards addressing the needs arising from discrimination in life insurance. Concerns over privacy could give this proposal a priority.

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<sup>74</sup> "wrt" = with respect to

Another thing I have left to policymakers to decide is the exact cover limit of guaranteed insurance and the upper limit of the full-disclosure insurance, as well as how much exactly the state and life insurers should contribute to the fund to support disadvantaged persons. How much should the state allocate to increasing the cover limit for the no-questions-asked guaranteed insurance vs. providing support for those who want more? In general, I have developed my rules of (genetic) non-discrimination to help policymakers navigate through these difficult questions, but how much is to be allocated and how exactly they are to be implemented will be decided by policymakers. The problem of genetic discrimination is in its infancy. To prepare for the future, researchers should also study how new genetic knowledge and technologies are likely to change the way that genetic discrimination takes place. It is for certain, for example, that as genetic technologies become more normalized in society, anti-genetic discrimination policies will have to be flexible enough to protect (epi)genetically edited and unedited members of society in many spheres of life.

## Appendix 1. Life insurance industry in Canada

The following facts are taken from the 2016 report titled, “Canadian Life and Health Insurance Facts”, published by the Canadian Life and Health Insurance Association (CLHIA). CLHIA is “...a voluntary association whose member companies account for 99% of Canada’s life and health insurance business.” (2016, p. ii). The report “...presents authoritative, factual information about life and health insurance in Canada.” (2016, p. ii).

### **Types of life insurance**

- There are two basic types of life insurance: *permanent* and *term* insurance, with variations on each to meet specific consumer needs (2016, p. 9).
  - Term insurance provides cost-effective temporary coverage over an insured's prime earning years. Premiums typically increase over time, in 5, 10 or 20 year "steps". Term insurance usually provides a right to convert to permanent insurance with the same insurer, without further underwriting, providing consumers with more flexibility (2016, p. 9).
  - Permanent insurance meets life-long protection needs. In addition to death protection, cash values are accumulated and can be used for financial emergencies, or to supplement retirement income. Premiums can be paid over a set number of years or for life (2016, p. 9).
    - *Whole life insurance* is the traditional form of permanent insurance, where the insurer takes on both the risk related to death and the underlying investment risk (2016, p. 9).

- Under *Universal life insurance*, consumers manage the investment risk and the insurer assumes the risk related to death (2016, p. 9).
- Canadians mainly buy life insurance on an "Individual" basis through an agent or an advisor. Simpler products sold by direct mail or on-line marketing, while increasing, still only account for 1% of individual premiums. Life insurance is also acquired on a "Group" basis through an employer or as members of an association, and is priced on the risk characteristics of the group as a whole, rather than of the individual consumer (2016, p. 8).
- Consumers choose the amount of life insurance they hold based on a number of factors: marital status, desired level of income to support dependents, outstanding mortgages, etc. There is a high degree of correlation in the distribution of life insurance protection and demographics (such as age and income level) (2016, p. 8).

### **The insurance market**

- There are more than 150 life and health insurers operating in Canada (including 41 foreign-owned life insurers) providing a competitive Canadian marketplace with a wide range of financial security products for businesses and individuals (2016, p. 4).
- Canadian life insurers operate in more than 20 countries — 3 Canadian companies rank among the top 15 largest life insurers in the world (2016, p. 2).
- Life insurers provide one of Canada's most important sources of long-term capital, including infrastructure financing (2016, p. 3).
- 22 million Canadians own \$4.3 trillion in life insurance coverage (2016, p. 4).

- Life insurers paid a total of \$11.1 billion in benefits in 2015; \$6.4 billion for death benefits, and \$4.7 billion to living policyholders as disability benefits, cash surrenders or dividends (2016, p. 4).
- Canadians paid \$18.5 billion total life insurance premiums in 2015 with 78% coming from individuals and 22% coming from group insurance (2016, p. 8).
- In 2015, the average protection per insured household was \$388,000, which approximates five times the household income (2016, p. 8).

## Appendix 2. Cost of whole life insurance

### Whole Life Insurance – Monthly Premiums – Male

Age	\$25k	\$50k	\$100k	\$250k
5	\$12	\$16	\$27	\$60
10	\$14	\$18	\$32	\$72
15	\$16	\$22	\$39	\$88
20	\$16	\$23	\$39	\$92
25	\$18	\$29	\$48	\$102
30	\$20	\$33	\$58	\$127
35	\$24	\$40	\$71	\$1161
40	\$29	\$47	\$85	\$205
45	\$35	\$60	\$109	\$259
50	\$42	\$74	\$132	\$328
55	\$54	\$92	\$169	\$417
60	\$68	\$125	\$223	\$554
65	\$90	\$172	\$314	\$749
70	\$121	\$237	\$423	\$1,007
75	\$157	\$310	\$550	\$1,341
80	\$222	\$443	\$792	\$1,810

\*Representative values, based on regular health

(Policy Advisor Magazine, 2020)

### Whole Life Insurance – Monthly Premiums – Female

Age	\$25k	\$50k	\$100k	\$250k
5	\$11	\$15	\$25	\$53
10	\$12	\$16	\$28	\$60
15	\$14	\$18	\$32	\$71
20	\$15	\$20	\$35	\$78
25	\$16	\$23	\$41	\$86
30	\$18	\$27	\$49	\$107
35	\$21	\$33	\$60	\$138
40	\$25	\$42	\$74	\$174
45	\$30	\$51	\$93	\$221
50	\$37	\$62	\$115	\$279
55	\$47	\$76	\$142	\$346
60	\$58	\$99	\$188	\$466
65	\$78	\$139	\$252	\$619
70	\$101	\$192	\$337	\$828
75	\$135	\$265	\$464	\$1,138
80	\$191	\$375	\$689	\$1,632

\*Representative values, based on regular health

(Policy Advisor Magazine, 2020)

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