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GENETIC KNOWLEDGE – IS IT MORALLY PERMISSIBLE TO USE GENETIC INFORMATION IN THE CONTEXT OF LIFE INSURANCE?

by

GLENN KENNETH HICKLING

"The only true wisdom is in knowing you know nothing."

— **Socrates**



A research report submitted to the Faculty of Arts and Humanities, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Arts in Applied Ethics for Professionals

Johannesburg, July 2021

DECLARATION

I, Glenn Kenneth Hickling declare that this research report is my own work. It is being submitted for the degree of Master of Arts at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



Signature .....

ABSTRACT

Private life insurance is a social co-operative mechanism facilitated by an insurer through which policyholders seek to protect themselves from the adverse financial consequences of uncertain future events such as death, disability or illness in return for the payment of a premium. To provide such protection an insurer seeks to ascertain the probability of such events manifesting. To do this it relies on medical and genetic information procured from the applicant for insurance by which it sets a commensurate premium. The moral ideal of this mechanism, known as actuarial fairness, is to match the premiums as closely as possible to the likelihood (as calculated by the insurer) of a risk manifesting itself. The Human Genome Project (HGP) has enabled insurers to calculate risks more finely. It is this capability and the use of genetic information that has given rise to considerable debate. On the one hand there are those (characterised as exclusionists) who object to the use of genetic information in the insurance context, saying that a person should not be prejudiced for something that they do not have any control over. On the other, there are those (characterised as inclusivists) who say that it would be unfair to the other members of the risk pool if the use of genetic information were forbidden. The purpose of this thesis is to explore the moral foundations of the exclusionist and inclusivist arguments, evaluate their plausibility and finally advance an argument that the use of genetic information in the context of private life insurance can be morally justified if viewed through the lens of the social contract theory espoused by John Rawls.

Key words: underwriting, risk pooling, mutuality, solidarity, anti-selection, actuarial fairness, luck egalitarianism, genetic information, premiums, cross-subsidies, justice, fairness.

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CHAPTER 1: INTRODUCTION

Overview

The Human Genome Project (HGP) was completed in April 2003.[1] Its goal was the complete mapping and understanding of all human genes which together are referred to as our 'genome' (Dupre, 2005). According to the Genetics Home Reference ("What is a genome?", n.d.), a genome is an organism's complete set of deoxyribonucleic acids, or DNA, including all of its genes. Each genome contains all of the information needed to build and maintain that organism. DNA is the instruction mechanism an organism needs to develop, live and reproduce.

The work of the HGP has therefore given scientists an understanding of how human beings are constituted. This raises the possibility that a human being could someday be built or cultivated. The HGP has, in short, given scientists a blueprint for the human organism. This knowledge has a major impact on the fields of medicine, biotechnology, life sciences, ethics, religion and, of course, private life insurance, which will be the focus of this research.

With the knowledge of our bodies' blueprints, practitioners are now able to test for conditions that each of us may be predisposed to or already show symptoms of having. There are various types of testing, including diagnostic, carrier and predictive testing. Diagnostic genetic testing is performed on individuals already experiencing symptoms of a disease or condition in order to diagnose and identify the disease or condition ("What are the types of genetic tests?", n.d.). Carrier testing determines whether an individual carries a certain genetic disorder or

[1] See also https://web.ornl.gov/sci/techresources/Human_Genome/project/hgp.shtml for the history of the HGP.

not (Fulda & Lykens, 2006). Predictive genetic testing is performed on individuals who are at risk of inheriting a familial condition but do not yet show any signs of doing so and is presently offered for several conditions. These include Huntington's disease, cystic fibrosis, sickle cell anaemia, breast cancer, and colon cancer (Evans et al., 2001). It is this final type of testing that is relevant for purposes of private life insurance.

Predictive genetic testing has important benefits irrespective of whether the test results are favourable. The outcome of a test can promote certainty and help a person make crucial life choices relating to their future healthcare needs. For example, a favourable result can eliminate the need for unnecessary check-ups and screening tests for conditions one might be concerned about. An unfavourable test result can direct a person towards available prevention, monitoring, and treatment options. Aside from these benefits the results of predictive genetic testing are especially useful in the field of private life insurance. It is a feature of the industry that when applying for insurance cover the applicant is asked a host of medical, lifestyle and financial questions. This is called underwriting. In some cases, the applicant is also obliged to undergo certain medical tests to enable the insurer to determine the applicant’s risk profile, which in turn enables the insurer to set a premium commensurate with that profile. Genetic information is therefore a new and particularly important source of information for an insurer; it can supplement the medical information upon which the insurer already relies.

The use of genetic information will be discussed in the context of private, mutualistic life insurance (private life insurance) specifically and not in the context of solidaristic insurance because access to solidaristic insurance is not dependent on any kind of genetic or medical information. Genetic information therefore does not offer any advantages or opportunities

for use in the context of solidaristic insurance. The differences between the two types of insurance will be set out in Section 2.2 below.

It has to date been accepted (albeit grudgingly) that insurers are legitimately allowed to discriminate between applicants according to specific statistically relevant risk factors such as age, gender, lifestyle choices (such as smoking) and health. These factors are gleaned from the medical and lifestyle questions elicited at the application stage of an insurance contract. The arrival of the HGP offers insurers the potential to discriminate and assess risk more finely. The information gained from genetic testing is of such a nature that it can enhance the insurer's capability to predict the probability of insured events occurring with greater accuracy and thus to set the appropriate (and fairer) premium. Despite its advantages the use of genetic information by insurers has, however, given rise to the debate as to whether genetic information is different to medical information, if so whether it has a different moral status from other medical information and whether reliance on this information by insurers ought to be allowed at all. The arrival of the HGP therefore brings with it various ethical challenges (see, for instance, Fulda & Lykens, 2006).

Some writers argue that genetic factors are beyond a person's control and therefore should not count in insurance evaluations because their use by insurers would lead to genetic discrimination. These writers claim that insurers would use the information to exclude an applicant from obtaining insurance or to charge higher premiums (O'Neil, 1996). They appear to regard the role of luck as an important determining factor in ethical considerations of fairness as genetic factors are the outcome of chance. On the other hand, there are those who argue that the possibility of more accurately measuring the future risk of disease through genetic testing is very attractive for insurers as a risk-pool allocation tool. Such

predictive power would make the determination of the appropriate premium much easier and thereby increase access to private life insurance, while disallowing the use of genetic information would have dire consequences for the industry. If genetic information was allowed to be withheld (i.e., to the exclusion of the insurer), one could apply for insurance with the comfortable expectation that the insured event was likely to occur. If enough of such high-risk individuals were to apply for insurance cover, the number of claims against the insurer would increase, which in turn would lead to the increase of the cost of life insurance. It would then follow that the number of low-risk people who make the risk pool viable would leave (Otlowski, 2002). The writers in favour of insurers having access to genetic information appear to regard the well-being of the private life insurance industry and the preservation of the ethical ideal of actuarial fairness (which I will explain in what follows) to be of overriding importance.

Whilst there may be other variations it is clear from the foregoing that there are two dominant schools of thought on whether genetic information obtained via predictive genetic testing has a role to play in private life insurance. The first, which I shall characterise as the 'genetic inclusivist' position, claim firstly that that genetic information is no different from other medical information (and should not be treated any differently) and secondly that it therefore has a role to play in the same way that other medical information does. The second school of thought, which I shall characterise as the 'genetic exclusionist' position, claims firstly that genetic information is unlike other medical information and must hence be treated differently and secondly should therefore not be used in the context of private life insurance because it may lead to genetic discrimination. To genetic exclusionists, genetic information has a different moral status to that of medical information.

I have characterised the inclusivist and exclusionist positions according to the position they take viz-a-viz medical and genetic information. The referenced literature predominantly points to the exclusionists making a moral distinction between genetic and medical information and that the use of genetic information is morally impermissible. This is not to suggest exclusionists could not argue that they do *not* make a moral distinction between medical and genetic information but rather regard the use of genetic information as morally impermissible for *othe*r reasons. This possible argument is not the focus of this thesis. Instead, the focus in respect of the exclusionist position will be on their two claims that:

- There is a moral difference between genetic and medical information; and
- The use of genetic information in the context of life insurance is morally impermissible.

The philosophical ambition of this thesis is to determine the plausibility and strength of the exclusionist and inclusivist positions by comparing the moral foundations upon which the respective positions could credibly be founded and by assessing the role that luck plays therein. In so doing I hope to show that the use of genetic information by insurers is not morally problematic and that the inclusivist position is the more realistic, preferable and more efficient way of distributing the benefits and burdens of private life insurance. What follows below is a brief overview of the two positions, which will be dealt with in more detail in Chapters 3 and 4.

In respect of the exclusionist position, that is founded on their distinction between genetic and medical information, I will propose that the moral objection of the genetic exclusionists to the use of genetic information in private life insurance is based on the idea that a person should not be disadvantaged for a genetic make-up that he or she has no control over. These

concerns correlate with the concerns addressed by the ethical theory of luck egalitarianism (whose name was coined by Elizabeth Anderson (1999)). In its purest form, the theory makes the distribution of goods, benefits and obligations insensitive to (some forms of) luck, or equalises the distributive effects of luck (Knight, 2013). The adoption of this view has led many jurisdictions to outlaw or severely curtail the use of genetic information in the insurance realm (see for instance Joubert, 2009, p. 21) and is codified in the UNESCO Universal Declaration on the Human Genome and Human Rights (1997) which provides at Article 6 that "no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity". The 1997 Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Applications of Biology and Medicine specifies in Article 11 that: "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited" (see Godard et al., 2003, p. 24).

In contrast to the exclusionists, the genetic inclusivists claim that the use of genetic information is morally unproblematic. Their claim supports the ideal of actuarial fairness which itself is subject to the qualification by the exclusionists that genetic information cannot be the sole determinant of how access to private life insurance is provided. I will propose that the inclusivist position and the ideal of actuarial fairness can be plausibly accommodated within the social contract theory espoused by John Rawls (1977).

As I shall argue in Chapter 3, factors that lie beyond the control of an individual (i.e. factors dependent on certain forms of luck) cannot be the sole determinant of how goods and benefits are distributed. The luck egalitarian position is focused on the neutralisation of a specific form of luck ('brute luck' which I will explain in Section 3.4) in the distribution of

benefits and burdens. In contrast, the Rawlsian version of justice is rooted in a more general conception of equality and justice premised on how individuals stand in relation to each other. On this conception, luck plays a role only if people's standing to one another may be affected. In the context of private life insurance, the Rawlsian moral foundation is far more plausible and accords better with prevailing social morality and our intuitions of justice.

In comparing the Rawlsian and luck egalitarian foundations, the shortcomings of the exclusionist position will become apparent, and the limitations of the luck egalitarian position demonstrated.

The exclusionist position is weakened further by the fact that insurers are already using genetic information (not acquired via predictive testing) and that the normal medical information upon which insurers rely may also deliver information about factors that are beyond the control of the persons affected. Unless the exclusionists revise their argument to demand a prohibition on the use of *any* information derived from any source that is the outcome of factors beyond a person's control (and thus make an argument for a solidaristic model of insurance) or adopt an entirely different foundation to their argument, there is no principled reason not to use genetic information acquired via testing in the context of private life insurance. At this stage in our practice, the moral position of the exclusionists is tenuous at best and will come under increasing moral scrutiny as the ability to obtain genetic information via predictive testing is 'out there' and will not vanish. It is therefore important to address the moral issues that this ability raises. In this regard Dr Roger Magnusson (Australian Law Reform Commission, 2010) writes:

"Genetic information is likely to become, in future, an integral part of each patient's individualised health care program. In my view, it is reasonable to assume that, over time, genetic information will become 'smeared across' – so to speak – the individual's clinical record, since it will be a relevant component of health status in many areas. Whether or not this information is or should be regarded as especially sensitive will depend, just like non-genetic information, on what it is.

The future role of genetic information within clinical care provides an important and pragmatic argument against genetic exceptionalism. Ultimately, there will be little point in seeking to compartmentalise and quarantine genetic health information behind additional privacy or security barriers. A generic solution to the privacy challenges of genetic health information is preferable".

In the circumstances it is more sensible to seek a morally justified role for genetic information, which I hope to do in this thesis.

Thesis outline

This thesis is organised as follows. In Chapter 2, I will set out a background to the various aspects and features of life insurance and will illustrate the different forms of insurance. The background provides context for the explanation of the concept of actuarial fairness which is currently the moral justification for the discriminatory practices inherent in private life insurance. These are the practices which the genetic exclusionists aim to temper by neutralising the impact of certain forms of luck. In Chapter 3, I will set out the objections to the use of information obtained via predictive genetic testing. I will characterise these

arguments as supporting the genetic exclusionist position. This will entail an elucidation of the moral theories of egalitarianism in general and luck egalitarianism in particular. I will thereafter present a critique of the luck egalitarian theory as the moral foundation of the exclusionist position, followed by a critique of some of the arguments exclusionists use in support of the premise that genetic information is different to medical information. In so doing, I will show that the exclusionist argument is problematic, and that the moral foundation of their position is an unsatisfactory and unsuitable theory for use in the private insurance realm. In Chapter 4, I will set out the arguments made for the use of genetic information which characterise the genetic inclusivist position, proposing that the position can be morally founded on John Rawls' social contract theory. I will show that, as viewed through the Rawlsian lens, the use of genetic information is morally unproblematic, and that the role of luck is more satisfactorily accounted for than in the exclusionist account. In Chapter 5, I will conclude by showing that there remains no principled reason why information procured via genetic testing cannot be used in the context of life insurance and that, by extension, applicants can therefore be asked to submit to predictive genetic testing without the risk of any moral sanction.

CHAPTER 2: BACKGROUND ON LIFE INSURANCE AND THE RELEVANCE OF GENETIC INFORMATION

2.1 Introduction

Life insurance (as opposed to other forms of insurance such as motor insurance) can broadly be described as financial protection against the adverse consequences flowing from the occurrence of a future uncertain event. In this regard, people insure themselves against the possibility of illness, disability, injury or death.

Simply stated, insurance can be characterised as a social co-operative mechanism, administered by an insurer, whereby groups of individuals put resources (premiums) into a pot (or fund) to be used to mitigate risk. For an individual, risk implies uncertainty. It is however very difficult, if not impossible, to calculate the chances of a risk manifesting for a particular individual. For instance, what are the chances of an individual suffering from a dreaded disease such as cancer, or becoming involved in a motor vehicle accident? The calculation becomes easier when applied to a group of individuals because uncertainty can now be converted into probabilities. The risk of each individual in the group is 'pooled' with the risks of the other individuals. This 'risk pooling' provides the opportunity to better calculate the probability of a particular risk manifesting for an individual. Take for example, the risk for an individual of becoming involved in a motor vehicle accident. If the risk were analysed just for that individual it would remain incalculable. In the group context however, the individual would know that he has, for instance, a 1:100 chance of becoming involved in a motor vehicle accident. The larger the group the more accurate the calculation of

probability becomes. In return, each individual in the pool pays for the expected costs for the occurrence of such risks via premiums. In that sense, insurance is about transforming uncertain adverse events with uncertain outcomes into statistical events with certain outcomes (Landes, 2015).

To calculate the probability of insurable risks manifesting for an applicant, the insurance company requires *inter alia* information relating to that applicant's health, lifestyle, socio-economic status and finances. The more information an insurer can obtain the more accurately it can assess the probabilities of various risks manifesting for that individual (which together constitute the applicant's risk profile); and the more information available, the more accurately the insurer can allocate that individual to a pool of individuals with similar risk profiles (a risk pool). Risk pooling implies discrimination because individuals are treated differently. The commercial justification for this discrimination is that individual destinies can be better predicted if they are assessed in a group context, through the application of the 'law of large numbers' (Landes, 2015).[2]

The discriminatory nature of private life insurance is tolerated, in practice, on the proviso that the information used to calculate probabilities is statistically relevant and does not result in reprehensible or prohibited forms of discrimination (such as discrimination based on racial, ethnic or religious considerations). There must be a statistical correlation between the use of discriminatory criteria and the occurrence of risk events (Zurich Insurance Co v Ontario (Human Rights Commission (11920 93 DLR (4^{th}) 346 (SC Can)).

[2] The law of large numbers, in probability and statistics, states that as a sample size grows, its mean gets closer to the average of the whole population. See James (2020).

The interaction between individual uncertainty and collective predictability makes it worthwhile for individuals to insure themselves against risk, and yet possible for insurers to sell policies profitably (O'Neill, 1997).

Genetic information obtainable via predictive testing is therefore of considerable interest to insurers. The results obtained from such testing would be statistically relevant as the heightened level of information about a person obtained from this source would offer the insurer the ability to define more distinct risk pools and to assign individuals to them more accurately (or not at all).

Before illustrating the potential impact and relevance of the use of genetic information in the context of private life insurance further, it is necessary to introduce some key insurance concepts and the moral ideal for the justification of discrimination in insurance.

2.2 Key insurance concepts and the moral ideal of private life insurance

2.2.1 Mutuality and solidarity

Life insurance can be founded on either the principle of *solidarity* or *mutuality*. The concept of *mutuality* applies to private voluntary life insurance and *solidarity* usually applies to national (compulsory) insurance schemes and social security systems, such as those found in most European countries.

Wilkie (1997, p. 1042) describes *mutuality* as the normal form of commercial private insurance, where participants "contribute to the [risk] pool through a premium that relates

to their particular risk at the time of the application". This form implies that insurance will be discriminatory in the sense that participants will not all be treated equally; participants will receive differential treatment (via differing premium rates or terms and conditions) due to their age, health, lifestyle choices and socio-economic status (subject, of course, to the prohibition of forbidden forms of discrimination). *Solidarity,* on the other hand, is the basis of most compulsory national or social insurance schemes. Participants in such compulsory schemes do not have any say over the level of cover they wish to enjoy or the terms thereof. The central idea of such a scheme is that there will be no (or limited) discrimination because an assessment of risk is not undertaken. The implication of this is that the participants enjoying healthy lives effectively cross-subsidise the unhealthy ones.

In the *solidarity* model insurance can operate even if the parties have different levels of information about the applicant's risk profile. The price of insurance is not related to the level of known risk of an applicant brought into the pool. Thus, high-risk individuals cannot benefit from any privately held information they may have about their risk profile by buying extra cover, nor do low-risk individuals have the option of not participating in the pool.

By contrast, the *mutuality* model is only stable under conditions of informational symmetry, hence the imperative to obtain as much information as possible about an applicant's risk profile in the underwriting process. In this model, the possibility exists for the applicant to withhold important medical and lifestyle information from the insurer and then to buy extra cover (known as an adverse- or anti-selection scenario). This is the possibility that fuels insurers' fears. If the incidence of anti-selection is too high, liabilities in the pool increase, driving up the cost of insurance. When this happens, low-risk individuals opt out of the pool and the 'death spiral' of the pool begins.

Genetic information is thus important to insurers on the mutuality model as it enables them to more accurately allocate applicants to the appropriate risk pools. As opposed to the solidarity model, health information (which includes genetic information, as I will demonstrate), plays a central role in the mutuality model. Herein lies the dilemma. If an applicant is allowed to keep genetic information private, the information may be used against the insurer, resulting in the destabilisation of the risk pool. However, if an applicant is deprived of privacy, the use of genetic information may lead to genetic discrimination (as the exclusionists say), thereby serving as a disincentive for individuals to undergo genetic testing at all.

2.2.2 Underwriting

Underwriting is the process of asking medical, health, lifestyle, family-historical and occupational questions to enable an insurer to determine the probability of an insured event befalling an applicant and to allocate the applicant to the correct risk pool. The art of underwriting is to aim at matching the premium to the risk. The main purpose of underwriting of any kind (be it medical, financial or lifestyle underwriting) is to identify and cater specifically for applicants with a higher-than-normal chance of claiming their insurance cover.

Underwriting is the cornerstone of the mutuality (voluntary) model. It reflects the axiom of private life insurance: “same rates for the same risks” (Nienaber & Reinecke, 2009, para 7.11) – reflecting a general sense that it would be unfair to charge differing rates for the same risk.

2.2.3 The 'risk pool' concept

It is not possible to predict with complete certainty how long any specific person will live, enjoy their physical and mental faculties unimpaired or suffer from a dreaded disease. But it is possible with reasonable certainty to predict how many people from a group with similar risk profiles will die or become disabled over a given period, through the application of the law of large numbers. The law of large numbers is the:

> *"mathematical premise stating that the greater the number of exposures, (1) the more accurate the prediction; (2) the less the deviation of the actual losses from the expected losses (X – x approaches zero); and (3) greater the credibility of the prediction (credibility approaches 1). This law forms the basis for the statistical expectation of loss upon which premium rates for insurance policies are calculated." (Rubin 2008, pp. 272-273).*

People are grouped into risk pools with each pool defined by a particular risk profile. Insurers underwrite risks to ensure that similar risks are grouped with similar expected-claims ratios. For each risk group the premium will be appropriate to the risk. The more information obtained about a person's health, lifestyle, socio-economic status or finances, the more accurately an applicant for insurance can be allocated into a risk pool of individuals with similar risk profiles. By doing this, the members of a particular risk pool will pay a premium that accurately reflects the likelihood of a claim event arising within the insured period. In this way actuarial fairness is achieved. (Actuarial fairness, as the moral ideal of the insurance industry, will be discussed in more detail in section 2.2.6 below.)

2.2.4 Anti- or adverse selection

Anti-selection occurs when applicants for insurance do not disclose (engage in 'non-disclosure') or under-disclose ('misrepresent') pertinent health, medical, or lifestyle conditions or factors despite being asked to do so. They do not answer the questions asked by the insurer truthfully or accurately. When the applicant applies for insurance knowing or suspecting that an insured event will or is likely to occur and does not disclose this to the insurer it can be seen as a species of fraud (Nienaber & Reinecke, 2009, para 23.29). Anti-selection causes the insurer to incorrectly price the applicant's risk profile and to misallocate the applicant into a risk pool. This has implications for the stability of the mutual insurance market. Such applicants take advantage of their private knowledge to garner benefits that they would not otherwise be entitled to.

2.2.5 Cross-subsidy

Common to both *mutuality* and *solidarity* insurance models is the sharing of loss, which is effectively a subsidy from those who do not claim to those who claim because they suffered the insured event. The major difference between the two approaches is that with *solidarity* there is *a cross-subsidy* of high-risk participants by low-risk participants(whereas with *mutuality* there is simply a *subsidy*), regardless of who claims, since there is no assessment of individual risk

A simple example may help to clarify: Consider 100 participants who buy lottery tickets for R10 each, where one winning ticket is randomly drawn from the 100 tickets. The winner, who

receives R1,000, is effectively 'subsidised' by the 99 other participants who receive nothing – but there is no cross-subsidy, for all participants have an equal chance of winning. Consider a contrasting situation in which the 50 men in the group each still get a single ticket for R10 while the 50 women each get three tickets for R10. If one winning ticket is randomly drawn from the 200 tickets now in the pool, a woman has a three times higher probability of winning the lottery than a man. It is still possible that a man could win, but the men as a group are cross-subsidising the women.

With *solidarity,* such cross-subsidies are an integral part of the process since all participants pay the same contribution. The young and healthy low-risk members are paying much more than what is actuarially required to cover their risk and they are effectively subsidising the old and sick high-risk members.

In the *mutualit*y model, cross-subsidies are kept to a minimum through effective underwriting, so that each member should contribute according to the level of risk that he or she brings (or 'imports') to the risk pool. Participation in the risk pool is voluntary and the amount of cover taken is at the discretion of the insured individual. Accurate individual risk assessment and premium rating is critical for the stability of the risk pool.

2.2.6 Actuarial fairness

Actuarial fairness is the moral ideal of the private mutualistic insurance market. It is also the central justification for the commercial freedom that an insurer enjoys in allocating applicants and policyholders into risk pools, setting appropriate contractual terms (premium loadings or

benefit exclusions) or refusing insurance coverage to an applicant. The ethical imperative is to set premiums or contractual terms justly – with the principle of actuarial fairness in mind; and justice, in this context, is expressed through the idea that premiums must be set at a level consistent with the risk represented by each person to be insured. Actuarial fairness requires that individuals should assume, via differential premiums, the costs of the risk that they import into the risk pool (Landes, 2015) .

If an applicant or policyholder is allowed to exploit his privately held knowledge (by anti- or adverse selection) relating to his genetic status, then actuarial unfairness will ensue. That applicant or policyholder will pay a premium that is not commensurate with the risk he or she imports into the risk pool and the other policyholders in the pool will effectively be subsidising this shortfall. Therefore, unfair discrimination occurs when equal risks are treated differently. This is different to the case of solidaristic insurance where justice is expressed through the idea that people are treated exactly the same despite their different risk profiles (which are thus not taken into account) and that the healthy members of the risk pool agree to cross-subsidise the unhealthy.

The ideal of actuarial fairness is best illustrated through an example. Imagine ten friends deciding to insure themselves through a personal, cell-captive arrangement (an insurance vehicle in miniature) for a period of one year. They each decide to insure their lives for R100,000 and represent to each other that they are healthy and do not suffer from any adverse health conditions or disclose to the other any conditions they suffer from. Relying on this information, their underwriter deems it probably that only one of the friends will make a claim during the year and sets the premiums at R10,000 each. This ensures that there will be enough money to cover a claim for one of the friends. Now, imagine that five of the friends

have deliberately withheld actuarially pertinent health information about themselves which increases the likelihood that two claims against their insurance fund will be made during the year. If their premiums were to remain the same, it would be impossible to fully indemnify the two claimants, given the total amount available as cover. Through the deception of the five friends the underwriter was denied the opportunity to correctly calculate the premium needed to ensure the solvency of the insurance arrangement. The arrangement was thus unfair to those friends who did not withhold their pertinent health information as they were paying for a benefit that would never have been realised in line with their expectations.

According to the principles of actuarial fairness, it would therefore be proper for an insurer to charge higher premiums (or deny insurance coverage entirely) to an applicant with adverse genetic test results, regardless of who the person is and what other considerations of justice might dictate. It would also be proper not to pay a claim for a benefit under an insurance policy where anti-selection was discovered and the policyholder had failed or neglected to disclose the results of an adverse genetic test or for the insurer to resile from the insurance contract completely.

2.3 The relevance of genetic information in private life insurance

Genetic information can be an extremely valuable tool for purposes of underwriting and risk-pool allocation. As pointed out above, it is capable of supplementing and providing a wider dimension to the medical information upon which insurers rely. It is 'out there' and 'knocking the door down', steadily gaining utility as awareness of its potential grows. According to the Swiss Re Institute (Rechfeld et al., 2019), genetic testing has become big business. An

increasing number of people are taking genetic tests as technology improves and the testing becomes cheaper.[3] The research conducted by Swiss Re has revealed that those who took genetic tests and received an adverse finding were four times more likely to buy life insurance; furthermore, 60% of survey participants confirmed that their own genetic test results motivated them to live a healthier lifestyle.

While about 60% of individuals who underwent predictive medical genetic testing reported a low or average risk of contracting a major disease, the other 40% were found to have an elevated risk for common disorders such as cancer, heart disease or nervous system diseases such as Alzheimer's or Parkinson's disease. The latter 40% are four times more likely to buy life insurance than individuals at lower risk, supporting the view that reliable and risk-relevant genetic information can support customers' decisions to purchase or change insurance cover (Rechfeld et al., 2019, p. 14).

The above statistic exacerbates the insurer's fear of actuarial fairness being undermined. If the results of predictive genetic testing were to be disallowed in risk assessment then applicants could potentially engage in anti-selective behaviour against the insurer by using their privately held (and protected) knowledge to buy more insurance than they ordinarily would have. Doing so would ultimately lead to the risk pool being filled with high-risk individuals whose risks would be unfairly subsidised by those at lower risk. In turn, low-risk individuals would begin withdrawing from the risk pool as premiums would be adjusted upwards and become unfeasible for them.

[3] "By the end of 2018, direct-to-consumer genetic testing companies tested more than 12 million people"[Rechfeld et al., 2019, P. 2].

On the other hand, there are those who say that the importance of genetic information in achieving actuarial fairness is overrated. They argue that genetic testing is not as statistically robust as it is made out to be because it merely assesses the *possibility* of developing a disease without providing a reliable measure of whether, when or how severely a disease will develop. Even if an insurance-relevant gene mutation is identified, the ultimate manifestation of the disease could be influenced by a variety of environmental factors, ways of life and the effect of the presence of other genes (Joubert, 2009). Some opponents to this objection say that the assessment of risk cannot be *too* accurate as the whole point of insurance would be undercut (O'Neill, 1997). Insuring our lives is worthwhile because the manifestation of risk is uncertain. If genetic information permitted extremely accurate computation of the probability of risk manifestation, then the benefits of risk pooling would be concomitantly reduced. In turn, the appeal of self-insurance would increase. In this scenario, the too-extensive elimination of uncertainty would undermine the basis of private insurance. So, the use of genetic information could ultimately be commercially self-defeating (O'Neill, 1997). The insurance industry can survive, the objection continues, without the use of genetic information. At the moment this remains a theoretical objection and would only deserve serious debate if the use genetic information becomes unconstrained.

In any event, the debate will not die down because the ability to obtain the information is present and persistent – the 'genie is out of the bottle', as it were. It remains for us to find a sensible role for information procured via predictive genetic testing to play in the context of private life insurance. This urgency is recognised by Rechfeld et al. (2019, p16), who state that:

> *"After more than 20 years of developments and careful observation, our industry is about to reach a critical tipping point around issues of genetic testing. There are great societal benefits of advances in genetic testing including enhancements in health prevention, diagnosis and treatment of critical diseases. Equally, genetic data can create new threats that can undermine the basic principles of fair access to information upon which insurers rely to assess risk and offer protection at an affordable price."*

The more accessible and affordable genetic testing becomes (there are even hand-held sequencing devices that can be used by individuals today) the more vulnerable the insurance companies become, which eventually may impel them to insist on some form of genetic testing, possibly leading to legislative sanction and public outcry (Malpas, 2008).

CHAPTER 3: THE GENETIC EXCLUSIONIST POSITION

3.1 Introduction

As stated above, the philosophical ambition of this thesis is to determine the plausibility and strength of the exclusionist and inclusivist positions by comparing the possible moral foundations upon which their respective positions could credibly be founded and assessing the role that luck plays therein. In this chapter, I will set out the genetic exclusionist position by examining their principal objection that the use of genetic information will lead to discrimination, reduce the argument for one of their key claims to its standard form and then motivate for the proposition that the position could be plausibly founded on the luck egalitarian theory. Before I explain what luck egalitarianism is, however, I must explain what its conceptual foundation – egalitarianism, in general terms – is. After these explanations, and to conclude the chapter, I will offer a critique of the luck egalitarian theory (as the moral foundation of the exclusionist position) and also demonstrate the incoherency of its proponents' argument after illustrating the dubiousness of the premises upon which it is based.

To recap, in Chapter 1 I introduced the principal objection to the use of information procured via genetic testing for purposes of private life insurance – that such use would lead to genetic discrimination and should therefore be prohibited. The exclusionists have not stated that the use of medical information should be prohibited, nor have they argued against the legitimacy of the mutualistic model of insurance or against private life insurance in its current form. This indicates that they accept some forms of discrimination in respect of private life insurance.

Put differently, they propose that actuarial fairness should be tempered by the prohibition of the use of genetic information procured via genetic testing.

Whilst there may be other versions or bases upon which the exclusionists may found their position as alluded to in chapter 1 and reflected on in the conclusion this genetic exclusionist view, upon which I will expand below, has influential adherents as it is the basis for the implementation of genetic non-discrimination legislation for life and health insurance in many European countries (see for instance Joubert, 2009, p. 21).

3.2 The principal objection: "Genetic information will lead to genetic discrimination"

The exclusionist's principal objection is that the use of genetic information will lead to genetic discrimination (see for instance, Lee, 1993, Ashcroft, 2007 or Rothstein, 2018). For them it is perfectly acceptable and morally unproblematic that an insurer may use and rely on medical information that is statistically relevant to assess an applicant's risk profile in the process of underwriting, but not genetic information. If insurers were allowed to obtain and rely on genetic information it is assumed that they would treat applicants differently by excluding them from obtaining insurance (Billings et al., 1992). In this regard the objection is best stated by Liukko (2010, p. 458) thus:

> *"Traditionally it has been widely accepted that private insurers are legitimately allowed to classify and discriminate between applicants according to specific statistically relevant risk factors, particularly age, gender and health. However, in the recent debate, genetic health information is often considered to have a different*

moral status than that of the other classification variables. Importantly, discrimination according to all other kinds of relevant health information is deemed fair, while genetic discrimination is not."

The objection implies that medical and genetic information must and can be separated from each other. The exclusionists do this by saying that genetic factors are beyond a person's control (Pokorski, 2000). Because genetic factors cannot be controlled, they "shouldn't count" (Pokorski, 2000).

With this in mind, it is argued that reliance on any genetic factor that forms the basis of an insurer's decision to exclude a person from obtaining access to private life insurance should be prohibited notwithstanding the statistical relevance thereof.

As alluded to in chapter 1 there may be those exclusionists who do not make a moral distinction between genetic and medical information but who regard the use of genetic information as morally impermissible for *other reasons* or who could regard the use of genetic information as morally impermissible in general but allow for its use under certain conditions (such as where an premiums may be 'loaded' or where certain eventualities may be excluded from application in the insurance contract) but this type of exclusionist claim is not the focus of this thesis. Rather the focus is on those exclusionists who do not make any allowance for the use of genetic information in the insurance context *at all* (see for instance, O'Neill,2006, Ashcroft,2007 and Rothstein,2018). This exclusionist position is affirmed by the codification of the prohibition in the various pieces of legislation such as for instance the UNESCO Universal Declaration on the Human Genome and Human Rights (1997) (see Godard et al., 2003, p. 24).

The type of exclusionists, who are the focus of this thesis, i.e. those, who do not allow for the use of genetic information *at all* appear to make a morally relevant distinction between genetic and medical information. Their particular position, as illustrated by Pokorski (2000), seems to assume that medical information does not contain any factors beyond a person's control or for that matter any statistically relevant genetic information – hence the claim that the use of medical information is morally unproblematic whilst the use of genetic information is not. This claim further assumes that genetic information is separately procured from medical information. If this was not their assumption then the exclusionists would have qualified their position by stating that if genetic information was capable of being revealed from medical information, reliance on the latter should similarly be prohibited. They do not make this qualification.

So, as it stands, the exclusionists differentiate between genetic and medical information on the basis that the one is the outcome of a certain form of luck arising from factors beyond one's control and the other is not. In further support of their argument that genetic information is different, they claim that genetic information is a special type of information and that its use could lead to racial and ethnic discrimination (O'Neill, 1997; and Lee, 1993). In the absence of an outright repudiation of the ideal of actuarial fairness exclusionists seem to make the claim that in the interests of justice, actuarial fairness should be tempered by a prohibition on the use of genetic information. For them, the interests of the individual override considerations of the overall solvency of the insurance industry, the stability of risk pools and the possibility of providing more people with access to cheaper private life insurance.

By seeking to exclude genetic information as a basis for risk assessment, the exclusionists derivatively seek to protect people from the 'genetic information dilemma'. The decision whether to take the predictive test is a "double-edged sword" (Lee, 1993) for a potential life insurance applicant. On the one hand, a potential applicant may choose not to undergo a genetic test for fear of what he might discover. By doing this he deprives himself of an opportunity to seek preventative medical treatment or to make the necessary lifestyle accommodations in the event of the test being adverse. On the other hand, he might deprive himself of access to cheaper life insurance in the event that the test is favourable.

Against this background, the exclusionist position can be seen to be committed to two distinct claims. The first, claim 1, is that medical information is different to genetic information. The second, claim 2, is that genetic information should not be used for purposes of private life insurance. The argument for the second claim can be presented in standard form thus:

Claim 2

1. People do not have any choice or control over their genetic predisposition; and
2. Information about factors beyond the control of a person should not count for purposes of granting a person access to private life insurance.

   Thus: Genetic information should not be used for purposes of granting a person access to private life insurance.

The premises of an argument support its conclusion if and only if the assumption that the premises are all true either guarantees or significantly increases the probability that the conclusion is true (Pendlebury, 2013, p. 29). In respect of claim 1 I will show that the basis used to make the distinction between medical and genetic information is problematic and that the two are not morally different, or at least that they cannot sensibly or practicably be

separated. I will also show that in respect of claim 2 the exclusionist argument is also problematic as the premises upon which it is based are either doubtful or false, and thereby fail to support the conclusion. Further compounding the problems of the exclusionist position, I will show that their overall position is incoherent as genetic information is already procured via other medical information, the use of which they do not object to.

Whilst the exclusionists have not openly proclaimed the moral foundation of their position, their reliance on the role of factors that are beyond a person's control (to distinguish medical from genetic information and then to use it as a justification to prohibit the use of genetic information) correlate with the concerns that are addressed by the ethical theory of luck egalitarianism. Luck egalitarianism claims that factors beyond one's control are the result of a specific type of luck ('brute luck', which I will explain hereunder) and should either be nullified or neutralised when it comes to the distribution of goods, benefits or obligations. As a person's genetic predisposition is beyond their control or is not the result of any choices they make, it is argued that it should be ignored or neutralised when it comes to the distribution of goods, benefits or obligations. The similarity between the two positions stretches further in that both have as their focus an object that must be fairly distributed – in the case of the exclusionists the object of their focus is fair access to the benefits provided by the insurance contract. It can therefore be plausibly claimed that the exclusionist position could derive its moral justification from the luck egalitarian theory.

3.3 What is egalitarianism?

Egalitarianism seems to require a commitment to equality between persons, where the kind of equality required might vary from account to account. Justice for the egalitarian therefore

requires that there be *something* that people should have equal amounts of. The accounts of egalitarianism vary according to *what* is characterised as important for equal distribution. Should the objects of distribution be material goods, access to opportunities, quality of life or how we are treated as citizens? Unequal distribution of whatever *object* (or *something*) is specified by the form of egalitarianism is accordingly understood as unjust. This theory is central to distributive ethics.

A standard justification for egalitarianism is that everyone has equal moral status. The fact that we differ in our abilities, resources, opportunities, preferences, and temperaments is irrelevant for purposes of assessing our moral worth (Parfit, 1991). The theory requires that where inequality is found, the eradication thereof through the equal distribution of whatever is specified (and can be measured in some way) by the relevant account becomes obligatory, because by doing so we affirm and recognise the moral equality of those who are helped. Understood in this way, a non-egalitarian would be someone who believes that, for instance, a person's social status or education or wealth or superior abilities or talent count for more than others when decisions about the distribution of goods or opportunities are being made.

Egalitarianism can be instrumental or non-instrumental. Given the particular specification of what should be equally distributed, a person might hold that the achievement of the equal distribution of that object is morally desirable either as an end in itself or as a means to an end. The instrumental egalitarian would value equality as a means to some end whilst the non-instrumental (or intrinsic) egalitarian values equality as its own end. For example, someone who believes that the achievement and maintenance of equality within a society promotes harmony and self-respect among its citizens is an instrumental egalitarian, while

someone who believes that equality is an expression of justice is a non-instrumental egalitarian (Arneson, 2013).

3.4 What is luck egalitarianism?

The egalitarian theory was modified by the introduction of the requirement that individual responsibility should play a role in the assessment of whether the distribution of goods and benefits is just or unjust. The term 'luck egalitarianism' was coined by Elizabeth Anderson (1999). In its purest form, luck egalitarianism makes the distribution of goods, benefits and obligations insensitive to (some forms of) luck, or equalises the distributive effects of luck (Knight, 2013). The development of the luck egalitarian theory took place in the last two decades of the 20th century, in a climate in which the imperatives of the markets, conspicuous consumerism and privatisation were eroding support for distributive egalitarianism.

The focus of this theory is to nullify and thereby avoid or neutralise any adverse effect that flows from luck. More specifically, the theory is not concerned with nullifying or avoiding all forms of luck but rather those forms of luck over which a person has no control. The theory thus makes the distinction between what Dworkin (1981b, 293) calls "option luck" and "brute luck". The brute/option luck distinction marks the divide between the type of luck that calls for redistribution and the type which requires no such correction. The divide, for luck egalitarians, is morally significant.

'Option luck' is what flows from one's own decision. An example of option luck would be if the person chose to place a bet on the roulette table and his number did not come up. The

decision was made with an appreciation of the risks of the number not winning. The person should not expect that any adverse effects of his decision should be compensated by placing a burden on others to do so. On this version, the inequality that flows from agent's decision is morally unproblematic. Put differently, this form of luck should not come into reckoning when a decision is made as to how goods should be distributed. Those with bad 'option luck' are due no assistance in the name of equality.

'Brute luck' is what flows from something that one had no control over or did not consciously decide. Being struck by lightning is an example of bad 'brute luck'. In such a case, the person could justifiably expect that society should provide health services to him in compensation. On the other hand, if the person became afflicted with a debilitating condition because of some ill-considered choices he made, such as ingesting forbidden narcotics, then he could not expect society to provide health services to him. Luck egalitarians therefore believe that justice requires the nullification of all differential effects of brute luck when it comes to the distribution of goods, benefits or burdens. Some people cannot be worse off than others simply because they have been unlucky, for instance because they have been born with mutant genes (Lippert-Rasmussen, 2018).

As a person's genetic predisposition is something that cannot be controlled, it is, as per Dworkin, the outcome of brute luck. Any decision, therefore, as to how goods, benefits or burdens should be distributed may not take into account the person's genetic predisposition. In this way, the distributive effects of genetics are nullified by not being accounted for (by not 'counting' in our evaluations). Distributive inequalities that could arise as a result of the person's genetic predisposition are thereby avoided.

In the case of private life insurance, the exclusionists are taking a similar position to the one a luck egalitarian would if confronted with the same question. They are saying that in any decision concerning whether a person should have access to private life insurance, his genetic predisposition may not be considered. The luck egalitarian would approach the issue in exactly the same way. A decision as to whether a person gains access to private life insurance must be made without that information in mind. A person cannot be worse off (denied access to private life insurance) than others simply because he was unlucky enough to be born with a mutant gene.

It may be counter-proposed that the moral foundation of the exclusionist position is not luck egalitarianism but actuarial fairness, because of the latter's permissive attitude to the use of medical information. Proponents of actuarial fairness suggest that the use of medical information is enough to allow for the ideal of actuarial fairness to prevail or, put differently, that the use of genetic information is not necessary to achieve it. But this argument would immediately flounder as such a position requires that the ideal of actuarial fairness be tempered by the prohibition of the use of genetic information, which would deprive it of the power to ensure the fairness it strives to provide. By disallowing the use of genetic information unfairness will ensue, as people with higher risks would not be paying a commensurate premium for the risk they import into the risk pool. A tempered actuarial fairness ideal is not a credible moral foundation at all.

It is submitted that because of the substantial similarities between the exclusionist and luck egalitarian positions and approaches, the latter is a plausible candidate moral theory on which exclusionists can found their position. Both place moral significance on unchosen factors (brute luck) in distributive decision making, both are focused on the fair distribution of

something (in the case of the exclusionists it is the provision of access to private life insurance) and both seek to nullify and avoid the effect that unchosen factors (brute luck) may have on the making of distributive decisions. It may be cautiously stated that the exclusionists are actually inadvertent luck egalitarians.

3.5 Critique of luck egalitarianism as the moral foundation of the exclusionist position

If luck egalitarianism is what in fact grounds the exclusionist position, discussed above, then the exclusionist position immediately becomes beset by problems of incoherence. Exclusionists seek to exclude the use of or reference to genetic information in the decision to grant access to private life insurance, quite plausibly because of elements of brute luck being involved. It does not appear that they are against the use of genetic information for any other reason. However, they simultaneously allow for the use of or reference to medical information. By doing so they demonstrate a belief that medical information does not contain genetic information or is not always the outcome of brute luck (such as injuries sustained after being struck by lightning) – otherwise they would have claimed that all medical information or any medical information that reveals genetic information should also be forbidden. But this assumption is incorrect. During the underwriting process, it is standard for an insurer to request an applicant to complete a family history questionnaire or to undergo blood tests. Information obtained from these sources *is* genetic information. If the family history questionnaires reveal that an immediate member of the family was a carrier of a mutant gene such as the BRCA1 or BRCA 2 genes then the possibility exists that the applicant

may also be a carrier thereof .[4] Similarly a mutant diabetes gene may be identified in a standard blood test during the process of underwriting.

As the exclusionists have not revised their argument to forbid the use of genetic information procured from *any* source, the moral foundation of their position is incoherent – they cannot hold the two diverging claims at the same time. If the exclusionists are to stay committed to their moral foundation, they must abandon their assumption that medical and genetic information differ and have different moral weights because of the assumed role brute luck plays in each. They would have to state that neither medical nor genetic information should be allowed to play a role in private life insurance since both are sources of brute luck. Once they do this, the exclusionists repudiate the mutualistic model of insurance and express a commitment to the solidaristic model instead, where a minimum of discrimination is tolerated. They simultaneously expose themselves to an objection usually directed at luck egalitarianism: that their position becomes blind to the plight of other policyholders who do not have any genetic abnormalities and must now pay more for less insurance, cross-subsidising the unhealthy members of the risk pool. These objections reveal that luck egalitarianism may not be an appropriate theory to deal with issues of genetic information. If the inappropriateness is conceded then the question arises as to why should we succumb to its demands in the first place. This misgiving is eloquently encapsulated by Maddox (1991) who notes that "the contention that people unlucky enough to carry identifiable genetic abnormalities should not be denied insurance on the same terms as other people begs the

[4] The name “BRCA” is an abbreviation for the “Breast Cancer gene”. BRCA1 and BRCA2 are separate genes that have been found to impact a person's chances of developing breast cancer. See www.nationalbreastcancer.org/what-is-brca

question why people relatively free from identifiable genetic abnormality should therefore pay more than would otherwise be necessary".

The foregoing thus illustrates the problems and incoherence of claims 1 and 2 of the exclusionist position. In respect of claim 1, the basis those like Pokorski (2000) use to make the distinction between medical and genetic information appears to be brute luck. The basis for the distinction appears to be contrived and unsatisfactory as certain medical information can also be the outcome of brute luck (such as a lightning strike). Thus, brute luck cannot cleanly drive a wedge between medical and genetic information. Even after the application of brute luck to a person's information it will still be found that medical information will reveal genetic information. In respect of claim 2, premise 2 (that information about factors beyond the control of a person should not count for purposes of granting a person access to private life insurance) is problematic because medical information also contains genetic information. If premise 2 is to hold then medical information must by extension also be excluded.

In support of their first claim (that medical information is different to genetic information) the exclusionists advance three further arguments. Whilst these arguments appear not to refer to the role of luck, it is nonetheless worthy to set them out if only to illustrate that they reinforce the incoherence and invalidity of the overall exclusionist position by not convincingly showing that genetic and medical information can be separated.

Firstly, genetic exclusionists such as Annas, Glantz and Roche (1995) say that genetic information is different to ordinary medical information because: (i) it is prophetic – giving a peek into a person's medical future; (ii) it is expository – a person's DNA reveals information about one's parents, siblings and children; and (iii) there is a possibility of

genetic discrimination occurring when such information becomes known to others. It is submitted that features (i) (ii) and (ii) are not peculiar to genetic information. They can apply equally to medical information. For example, according to the Cystic Fibrosis Trust (How is cystic fibrosis diagnosed?, n.d) a simple blood test can, for instance, determine if someone is a carrier of the faulty gene that causes cystic fibrosis. This information can accordingly, (i) give a peek into a person's medical future, (ii) reveal information that is relevant to one's parents, siblings and children (in that they may be carriers as well) and (iii) carries with it the potential for discrimination.

Chambers (1998) states that genetic information should be treated differently to ordinary medical information because the possession of it is far more sensitive. This argument fails as medical information can be just as sensitive. It will be difficult to convincingly argue that the revelation of a mutant gene obtained via genetic test is more sensitive than for instance the revelation of cystic fibrosis obtained via a blood test. Genetic information is therefore;

> "*not inherently more specific, predictive, sensitive, or private than other kinds of health information*" (Malpas, 2018).

There may be an argument that due to the alleged heightened sensitivity of genetic information (for instance, because of the way that a person's life might play out) it should benefit from heightened protection. There does not seem to be any evidence to show that current data protection measures (in the South African context genetic information would be protected by the Protection of Private Information Act, 4 of 2013) in respect of medical information is not adequate to protect genetic information or that current legislation separately caters for genetic information.

Secondly, information acquired via predictive genetic testing is characterised as inaccurate and unpredictable. This is not a plausible basis on which to distinguish genetic information from medical information. We have good reasons to allow insurers access only to information that is properly validated and statistically relevant but medical information suffers from the same weakness insofar as it is also sometimes inaccurate and unpredictable. As Holm points out (Ashcroft, 2007), genetic information is not more inferentially fertile than any other medical information.

The exclusionists' third argument in support of differentiation is perhaps their most emotive. They argue that once actuarial fairness is based on precise genetic information, we will have sanctioned oblique forms of racial and ethnic discrimination in life insurance. This is because some genetic diseases are closely associated with discrete ethnic or racial groups such as African Americans, Ashkenazi Jews or Armenians. This would obviously have the potential of compounding racial discrimination (Lee, 1993, p. 5).

It is submitted that if writers such as O'Neill (1997) and Lee (1993) know that certain racial and ethnic groups are susceptible to certain diseases then insurers already know this as this information would be revealed to them by means other than through genetic testing. The genetic tests will not reveal the susceptibility of the racial groups but will objectively confirm the susceptibility that the insurer already knows about. The objection can, in any event, easily be overcome by imposing a moral or legislative obligation on the insurer not to use the information in a racially or ethnically discriminatory manner. Should an insurer engage in such practices it would not easily escape notice and the insurer would quickly find itself at the brunt of legislative sanction and public outrage. There is, in any event, nothing inherent in the use of genetic information that legitimises racial profiling or lends itself to disguised racial

profiling . In the South African context, an insurer is prohibited in precisely this fashion from using such information to discriminate against any susceptible group. In this regard Section 7(e) of the Promotion of Equality and Prevention of Unfair Discrimination Act 2000 forbids "the denial of access to opportunities, including access to services or contractual opportunities for rendering services for consideration, or failing to take steps to reasonably accommodate the needs of such persons".

Given that insurers are already using genetic information acquired by means other than predictive testing, there remains no principled reason why the use thereof should be forbidden (see Holm in Ashcroft, 2007).

A further difficulty faced by exclusionists is that by differentiating between medical and genetic information they assume that a separation between the two is possible. According to Thomas Murray (Australian Law Reform Commission, 2010) practical separation would require that health systems be able to adopt a 'two-bucket theory of disease', categorising and tossing every disease and risk factor into either the 'genetic' or 'non-genetic' bucket. In fact, Murray explains that "many diseases and risks don't fit neatly into either bucket" (Australian Law Reform Commission, 2010, para 3.50).

3.6 Conclusion

In light of the above it has been shown that the exclusionists have not provided a plausible argument to show a morally relevant distinction between genetic and medical information. Their argument in respect of this claim is incoherent. Because of this it cannot be used as support for the second claim that genetic information should not be used in the context of private life insurance at all. That does not mean that the exclusionists cannot argue in favour

of the second claim, it just means that their first claim does not provide support for their second claim due to its incoherence.

Turning to the second claim we cannot come to the conclusion that genetic information should not be used for purposes of life insurance. The important point to bear in mind is that if the exclusionist's two claims are to be sustained they need to revise their arguments, either by identifying other morally relevant ways in which the use of genetic information is different to the use of medical information, or by finding other reasons entirely for why the use of genetic information is impermissible.

In the absence of a revision of their problematic argument that genetic and medical information is morally different and that all medical and genetic information should be prohibited, the exclusionist position is incoherent and does not offer a morally justifiable basis for the prohibition of the use of genetic information in the context of private life insurance. As has been argued, the exclusionists' first claim assumes that medical information is not the outcome of brute luck – hence their acceptance of its use. This claim is doubtful as some medical information contains genetic information and other medical information may well be the outcome of brute luck, such as suffering injuries sustained after a lightning strike. The second claim is similarly doubtful because there is no agreement that it is practically possible to clearly differentiate between medical and genetic information (see Australian Law Reform Commission, 2010).

Further complicating issues for exclusionists is that the position's moral foundation – luck egalitarianism – is not suitable for application within the mutualistic insurance model (if the continued existence thereof is to be accepted) because it cannot adequately guarantee the

viability or continuance of the model. By focusing on the personal features of a small portion of the risk pool, the interests of the majority are overlooked.

The exclusionists have not provided credible arguments for the prohibition of the use of genetic information in the context of private life insurance. They should rather 'let go'; the continuance of their embargo sustains a 'moral hazard' to the mutualistic model because of the potential for a person who receives an adverse genetic test to use that information to the detriment of the insurer and the members of the risk pool (to engage in adverse selection) by buying "too much insurance too cheaply" (O'Neil, 2006).

CHAPTER 4: THE GENETIC INCLUSIVIST POSITION

4.1 Introduction

In the previous chapter, the argument for and moral foundations of the exclusionist position were challenged. If the theory of luck egalitarianism is unsuited to the mutualistic insurance model then an enquiry must be made into whether other plausible and applicable moral theories that involve the role of luck exist. Just as the exclusionists are committed to two claims so are the inclusivists. They say that (i) there is no morally relevant distinction between genetic and medical information and that accordingly (ii) the use of genetic information in the private life insurance context is morally permissible. In this chapter, I will focus on the two inclusivist claims and explore positive arguments for the use of genetic information in the context of private life insurance and propose an attractive moral foundation for the inclusivist position – the social contract theory propounded by John Rawls. This is not to exclude the possibility of other moral theories grounding the position. It is simply to say that Rawls' social contract theory is appropriate not only because it sensibly explains the role that luck should play in the distribution of goods and resources but also because it accords with our everyday conception of fairness and justice while overcoming the objections to and double standards inherent in the exclusionist position.

4.2 Rawls and justice as fairness

The exclusionist position presented above is founded on a distributive ideal. The conceptual distinction between medical and genetic information is made precisely because it affects how private life insurance is distributed. In its untempered form, exclusionists claim, actuarial

fairness will lead to unfairness. The differentiation is made on the basis of the role of certain kinds of luck. In contrast, inclusivists do not attach any moral significance to the difference between the two types of information. For them, both are statistically relevant grounds upon which an insurer may rely in the process of underwriting (subject to the proviso that racial and other prohibited forms of discrimination are avoided). In other words, inclusivists subscribe to the *untempered* ideal of actuarial fairness. Can the use of untempered actuarial fairness be morally justified though? Whilst the inclusivists have not openly proclaimed the moral foundation of their position, I will propose that it could plausibly be accommodated under a Rawlsian social contract theory. By situating the inclusivist position there, the moral justification for the use of genetic information and the role of luck will be revealed.

In his seminal project *A Theory of Justice* (1971), Rawls presents his conception of justice as a liberal version of the egalitarian proposition. He moves away from conceptualising equality as the correct expression of fairness, instead claiming that *justice* is its correct expression. Realising that equality is a nigh-impossible goal to achieve given the differences in people's talents, abilities, circumstances and motivations and that universal agreement on the object and quantity of distribution is unattainable, Rawls presents a theory that strikes a balance between rewarding personal endeavour and uplifting those that are worse-off in society. Justice conceptualised as fairness will be achieved if all citizens can pursue their diverse plans of life within a framework to which all citizens would rationally subscribe (Scheffler, 2003). The framework must consist of a set of principles which are initially identified via a thought experiment and which all citizens would regard as binding on them no matter what their preferred moral theory may be. "They are the principles that free and rational persons

concerned to further their own interests would accept in an initial position of equality as defining the fundamental terms of their association" (Rawls, 1971, p. 10).

The thought experiment works along the following lines. We are asked to imagine a meeting of citizens in which, using only their reason and logic, they must choose a set of principles of social justice which should apply to their society and be regarded as binding on them all. Rawls calls this imaginary meeting the 'original position'. To ensure that the decisions that the citizens made were truly impartial and purified of all other influences, Rawls adds the requirement that the citizens must choose their principles under a 'veil of ignorance'. They are to imagine that they have no knowledge of their own backgrounds, circumstances, upbringing, or abilities. The veil of ignorance ensures that the fairest and most legitimate decision can be made by citizens because they will not be biased by their status, wealth, circumstances or privilege. Principles of justice for a society that emanates from this thought experiment would be the fruit of reasonable agreement reached between rational citizens. In such a society justice is expressed through the idea that all of its citizens have equal moral worth and that they can participate in and enjoy the benefits and burdens of such as society as equals.

So how would goods or benefits be distributed within this fictional society? Firstly, an assessment would have to be made as to whether inequality exists and if so, to what extent. The extent of inequality would determine the ebb and flow of goods and benefits. What determines the assessment is citizens' access to 'primary goods'. These are goods that "every rational man is presumed to want" (Rawls, 1971, p. 54). These goods must have a use *whatever* the citizen's rational plan of life is. They are such that if citizens did not have access to these goods, they could not participate in their society as equals. Primary goods are

therefore the yardstick of equality. The primary goods that Rawls' citizens would be *presumed to want* (Rawls, 1971, p. 54) are:

- wealth and income
- rights and liberties
- opportunities for advancement
- self-respect

The idea here is that if citizens were unable to, for instance, clothe, feed or shelter themselves, have access to education or the ability to vote, they would be unable to participate in society as equals. In such situations the citizens would have a legitimate claim to assistance.

Once inequality is identified using the yardstick of primary goods, citizens would have to decide how these primary goods would be distributed. Understanding that distribution only to the worst- or best-off in society would not constitute justice, Rawls proposes that his fictional citizens would reasonably conclude that some form of distribution is necessary but that inequalities will nonetheless remain. In recognition of people's differing talents, abilities and motivations, the personal endeavour of each should be incentivised and rewarded so as to improve the overall wealth of society. For example, there are skills required for the orderly functioning of society, employed by people such as road engineers, and these skills are to the advantage of society as a whole. The citizens would not reasonably object to the allocation of a larger slice of personal wealth being allocated to the road engineer than to others, provided that the lot of those worse-off because of the allocation is also relatively improved. This principle is given effect by the maximum-minimum ('maximin') rule, which directs that if the

citizens were to be given a host of alternatives in the distribution of goods, they would choose the alternative whose worst outcome leaves the citizens better off than the worst outcome of all other alternatives.

In deciding which principles his rational and free-thinking citizens in the initial position would choose, Rawls immediately scotches the idea that the principle of utility would be chosen. He suggests that it is unlikely that citizens who regard themselves as being equal with everyone else would agree to a principle through which some citizens could be denied access to benefits or advantages simply because it may be to the benefit of a greater majority. Utilitarianism is anathema to the idea that all citizens are equal.

Accordingly, Rawls expresses his social theory through his two principles of justice as fairness (1971, p. 53) thus:

> **First Principle**: Every person has the same right to equal basic liberties (e.g., the right to vote, freedom of speech, liberty of conscience, freedom of thought, freedom from oppression, the right to hold property, and freedom from arbitrary arrest and seizure).
>
> **Second Principle**: Social and economic inequalities are to satisfy two conditions:
>
> a. They are to be attached to offices and positions open to all under conditions of *fair equality of opportunity*; and
> b. They are to be to the greatest benefit of the least-advantaged members of society (the '*difference principle'*).

The first principle must necessarily rank prior to the second since the second principle depends on the first. The conditions for the second principle cannot be satisfied if the citizenry is deprived of basic liberties (granted by the first principle).

The second principle of justice has two parts. The first part requires that people with the same talents, abilities and motivation to use the talents have the same educational and economic opportunities regardless of their personal circumstances.

The second part of the second principle is the 'difference principle', which regulates the distribution of goods and benefits. The idea is not to eradicate inequality, because this cannot be done. However, whatever happens, the lot of the worst-off cannot remain static or worsen. "Injustice, then, is simply inequalities that are not to the benefit of all" (Rawls, 1971, p. 54). The principle does not demand that inequality be eradicated by taking from the rich to give to the poor; rather, it demands that opportunities be created for everyone to prosper, the benefits of such prosperity being utilised for the upliftment of the worst-off. By allowing and incentivising those that are better-off to continue with their projects on the condition that the lot of the worst-off is improved, the size of the pie, as it were, is enlarged.

As the Rawlsian theory is being proposed as an alternative to the luck-egalitarian theory, the question of how it deals with unchosen factors such as a person's talents, abilities and circumstances (in other words factors of brute luck) arises. Specifically, how would it deal with a person's genetic predisposition in the realm of private life insurance? Rawls observes that the system of natural liberty permits the distribution of resources to be "*strongly influenced*" by people's natural talents, abilities and circumstances. This aspect has often been cited by

writers as evidence of Rawls' unwitting endorsement of luck egalitarianism (see for example Scheffler, 2003, pp. 8–9).

On the face of it, therefore, there seems to be some endorsement for the luck egalitarian position. However, this is not the case. Rawls does not attribute the same significance to brute luck as the egalitarians do – he does not seek to eradicate or neutralise its influence. Instead, he seeks only to mitigate the influence of brute luck to the extent necessary to facilitate the upliftment of the worst-off in accordance with his difference principle. Luck therefore has a limited and facilitative role to play in the Rawlsian system and is not the defining feature of the theory. Put simply, luck cannot serve as an absolute barrier in the distribution of goods and benefits.

The principles are a more general conception of justice, expressed by Rawls (1971, p. 54) as follows:

> *"All social values – liberty and opportunity, income and wealth, and the social bases of self-respect – are to be distributed equally unless an unequal distribution of any, or all, of these values is to everyone's advantage".*

Injustice, according to this mantra, exists where inequalities that are not to the benefit of all citizens arise. This general conception of justice thus tolerates inequalities, but only subject to the proviso that everyone's (relative) position be improved.

Instead of expressing the ideal of *equality* (as in the case of luck egalitarianism) the difference principle expresses the ideal of *social unity*. Citizens are entitled to lay claim upon one another by virtue of their status as equal participants in society, without the need for any moralised accounting of the details of their particular circumstances (Scheffler, 2003, p. 22).

The difference principle means that inequality flows from situations where citizens are unable to conduct their rational plan of life and are, by extension, unable to exercise their rights as equal members of society. This would occur, for instance, if they were deprived of the right to vote (granted by the first principle) or if they were forbidden from standing for public office (granted by the second principle). If society seriously intends for all citizens to have equal moral standing and an equal claim to living according to their rational plan of life within a fair, co-operative framework, then it is illogical for citizens in the original position to agree to an institutional framework that makes their chances of carrying out their plans depend on social and personal contingencies.

The theory is realistic in that citizens with differing moral viewpoints can all be accommodated within its framework. Such citizens are not expected to forego their disparate moral preferences in favour of a single preference. They are free to adhere to their preferences and diverse plans of life but must do so within the scope of the overarching set of rules the citizens have agreed to. In so doing, the Kantian imperative is satisfied in that citizens are treated as ends in themselves (are recognised as having an equality of moral worth) and not as mere means to an end (as the basis for assessing inequality). The theory sensibly recognises that whilst inequality cannot be eradicated it ought to be lessened. Instead of attributing significance to personal differences, the theory is focused on the social framework within which citizens operate and exist. If the social framework or system of co-operation is unfair,

it is unlikely that any focus on personal differences will eradicate inequality. If, however, the framework is fair, inequality will be lessened notwithstanding personal differences – the welfare of the citizenry will be maximised.

4.3 The Rawlsian theory and genetic information

The human genome project (HGP) has provided the insurance industry with a convenient, valuable and tempting source of information. The use of genetic information will enable the insurance industry to better allocate applicants into the correct risk pools, widen the insurance base by making the cost of insurance cheaper and in the long run ensure the viability of the current mutualistic insurance system. Genetic information can bolster the ideal of actuarial fairness.

The inclusivists do not attribute any significance to the difference between medical and genetic information. If any distinction is made, it is in the light of the acknowledgement that both enjoy equal moral status and are sources of information used in the service of the actuarial fairness ideal through which the inclusivists' conception of justice is expressed. But this is the very ideal that the exclusionists say should be tempered by the nullification of the operation of brute luck.

Initially, the idea that a person should not be prejudiced by something that he does not have control over does resonate with us. After all, why should a person's genetic make-up determine whether he gains access to private life insurance? It feels as if luck is a factor that should be accounted for somehow. After some consideration, however, we realise that the

luck-egalitarian ideal is a lofty one and not practical or wholly in touch with contemporary social and political morality. There are everyday instances where we have no objection to a person being treated differently because of some unchosen personal trait. Take for example a person who is endowed with superior (and unchosen) talents, abilities and determination and who uses those talents and abilities by working longer hours to earn a greater income than others endowed with lesser abilities. Those who have optimally used their unchosen talents and abilities will be obliged to pay a higher tax rate than others. We do not see anything wrong with this. Consider another example. Access to professional sport is also largely dependent on the endowment of certain unchosen physical features. Not every person will gain professional access to a particular sport no matter their enthusiasm for it. A person born with a condition that renders him unable to run will not gain any support for a claim to join Lionel Messi in the starting line-up of the Barcelona football team. If the luck egalitarians were to have their way, then some accommodation would have to be made for our non-runner. This may entail that Messi or some other equally talented member of the team would have to make way. Understandably, the dropped member will consider this to be extremely unfair.

Seen this way, the tempering of actuarial unfairness appears artificial, intrusive and unsatisfactory. We are all different and these differences shape the decisions we make, the opportunities we have and the course our lives take. We have accepted this because we know that we can never be physically identical to each other. It is simply a consequence of the unfairness of the natural lottery of life. It is this realisation that Rawls taps into when he proposes that his fictional citizens would reasonably conclude that some inequalities must exist within their society in recognition of peoples differing talents, abilities and motivations,

and that they would propose that people's personal endeavours should be incentivised and rewarded so as to improve the overall wealth of their society.

The inclusivist position has the advantage of avoiding these complications since actuarial fairness (the moral ideal) does not depend on distinctions between choice and circumstance or between medical and genetic information. Theirs is not a distribution-based concept – inclusivists do not seek to ensure equal access to private life insurance or the equal treatment of members within their risk pools. Inclusivists merely claim that those who elect to participate in and manage to gain access to the social co-operation mechanism (the institution of the risk pool) must pay a premium that is commensurate to the risks that they import into it. The position is an interpersonal conception of fairness in terms of which members participate in the risk pool for only so long as they believe its rules are fair and consistently applied. Participants accept that relative to their own circumstances they are being treated fairly. Justice for the members of the risk pool is therefore rooted in how they stand and are treated in relation to one another and not in how the benefits of the risk pool are distributed. This view aligns substantially with the Rawlsian conception of justice and could plausibly be founded on it.

Genetic information (a result of brute luck), as viewed through the Rawlsian lens, would only obtain moral significance if private life insurance were to be considered a primary good. In that case, the use of genetic information in the process of underwriting would be permitted but with a corresponding moral obligation to apply a flexible approach when deciding to admit or reject the application. For instance, in the event of the revelation of a mutant gene, the underwriter could be encouraged to consider excluding the condition from the operation of the policy contract instead of rejecting the application outright or to impose a higher

premium (called 'loading' the premium). By acting in this manner, the insurer would be protected if the condition manifested, while simultaneously granting applicant conditional entry into the risk pool and avoiding possible allegations of discrimination such as by using racially based underwriting practices (in that a vulnerable groups will not be excluded). In this way, the moral permissibility of the use of genetic information is confirmed, access to private life insurance is broadened, the worst-off are uplifted, the survival of the risk pool is enhanced and the ideal of actuarial fairness remains untempered notwithstanding the presence of inequalities (which is tolerated by the theory).

If private life insurance is *not* considered a primary good, then the use of genetic information is unproblematic for the Rawlsian because this would have no effect on how citizens stand in relation to one another nor would it impede the pursuance of their rational and diverse plans of life. Luck would not play a role. Whatever type of good private life insurance may be, the use of genetic information is morally permissible and compatible with considerations of justice on Rawls' account. It only remains to assess whether private life insurance is indeed a primary good.

4.4 Is private life insurance a primary good?

Is private life insurance a primary social good, i.e., something that *every rational man is presumed to want* without which citizens could not pursue their rational, diverse plans of life and participate in society as equal citizens? Asked differently, is private life insurance the kind of thing that Rawls' fictional citizens would regard as a *sine qua non* for participation as equals within society and as an essential yardstick for the determination of inequality?

To make this assessment, it is first necessary to determine the nature and role of primary goods for Rawls. Primary goods may be defined as those things that free and equal citizens need *all through* their lives to live as normal and social members of society (Ekmekçi & Arda, 2015b). These goods are either natural or social. Natural primary goods are those distributed by nature (e.g., intelligence, imagination, health etc.) while social primary goods (e.g., rights, liberties, income, wealth and the social bases of self-respect) are distributed by social institutions. Because of the arbitrary lottery of nature, society does not have any obligation to redistribute natural goods on the grounds of fairness principles (Ekmekçi & Arda, 2015a). Natural primary goods would therefore not qualify yardsticks for the assessment of inequality – the assessment must be based on what society can distribute. Rawls' yardstick for measuring inequality is accordingly confined to primary *social* goods. Private life insurance must consequently be assessed against in the framework of primary *social* goods: is private life insurance a primary social good?

In pursuing this question, it is useful to understand what the different types of goods are. Sandberg (1995) makes a distinction between three types of social goods: 'primary social goods', which are "goods that everybody needs for leading a life under decent physical conditions" (Sandberg, 1995, p. 1554); 'commodities', which are trading goods that do not impose an obligation on society to be distributed fairly; and 'non-primary social goods', that do not serve *basic* human needs. Sandberg's definition of primary social goods accords with what "every rational man is presumed to want".

Private life insurance is not the type of good that is needed throughout a person's life

Some writers claim that private life insurance plays a significant social and economic role in our lives insofar as obtaining a mortgage loan or ensuring the standard of living for surviving family members depends on it. "At a certain stage of life, life insurance is not an optional extra", says Onora O'Neill (1997, p. 1091). According to Martin O'Neill (2006), private life insurance is best seen a *gateway social good* through which economic and social activities are facilitated via access to mortgage finance and the housing market. These statements affirm the transience of the need for private life insurance. Insurance needs appear to be greater during one's economically productive years. The need does not endure *throughout* a person's life. It therefore cannot satisfy the most important criterion for a primary social good (persistent necessity). If private life insurance was to be used as a yardstick for assessing inequality, the assessment would be influenced by where people stood in the economic cycle at that point in their lives. Periodic assessments to compare variances would be inaccurate and meaningless. Private life insurance is therefore unsuited to being thought of as an inequality yardstick.

Access to private life insurance is conditional

Private life insurance, furthermore, does not lend itself to being thought of as a yardstick due to its conditional nature. In pursuance of actuarial fairness not everyone will gain access private life insurance. As explained above, the fairness of the risk pool is expressed by how people stand in relation to one another. The citizens of Rawls' thought experiment would understand that actuarial fairness means that some people may be excluded from the pool.

It is, in other words, not the kind of product that people will ordinarily expect to be provided with by right (unlike food, clothing, shelter etc.).

If the proposition is instead that everyone has a right to *insurance*, then a claim is being made for a *solidaristic model* of insurance, which is not dependent on health or genetic information. This may qualify as a primary social good, but its examination is beyond the purview of this thesis; I am interested simply in the role of genetic information in the *mutualistic model* of insurance.

Private life insurance is not needed to live as a normal and social member of society

A further aspect counting against private life insurance as a yardstick, aside from the conditional nature thereof, is that many people also do not avail themselves to private life insurance due *to inter alia* affordability, lack of an insurance culture, state social security or simply that some people have no need therefor.

Private life insurance is not a primary social good

Against the background of the above, it is doubtful that a claim can be made that a person's pursuance of his rational plan of life or his status as an equal citizen would be compromised by the deprivation of private life insurance for whatever reason. According to the Rawlsian vision it is simply not the type of good that defines or should influence a person's moral equality within a society.

It may be argued that in a context where only mutualistic insurance is available the requirements of justice may demand that actuarial fairness be tempered to allow for the inclusion of genetically disadvantaged participants. A possible solution to this is that a certain modest amount of private life insurance be made available to everyone with insurance companies being allowed to seek the use of genetic information only in respect of insurance over and above the minimum threshold (Klitzman et al., 2015).

The inclusivist claims

Given that the Rawlsian theory does not attach any relevance to the distinction between genetic and medical information and that it can be argued that private life insurance is not a primary social good it can be safe to say that the use of genetic information is therefore permissible.

4.5 Conclusion

The significant question for the Rawlsian is whether the use of genetic information in the realm of private life insurance would affect a person's standing in society or his ability to pursue his rational plan of life. If the answer is no, then the use thereof is morally unproblematic. In this chapter I have attempted to show that the use of genetic information will not thwart a person's standing in society regardless of whether private life insurance is considered a primary social good or not. In conclusion, the Rawlsian theory provides a credible moral foundation for the exclusionist and by extension a bulwark for the ideal of actuarial fairness.

CHAPTER 5: CONCLUSION

The difficulties and incoherence of the exclusionist position in respect of claims 1 and 2 have been shown. It may be wiser and more practicable for the exclusionists to acknowledge that genetic information cannot simply be "written out of the insurance story" and rather adjust their position to allow for the use of genetic information in the context of life insurance even if it is in limited and well-defined circumstances (by applying loadings or exclusions) or allowing for the use of genetic information over and above a minimum threshold amount. Justice will be better served this way.

In the end, the discussion about the role and moral justification of genetic information in the context of private life insurance (the mutualistic model of insurance) depends on the lens through which it is viewed. In the preceding pages, the differences between the plausible moral foundations of the exclusionists and the inclusivists have been set out and assessed.

On the one hand, it has been shown that the exclusionist position, that claims both that the use of genetic information is morally different to the use of medical information and that the use of genetic information is morally impermissible, risks incoherency and that its moral foundation suffers from the same disadvantages that are inherent in the luck egalitarian position. The exclusionist theory is blind to the possible negative implications its adoption could cause for the mutualistic model of insurance. This invites the objection that the exclusionist position is unattractive because of the number of people it would deprive of access to cheap insurance. The focus on the individual and the role of luck can ironically lead to insurance becoming more expensive and less accessible. Whilst there may be other approaches that exclusionist could adopt, the exclusionist (and hence the luck egalitarian)

position that I have focused on is unsatisfying and out of sync with our intuitions about justice. Unless the exclusionists modify their argument to exclude all forms of medical and genetic information (making a claim for a solidaristic model of insurance) or unless they argue for the exclusion on an entirely different basis their tenuous argument will not have a realistic chance of keeping the use of genetic information in abeyance for much longer.

On the other hand, it has hopefully been shown that from a Rawlsian perspective the use of genetic information is morally permissible. The inclusivist position (discussed above as grounded on Rawls social contract theory) is in accordance with our everyday social and political morality and ensures the viability of the mutualistic model of insurance.

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