GENETIC TESTING AND ITS IMPLICATIONS FOR AUSTRALIAN INSURANCE LAW

George Spiteri[*]

INTRODUCTION

This article aims to address recent scientific developments in the sphere of genetic science, particularly genetic testing. Central to this article is an evaluation of the tension that exists between scientific progress in genetic testing and the discriminatory effects that such testing has on human rights. Part I of this article will present a brief overview of the advancements in genomic research, particularly those scientific advancements related to Australian insurance underwriting. Insurance law is an area where discrimination is often considered permitted, based on risk classification of insurance applicants. Part I aims to challenge "permitted discrimination" of prospective customers, where developmental genomic data may be misrepresented in the determination of risk classification. Part II will evaluate the scientific implications raised in Part I, under established insurance law in Australia. Part III will assess whether under current domestic Australian anti-discrimination mechanisms, the law balances the discriminatory potential of developmental genomic data used in the assessment of income protection insurance. Part IV considers proposed and established domestic and international legislative approaches to genetic testing in insurance. This part considers the social fabric that underpins health and income protection insurance as a "common good" or "commodity" in Australia. This author submits that whilst health insurance is an immutable common good that demands universal protection, income protection insurance is a lesser good in the ordering of social goods, which requires intermediate protectionist policy. This part will focus primarily on two approaches, namely, the "genetically exceptionalist"[1] approach and the "ceiling method".[2] The author argues that a false reliance on genetic essentialism leads to legislative reform that is genetically exceptionalist. Moreover, this author submits that

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* LLB (Hons) JCU. I would like to dedicate this article to Dr Alex Amankwah, my Honours supervisor and friend, without whom none of this would have been possible. I would also like to extend my thanks to Ms Marylyn Mayo, who inspired me to pursue genetics and law. Thanks also to Euan Ritchie and David Keays, whose critical comments on scientific and legal aspects proved invaluable.

1 Genetically exceptionalist legislation provides exclusive protection to those persons whose predisposition to disease is classed as genetically linked.

2 The ceiling method adopts a monetary ceiling below which genetic information can not be used to underwrite insurance. See detailed discussion below.

genetically exceptionalist laws are flawed, as they rely on a false assumption that genetic information is qualitatively distinct from other predicative medical information. Finally, Part IV will advance the "modified ceiling method"[3] as a possible approach to the use of medical information to underwrite income protection insurance.

PART I: GENETICS: THE BASICS

Prior to proceeding with a detailed evaluation of the legal issues enlivened by genetic testing, it is first necessary to chronicle the significant scientific developments in genetics. It is essential to have an understanding of the scientific fundamentals on which advances in genomics are based, as they lead to the central issues addressed in this article.

The Genome – The human road map

Deoxyribonucleic acid or DNA, forms the foundations of life itself. DNA is the chemical blueprint that contains the information required to create and maintain all life's structures and activities. Certain pieces of DNA, known as genes, contain instructions for building particular proteins that provide the structural components of all cells and tissues.[4] Through these proteins, our genes dictate not only how we look but also how well we process foods, detoxify poisons, respond to infections and what diseases we are predisposed to developing. The human genome[5] is the complete set of DNA that contains within it, all of the genes that make and maintain the human body. Information coded in the human genome is of critical importance, as it shows not only who we are but also who we *might* be in the future.

The wealth of knowledge that the human genome may provide, will impact upon a broad spectrum of legal areas, the number of which is beyond the scope of this article. The scientific implications addressed herein are limited to the information that has a direct discriminatory impact in the area of insurance law in Australia.

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3 The modified ceiling approach adopts a monetary ceiling below which medical information (ie genetic and non-genetic) can not be used to underwrite insurance. The modified ceiling approach protects all medical information, whether genetic or non-genetic information.

4 3% of all DNA.

5 The genome is the 'road map' that makes us who we are; it might be likened to a computer operating system, made up of more then 3 billion microscopic pieces of information – nucleotides, the equivalent to the letters A,T,C,G.

Genetic Disorders – Genetic Uncertainty in Developmental Scientific Research

Research into the human genome[6] and the matrix of genes that it is comprised of, has led to the development of numerous genetic tests.[7] Genetic testing can be defined as the analysis of DNA, RNA and protein sequences to determine the existence or pre-disposition to a genetic disorder.[8] Genetic mutations are either "inherited" from a parent who donates an aberrant gene through the chromosomes, or "acquired" spontaneously from "environment" or age-related factors. Thus, even at this early stage, the diligent reader will have noticed the importance in the identification of the difference between "inherited" and "environmental" disorders. The distinction puts in issue, the validity of drawing a nexus between gene characteristics and diseases yet to be acquired, where environmental factors may influence a person's genome.

In addition, within the family of disorders that are "inherited", such genetic mutations can be further sub-classed as either "multi-factorial" or "single-gene" genetic conditions.[9] Mutations that are multi-factorial may not necessary manifest into a disease or disorder, where certain environmental conditions are absent. An example is where:

> [A] person may have a gene which makes him susceptible to lung cancer. If he avoids smoking, he might not develop lung cancer. In other words, by eliminating the environmental factors, the disease may not manifest itself.[10]

A "single-gene" disease, is a disease that will manifest itself regardless of environmental factors, so that despite what a person does in his/her lifetime, the symptoms of the disease will still form. However, the certainty in the manifestation of disease does not indicate severity of symptoms that will be encountered by the carrier. Thus, where the degree or the severity of manifestation is not currently discernible, the value of knowing that the disease will manifest is of limited benefit. Moreover, some commentators

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6 In 1988, a US government funded consortium, the *Human Genome Project* (HGP) set forth with the goal of mapping the entire human genome, the 100,000 genes that are thought to exist within our DNA. The challenge was to sequence all of the genes, putting them all in the right order. Scientists from HGP combined their efforts with Celera Corporation, announcing the completion of the sequencing of the human genome in June 2000. With further research, scientists hope to understand the genes independent functions, how they interact with each other and eventually, manipulate genes to achieve a desired result.

7 For example, scientists have found genes that are linked to cystic fibrosis, Huntington's disease, duchenne muscular dystrophy, some breast and ovarian cancers, and Alzheimer's disease: See P T Rowley, 'Genetic Screening: Marvel or Menace?' (1984) 225 *Science* 138, 138

8 United States Department of Energy: *Human Genome Project*, URL: http://www.ornl.gov/hgmis/medicine/genetest.html#whatis.

9 C Keefer 'Bridging the Gap Between Life Insurer and Consumer in the Genetic Testing Era: the RF Proposal' (1999) 74 *Indiana Law Journal* 1375 at 1379.

10 *Id.*

have questioned the wide existence of simple "single-gene" disorders. For example where once cystic fibrosis and huntington's disease, 'were thought to be completely predictable on the basis of the presence or absence of a particular gene, [such diseases] are displaying a remarkable complexity, not yet known.'[11]

It follows that even within "inherited" genetic disorders, only "single-gene" disorders are "possibly"[12] certain of manifestation into disease at some stage during the individuals lifetime. It is therefore submitted that the "genetic essentialism"[13] argument proffered by some commentator's, is becoming increasingly untenable.[14]

Firstly, the full value that may be attributed to a particular genetically linked disease will not be known until scientists have a complete understanding of the human genome and how it relates to particular disorders. Therefore, any pre-emptive use of tenuous data that links a gene based disorder will, at best, be a general indicator of a predisposition to disease or at worst discriminatory. Prima facie, the use of developmental genomic data in the lead time before scientists have a fuller understanding of the human genome may lead to discrimination predicated on data whose reliability remains unproven.

Secondly, in the long term, even where a detailed understanding of the human genome derives with certainty those diseases that are genetically based, there will still be many diseases that are multi-factorial and thus not solely dependent on one's genetic composition. The pertinent question as regards multi-factorial genetic information, is how much weight is to be attached to such information when used by a third party? This writer submits that multi-factorial genomic data should only be used in conjunction with a consideration of environmental factors and other medical information (genetic and non-genetic), where the probative value of genomic data in isolation has the potential to discriminate.

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11 J Beckwith and J Alper 'Reconsidering genetic antidiscrimination legislation' (1998) 26 *Journal of Law Medicine & Ethics* 205.

12 This qualification is important in the short term, where scientists will not know with certainty whether a particular disease is single-gene dependant, until the full compliment of genes are understood.

13 Genetic essentialism rests on the proposition that our genes determine "exactly" who we are and what diseases we will contract.

14 For an example canvassing genetic difference, see R M Green and A M Thomas 'DNA: Five Distinguishing Features for Policy Analysis' (1998) 11 *Harvard Journal of Law and Technology* 571 cf. J Beckwith and J Alper, *supra* n. 11; T Lemmens 'Selective Justice, Genetic Discrimination, and Insurance: Should we Single out Genes in our Laws' (2000) 45 *McGill Law Journal* 347; L O Gostin and J G Hodge Jr 'Genetic Privacy and the Law: An End to Genetics Exceptionalism' (1999) 40 *Jurimetrics* 21; M S Yesley 'Protecting Genetic Difference' (1998) 13 *Berkeley Technology Law Journal* 653.

PART II: GENETIC INFORMATION AND THE IMPACT ON INSURANCE

The impact the use of genetic information in insurance may have, will vary depending on what actuarial basis is utilised in assessing that information. In the short and long terms, the potential for unfair discrimination based on genetic information will exist under the broad strand of medical insurance (ie health, life, disability or accident). An important distinction should be drawn between the various types of medical insurance in Australian law. Under section 73(2A) of the *National Health Act 1953 (Cth)*, health insurers may not risk classify applicants of health insurance.[15] In Australia, health insurance is predicated upon the notion of 'community rating'. Community rating based insurance makes no class recognition, through risk classification, as is the case with "mutuality based insurance", which differentiates premiums on the basis of the level of risk each person brings to the pool. In the United States for example, applicants are classified as "standard", "substandard" or "declined", based on a personal risk relative to the risks of other policyholders.[16] The impact of genetic test information in Australia, at least in the foreseeable future, will thus have the greatest impact in the area of income protection insurance, which is mutuality based (ie life insurance, total and permanent disability and trauma insurance). Therefore, the context in which genetic information is relevant to this article is limited to the area of income protection insurance.

Use of "single-gene" and "multi-factorial" gene disorder information

In the short term, the lead time between scientists' ability to identify a gene that is associated with a disease and identify with certainty whether it is a single-gene disorder, may lead to discrimination. Potentially, in the short term, an insurer may use erroneous information based on tenuous data, to raise the premium or exclude an insurance applicant from a policy.

In the long term, where multi-factorial genetic information is used by insurers, there is also the potential that an insurer may attach more weight to the genetic information than is warranted in those circumstances. For example, if an insurance applicant had a multi-factorial susceptibility to developing lung cancer, then it may be unfairly discriminatory to require an increase in the applicant's premium based solely on genomic data. It is submitted that where the development of the disorder is also dependent on environmental factors, then such considerations must be taken into account in determining any risk classification of the applicant. Therefore, where in the

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15 The only matters that health insurers may take into account are the applicants age and whether or not they have dependants: M Otowski 'Resolving the Conundrum: Should Insurers be Entitled to Access to Genetic Test Information' (2000) 11 *Insurance Law Journal* 193 at 196.

16 C M Keefer *supra* n. 9 at 1385.

example of lung cancer, if the insured was a non-smoker, an increase in premium would be unwarranted.

Use of Indirect Genetic information

The potential for discrimination to manifest in medical insurance is not strictly limited to situations where a genetic test is derived directly from a sample of the insured. The nature of genetic testing, like other forms of genetic and non-genetic information (eg family history), can reveal similar information regarding a person's relatives or entire groups of people.[17] Therefore, even where the insured refuses to supply information of a prior genetic test result, an existing genetic test or other medical information held by an insurer, derived from the insured's relatives or ethnic group, may possibly be used to underwrite an insurance policy of the insured. In Australia, it is already accepted practice for life insurers to ask specific questions about family medical history.[18] Thus, the information that genetic testing may yield is not qualitatively different if used in the same manner. Notwithstanding this, genetic testing offers life insurers an opportunity to broaden the indirect catch, through the possible inference of ethnic or racially based genotypes. This is a practice that was not available to insurers prior to genetic testing, and is fraught with unfair discriminatory potential, where the nexus between the applicant and the racial genotype is more tenuous than between family members. The author submits that whilst knowledge of racial genotypes is still developmental, the use of a racial genotype to underwrite insurance may be unfairly discriminatory.

The Right of Privacy - Refusal to submit to a genetic test

The final possibility where the manifestation of genetic discrimination may arise is in relation to access. Interestingly, issues of disclosure, privacy and autonomy of genetic information can plausibly disadvantage both the insured and insurer.

The insured may feel pressured to undertake a genetic test in an insurance market where the use of genetic testing is common practice. The obvious disparate positions in bargaining power that exist between the insured and insurer, may force the insured to undertake a genetic test, or face the prospect of being refused insurance.

On the other hand, the insurer may argue that refusal to supply the results of a genetic test may result in misrepresentation, where those applicants who withhold genomic data have full knowledge of their genetic futures, whilst the insurer does not. This argument is premised on the duty of utmost good faith, which is a reciprocal duty upon both the insured and insurer. Utmost good faith 'encompasses a notion of fairness, reasonableness and community

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17 L O Gostin J and G Hodge *supra* n 14 at 34-36.

18 M Otlowski *supra* n. 15 at 197.

standards of decency and fair dealing.'[19] Lord Justice Scrutton in the oft-quoted passage in *Rozanes v Bowen*[20] best describes the basis of the rule of utmost good faith:

> As the underwriter knows nothing and the man who comes to him to ask him to insure knows everything, it is the duty of the assured, the man who desires to have a policy, to make a full disclosure to the underwriters without being asked of all the material circumstances, because the underwriters knows nothing and the assured knows everything. That is expressed by saying that it is a contract of the utmost good faith – uberrima fides.[21]

Statutorily, section 13 of the *Insurance Contracts Act 1984 (Cth)* [herein referred to as ICA], provides for the common law duty of utmost good faith. Section 13 extends the common law definition, making the duty reciprocal and implied in all contracts of insurance. Section 21 of the ICA imposes a specific duty on the insured to disclose a 'matter which the insured knows to be as relevant to the insurer.' The central issue which the common law and statutory provisions raise *vis-à-vis* genetic testing is essentially one of materiality. That is, whether genetic test data represents information that would have a material affect on the judgment of a reasonable man in determining the terms of the contract of insurance.[22]

It follows that failure to inform an insurer of poor results in genomic data may potentially result in a breach of this duty. The question is: should genomic data be treated any differently than other medical information? More fundamentally, should genetic testing be treated as a condition precedent in a contract of medical insurance? The *Investment and Financial Services of Australia* (herein referred to as IFSA), the peak group that represents insurer's interests in Australia, has stated that 'genetic tests performed prior to the application for insurance should be treated no differently to any other information relevant to the risk.'[23] It has been suggested that "adverse selection" may result, where the applicant knows more about his risk then the insurer. Adverse selection is a situation where 'customers with a poorer than average health expectation apply for or renew insurance to a greater extent then persons with average or better health expectations.'[24] For example, where an applicant withheld a genetic test result that appeared to indicate that she was predisposed to developing breast cancer, the insured may potentially buy up more life insurance based on the strength of the genetic

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19 M Fotheringham 'Insurers and Genetic Testing: an Uncertain Future' (1999) 11 *Insurance Law Journal* 1 at 6.

20 (1928) 32 Lloyd LR 98.

21 *Id.*

22 Treitel, *The Law of Contract,* (Sydney: LBC 1987) 260.

23 *Draft Policy on Genetic Testing,* Investment and Financial Services of Australia, (1999) 4.

24 Fotheringham, *Supra* n. 19.

test. The insurer in this case may argue that the applicant has breached her duty of utmost good faith, in failing to inform the insurer of the genomic data that was relevant to the assessment of risk in the life policy. Indeed, where medical information (including an accurate genetic test) indicated that the applicant was predisposed to breast cancer, a breach of utmost good faith may occur, where such genetic information "material" to the risk was not disclosed when specifically asked.

The inclusion of any medical information, including a genetic test, thus rests upon the materiality of such data. In the case of *Barclay Holdings (Aust) v British National Insurance Co Ltd*[25], Kirby P formulated the relevant test for materiality:

> I would read the test... to require that the effect on the mind of the insurer.... should be something more than the effect produced by information which the insurer would have been generally interested to have. If, though interested to have it, such information would not, in the end, have determined for a reasonably prudent insurer the acceptance or rejection of insurance, the setting of the premium or the attachment of conditions, there is no such effect on the mind as requires disclosure by the insured. The information, although of interest is not material. As such it is not information which must be disclosed by the insured.[26]

Furthermore, proving materiality for the purposes of sections 13 and 21 of the ICA has been held to be a question of fact, the burden of which rests with the insurer.[27] It is submitted that the developmental nature of genomic data (see Part I) indicates that in the short term, the relevance of such data would not be known until the complete set of the human genome is understood. Therefore, where the relevance of genomic data in drawing meaningful information is in question, the materiality of such data in insurance remains also indeterminable. Hence, this writer submits that where genomic data is not material information, no duty of disclosure will exist on the insured. *A priori*, if the submissions by IFSA were followed, and *inaccurate* genetic test data did constitute information that was relevant and material to the assessment of medical insurance, such use may possibly constitute a ground of unfair discrimination against the insured.

In the short term, the discriminatory impact that the use of developmental genetic test data may have on individuals far outweighs the potential harm to the insurer. In the long term, where unfair discrimination results from misrepresentation of certain genetic test data that is not protected under existing insurance law, established domestic anti-discrimination law would come into play.

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25 (1987) 8 NSWLR 514.

26 *Id* at 517.

27 *Western Australian Insurance Co Ltd v Dayton* (1924) 35 CLR 355 at 379; *Visscher Enterprises Pty Ltd v Southern Pacific Insurance Co Ltd* [1981] Qd R 561 at 579.

The discussion in this Part expounds two general aspects of genetic discrimination. Firstly, those acts of discrimination that arise from the short term use of genomic data; and secondly, those acts of discrimination that could arise from the use of genetic information in the long term. Having highlighted the areas where discrimination may arise, it is now necessary to consider whether such acts come within the ambit of the protection provided by domestic anti-discrimination law.

PART III: THE RELEVANCE OF ANTI-DISCRIMINATION LAW

The Anti-discrimination Regime

The assertion that a matter or act is "discriminatory" *per se* is insufficient to establish that the discrimination was unlawful under domestic discrimination law. The alleged discriminatory act or matter must come within one of two statutory[28] definitions of discrimination, namely direct discrimination[29] or indirect discrimination.[30] Direct discrimination deals with discrimination that arises in individual scenarios 'where the exchange or decision is based on an act or decision or series of acts or decisions relating specifically to the event or circumstance in question.'[31] On the other hand, indirect discrimination is the situation where the law has provided:

> [A] mechanism for examining the impact of policies and practices which on their face appear to operate in a neutral or non-discriminatory manner. It reviews the basis for systemic discrimination and identifies the factors which leads to a result which disadvantages one particular group.[32]

The nature and extent of the impact that genetic discrimination has in insurance, necessitates a review of both heads of direct and indirect discrimination.

Direct Discrimination

The Australian approach adopts a three-stage test in establishing direct discrimination, both at State and Federal levels, with exception to the *Racial Discrimination Act 1975 (Cth)*. It is within this framework that the acts of genetic discrimination discussed in Part II will be considered.

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28 *Anti-Discrimination Act 1991 (Qld)*, s9

29 *Anti-Discrimination Act 1991 (Qld)*, s10(1)

30 *Anti-Discrimination Act 1991 (Qld)*, s11(1)

31 Ronalds C, *Discrimination Law and Practice*, (Sydney: The Federation Press 1998) 26.

32 *Id.*

The first step in establishing unlawful discrimination is to show that genetic discrimination is an act that falls within a specific "ground"[33] or "attribute"[34] of the relevant legislation. The State statutory requirement that the discriminatory act be primarily based on a "ground" or "attribute" was clearly stated in the case of *Aboriginal Legal Rights Movement Inc v South Australia*:

> [Direct discrimination] is not attracted unless an act (the relevant act being the appointment of the Royal Commissioner) is done which in fact produces a distinction on the base [SIC] of race (which has occurred here because the inquiry is into and affects Aboriginal beliefs only) and the existence of that racial discrimination is the basis of the relevant act in the sense that the act occurred by reason of or by reference to the racial distinction. This does not mean that the inquiry is one as to motive. The inquiry is into whether the racial distinction is a material factor in the making of the relevant decision or the performing of the relevant act. [35]

Essentially, the specified ground that will apply in a case where an insurer uses genetic test data or information which discriminates, will be "impairment" [36] or more precisely "alleged impairment", in the case of the short term use of uncertain data. The Federal *Disability Discrimination Act 1992 (Cth)*,[37] provides specifically for discrimination based on disability. The basis of a comparison of the alleged discriminatory acts in Part II and the relevant grounds in the anti-discrimination legislation, the insured may frame his/her ground in one of three ways:

(1) "I was discriminated against where **my** alleged/genetic **impairment** was used to increase my insurance premium or exclude me from insurance"

(2) "I was discriminated against where **my relatives** alleged/genetic **impairment** was used to increase my premium or exclude me from insurance."

(3) "I was discriminated against where **my race's** alleged/genetic **impairment** was used to increase my premium or exclude me from insurance."

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33 "Ground" is the term used in the in *Anti-Discrimination Act 1977 (NSW)*; *Equal Opportunity Act 1984 (SA)*; and *Equal Opportunity Act 1984 (WA)*.

34 "Attribute" is the term used in *Equal Opportunity Act 1984 (Vic)*, s6; *Anti-Discrimination Act 1991 (Qld)*, s7(1); *Discrimination Act (ACT)*, s7(1); *Anti-Discrimination Act (NT)*, s19(1).

35 (1995) 64 SASR 551 at 553. Cf *Australian Medical Council v Wilson (Siddiqui's Case)* (1996) 68 FCR 46 at 58.

36 *Anti-Discrimination Act 1977 (NSW)*, s49A,B; *Equal Opportunity Act 1984 (SA)*, s66; *Equal Opportunity Act 1984 (WA)*, s66A; *Equal Opportunity Act 1984 (Vic)*, s6(b); *Anti-Discrimination Act 1991 (Qld)*, s7(1)(h); *Discrimination Act (ACT)*, s7(1)(i); *Anti-Discrimination Act (NT)*, s19(1)(j). Note. Discrimination legislation in Tasmania deals within the scope of the *Sex Discrimination Act 1984 (TAS)*, which does not include "impairment".

37 Herein referred to as DDA; see s5(1)

The framed statements above raise two more possible grounds of discrimination. Firstly, ancillary to either statement (2) or (3), is discrimination by "association, or relation"[38] against a person identified on the basis of impairment. Secondly, under statement (3) the ground of discrimination based on "race" may apply.[39]

In relying on any of the grounds, the insured must also establish that discrimination was on the basis of a "characteristic",[40] that 'appertains generally'[41] or can be 'imputed'[42] to the group of which the insured is a part of. In the case of genetic discrimination, the insured might clearly be able to establish that he/she formed part of an impaired group based on genetic make-up that was discriminated against generally. Moreover, the insured will very likely be able to show that "less favourable treatment"[43] resulted as a consequence of his or her being genetically defective, in the form of an increase in premium or exclusion from insurance altogether.

At the State level, the next step in the process of establishing unlawful discrimination is to establish an "area" under the legislation that deals with insurance. The area of insurance is dealt with specifically in Queensland[44] and Northern Territory,[45] whilst only exceptions to insurance are expressly stated in New South Wales,[46] ACT,[47] South Australia[48] Victoria,[49] and Western

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38 *Anti-Discrimination Act 1977 (NSW)*, s49A,B; *Equal Opportunity Act 1984 (Vic)*, s6(b),(m); *Anti-Discrimination Act 1991 (Qld)*, s7(1)(h),(m); *Discrimination Act (ACT)*, s7(1)(i),(j), s8(1); *Anti-Discrimination Act (NT)*, s19(1)(j)(r). Note. No provisions in the (TAS), (SA) or (WA) discrimination Acts provide for the ground of "association or relation".

39 *Racial Discrimination Act 1975 (Cth)*, s13. *Anti-Discrimination Act 1977 (NSW)*, s7; *Equal Opportunity Act 1984 (SA)*, s51; *Equal Opportunity Act 1984 (WA)*, s36; *Equal Opportunity Act 1984 (Vic)*, s6(i); *Anti-Discrimination Act 1991 (Qld)*, s7(1)(g); *Discrimination Act (ACT)*, s7(1)(g),8(1); *Anti-Discrimination Act (NT)*, s19(1)(a).

40 *Disability Discrimination Act 1992 (Cth)*, s5; *Anti-Discrimination Act 1977 (NSW)*, s49B; *Equal Opportunity Act 1984 (SA)*, s66; *Equal Opportunity Act 1984 (WA)*, s66A; *Equal Opportunity Act 1984 (Vic)*, s7; *Anti-Discrimination Act 1991 (Qld)*, s8; *Discrimination Act (ACT)*, s7; *Discrimination Act (NT)*, s19(2)(3)

41 See. *Commonwealth v Human Rights and equal Opportunity Commission (Dopking No 1)* (1993) 46 FCR 191 at 208.

42 *Id.* at 191.

43 *Disability Discrimination Act 1992 (Cth)*, s5; *Anti-Discrimination Act 1977 (NSW)*, s49B; *Equal Opportunity Act 1984 (SA)*, s66; *Equal Opportunity Act 1984 (WA)*, s66A; *Equal Opportunity Act 1984 (Vic)*, s8; *Anti-Discrimination Act (Qld)*, s10(1); *Discrimination Act (ACT)*, s8; *Discrimination Act (NT)*, s19(3)

44 *Anti-Discrimination Act (Qld)*, Pt 4, Div 6

45 *Discrimination Act (NT)*, Pt 4, Div 7.

46 *Anti-Discrimination Act 1977 (NSW)*, Pt 4A, Div 4.

47 *Discrimination Act (ACT)*, Pt IV, Div I.

48 *Equal Opportunity Act 1984 (SA)*, Pt I, Div VII.

49 *Equal Opportunity Act 1984 (Vic)*, Pt 3, Div 4.

Australia.[50] The relevant discriminatory alleged act at both State and Federal levels will be in the supply of "goods and services", namely insurance.[51]

The Queensland anti-discrimination regime provides an example that in effect is reflective throughout all jurisdictions. Part 4 of the *Anti-Discrimination Act 1991(Qld)* [herein referred to as ADA] sets out 'areas of activity in which discrimination is prohibited'. More specifically, Division 6 comprehensively deals with the area of insurance. Section 67 provides:

> A person must not discriminate—
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> (1) by failing to supply insurance; or
>
> (2) in the terms on which insurance is supplied; or
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> (3) in the way in which insurance is supplied.

The implication of section 67, for individuals with unfavourable genotypes, is that under all three framed grounds an insurer would possibly be held to have discriminated against the insured. This would be the case where based on impairment, relation or race, the insurer increased the premium[52] or excluded the insured from a policy.[53] However, in the case under consideration and despite the possible breach, the general exemptions under all of the domestic discrimination legislation allow for discrimination based on "impairment" in the area of insurance.[54] In Queensland for example it is not unlawful under section 74 of the ADA, to discriminate against any of the matters listed in section 67, where the discrimination arose from 'reasonable actuarial or statistical data.' Moreover, section 75 removes any doubt as to whether it may be argued that the alleged genomic data used by the insurer is uncertain and thus not accurate statistical data (See Part II). Section 75 provides:

> It is not unlawful for a person to discriminate on the basis of age or impairment with respect to a matter that is otherwise prohibited under subdivision 1 if—
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> (1) there is no reasonable actuarial or statistical data from a source on which it is reasonable for the person to rely; and

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50 *Equal Opportunity Act 1984 (WA)*, Pt IVA, Div 4.

51 *Disability Discrimination Act 1992 (Cth)*, s24; *Racial Discrimination Act 1975 (Cth)*, s13; *Anti-Discrimination Act 1977 (NSW)*, ss49M,19; *Equal Opportunity Act 1984 (SA)*, ss76,61; *Equal Opportunity Act 1984 (WA)*, ss66K,46; *Equal Opportunity Act 1984 (Vic)*, s42; *Anti-Discrimination Act (Qld)*, s46; *Discrimination Act (ACT)*, s20; *Discrimination Act (NT)*, s41.

52 Contra s67(b).

53 Contra s67(a).

54 *Disability Discrimination Act 1992 (Cth)*, s46; *Anti-Discrimination Act 1977 (NSW)*, s49Q; *Equal Opportunity Act 1984 (SA)*, s85; *Equal Opportunity Act 1984 (WA)*, 66T; *Equal Opportunity Act 1984 (Vic)*, s39(c),(d); *Anti-Discrimination Act 1991 (Qld)*, ss73-75; *Discrimination Act (ACT)*, s28; *Anti-Discrimination Act (NT)*, s49.

(2) the discrimination is reasonable having regard to any other relevant factors.

It follows that the consequences of the exemptions in Australian domestic discrimination legislation will counter balance the first two grounds, namely "impairment" and the ground of discrimination by "association, or relation", where it is ancillary to the operation of "impairment". The final ground of "race" may be the only viable ground that the insured might rely upon.

Racial Discrimination

The scope of the protection afforded under race may be of limited application. In practice, an insured may only be able to establish racial discrimination in those limited situations where it could be shown that an ethnic group which the insured identified with genetically, had a pronounced susceptibility to genetically influenced disorders that the insurer relied upon to underwrite or deny an insurance policy. However, an insurer may argue that *prima facie*, reliance was based on the ground of the insured's impairment and that it was incidental that the insured's "race/class" also had a susceptibility to that genetic disorder. This argument raises the issue of indirect discrimination, where on the face of it, discrimination based on impairment is permitted and appears to operate in a neutral non-discriminatory manner, notwithstanding the effect that it indirectly discriminates against a particular racial group.

Indirect Discrimination

Justice Sackville, in the of case of *Australian Medical Council v Wilson (Siddiqui's case)*,[55] delineated the rationale underlying indirect discrimination:

> [It] is to prevent individuals from the effect of apparently neutral conditions or requirements, which in fact operate in a manner that discriminates against particular groups the members of which have characteristics in common (such as race or national origin). A particular individual within a group subjected to discriminatory practices often will have some chance of complying with the offending condition or requirement. The chances of compliance may depend on how the condition is administered, or on whether the individual is able to overcome the practical obstacles placed in his or her path by the invidious condition or requirement.[56]

Statutorily, indirect discrimination is defined specifically in Queensland[57], Victoria[58] and Federally.[59] In Queensland for example, section 11(1) provides:

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55 (1996) 68 FCR 46.

56 *Id* at 79-80.

57 *Anti-Discrimination Act 1991 (Qld)*, s11.

58 *Equal Opportunity Act 1984 (Vic)*, s9.

Indirect discrimination on the basis of an attribute happens if a person imposes, or proposes to impose, a term—

(a) with which a person with an attribute does not or is not able to comply; and
(b) with which a higher proportion of people without the attribute comply or are able to comply; and
(c) that is not reasonable.

(2) Whether a term is reasonable depends on all the relevant circumstances of the case, including, for example—

(a) the consequence of failure to comply with the term; and
(b) the cost of alternative terms; and
(c) the financial circumstances of the person who imposes, or proposes to impose, the term.

(3) It is not necessary that the person imposing, or proposing to impose, the term is aware of the indirect discrimination.

"Term" includes condition, requirement or practice, whether or not written.

The statutory definition of indirect discrimination necessarily raises three requirements in establishing indirect discrimination.

Firstly, the discrimination must be on the basis of an "attribute" or "ground". The ground claimed with respect to a genetically defective insured will rest on "race", where the insurer imposes a scheme of genetic screening that the insured can not comply with, because he/she belongs to a particular ethnic group.

Secondly, the insured must show that a "higher proportion of people", without the attribute are able to comply with the condition. In medical insurance, the nature of genetic screening is such that distinct differentiation between the genetic make-up of particular ethnic groups will highlight the disorders that are peculiar to one ethnic group.[60] It follows that where the insured falls within an ethnic group that has an identified peculiar genetic disorder, more predominant or exclusive to that group, a higher proportion of

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59 *Disability Discrimination Act 1992 (Cth)*, s6; *Sex Discrimination Act 1984 (Cth)*, s5(2). Note. The *Racial Discrimination Act 1975 (Cth)* does not provide a definition of indirect discrimination, however the operation of s6A provides that the RDA will not impede State legislation, but is intended to act concurrently.

60 However unfounded such an inference may be, the potential for ethnic distinction based on genetic traits has been demonstrated in the past and is likely to continue in the future. In the past genetic predispositions to Tay Sachs disease in Jewish populations and sickle-cell anaemia in black African American populations provides the clearest example of the way in which genetic traits in populations may be used in a discriminatory fashion: See J Seltzer 'Note: The Cassandra Complex: An Employer's Dilemma in the Genetic Workplace' (1998) 27 *Hofstra Law Review* 411 at 418-420.

people who fall outside the insured's ethnic group will be able to comply with genetic screening.

Finally, the insured must show that the condition of genetic screening imposed by the insurer is not reasonable. In Queensland, section 11(2) of the ADA provides that all relevant circumstances of the case will be considered in determining reasonableness. Section 11(3), provides three further considerations in adjudging reasonableness, namely the "consequences", "cost of alternative terms" and "the financial circumstances of the person imposing the term". Consequently, failure of the insured to comply with an imposed genetic test may result in either an increase in premium or exclusion from insurance, based on a negative inference drawn from non-disclosure. The cost of alternative terms, where the insurer is denied access to genomic information, was considered in Part II. It is submitted that a claim of adverse selection in the short term is unjustified, where the reliability of genomic data is uncertain whilst still in its developmental stages. In the long term however, the cost to the insurer will have a significant impact on the reasonableness of the imposition of genetic screening. In the long term, a situation where the insured withheld reliable information about his/her genetic future would significantly disadvantage the insurer. A *priori*, the financial position of income protection insurers in Australia in the short term is secure. In the long term however, an insurer's financial position may be in question in a market that restricts access to relevant genomic information.

It follows that upon a statutory application of indirect discrimination to the genetically impaired, the insured may possibly succeed in showing the first two elements of indirect discrimination, he/she however, may fail on the ground of reasonableness. The statutory approach in Queensland denies any discriminatory claim of the genetically defective insured.

The situation may however be different in other jurisdictions. The approach taken by the High Court indicates a willingness to secure certain rights in preference to economic and financial considerations. In *Waters v Public Transport*,[61] the High Court considered the effect of the Victorian discrimination legislation,[62] in relation to disability, where indirect discrimination was claimed. In that case, the complainant claimed that the effect of a scheme to remove ticket conductors from trams and implement "scratch tickets" for use on public transport was an act of indirect discrimination. It was asserted that direct removal of conductors, indirectly discriminated against disabled passengers, where they were excluded from using public transport. In that case the majority held that the imposition of the scheme was indirectly discriminatory as a matter of law. In considering the element of reasonableness, Mason CJ and Gaudron J stated:

> One very powerful reason for confining the meaning of the word "reasonable" in the context of. s17(5)(c) in this way is that an extension of

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61 (1992) 173 CLR 349.

62 *Equal Opportunity Act 1984 (Vic)*.

> the concept to embrace all the circumstances of the case would open the way to justification of indirect discriminatory practices on grounds which are not available in the case of direct discrimination... In this situation a narrow reading of s17(5)(c) is more apt to secure the attainment of the statutory objects than a reading which permits the adoption of a discriminatory practice merely because it is "reasonable" having regard to economic and financial considerations. [63]

This writer submits that the effect of genetic screening may be analogous to the situation in *Water's Case*,[64] where the statutory objective, namely the protection from racial discrimination, may outweigh the financial and economic considerations in circumstances in which genomic information is used in medical insurance. It is perhaps rational to infer that the ground of racial indirect discrimination may be upheld within the limited context that the use of genetic screening discriminates against ethnic groups.

Aside from domestic insurance and anti-discrimination legislation, genetic test data might be excluded on grounds of the social function of insurance, a situation that may warrant protectionist legislative reform generally.

PART IV: LEGISLATIVE REFORM

The call for legislative reform domestically and internationally, to provide meaningful protection to insurance applicants and guidance to insurers has ushered in the formulation of two main models, namely: "genetic specific legislation" and the "ceiling approach".[65]

Genetic Specific Legislation

Proposed legislation in Australia[66] and existing legislative initiatives in the United States,[67] focus specifically on the exclusion of all "genetic

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63 *Id.* at 364.

64 *Id.*

65 M Otlowski *supra* n. 15 at 208.

66 See *Genetic Privacy and Non-discrimination Bill 1998* (Cth). The bill was introduced by Democrats Senator Stott Despoja. It adopted a similar anti-discrimination model to that proposed in the United States, however the bill has been rejected.

67 See US Federal Legislation: *Health Insurance Portability and Accountability Act 1996* 42 USC §§300gg to 300g-92 (1999); *Americans with Disabilities Act 1990* §§12101-12213. See also State Legislation: Ala Code §27-53-1 to -2 (1998); Alaska State § 21.54.100 (1998); Ariz Rev Stat Ann §§ 20-1051, 20-1379 (1998); Cal Ins Code §10123.3 (1999); Cal Health & Safety Code §1374.7 (1999); Colo Rev Stat §10-3-1104.7 (1998); Conn Gen Stat Ann §38a-816 (1999); Fla Stat Ann §627.4301 (1999); Ga Code Ann §33-54-4 (1996); Haw Rev Stat §§431:10A-118, 432:1-607, 432D-26 (1998); 215 Ill Comp Stat Ann §5/356v (1999), 410 Ill Comp Stat Ann §513/20 (1997); Ind Code Ann §27-8-26-5 to -9 (1998); La Rev Stat Ann §22: 213.6-:213.7 (1999); Md Code Ann Ins §27-909 (1997); Minn Stat Ann §72A.139; Nev Rev Stat §695B.317 (1998); NH Rev Stat Ann §§141-H:1, 141-H:4 (1996); NJ Stat Ann §§17:48-6.18, 17:48A-611, 17:48E-15.2,

information" in the underwriting of insurance. Legislation that is genetic specific is based on the notion of "genetic essentialism". As detailed earlier, genetic essentialism rests on the basis that genes are determinative of who you are, thus providing medical information that is qualitatively different to any other predicative information. It is the view of this writer however, that genetic testing is not the only tool that can be used to evaluate a persons health prospects. Information that might be gathered from questionnaires about family diseases or habits, or medical tests indicating high cholesterol levels, are examples of other tests or methods that provide or yield similar information.[68] Thus, a non-genetic test can often give information of a genetic nature (ie genetic mutations). For example, a positive non-genetic test for high cholesterol could be linked to a genetic mutation that indicates a higher susceptibility to heart disease.[69]

On the one hand, reliance by an insurer on the notion of genetic essentialism, can lead to unfair discrimination where insurers misinterpret a genetic test result as determinative that disease will manifest. On the other hand, unwitting reliance on genetic essentialism by legislators, leads to laws that are "genetically exceptionalist" in nature.[70]

The operative effect of genetic specific legislation requires definitional terms of some description that set out the scope of genetic information that it wishes to protect. This has been viewed by legal commentators as perhaps one of the greatest failures of genetic specific legislation, namely, a problem of definition.[71] Legislation that is genetically exceptionalist requires some form of definition of genetic information that distinguishes it from non-genetic information. Genetic information could be narrowly construed as being restricted to actual genetic material itself, such as DNA and RNA collected directly or indirectly[72] from an insurance applicant.[73] Alternatively, it could be extended more broadly to include gene products and family inherited traits.[74] Either definition might be problematic. A narrow definition runs the risk of being under-inclusive and thus may indirectly exclude those that

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17B:27-36.2 (1999); NM Stat Ann §§27-21-2, 24-21-4 (1998); NY Ins Law §§3232, 4305, 4318 (1985) (1999); NC Gen Stat §§58-3-215 (1998); Ohio Rev Code Ann §§1751.64, 1751.65, 3901.49, 3901.5, 3901.50.1 (1996)(1997)(1998); Or Rev Stat §§746.135 (1997); Tenn Code Ann §§56-7-2702 to –2704 (1998); Tex Ins Code Ann art 21.73 (1998); Va Code Ann §§38.2-508.4 (1998); Wis Stat Ann §631.89 (1998); NM Admin Code tit §§13, 10.13.22.4 (1997).

68 T Lemmons *supra* n. 14 at 370.

69 J Beckwith and J S Alper *supra* n. 11.

70 M A Rothstein 'Genetic privacy and confidentiality: why they are so hard to protect' (1998) 26 *Journal of Law, Medicine & Ethics* 198 at 199

71 *Supra* n. 14.

72 Indirect DNA samples would include those collected from family or similar ethnic groups to make an inference on the applicant's policy.

73 M A Rothstein *supra* n. 70.

74 M S Yesley *supra* n. 14.

equally deserve protection. For example, it may be queried why existent family history is not included within a narrow definition of "genetic information under protection". Is "accepted practice" a reasonable ground, sufficient to warrant the distinction between two sources of information that can essentially yield similar predicative conclusions? In fact, one might argue that information gained from family history is less accurate than predicative genetic testing (in the long term at least) and thus is more likely to be unfairly discriminatory.

Again, even a broad definition of genetic information is problematic. An all-inclusive definition of genetic information will still not attach to non-genetic causal information that may equally require protection. Ethically, Australian legislators need to consider whether individuals with genetic and non-genetic predispositions should be treated similarly.[75] The practical effect of distinguishing between genetic and non-genetic information is that it discriminates between people who can find a genetic causal nexus and those that can not. Suppose, for example, that two individuals both had a higher risk to develop the mental disorder of schizophrenia. If one person's risk was as the result of a genetic test (ie. asymptomatic), that person would be protected, however if the other individuals' higher risk was due to being treated for depression (ie symptomatic), this person will not be protected. Under genetic specific legislation, the interests of the person who has a non-genetic risk go unprotected.

On the basis of the foregoing, it can be argued that genetic specific legislation is not a viable legislative solution. The under-inclusive nature of genetic specific legislation rests on a superficial notion of genetic difference which in practice results in discrimination.

Ceiling Approach and Modified Ceiling Approach

The ceiling approach was first proposed by the Dutch insurance industry as a means of addressing the use of genetic testing information. Under a moratorium, insurers are not permitted to request access to genetic information unless the contract exceeds a specific monetary ceiling.[76] Where the insurance contract exceeds the monetary limit, insurers are permitted to access genetic information already available in medical files upon request, however, applicants can not be required to submit to genetic tests. The Dutch approach represents a proposal founded on maintaining a safety net, in the form of monetary minimum, below which all genetic information is protected. It is submitted that a modified Dutch model which includes genetic and non-genetic information (ie medical information) might be an appropriate model. The ceiling approach appears to be based on the social function that underpins income protection insurance.

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75 L O Gostin and J G Hodge Jr *supra* n. 14 at 21.

76 T Lemmens *supra* n. 14 at 360.

"Common Goods" and "Commodities"

The social function of insurance is discernible from an examination of the concepts of "commodities" and "common goods". A commodity can be distinguished from a common good in that a commodity can be bought and sold in trade or commerce, whilst a common good, is that which naturally is or should be available to all. According to Rawls, 'the medieval maxim, that what touches all concerns all is seen to be taken seriously and declared as the public intention.'[77] For example, "health" or the maintenance thereof, is an example of that which is universally desirable, thus the protection provided for health related services, including health insurance is easily transposed into a common good that requires universal protection.

On the other hand, whether income protection insurance may be regarded as a commodity or common good will depend on its universal desirability when compared to other goods. Thus, whilst some goods will always have a value which seems universal, such as health, the precise value-content of other goods varies according to time and place. For example, in the United Kingdom, where life insurance is required for mortgages (ie mortgage protection insurance), life insurance might be properly classed as a common good, requiring greater protection. On that analogy, income protection insurance, within the Australian context, is a "lesser" good, in terms of the ordering of social goods. It would seem therefore, if income protection insurance is to warrant protection in the form of denial in the use of medical information by insurers, it will have lesser value than health insurance under Australian law.[78] This is not to say, however, that superseding factors may not increase the need for greater restrictions in the use of genomic data, regardless of whether the type of insurance is considered higher or lower in the social ordering of goods. For example, where the possibility of misinterpretation of genetic test information exists in the short-term, such genetic information may require greater protection under existing anti-discrimination law regardless of its social ordering as a good.

Finally, it is submitted that if income protection insurance is seen as a lesser social good than health insurance, but still a necessary form of common good in Australian society, then an approach that sets out when the common good of insurance becomes a commodity is appropriate. Therefore at some point, when the common good of income protection insurance becomes a tradeable commodity, the use of medical information could be sanctioned in the underwriting of an insurance policy beyond the common good limit. It is submitted that the precise monetary limit should be determined by an established working group, representative of all stakeholders in income protection insurance.

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77 J Rawls *A Theory of Justice* (Clarendon Press: Oxford, 1972) 233.

78 See *National Health Act 1953 (Cth)* s73(2A).

CONCLUSION

The use of genetic testing as a predicative tool is becoming more economically viable as technology improves and the cost of testing decreases. With new genetic testing technologies, as is the case with any new technology, novel challenges test established doctrine in actuarial analysis. Moreover, existing problems of social function in established areas of income protection insurance are drawn out more acutely by new predicative methods like genetic testing.

Throughout this work, it has been argued that predicative information derived from genetic test data is not significantly different from predicative information already available from a host of other non-genetic medical sources. Part I considered the scientific aspects of genetic testing, in particular the predicative value of genetic test data. Moreover, this Part considered the notion of genetic essentialism. It was concluded that genetic essentialism lacks a sound foundation and that a false reliance on developmental genetic test data by insurers may lead to unfair discrimination where that data was misrepresented. Part II considered how genetic test data might be used by insurers to discriminate and when discrimination is sanctioned under established concepts of insurance law. Part III provided an evaluation of the applicability of domestic anti-discrimination legislation, where tenuous or uncertain genetic test information is used to underwrite insurance. It was observed that current domestic legal mechanisms fall short of the protection required, to safeguard against unfair discrimination in the use of developmental genetic test data. Finally, Part IV considered the social function of insurance, within the framework of an evaluation of proposed law reform regarding genetic test information. This part examined two proposals, namely, the genetically exceptionalist approach and the ceiling method. It was argued that a *modified ceiling approach* based on the social function of insurance, which is considered a common "good", would necessitate semi-protectionist reform in Australia.

It has been argued that false reliance by legislatures on the qualitative uniqueness of genetic test information leads to legislation that is genetically exceptionalist. Legislation that distinguishes genetic from non-genetic medical information discriminates against those who are unable to establish a genetic causal nexus. The modified ceiling approach protects genetic and non-genetic medical information to the extent that it is considered a common good in Australian society. Thus, the protection afforded by the modified ceiling approach would offer Australian legislatures an equitable non-discriminatory solution.