

*Unzipping Our Genes for
Insurers?*

**Regulating the Use of
Genetic Information in
Insurance**

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Introduction

Discrimination between individuals on the basis of health information has long been a fundamental principle of private insurance. Over the past fifty years, advances in genetic technology mean we are now far more informed about how genes influence our health. To insurance companies, a predictive genetic test is just another way of more accurately classifying the risk an insurance applicant brings to the insurance risk pool. However, the prospect of 'genetic discrimination' has raised significant concern from many groups in society. As a result, many countries have moved to restrict the use of genetic information in insurance underwriting.

An analysis of the ethical basis for the move to restrict the use of genetic information concludes that regulation may not necessarily be appropriate. Although the use of genetic information in insurance could lead to people being unable to access basic social goods like housing, health care, food and education, this is unlikely in New Zealand. In any case, private insurance is not an appropriate avenue for the provision of such goods. The public health and welfare systems are more appropriate redistribution mechanisms. In addition, restricting the use of genetic information, while still allowing the use of other health information in underwriting creates an arbitrary distinction between genetic information and other health information that cannot be justified. 'Unzipping our genes' for insurers is really no different from stripping down for an insurance medical examination.

However, using genetic information in underwriting raises some issues which must be addressed. If we allow discrimination on the basis of genetic information, then its use must not be illogical and uninformed. People should not be deterred from taking genetic tests for fear of an inability to obtain insurance. These two risks can be minimised by cooperation between the insurance industry and the government in ensuring that the underwriting process is open and transparent, and encouragement of public awareness about how genetic information is used in insurance.

CHAPTER ONE

An Introduction to Genetics, Genetic Testing and Insurance Law

1.1 The Scientific Background – An Introduction to Genetic Testing and its Terminology

On 28 February 1953, Francis Crick wandered into his local pub and announced that he and James Watson had discovered the ‘secret of life’. What they had discovered was the structure of deoxyribonucleic acid (DNA).¹ Just shy of fifty years later, a draft sequence of the complete human genome was published,² and in 2003 the Human Genome Project was declared complete.³ The biotechnological advances of the last half century mean that we are becoming increasingly informed about how genes influence our health. This section will provide background to the science and technology behind genes and genetic testing.

1.1.1 The Cell, DNA and Genes

Every cell in the human body (except for the gametes) contains a nucleus, which in turn contains 23 pairs of different chromosomes. Consisting of DNA, these chromosomes are the genetic material which is passed on from one generation to the next. Contained on these chromosomes are genes, the basic unit of inheritance. An error or mutation in a gene often leads to a recognisable disease.⁴

Proteins are the building blocks of the body. The DNA sequence of a gene codes for a protein, which is manufactured by the processes of transcription and translation. Transcription is the process by which a ribonucleic acid (RNA) sequence is formed from the DNA template. This ‘messenger’ RNA serves as another template to specify

¹ Their model was published in Francis Crick and James Watson, 'Molecular Structure of Nucleic Acids; a Structure for Deoxyribose Nucleic Acid' (1953) 171 *Nature* 737.

² Efforts were made by both the public and private sectors and published almost simultaneously. See International Human Genome Sequencing Consortium, 'Initial Sequencing and Analysis of the Human Genome' (2001) 409 *Nature* 860 (a public consortium) and Craig Venter et al, 'The Sequence of the Human Genome' (2001) 291 *Science* 1304 (Celera Genomics).

³ International Human Genome Sequencing Consortium, 'Finishing the Euchromatic Sequence of the Human Genome' (2004) 431 *Nature* 931.

⁴ Lynn Jorde et al, *Medical Genetics* (2 ed, 2003), 6.

a sequence of amino acids during the process of translation, after which the strings of amino acids undergo modification to become a functional protein.⁵

An error or mutation in a gene often leads to a gain or loss of function in the associated protein. Some mutations result in genetic disease, but others may not have any apparent effects.⁶ Many genetic variations have no effect on the health of an individual, for example eye colour and hair colour. However, some mutations have health effects which range from minor to severe.

1.1.2 Types of Genetic Disorders

There are several major categories of genetic disorders:⁷

- (i) *Chromosomal disorders* – entire chromosomes or large segments of them are missing, duplicated, or otherwise altered. Examples include Down's syndrome and Turner syndrome.
- (ii) *Single gene disorders* – disorders which are the result of mutation in a single gene. Examples include cystic fibrosis and haemophilia.
- (iii) *Multifactorial disorders* – disorders which are due to a combination of multiple genetic and environmental factors. Most genetic disorders belong in this category.

1.1.3 Patterns of Inheritance

In each pair of chromosomes, one chromosome is inherited maternally, the other paternally. In each pair the chromosomes are largely of the same composition, in that they contain mostly the same genes.⁸ For most genes, therefore, there are two 'copies' of each gene. These copies may differ slightly in their DNA sequence. These different versions of genes are called 'alleles'.

The combination of alleles a person has at a specific chromosomal locus is referred to as their genotype, and how these alleles manifest themselves physically is called the phenotype. Where there are two copies of the same allele, the genotype is

⁵ This is the traditional model, but now only a small portion of the total DNA in a cell is thought to be made up of genes which fit it. The remainder of the genome, referred to as 'non-coding' regions, was originally referred to as 'junk DNA' but is now thought to be involved in gene regulation among other things. Some RNA produced is not translated into protein but still has a regulatory function within the cell. This is currently the subject of scientific debate. See Helen Pearson, 'Genetics: What is a gene?' (2006) 441 *Nature* 398.

⁶ Jorde et al, above n 4, 31.

⁷ Ibid 3.

⁸ With the exception of the pair of sex chromosomes, which are significantly different from each other.

referred to as homozygous. Where the two alleles are different, the genotype is referred to as heterozygous. However, even in the case of a single gene disorder, having one 'faulty' allele does not necessarily mean that there will be expression of the associated disorder. The resulting phenotype can also be affected by both genetic and environmental factors. The expression of a trait over several generations – the pattern of inheritance – can determine how a gene is expressed. There are three common patterns of inheritance – recessive, dominant and X-linked.⁹

1.1.3.1 Recessive

A recessive trait is only expressed as a phenotype if there are two copies of the recessive allele present. Both parents need to carry the mutant allele in order for a child to express the trait. Two parents who do not express the trait may still have a child who does if they are both a 'carrier'.¹⁰

1.1.3.2 Dominant

A dominant trait will express as a phenotype in the presence of just one mutant allele. This means that the mutant allele need only be inherited from one parent in order for the phenotype to be expressed.¹¹

1.1.3.3 X-linked

One of the 23 pairs of chromosomes is a sex chromosome pair, which determines maleness or femaleness. The presence of two X chromosomes determines femaleness, while one X and one Y chromosome determines maleness. Some traits are inherited through genes located on the sex chromosomes, and are thus often expressed more frequently in one sex. A woman has two X chromosomes, so a recessive mutant allele on one of these is unlikely to be expressed. However, one mutant allele inherited by a male will likely result in the trait being expressed, because he lacks another X chromosome.¹²

1.1.4 Factors which Complicate Patterns of Inheritance

When a genetic test is carried out it is essentially an analysis of the DNA sequence at the location of the given gene. However, the mere presence of a mutation does not mean that the disease phenotype will present itself clinically. In addition to the pattern of inheritance, there are a number of other factors which determine whether or not a mutant gene is expressed as a disorder. This makes the interpretation of genetic

⁹ Jorde et al, above n 4, 30-33.

¹⁰ Ibid. A carrier is someone who has one copy of mutant allele and one copy of the normal allele.

¹¹ Ibid.

¹² Ibid.

tests incredibly complex and is why we still know so little about so many inherited diseases. The primary additional factors which affect expression are delayed age of onset, penetrance and expressivity.

1.1.4.1 Delayed Age of Onset

Many genetic diseases are expressed at birth or shortly afterwards, but others do not become apparent until late adulthood. This is referred to as delayed age of onset. A number of genetic diseases have delayed age of onset, including Huntington's disease, familial Alzheimer disease, and hereditary breast and ovarian cancer.¹³

1.1.4.2 Penetrance

Even though an individual has a disease genotype, they may never actually exhibit the disease phenotype. Penetrance describes the likelihood that an individual carrying a given gene will eventually express the associated disease. Penetrance is calculated from clinical studies, and is highly variable from gene to gene. In addition, different mutations in a gene may have different penetrance.¹⁴ Huntington's disease has extremely high penetrance, almost 100 per cent, which means that someone who tests positive for the mutation will almost certainly develop the disease eventually. As a contrast, different mutations in the BRCA1 and BRCA2 genes have varying penetrance.¹⁵

1.1.4.3 Expressivity

Even where penetrance is approaching 100 per cent, the severity of the disease can still vary greatly. Expressivity describes the severity with which the disease manifests itself. This variable expressivity may be caused by environmental factors, genes which modify the effect of the mutant gene, or different types of mutation at the same position in the gene.¹⁶

1.1.5 Three Illustrative Examples

1.1.5.1 Huntington's Disease

Huntington's disease is an extremely rare neurological disorder, characterised by a progressive loss of motor control and psychological problems. It is an autosomal dominant disorder, caused by the repetition of three DNA bases (trinucleotide repeat

¹³ Ibid 70-73.

¹⁴ Ibid.

¹⁵ See below 1.1.5.3.

¹⁶ Jorde et al, above n 4, 70-73.

expansion) in the Huntingtin gene.¹⁷ Onset of the disorder is correlated to the number of trinucleotide repeats, with a higher number of repeats indicating earlier onset. Symptoms usually become noticeable in the mid 30s to mid 40s.¹⁸ The period from onset to death is usually 10 to 15 years. There is no treatment and, there are no proven preventative measures, but some of the symptoms are controllable to a limited degree.

1.1.5.2 Haemochromatosis

Hereditary haemochromatosis is an autosomal recessive disorder in which excessive iron is absorbed into the body and accumulates in a variety of organs. The most common symptom of undiagnosed haemochromatosis is fatigue. It is a delayed onset disorder; symptoms often do not present until the age of 50. Women usually develop clinical symptoms about 20 years later than men, because menstruation tempers the iron overload. There are two common mutations of the HFE gene, which account for 90 per cent of clinical iron overload.¹⁹ One of the two common mutations has very low penetrance.²⁰ Treatment and prevention is by regular blood donation, which reduces the accumulation of iron in the body, and is very effective when started before symptoms are observed. If iron is allowed to accumulate there will be organ damage, particularly to the liver and pancreas.

1.1.5.3 Hereditary Breast and Ovarian Cancer

Several genes are known to predispose women to developing hereditary breast cancer, the most important of which are the BRCA1 and BRCA2 genes, particularly in early onset cases.²¹ The lifetime prevalence of breast cancer in women is about one in eight, with only about one per cent to three per cent of cases attributed to mutations in BRCA1 or BRCA2. Sixty to eighty per cent of women who have a family history of breast and ovarian cancer have inherited a BRCA1 or BRCA2 mutation.²²

Both genes have penetrance less than 100 per cent, with a woman who has a BRCA1 or BRCA2 mutation having a 50 to 80 per cent lifetime risk of developing breast cancer. BRCA1 mutations also increase the risk of ovarian cancer in women (20 to 50 per cent), and modestly increase the risk of prostate and colon cancers.

¹⁷ Ibid 72.

¹⁸ Ibid 69.

¹⁹ Ibid 153.

²⁰ Ibid 154.

²¹ Ibid 254.

²² Ibid 269.

About 6 per cent of males who inherit a BRCA2 mutation will develop breast cancer (a 100-fold increase over the general male population risk).²³

Interpretation of BRCA1 and BRCA2 tests is difficult because of the large number of identified mutations (about 600 in BRCA1 and 450 in BRCA2), not all of which are linked to an increase in the lifetime risk of developing breast or ovarian cancer.²⁴

Preventative treatment options include prophylactic mastectomy, which reduces the chance of breast cancer by about 90 per cent. Removal of the ovaries is possible but less common. There are some unproven medications which could reduce lifetime risk, but regular surveillance is the most common method for reducing mortality. Known environmental risk factors for breast cancer include not bearing children, a high-fat diet, excessive alcohol consumption and oestrogen replacement therapy. The effect of these factors on lifetime risk for a woman with a known genetic predisposition is unclear.²⁵

1.1.6 Genetic Testing

There are five common types of genetic testing which insurance companies may seek to use:²⁶

- (i) *Diagnostic testing* – Diagnostic testing is used for diagnosis of a specific disorder where the person already has symptoms of that disorder.
- (ii) *Predictive testing* – Predictive testing is usually performed on an asymptomatic person in order to determine whether that person has genetic variations which indicate an increased risk of developing a specific disorder in the future. This type of testing is often used for late onset disorders, and at the moment is most often used where there is family history of a genetic disorder.
- (iii) *Genetic carrier testing* – Genetic carrier testing is used to determine whether a person has a genetic abnormality that does not affect the person's health but increases the chance of having a child with a given disorder.

²³ Ibid 269.

²⁴ Ibid 269.

²⁵ Ibid 254.

²⁶ Australia Law Reform Commission, National Health and Medical Research Council and Australian Health Ethics Committee, *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96 (2003), 323 (*Essentially Yours*).

- (iv) *Screening testing* – Screening testing is performed on people who are not necessarily known to be at increased risk of a given genetic disorder.
- (v) *Research testing* – Research testing is the systematic analysis of genetic information in order to gain knowledge as to how genes can influence the health of individuals or entire populations. Research testing is often conducted using samples which are ‘de-identified’ in that there is no direct link to the person from whom they were obtained.²⁷

1.1.7 The Potential for Genetic Testing

Currently, one of the crucial problems with genetic tests is that they are unreliable in a number of ways. Lab testing procedures are not error-proof because the amplification process which allows large enough quantities of DNA for sequencing is prone to contamination and there are often replication fidelity issues.²⁸

Apart from technical issues with the testing process, there are also issues of interpretation of predictive genetic tests. Currently, very few diseases are able to be predicted by genetic tests, so the potential for genetic discrimination is correspondingly small.²⁹ At the outset of the Human Genome Project, there were great hopes that the genetic basis of many diseases would be discovered. However, the Human Genome Project seems to have only revealed the complexity of genetics rather than simplifying it. The extent to which a particular mutation in a particular gene is considered to increase the chance of developing the associated disorder is open to interpretation and evidence can often be conflicting. It takes a long time for a body of research to build up confirming the degree to which a given mutation increases (or not), the risk of developing the disease.

This difficulty in interpreting genetic tests is a significant issue in the use of genetic information in risk classification. The UK only allows tests which have been proved as actuarially significant to be used in risk classification.³⁰ Currently the only test considered to be appropriate is that for Huntington’s disease, which is rare in its

²⁷ See below n 30.

²⁸ Ibid 235.

²⁹ See Margaret Otlowski et al, 'Investigating Genetic Discrimination in the Australian Life Insurance Sector: The Use of Genetic Test Results in Underwriting, 1999-2003' (2007) 14 *Journal of Law and Medicine* 367 ('Industry Study'). In this Australian study, only 15 different genetic tests for adult onset conditions had been disclosed in the applications reported by the Investment and Financial Services Association for the study. There were total of 234 applications with interpretable results. Sovereign Group Limited (New Zealand’s largest life insurer with 30 per cent market share) only receives one or two applications each year which disclose genetic tests: Sovereign Group Limited, 'Response to the Human Rights Commission on Review of the Guidelines on Insurance and the Human Rights Act 1993' (2006).

³⁰ See below 2.4.1.

status as a late-onset, single gene disorder with penetrance approaching 100 per cent. Apart from the possibility of tests for breast and ovarian cancer (which are still limited in their predictive value), it is unlikely that any further tests will be moved for approval in the near future.³¹

In the past year however, high-throughput experimental techniques have allowed the discovery of previously unknown genetic variants for a number of common diseases like depression, heart disease and rheumatoid arthritis.³² This research has been hailed as a 'new dawn' in genetic research, because it has uncovered more in the last 12 months than have been uncovered in the last 15 years.³³ However, the researchers acknowledged that most common diseases were very complex, and that the interaction between genes and the environment would be difficult to unravel.³⁴ This means that although more predictive tests may be developed in the near future, their accuracy in light of environmental factors may be limited.

1.2 An Introduction to Insurance Law

1.2.1 What is Insurance?

The general principles of insurance law have long been established in the English common law, which is still the main source of insurance law in both the United Kingdom and New Zealand. There is no legislative definition of insurance, however the judgment of Channell J in *Prudential Insurance Co v Inland Revenue Commissioners*³⁵ is commonly cited. Justice Channell stated that a contract of insurance is³⁶

a contract for the payment of a sum of money, or some corresponding benefit such as [the payment of medical treatment], to become due on the happening of an event [such as the development of a disease], which event must have

³¹ Genetics and Insurance Committee, *Fifth Report from January 2006 to December 2006* (2007) ('Fifth Report').

³² The diseases studied were depression, Chron's disease, coronary heart disease, hypertension, rheumatoid arthritis and type one and two diabetes. The study used 'gene chip' technology to scan hundreds of thousands of DNA markers, which allowed the identification of genetic differences. For each of the seven conditions studied, 2,000 patients were sampled and compared to 3,000 healthy volunteers: Wellcome Trust Case Control Consortium, 'Genome Wide Association Study of 14,000 Cases of Seven Common Diseases and 3,000 Shared Controls' (2007) 447 *Nature* 661. See also 'Serious Disease Genes Revealed' BBC News Online (<<http://www.bbc.co.uk>>, 6 June 2007); 'Do Not Ask or Do Not Answer', *The Economist* (London), 25 August 2007, 77.

³³ 'Serious Disease Genes Revealed', above n 32.

³⁴ *Ibid.*

³⁵ *Prudential Insurance Co v Inland Revenue Commissioners* [1904] 2 KB 658 at 664.

³⁶ *Ibid.* Wording in square brackets from Anton Usher, 'Genetic Testing and Insurance: The potential for legal discrimination in New Zealand' (2002) 1 *New Zealand Law Students' Journal* 1, 6.

some amount of uncertainty about it, and must be of a character more or less adverse to the interest of the person effecting the insurance.

1.2.2 General Principles of Private Insurance

The purpose of private (or voluntary) insurance can be seen as a means of sharing financial loss.³⁷ Small, regular contributions by a large group in the form of premiums are pooled, allowing the financial losses of an insured individual, caused by an insured event, to be covered. The idea behind this is that the loss of the individual is unpredictable, but the loss of the group as a whole is predictable. This ensures that premiums paid in are sufficient to cover the claims paid out.³⁸

Private insurance allows an individual to choose the extent of the insurance cover they want to purchase, and when they want to purchase it.

There are two broad ways in which private insurance can operate in terms of calculation of premiums: community rated insurance and mutually rated insurance. Most private insurance in New Zealand is mutually rated. This means that insurers vary premiums according to the risk an individual is estimated to bring to the risk pool.³⁹ Any number of characteristics can be used to make this assessment, including age, smoking status, and medical history. The fundamental principle here is equity, so applicants and policyholders are treated on an equitable rather than an equal basis.⁴⁰

Contrasted to this is community rated insurance, in which insurance companies do not discriminate on the basis of the risk each insured will bring to the risk pool. This means that risk is shared collectively across the pool of insureds, irrespective of the likelihood of their making a claim. Any form of compulsory social insurance is community rated.

Private insurance in New Zealand can be divided into three general categories: life insurance, health insurance and general insurance. Each category may include a variety of different products. Classifying risks on the basis of health information is common in both life insurance and health insurance, which is why they are the focus of this paper.

³⁷ Investment Savings and Insurance Association, *ISI Underwriting Guide* (2000), 5 ('Underwriting Guide').

³⁸ *Ibid.*

³⁹ The term risk is used to describe the likelihood that the event insured for will occur, which would result in a claim being paid.

⁴⁰ Usher, above n 36, 6.

1.2.3 Insurance as a Contract *uberrimae fidei* and the Balance of Information

A contract for insurance is a special type of contract in that it is considered a contract *uberrimae fidei* (of the utmost good faith). The doctrine has its foundation in the judgment of Lord Mansfield CJ in *Carter v Boehm*,⁴¹ and means that the insured and the insurer are bound to make full disclosure of anything which may materially affect the risk to the other, before the contract is complete. This is in contrast to the general law of contract where there is no general positive duty of disclosure.

As health information is relevant to classifying risk for life and health insurance policies, any genetic tests undertaken will be relevant to the risk an applicant is bringing to the insurance pool and so must be disclosed. This means that full disclosure of any genetic tests undertaken is necessary or the contract will later be rendered void for non-disclosure.⁴²

1.2.4 The Underwriting Process

Insurers rely on a range of information when classifying a risk.⁴³ The application form completed by an applicant is the primary source of information, but other sources of information may also be used. Doctors' reports, medical examinations, medical tests and financial evidence may be consulted, among other sources. Age, gender and smoking status are first used to calculate a 'standard' premium.⁴⁴ The underwriter will then make an assessment of other risk factors, including medical risk factors. This assessment is guided by an underwriting manual⁴⁵ and expert medical opinion. These manuals are compiled using statistics and specialist knowledge, and provide a general guide to an appropriate assessment. However, the manual is not determinative of an underwriter's decision, and each decision is made on a case by case basis.

It is not commercially viable to offer unique terms and prices to each individual applicant, so insurers group together into 'pools' those applicants who represent approximately the same risk of a claim. This is sometimes referred to as premium 'banding'. A good example is the 'age bands' used to calculate health insurance

⁴¹ *Carter v Boehm* (1766) 3 Burr 1905 at 1909.

⁴² *Ibid.*

⁴³ The information in this section is drawn from Investment Savings and Insurance Association, 'Underwriting Guide', above n 37. ISI members are life and disability insurers, but the process applies equally to health insurance underwriting where health information is used in differentiating premiums for health insurance policies.

⁴⁴ Disability income insurance may also use occupational class in this calculation.

⁴⁵ This may be the company's underwriting manual, although most companies use underwriting manuals provided by reinsurance companies. This is almost always the case in New Zealand, where the small insurance market means that there is seldom enough data to generate reliable statistics.

premiums. As an individual ages, they progress from one five or ten year 'age band' to the next, with premiums increasing in proportion to the increased risk of a claim by that age group.

Most applications for life and disability income insurance in New Zealand are accepted at standard rates. This means that the risk of a claim is considered the same as average, and the standard premiums will be charged with the standard benefits. If there are pre-existing conditions, the risk may still be assessed as standard but the pre-existing condition may be excluded. If the risk is assessed to be higher than average, cover may be accepted at a higher rate; accepted with an exclusion; accepted with modified terms; or postponed for later consideration.

1.2.5 The Human Rights Act 1993 and the Exception for Insurers

The Human Rights Act 1993 (HRA) is the primary piece of legislation which affects private insurance in New Zealand,⁴⁶ protecting people from unlawful discrimination in the provision of insurance.⁴⁷

Section 44 of the HRA makes it unlawful to refuse or fail to provide a facility, or to provide it on less favourable terms, on the basis of one of the prohibited grounds in the Act. 'Facilities' expressly includes the provision of insurance.⁴⁸ The prohibited grounds of discrimination include disability, which is defined as including physical disability or impairment, physical illness, and 'any other loss or abnormality of psychological, physiological or anatomical structure or function'.⁴⁹ Once a person has physical symptoms caused by a genetic mutation, this condition undoubtedly falls within the definition of disability. However, it is unclear whether merely having a predisposition to this condition falls within the definition of disability. It can be argued that the mutation which causes the predisposition is an abnormality of physiological structure or function. There is no case law on this point. However, it seems plausible that a genetic mutation be included, given that the HRA is to receive a liberal interpretation, and that knowledge of a condition will amount to a disability in its own right.⁵⁰

⁴⁶ There are a number of pieces of legislation which affect insurance specifically in New Zealand, but these have no provisions relating to the underwriting process: Life Insurance Act 1908; Insurance Law Reform Act 1977; Insurance Law Reform Act 1985.

⁴⁷ In addition to the controls on underwriting in the Human Rights Act, the Privacy Act 1993 and the associated Health Information Privacy Code 1994 protect the privacy of applicants or policyholders in the collection, storage, use and disclosure of any information about them, including health information.

⁴⁸ *Ibid* s 44(2).

⁴⁹ *Ibid* s 21(1)(h)(iv).

⁵⁰ Andru Isac, 'Genetic Testing and Insurance: The Role of Industry and the Welfare State' in Duncan Webb and David Rowe (eds), *Insurance Law: Practice, Policy and Principles* (2004) 1, 13.

Even if a genetic predisposition to a condition is considered to be within the definition of disability, the HRA provides an exception to the general prohibition on discrimination for insurers. Section 48 provides that

- (1) It shall not be a breach of section 44 to offer or provide ... life insurance policies ... or other policies of insurance, whether for individual persons or groups of persons, on different terms or conditions for each sex or for persons with a disability or for persons of different ages if the treatment—
 - (a) is based on—
 - (i) actuarial or statistical data, upon which it is reasonable to rely, relating to life-expectancy, accidents, or sickness; or
 - (ii) where no such data is available in respect of persons with a disability, reputable medical or actuarial advice or opinion, upon which it is reasonable to rely, whether or not contained in an underwriting manual; and
 - (b) is reasonable having regard to the applicability of the data or advice or opinion, and of any other relevant factors, to the particular circumstances.

Essentially, s 48 allows discrimination on the grounds of sex, age or disability where it is based on reasonable statistical data, or reasonable professional opinion. The exception does not allow an insurer to refuse cover on one of the prohibited grounds – it only allows a variation of the terms or pricing of the insurance.

If a genetic predisposition is not included in the definition of disability, then the limited protection provided by the HRA will not apply because genetic status will not be one of the prohibited grounds of discrimination. This would mean insurance companies would still be allowed to discriminate on the basis of a genetic predisposition.

1.2.6 The Guidelines on Insurance

In 1997 the Human Rights Commission published the *Insurance Guidelines*,⁵¹ which were intended to 'help insurers and consumers understand their rights and meet their responsibilities under the Human Rights Act'.⁵² The Guidelines represent the Commission's views on the interpretation of the Human Rights Act, but are not binding on consumers or the insurance industry. The guideline with regard to genetic testing is as follows:

⁵¹ Human Rights Commission, *Insurance Guidelines* (1997). These guidelines were issued pursuant to s 5 of the Human Rights Act which states that one of the functions of the Commission is to publish guidelines for the avoidance of practices that may be inconsistent with the Act.

⁵² Human Rights Commission, *Discussion Paper: Review of the Guidelines on Insurance and the Human Rights Act 1993* (2006), 1 ('Discussion Paper').

Insurance companies can request that existing results are made available for the purposes of classifying a risk, but cannot insist that applicants undergo genetic tests.

The commentary to the guideline states that this is an interim approach until the issues involved are more settled. In October 2006 the Commission issued a discussion paper for review of the *Insurance Guidelines*,⁵³ which recognises that the improvement of technology in the ten years since the guidelines were formulated has increased the potential for 'genetic status discrimination'. However in the recently released new Draft Insurance Guidelines,⁵⁴ the status quo is maintained, although there was further recognition of the moratorium as not being a permanent solution, and needing to be addressed.⁵⁵

1.2.7 The ISI Underwriting Guide – 'the Moratorium'

The Investment Savings and Insurance Association of New Zealand (ISI) *Underwriting Guide*⁵⁶ sets out a policy on genetic testing. The policy is a moratorium on insurance companies initiating genetic tests, taking the same approach as the Insurance Guidelines.⁵⁷ The moratorium is voluntary because the guide is not binding on the member companies, however it has not been challenged. The crucial points of the policy are:

- (i) Insurers will not initiate genetic testing of applicants;
- (ii) Insurers may request that existing test results be made available for the purposes of underwriting.
- (iii) Insurers will not use genetic tests as the basis of preferred risk underwriting.⁵⁸

The guidelines are based on the Australian Investment and Financial Services Association policy, on the basis that the Australian and New Zealand situations are substantially similar.⁵⁹ The policy acknowledges the Human Rights Commission's Insurance Guidelines, which take the same approach.

⁵³ Ibid.

⁵⁴ Human Rights Commission, *Insurance Guidelines: Draft for Public Consultation (2007)* ('Draft Insurance Guidelines').

⁵⁵ Ibid 15.

⁵⁶ Investment Savings and Insurance Association, 'Underwriting Guide', above n 37.

⁵⁷ Ibid Appendix Three.

⁵⁸ Preferred risk underwriting is the practice of offering an applicant insurance at a lower than standard rate because they are perceived to be a better risk.

⁵⁹ Investment Savings and Insurance Association, 'Underwriting Guide', above n 37.

The Health Funds Association of New Zealand (HFANZ) has issued a policy almost identical to that of the ISI.⁶⁰

1.2.8 The Human Rights Commission Complaints Process

There is currently no legal obligation on insurers to provide reasons for an adverse underwriting decision.⁶¹ However, where an applicant for insurance considers that they have been unfairly discriminated against, they can lodge a complaint with the Human Rights Commission.⁶² The Human Rights Amendment Act 2001 introduced a new complaints system for allegations of unlawful discrimination, intended to facilitate resolution of claims.⁶³

Under the new process it is unnecessary to submit a written complaint initially, however a complaint form is available on the Commission's website for more complex claims.⁶⁴ Once made, a complaint proceeds through a variety of steps with the goal of conciliation,⁶⁵ but if the complaint cannot be resolved through these channels then the matter may proceed to the Human Rights Review Tribunal. The Director of the Office of Human Rights Proceedings may take the dispute to the Tribunal, or the complainant may take it to the Tribunal at their own cost. In assessing whether an underwriting decision is reasonable as per the requirements in

⁶⁰ Health Funds Association of New Zealand, *HFANZ Policy on Genetic Testing* (2001).

⁶¹ This is in contrast to Australia where s 75 of the Insurance Contracts Act 1984 (Cth) (Australia) requires and insurer to provide reasons upon request.

⁶² The Insurance and Savings Ombudsman also has the ability to deal with complaints regarding insurance, but is unable to consider complaints regarding underwriting and premium decisions, which means it is of limited value as a complaints avenue in the context of genetic testing and insurance. The ISO has no statutory basis and no affiliation with the government, so can only deal with participating companies. Membership is voluntary so decisions are not binding on participants. Under its terms of reference, the ISO can consider a complaint about a company if it relates to health, income protection, mortgage protection, critical illness and life insurance (among other types of insurance) and the claim is not in excess of \$150,000 (or \$1,000 per week for a disability benefit). The ISO may be of limited use as a complaints avenue in the event there is a dispute regarding whether a disclosed genetic predisposition is a pre-existing condition if it is not specifically listed under the policy: Insurance and Savings Ombudsman, 'Complaints the ISO Can Consider', <http://www.iombudsman.org.nz/html/what_we_do/type_of_complaints.aspx>, accessed 25 August 2007.

⁶³ The information in this section was drawn from the Human Rights Commission dispute resolution fact sheet: Human Rights Commission, 'What is the Process for Dealing with Disputes?', <<http://www.hrc.co.nz>>, accessed 21 August 2007 ('Disputes Process').

⁶⁴ Available at <www.hrc.co.nz>.

⁶⁵ Human Rights Commission, 'Disputes Process', above n 63. Complaints are received by the Commission's 'Information Advisors' who gather data, provide information and help with deciding what the next step should be. If the issue cannot be resolved with referrals to other services, self-help or other options, the issue will be passed on to a 'Duty Mediator'. Duty Mediators 'provide informal intervention' and act as an informal forum for discussion and information gathering. If the issue cannot be resolved at this point, then it is referred for assessment and transfer to a mediator. If the complaint cannot be resolved by mediation then it may proceed to the Human Rights Review Tribunal.

s 48 of the HRA, the Commission may require justification to be provided for reliance on the data, advice or opinion used in assessing the application and for the different treatment.⁶⁶ The Commission may also request the views of the Government Actuary as to the justification.⁶⁷

To date no complaints have been made to the Commission regarding genetic status discrimination and insurance.⁶⁸

1.3 Types of Insurance Affected by Genetic Information

There are three distinct categories of private insurance: life, health, and general insurance. Generally, only life and health insurance utilise health information in underwriting, therefore it is these types that will be the focus of this paper.

Traditional life insurance policies combine a savings scheme and risk protection, but most life policies today are term policies which provide risk protection only.⁶⁹ Most of these policies are 'guaranteed renewable' by the policyholder at standard premiums, which is valuable if the insured's health deteriorates or they receive a positive genetic test result.⁷⁰

In addition to traditional life policies, the life insurance industry has developed other products, which are often termed 'quasi-life' policies, in response to market demand for protection in the event that the insured individual is unable to work.⁷¹ Broadly, these policies fall into three categories:⁷²

- (i) *Disability Income Insurance* – Provides income replacement when a person is incapacitated and unable to work.
- (ii) *Total and Permanent Disablement Insurance* – Provides a lump sum when the policyholder is so disabled as to be unlikely to ever regain employment.

⁶⁶ Human Rights Act, s 48(2)(a).

⁶⁷ Ibid s 48(2)(b). The office of the Government Actuary is part of the Insurance and Superannuation Unit of the Ministry of Economic Development. See <www.isu.govt.nz>.

⁶⁸ Email from Robert Hallowell to Katharine Reynolds, 24 August 2007. Robert Hallowell is Legal Counsel for the Human Rights Commission.

⁶⁹ New Zealand Law Commission, *Life Insurance*, Preliminary Paper 53 (2003), 5.

⁷⁰ 'Positive' is used to indicate the presence of a mutation which is considered to increase the risk of the disease phenotype presenting.

⁷¹ New Zealand Law Commission, *Life Insurance*, Report 87 (2004), 114.

⁷² Investment Savings and Insurance Association, 'Underwriting Guide', above n 37, 16.

- (iii) *Dread Disease Insurance* – Benefit is paid on diagnosis of a specified range of medical conditions or accidents (e.g. cancer, heart attack, stroke). Sometimes referred to as ‘Critical Illness’ or ‘Trauma Insurance’.

Health insurance is currently only risk-rated on the basis of age and smoking status, but this is merely industry convention and is subject to change under competition pressures. Increased risk caused by pre-existing conditions is usually mitigated by the exclusion of pre-existing conditions from cover. As genetic testing improves it may be used in underwriting health insurance.

1.4 The Problem with Regulation – Adverse Selection

Many countries have moved to restrict the ability of insurers to use the results of genetic tests in risk classification, to avoid discrimination on the basis of genetic status.⁷³ Traditionally, the applicant must make full disclosure of any relevant information to the insurer,⁷⁴ and there is a resulting balance of information between the applicant and the underwriter. However, if an applicant is not required to disclose something which increases the risk they are bringing to the pool, they will be charged a premium disproportionate to the cost of providing the insurance (because the chance of their making a claim is higher than is reflected in the premium). The individual’s premium is effectively being subsidised by the rest of the risk pool.

Economic theory tells us that subsidies influence demand. Therefore, those who know they are at high risk will likely procure insurance on a larger scale than if they were to pay a premium proportionate to this higher risk. As the cost of payouts increases, premiums as a whole will have to increase. This may result in lower risk individuals limiting the extent to which they insure, or not insuring at all (‘proverse selection’). This further amplifies the gap between premiums and payouts, and once again premiums will rise. The result is a cycle of an increasing proportion of high risks in the pool and premium hikes. This can eventually destabilise the industry or cause it to collapse.

A good example of adverse selection is the introduction of premium discounts for non-smokers.⁷⁵ When the discounts were first introduced, companies which did not offer discounts attracted a higher proportion of smokers. Non-smokers also moved to the companies that gave discounts, leaving those which did not, with a higher proportion of smokers than previously. This meant that the insurance costs of the

⁷³ See below chapter two.

⁷⁴ See above 1.2.3.

⁷⁵ See Human Rights Commission, ‘Discussion Paper’, above n 52, 4.

companies which did not differentiate increased once again. Eventually all companies had to differentiate their premiums.

CHAPTER TWO

International Responses

Most countries have moved to restrict the use of genetic information in underwriting to avoid the possibility of genetic discrimination. However, approaches to regulation vary internationally. The use of genetic information in insurance raises ethical issues relating to privacy, autonomy, fairness and justice. The varying approaches reflect the contentious and complex ethical nature of the issue, and the differing social and economic circumstances in each country.⁷⁶ This chapter contains a summary of the international response to the prospect of genetic discrimination in insurance.

2.1 General Approaches to Regulation

Different jurisdictions have taken different approaches to the problem of genetic discrimination in insurance, but these can be isolated into a number of categories, which are implemented alone or in combination.⁷⁷

- (i) *Human Rights Approach* – Based on principles set out in UNESCO declarations, and other multilateral international documents.
- (ii) *The Therapeutic Model* – Allows genetic tests only to be done for scientific or medical purposes. Usually complemented by another approach because does not deal with the way in which existing test results can be used.
- (iii) *Specific Legislation* – Legislation which specifically deals with whether insurers can require that tests be disclosed or undertaken.
- (iv) *Regulatory Review* – Review of specific genetic tests by an independent body, to ensure they are scientifically and actuarially reliable. Allows discrimination if actuarially fair.
- (v) *Voluntary Moratorium* – Voluntary industry moratoriums on requiring applicants to undergo genetic tests. Usually requires disclosure of existing tests.

⁷⁶ See below chapter three.

⁷⁷ These categories were drawn from Human Rights Commission, 'Discussion Paper', above n 52, 13-14.

- (vi) *Proportional Approach* – Disclosure requirements and whether an applicant can be required to undergo a genetic test differ, depending on the value of the insurance.

However the restriction is implemented, any regulatory regime usually addresses two key issues:

- (i) Whether insurers are able to require applicants to disclose the results of any genetic tests.
- (ii) Whether insurers are able to require applicants to undergo a genetic test before approval of the application.

2.2 The Multilateral International Response

2.2.1 UNESCO Declarations

A Human Rights approach to regulation is generally based on the principles set out in UNESCO declarations.⁷⁸ The three declarations with direct bearing on the issue of genetic testing and insurance are:

- (i) Universal Declaration on the Human Genome and Human Rights.⁷⁹
- (ii) International Declaration on Human Genetic Data.⁸⁰
- (iii) Universal Declaration on Bioethics and Human Rights.⁸¹

These declarations emphasise the importance of balancing the public good with the need for confidentiality. The Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data stress that there is a need for non-discrimination and non-stigmatisation.⁸² The International Declaration on Human Genetic Data takes the view that genetic information has special status,⁸³ and therefore we should ensure that its use is particularly protected. Article 7(a) requires that genetic information is not used in a way that infringes on

⁷⁸ Human Rights Commission, 'Discussion Paper', above n 52, 13.

⁷⁹ UNESCO, *Universal Declaration on the Human Genome and Human Rights*, 29th General Conference, 11 November 1997.

⁸⁰ UNESCO, *International Declaration on Human Genetic Data*, 32nd General Conference, 16 October 2003.

⁸¹ UNESCO, *Universal Declaration on Bioethics and Human Rights*, 33rd General Conference, 19 October 2005.

⁸² Human Rights Commission, 'Discussion Paper', above n 52, 13.

⁸³ UNESCO, *International Declaration on Human Genetic Data*, above n 80, art 4.

'human rights, fundamental freedoms or human dignity ... or for purposes that lead to the stigmatisation of an individual [or group]'.⁸⁴

This essentially reiterates that genetic information should not be used in a way that is contrary to international human rights law. In particular, the Declaration aims to avoid an individual's identity being reduced to genetic characteristics, because identity is determined by a complex variety of influences (such as environmental and social factors).⁸⁵

2.2.2 Council of Europe

In 1997 the Council of Europe⁸⁶ passed the Convention on Human Rights and Biomedicine.⁸⁷ The Convention is based on the idea that the interests of human beings should come before the interests of science and society. Article 1 states that parties to the Convention should 'protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other fundamental rights and freedoms'.

In specific reference to genetic information, Article 11 states that 'any form of discrimination against a person on the grounds of his or her genetic heritage is prohibited'. This could be interpreted as prohibiting the use of family history in underwriting, as this surely is part of an individual's genetic heritage, but countries who have ratified the convention and implemented legislation have not banned the use of family history.⁸⁸ Article 12 goes on to specifically restrict the use of predictive tests to health purposes or for scientific research linked to health purposes. Where a genetic test is required to be undertaken, this is a 'disproportionate interference in the rights of the individual to privacy'.⁸⁹ Article 26 permits states to restrict the rights in the Convention provided that those restrictions are 'such as are prescribed by law and are necessary in a democratic society'. However, the Convention does not allow

⁸⁴ UNESCO, *International Declaration on Human Genetic Data*, above n 80, art 7(a).

⁸⁵ Andru Isac, 'Latent Defects in Human Capital: Regulating Genetic Testing and the Insurance Market' (2003) 9 *New Zealand Business Law Quarterly* 315, 320.

⁸⁶ The Council of Europe was founded in 1949 and has 47 member states. It aims to develop common democratic principles throughout Europe, based on its *Convention for the Protection of Human Rights and Fundamental Freedoms* (1950).

⁸⁷ Council of Europe, *Convention for the Protection of Human Rights and the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, Oveido (1997).

⁸⁸ See below 2.3. There is no general consensus as to what 'genetic heritage' means. See Trudo Lemmens, 'Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws' (2000) 45 *McGill Law Journal* 347, 359.

⁸⁹ Council of Europe, *Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (1997), [85].

such restrictions to be placed on Article 11. A number of European countries have ratified the Convention.⁹⁰

2.3 The Legislative Approach – Europe

Legislation has been implemented throughout Europe to limit the use of genetic information by insurers, although the extent of this regulation varies. Norway and Denmark have both moved to implement the requirements of the *Convention on Human Rights and Biomedicine*.⁹¹

In both Norway⁹² and Denmark,⁹³ the laws have similar effects.⁹⁴ Predictive, presymptomatic tests may not be used in underwriting, nor may insurers request that they be carried out. In both countries, the results of diagnostic tests may be used in risk assessment, and in Denmark a diagnostic test may even be requested as part of the assessment process. In contrast, Norway only permits genetic testing in medical contexts for the purposes of diagnosis or treatment. Neither country places an express restriction on the ability to use family medical history, although the Danish provisions could possibly be read as doing so.⁹⁵ Neither country places a restriction on the use of exclusion clauses to eliminate cover for certain diseases.

A similar scheme has been implemented in Austria, where insurers cannot require applicants to undergo a genetic test, nor can they use results of tests already undertaken.⁹⁶ In France,⁹⁷ and the Netherlands, genetic tests cannot be conducted

⁹⁰ As at 1 October 2007, the Convention has been signed by 33 member states and ratified by 21 states (four ratified with reservations).

⁹¹ Council of Europe, above n 87.

⁹² Act on the Medical Use of Biotechnology 1994 (Lov av 5 August 1994 nr 56 om medisinsk bruk av bioteknologi) (Norway). The Act prohibits the use of genetic testing for purpose other than diagnosis or treatment: s 6-2. Presymptomatic tests require the tested person's consent, and authorisation from the Ministry of Health and Social Welfare: s 6-3; s 6-4. Violations are punishable by fine: s 8-5.

⁹³ Insurance Contract Law (Lovbekendtgørelse 1986-10-24 nr. 726 om forsikringsaftaler) (Denmark) s 3a.

⁹⁴ Marcus Radetzki, Marian Radetzki and Niklas Juth, *Genes and Insurance: Ethical, Legal, and Economic Issues* (2003), 31.

⁹⁵ The Act (above n 93) prohibits insurance companies from dealing with genetic information or using any information that can shed light on an individual's genetic predisposition and the genetic risk of developing a disease: Ibid.

⁹⁶ Federal Law of 1994: Regulating Work with Genetically Modified Organisms and the Use of Genetic Testing and Gene Therapy in Humans, art 67 (Austria). See Radetzki, Radetzki and Juth, above n 94, 31.

⁹⁷ Law No 2002-303 Relating to the Rights of Patients and the Quality of the System of Health (1) art 98 (France). See Radetzki, Radetzki and Juth, above n 94, 31.

for purposes other than scientific research or medical purposes, but insurers may use the results of tests already undertaken.⁹⁸

The varying legislative approaches demonstrate the difficulties in defining what genetic discrimination is, and the difficulties in establishing a scheme with certain scope.

2.4 Self-Regulation – the UK and Australia

The UK and Australia are similar to New Zealand in their economic and social policy, and have similarly structured anti-discrimination legislation and insurance industries. Their approaches to this issue are similar in that self-regulation is seen to be the best solution currently, at least until there is more certainty as to how genetic technology will progress.

2.4.1 United Kingdom

The current approach in the United Kingdom is a type of moratorium. In 1997 the Association of British Insurers (ABI) put in place a self-imposed moratorium on requiring applicants to undergo genetic tests. This was originally planned for two years but was extended while the ABI entered discussions with the Department of Health. The result of these discussions was a more formal moratorium which was published in October 2001, to last for five years. The moratorium on requiring applicants to undergo genetic tests remained, but a two tier scheme whereby applicants for insurance below a certain value do not have to disclose the results of any genetic tests undergone previously was also introduced.

In March 2005, the Department of Health and the ABI issued another policy document, which continues the voluntary moratorium until 2011. The Concordat and Moratorium on Genetic Testing and Insurance ‘provides a single high-level policy agreement on the use of genetic test results in insurance underwriting practices’,⁹⁹ and reiterates the terms of the moratorium. The terms of the two tier scheme are:¹⁰⁰

- (i) Applicants will not be required to disclose the results of predictive genetic tests for policies up to:
 - a. £500,000 of life insurance;
 - b. £300,000 for critical illness insurance;

⁹⁸ Radetzki, Radetzki and Juth, above n 94, 100.

⁹⁹ HM Government and Association of British Insurers, *Concordat and Moratorium on Genetics and Insurance* (March 2005), 1.

¹⁰⁰ *Ibid* 4-5.

- c. £30,000 per annum benefits for income protection insurance.
- (ii) When the cumulative value of insurance exceeds these limits, insurers may request the results of predictive genetic tests *approved by the Genetics and Insurance Committee for that particular insurance product.*

Predictive genetic test results may not be used at all in the underwriting of medical, travel or long term care insurance.

The Genetics and Insurance and Insurance Committee (GAIC) is a Ministerial Advisory Body whose primary function is to consider applications by the industry for the use of predictive genetic tests in underwriting.¹⁰¹ Currently, the only test approved is for Huntington's disease, and only with respect to life insurance policies above the financial limit. The GAIC also monitors industry compliance with the ABI Code of Practice, advises Ministers and considers complaints from individuals.¹⁰²

The ABI has indicated that in the future it may lodge applications covering specific genes for hereditary breast and ovarian cancer.¹⁰³ These applications would concern the BRCA1 and BRCA2 genes, but the applications are unlikely to be lodged before 2009.¹⁰⁴

2.4.2 Australia

Australia differs from both New Zealand and the UK in that private health insurance is community rated, therefore genetic testing is only relevant to the provision of life insurance and its associated products.

In respect of life insurance, there is a moratorium in place similar to that in New Zealand. The Investment and Financial Services Association (IFSA) is a national organisation which represents the life insurance industry along with other financial service industries. Their 'Genetic Testing Policy'¹⁰⁵ applies to all member life insurance companies.¹⁰⁶ The three main aspects of the standard are:¹⁰⁷

- (i) Insurers will not initiate any genetic tests on applicants for insurance.

¹⁰¹ Genetics and Insurance Committee, 'Fifth Report', above n 31, 4.

¹⁰² Ibid 5-6.

¹⁰³ Ibid 5. See Paul Rincon, 'Insurers Mull Cancer Gene Tests' (5 May 2007) *BBC News Online* <<http://news.bbc.co.uk/2/hi/health/6634969.stm>> at 25 August 2007.

¹⁰⁴ See GAIC website www.advisorybodies.doh.gov.au/genetics/gaic/.

¹⁰⁵ Investment and Financial Services Association, *Genetic Testing Policy* (IFSA Standard No 11.00, 2005).

¹⁰⁶ Ibid 4. 34 out of the 37 registered life insurers in Australia are members of the IFSA.

¹⁰⁷ Ibid 6.

- (ii) Insurers may request that existing genetic test results be made available for the purposes of underwriting.
- (iii) Insurers will not use genetic tests as the basis of 'preferred risk underwriting'.

When introduced in 2000, the policy was considered to have a possible anti-competitive effect, and so had to be authorised by the Australian Competition and Consumer Commission. The policy was reauthorised for another five years in 2006.¹⁰⁸

Life insurance was recently a major focus of an inquiry into the protection of human genetic information in Australia. This inquiry culminated in the report of the Australian Law Reform Commission and Australian Health Ethics Committee's in the report *Essentially Yours – The Protection of Human Genetic Information*.¹⁰⁹ The report recommended the creation of the Human Genetics Advisory Committee (HGAC), a committee of the National Health and Medical Research Council. The Industry and Commercialisation Working Group of the HGAC is currently reviewing the IFSA's implementation of the recommendations in *Essentially Yours* which were directed at the insurance industry.¹¹⁰

¹⁰⁸ Australian Competition and Consumer Commission, 'ACCC re-authorises life insurance bar on genetic testing' (Press Release, 9 March 2006) accessible at <<http://www.accc.gov.au/content/index.phtml/itemId/726811/fromItemId/621589>>.

¹⁰⁹ *Essentially Yours*, above n 26.

¹¹⁰ See HGAC website, <<http://www.nhmrc.gov.au/about/committees/hgac/index.htm>>, accessed 1 August 2007.

CHAPTER THREE

The Ethics of Using Genetic Information in Insurance

Most restrictive regulation has its basis in ethical concerns about the use of genetic information in underwriting. These ethical concerns involve ideas of privacy, autonomy, fairness and justice. The variations in regulation reflect the complex and contentious of nature the ethical concerns. This chapter contains an analysis of these ethical arguments, concluding that regulation is not necessarily an appropriate response to the issues raised.

3.1 *The Ethical Questions and the Options for Reform*

The two main ethical questions that need to be addressed are:

- (i) Should insurance companies be allowed to require that an applicant undergo genetic testing?
- (ii) Should insurance companies be able to request the results of an applicant's previous genetic tests?

These questions lead to four general options for regulation:¹¹¹

- (i) *No regulation* – The insurer can require that tests be taken and that previous results are disclosed.
- (ii) *Partial regulation* – The insurer cannot require that tests be taken, but can require existing results to be disclosed.
- (iii) *Total regulation* – The insurer has no access to genetic information.
- (iv) *Tiered regulation* – Up to a certain level of insurance, an insurer can neither require disclosure of previous tests nor require that tests be undertaken. Above this level, regulation may vary.¹¹²

¹¹¹ These first three options for regulation are common to many commentators, here the category labels are borrowed from Radetzki, Radetzki and Juth, above n 94, 100.

¹¹² This is the structure of the current moratorium in the UK. See above 2.4.1.

3.2 *The Analysis*

3.2.1 Actuarial Fairness

The basis of the idea of actuarial fairness is that no one should pay more or less in premiums than the risk he or she is perceived to bring to the risk pool. To allow otherwise would mean those at low risk are subsidising those at high risk, who are not paying premiums proportional to the risk they represent. This matters in two ways. Firstly, it is generally accepted that a contract of insurance is part of the private sphere,¹¹³ and therefore it could be argued that to have a third party (the high risk, low premium applicant) pushing up the price of the insurance is unfair.¹¹⁴

Secondly, the consequences of a lack of actuarial fairness can be severe.¹¹⁵ A lack of actuarial fairness means that premiums collected may not cover the cost of payouts and running costs for the company. This is particularly likely if adverse selection occurs.¹¹⁶ This could lead to customers paying higher premiums, and in the extreme situation lead to customers not being paid out in the event of a claim, because their insurance company has collapsed. If adverse selection is severe enough, the loss of an industry as large as the life insurance industry would also bring about negative consequences in terms of the economy, which would in turn affect the welfare of the population at large. Thus the concept of actuarial fairness speaks in favour of no regulation.

3.2.2 Risk of Irrational Discrimination

All underwriting requires discrimination between individuals. *Irrational* discrimination occurs when an applicant is discriminated against in a way which does not reflect the risk they are bringing to the insurance pool. It means that the premium assessment, conditions, or refusal to write any policy is actuarially unfair.¹¹⁷ This is especially likely with genetic information, because of the difficulties of interpretation.¹¹⁸

However, the risk of irrational discrimination does not necessarily support regulation. Regulating access to genetic information may not be the best way to deal with this issue. Improving the underwriting process so that the possibility of underwriters

¹¹³ See below 4.3.

¹¹⁴ Greg Lewis, *Genetic Information in Life Insurance: Legal and Ethical Implications for New Zealand* (Dissertation Thesis, University of Otago, 2001), 71.

¹¹⁵ Richard Ashcroft, 'Should Genetic Information be Disclosed to Insurers? No' (2007) 339 *British Medical Journal* 1197, 1197.

¹¹⁶ See above 1.4.

¹¹⁷ Beatrice Godard et al, 'Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical issues' (2003) 11 *European Journal of Human Genetics* 5123, 5127.

¹¹⁸ See above 1.1.7.

misinterpreting genetic information is reduced is also an option. A response such as this would promote confidence in the industry and possibly encourage participation, which would benefit both consumers and the industry. The use of any type of health information in underwriting will involve the underwriter exercising their own judgment,¹¹⁹ so in this sense genetic information does not create a new problem but merely highlights an existing one, because any exercise of discretion brings with it the risk of irrational discrimination.

3.2.3 Consequences of Regulation

Taking a consequentialist approach,¹²⁰ regulation can have negative consequences in terms of the welfare of insured individuals. This is because they may not receive the benefit of their policy when they need it, due to the insurance company being insolvent. However, failing to regulate may also result in negative consequences for another group of people – those who cannot obtain insurance at a price they can afford due to their genetic makeup.

It seems then, that both no regulation and total regulation result in negative welfare consequences. The severity of these consequences will depend on the unique social and political situation in each country. It therefore follows that partial regulation may be the answer, as it prevents the possibility of being completely uninsured (because an applicant could choose not to have a genetic test), but reduces the chance of adverse selection, because of the inability to obtain extremely high benefits. However, this too has potential adverse consequences. The problem here is deterrence, where a person does not undergo a potentially beneficial genetic test for fear of the effect this will have on their ability to obtain insurance at the level they wish, or the ability of their family to obtain insurance.¹²¹

Deterrence has negative welfare consequences for both the individual and the community. A positive genetic test may mean that someone can undertake preventative measures to decrease the chance of the disease manifesting itself. An example of this would be someone with a positive BRCA1 or BRCA2 test (or both) eliminating smoking and drinking from their lifestyles, because they are also risk factors for eventually developing breast cancer. Potentially, deterrence can be

¹¹⁹ See above 1.2.4.

¹²⁰ Consequentialism for the purposes of this analysis can be defined as the belief that the morality of an action derives solely from its consequences: *Shorter Oxford English Dictionary* (5th ed). The predominant species of consequentialism is utilitarianism. See Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (1789); John Stuart Mill, *Utilitarianism* (1863). Modern proponents of the theory include Peter Singer and Torbjörn Tännsjö.

¹²¹ See below 4.5.

avoided by a tiered regulation scheme, however this too raises issues of consistency within the law.¹²²

Whether these negative consequences justify regulation depends on whether we consider that private insurance of the type we are looking at is vital in terms of a person's basic welfare – whether people rely on it to provide them with basic social goods like food, housing, education and health care.¹²³

3.2.4 Autonomy

The idea of autonomy raises a number of issues, the most often mentioned of which is the proposition that an individual has the right to remain in ignorance of their genetic makeup.

The concept of autonomy has varied meanings, although it is always linked to the ideas of freedom and liberty.¹²⁴ There are two common ideals of autonomy.¹²⁵ The first is John Stuart Mill's conception, that our autonomy is violated when someone actively prevents us from acting according to our own decisions.¹²⁶ This conception cannot be seen as supporting any option for regulation, because the insurance company is simply making an offer to contract; it is up to the applicant whether or not they want to accept the terms.

Another common view is of autonomy as a precondition to self-fulfilment.¹²⁷ The interpretation of autonomy as self-realisation calls for refrain from the active infringement of other people's autonomy, but also active promotion of their autonomy.¹²⁸ This idea is about being able to live life according to one's own important plans and values, making the concept of autonomy according to this conception far more a matter of degree than Mill's conception.¹²⁹ The severity of the limitation on autonomy depends on the circumstances of the choice and the plans and values of the choice-maker. In this context, the severity of the limitation depends on the extent to which an individual needs insurance in order to realise these plans and values. Where the inability to obtain insurance is more of an inconvenience than anything else, the limitation is not severe. If insurance is not necessary in order for

¹²² See below 4.4.

¹²³ Radetzki, Radetzki and Juth, above n 94, 136.

¹²⁴ See Radetzki, Radetzki and Juth, above n 94, 110.

¹²⁵ Ibid 113.

¹²⁶ Ibid 113.

¹²⁷ Ibid 144.

¹²⁸ This ideal of autonomy is common in medical ethics discussion. See John Harris, *Clones, Genes and Immortality: Ethics and the Genetic Revolution* (1998).

¹²⁹ Radetzki, Radetzki and Juth, above n 94, 114.

someone to be able to realise their plans and live according to their values, then the concept of autonomy may not support regulation. However, if insurance is necessary to gain access to basic social goods, restricting access to it will be a serious infringement of an individual's autonomy because they may not be able to realise their important plans and live their life according to their values.

The argument can be raised that total regulation would also limit the autonomy of some people because they would be unable to disclose a test result for the purposes of preferred risk underwriting.¹³⁰ However, this could not be seen as a severe limitation on their ability to live life according to their important plans and values, so is not a compelling case for regulation.

3.2.5 Privacy

It is generally accepted in academic and policy literature that genetic information is not significantly different from other health information.¹³¹ However, the fact that many people consider genetic information to be of a highly intimate and personal nature can be used to argue that it should be protected more than other information. In many jurisdictions privacy laws are justified by the importance of respecting what people feel is personal and private, and because its disclosure will cause distress.¹³² There are two problems with using this as a justification for regulation.

Firstly, using privacy as a justification for protecting genetic information is counter-productive because it only fosters the idea that genes are something mysterious and possibly dangerous to be kept a secret.¹³³ Secondly, there are other ways in which the distress can be avoided without regulation. One solution is to offer more choice as to whether or not someone has to reveal their genetic makeup, by the provision of public health and welfare systems which allow the individual to choose whether they disclose their genetic makeup without losing access to basic goods.¹³⁴

We can protect privacy by offering choice as to whether an individual has to disclose genetic information by providing an adequate public health and welfare systems. If

¹³⁰ Greg Lewis, *Genetic Information in Life Insurance: Legal and Ethical Implications for New Zealand* (Dissertation Thesis, University of Otago, 2001), 72.

¹³¹ See, eg, Richard Ashcroft, 'Should Genetic Information be Disclosed to Insurers? No' (2007) 339 *British Medical Journal* 1197, 1197; Soren Holm, 'Should Genetic Information be Disclosed to Insurers? Yes' (2007) 334 *British Medical Journal* 1196, 1196; Soren Holm, 'There is Nothing Special About Genetic Information' in Alison Thompson and Ruth Chadwick (eds), *Genetic Information: Acquisition, Access and Control* (1999), 99; Radetzki, Radetzki and Juth, above n 94, 118; *Essentially Yours*, above n 26.

¹³² Radetzki, Radetzki and Juth, above n 94, 119.

¹³³ *Ibid.* See below 4.4.

¹³⁴ *Ibid.*

someone does not need insurance for access to basic social goods, then the use of genetic information in insurance is more justifiable. Once again, whether private insurance is necessary for access to these basic social goods is crucial.

3.2.6 Justice

Allowing complete access to genetic information may lead to a situation that is fair in the actuarial sense of the word, but leads to consequences which we regard as socially unfair. Actuarial fairness or justice does matter morally, but it cannot be the only consideration.

A common theory of justice is that of John Rawls.¹³⁵ His theory is often referred to in modern literature, in particular the idea that principles of justice include the idea of equality of opportunity.¹³⁶ What equality of opportunity entails is debateable, but three primary interpretations can be established from the literature.¹³⁷ These major categories of the requirements for equality of opportunity are:¹³⁸

- (i) The elimination of any legal grounds for discrimination.
- (ii) The elimination of both legal and informal discrimination for persons of similar talents and abilities.
- (iii) In addition to the above, efforts should be made to eliminate handicaps in whatever field, following from bad luck in the 'social lottery' for which the individual cannot be made responsible.

New Zealand's intention to eliminate legal and informal discrimination (the first two categories above) is apparent through anti-discrimination and human rights legislation.¹³⁹ The third view is selectively applied in countries like New Zealand, for example in the provision of schooling for all children, but universal application is in no way generally accepted. The suggestion that all inequalities due to a circumstance beyond the person's control should be eliminated would be at odds with New Zealand's general social values.¹⁴⁰

The principle of equality of opportunity seems to speak in favour of regulation, but on a closer analysis, this may not be the case. If we do we accept the third category of

¹³⁵ The concept of justice has debatable meaning, although it is always positively valued. Ibid 121.

¹³⁶ Allen Buchanan et al, *From Chance to Choice - Genetics and Justice* (2000), 65.

¹³⁷ Ibid.

¹³⁸ Ibid. See also Allen Buchanan, 'Equal Opportunity and Genetic Intervention' (1995) 12 *Social Philosophy and Policy* 105.

¹³⁹ See Human Rights Act 1993; New Zealand Bill of Rights Act 1990.

¹⁴⁰ See below 4.3.

equality as persuasive, those who are afflicted with a genetic constitution which may inhibit their ability to obtain insurance should be compensated by those who are more fortunate. However, this does not lead to the conclusion that insurance companies (and therefore other purchasers of insurance) should bear this cost; it merely tells us that there should be some redistribution in favour of those unable to obtain insurance.

Again, these arguments tend to the conclusion that intervention is justified if we consider that private insurance is vital to a person's basic welfare. We need to assess whether the ability to obtain insurance is crucial to equality of opportunity – whether it provides access to basic social goods.

3.3 Conclusion

The ethical arguments do not unanimously support any particular regulatory approach. What they do suggest though, is that if we consider that the ability of insurers to use genetic information affects basic welfare by denying people access to a basic social good, then something should be done to remedy this. If the use of genetic information in insurance does affect basic welfare, regulation still may not be an appropriate response, for a number of reasons. With the ethical analysis as background, chapter four will evaluate what the appropriate response is for New Zealand.

CHAPTER FOUR

Factors Influencing an Approach in New Zealand

The ethical analysis in chapter three will serve as the background to the discussion in this chapter of factors which should influence a decision to regulate (or not) in New Zealand.

The discussion begins with the philosophy of financial regulation, given New Zealand's status as a market economy. The cost of regulation is then assessed, focusing on the extent to which adverse selection is in fact a real phenomenon. The role of private insurance in New Zealand is then analysed, concluding that it would be unreasonable to consider private insurance as a basic social good in New Zealand. This is followed by a discussion of genetic exceptionalism and the artificiality of drawing a distinction between genetic information and other health information. All this leads to the conclusion that regulation is not an appropriate response.

Despite this, the possibility of deterrence is still a strong argument in favour of regulation. However, when bearing in mind that deterrence can occur with other forms of medical tests, it is not strong enough to overcome arguments against regulation.

4.1 The Philosophy of Financial Regulation

New Zealand has a market based economy.¹⁴¹ As such, regulation of markets such as the insurance market is not the norm and generally is directed at avoiding market failure. In the Preliminary Paper for reform of Life Insurance,¹⁴² the Law Commission takes the view that regulation can be justified on one of three grounds:¹⁴³

- (i) *General market regulation* – Aims to ensure that markets work fairly and efficiently.

¹⁴¹ *Te Ara: The Encyclopaedia of New Zealand* (at 2 October 2007) New Zealand in Brief, 'Economy: Distinctive Features', <<http://www.teara.govt.nz/NewZealandInBrief/Economy/1/en>>.

¹⁴² New Zealand Law Commission, 'Preliminary Paper', above n 69, 7.

¹⁴³ New Zealand Law Commission, above n 69, 7. The Commission draws from the report of an inquiry into the Australian financial system: Australian Financial System Inquiry, *Final Report* (1997).

- (ii) *Safety regulation* – Prescribes particular standards or qualities of goods or services where those goods or services carry risk.
- (iii) *To achieve social objectives* – This form of regulation is rarely applied but can include regulation conferring subsidies on some groups of consumers.

Regulation which confers subsidies on some groups was considered by the Inquiry to be the least persuasive argument for regulation, because financial institutions like insurance companies are designed to produce wealth rather than redistribute it, and are therefore not well suited to the latter purpose.¹⁴⁴ If there are social concerns over imposing the real cost of services like insurance on consumers, then direct government funding is the most efficient way to deal with the issue. The Law Commission stated that '[o]bliging financial institutions to subsidise some activities may compromise their efficiency' and that 'it is usually better for the government itself to provide these subsidies to the financial institutions'.¹⁴⁵

What we can draw from this is that the costs and economic effects of regulation should be carefully considered. Regulation of an otherwise efficient market should be avoided where there are other options to achieve the social objective, as regulation is unlikely to be the most efficient option. An assessment of the cost of regulation is therefore required, but the government will usually be the most appropriate mechanism for redistribution of wealth.

4.2 What is the Cost of Regulation? The Reality of Adverse Selection

The main cost of regulation cited by the industry and some commentators is that of adverse selection. Adverse selection occurs when those consumers who know they are a high risk procure insurance at higher levels than they would have otherwise.¹⁴⁶ However, there is debate over the extent to which this theoretical phenomenon occurs in reality.

Some commentators argue that the possibility of adverse selection has been exaggerated by the insurance industry, and that in practice it will have negligible effect on its efficiency.¹⁴⁷ It can be argued that adverse selection is only a problem when it causes markets to break down.¹⁴⁸ Theoretically break-down of the market

¹⁴⁴ Australian Financial System Inquiry, above n 143, 196.

¹⁴⁵ New Zealand Law Commission, above n 69, 11.

¹⁴⁶ See above 1.4.

¹⁴⁷ See, eg, Guy Thomas, 'Genetics and Insurance: An Actuarial Perspective with a Difference' (2001) <<http://www.guythomas.co.uk>>, at 25 August 2007 .

¹⁴⁸ Ibid 5.

requires a series of events,¹⁴⁹ and there is little evidence of this series of events ever happening.¹⁵⁰ There are a number of factors which will affect the degree to which adverse selection occurs:¹⁵¹

- (i) The extent to which people who are at higher risk in fact procure insurance at higher levels;
- (ii) How many diseases can be predicted by genetic testing, how common these diseases are, and the effect they have on insurance pay-outs;
- (iii) The extent to which the supposed subsidisation of the high risks results in the lower risks taking their business elsewhere. This also depends on a number of factors:
 - a. The size of the premium rise (depends on the above factors);
 - b. Ability to obtain insurance at lower premiums (depends on competition in the market and access to international markets);
 - c. The cover provided by the public health and welfare systems.
- (iv) The form of insurance.¹⁵²

The only good example where adverse selection is a real problem in terms of (i), is with regard to age. Problems with private health insurance in Australia (where health insurance is community rated) as the only significant example of the negative effects of adverse selection.¹⁵³ There is evidence that positive HIV status has led to adverse selection. However comparing HIV to a genetic test for a mutation with much less than 100 per cent penetrance is not compelling. A number of papers have been published regarding the effect of a positive BRCA1 or BRCA2 test on insurance purchasing behaviour, and most show only weak support for significant adverse selection.¹⁵⁴ A recent example studying the effect of both BRCA tests on term life

¹⁴⁹ See above 1.4.

¹⁵⁰ Thomas, above n 147, 5.

¹⁵¹ Radetzki, Radetzki and Juth, above n 94, 105.

¹⁵² This is related to (ii), in that adverse selection may be more of a problem in life insurance where final pay out is determined by the purchaser of the insurance, so the ability to obtain insurance with high benefits is greater. This risk may be even greater for disability income insurance because the risk of early disablement is higher than the risk of early death. Health insurance, on the other hand, operates on an indemnity basis so the potential to procure extremely high benefits is less: Thomas, above n 147, 6.

¹⁵³ Ibid 7.

¹⁵⁴ See, eg, Eng Hock Gui et al, 'The Genetics of Breast and Ovarian Cancer III: A new model of family history with insurance applications' (2006) *Scandinavian Actuarial Journal* 338; Angus MacDonald, Howard Waters and Chessman Wekwete, 'The Genetics of Breast and Ovarian Cancer II: A Model of

insurance purchasing, concludes that adverse selection could be 'a manageable problem for insurers' in terms of BRCA testing,¹⁵⁵ if family history and other medical information is used in the underwriting process. The paper also noted that the small projected increase in claim costs (16 per cent over 20 years) would be offset by lower mortality rates due to advances in prevention, detection and treatment.¹⁵⁶

The international market may amplify the effect of adverse selection if consumers are able to obtain insurance from overseas companies not subject to restrictions on the use of genetic information.¹⁵⁷ Low risks who might otherwise have bought insurance, despite the fact that they are subsidising higher risks, may exit from the domestic insurance market to purchase insurance at a price more reflective of the risk they represent. This will further increase the proportion of high risks in the pool.

The arguments made by the insurance companies about adverse selection seem to ignore the fact that many people ordinarily pay premiums not commensurate with the risk they bring to the risk pool. This is because it is inefficient and sometimes impossible to accurately assess risk, so applicants are grouped into broad 'bands' for the purposes of premium setting.¹⁵⁸

Despite the claims of the industry, adverse selection may not materialise to the extent theory predicts. If the costs of regulation are likely to be lower than has been claimed, this indicates that perhaps we should more readily impose regulation. However, taking into account that other factors do not speak clearly in favour of regulation, a cautious approach should be adopted.

4.3 The Role of Private Insurance in New Zealand

The persuasiveness of the ethical arguments in favour of regulation depend largely on whether private insurance is considered to be a basic social good.¹⁵⁹ Whether this is so will depend on the unique social and political context of each country. New

Critical Illness Insurance' (2003) *Scandinavian Actuarial Journal* 28; Krupa Subramanian et al, 'Estimating Adverse Selection Costs from Genetic Testing for Breast and Ovarian Cancer: The Case of Life Insurance' (1999) 66 *Journal of Risk and Insurance* 531; Krupa Viswanathan et al, 'Adverse Selection in Term Life Insurance Purchasing Due to the BRCA1/2 Genetic Test and Elastic Demand' (2007) 74 *Journal of Risk and Insurance* 65; Cathleen Zick et al, 'Genetic Testing, Adverse Selection, and the Demand for Life Insurance' (2000) 93(1) *American Journal of Medical Genetics* 29.

¹⁵⁵ Krupa Viswanathan et al, 'Adverse Selection in Term Life Insurance Purchasing Due to the BRCA1/2 Genetic Test and Elastic Demand' (2007) 74 *Journal of Risk and Insurance* 65.

¹⁵⁶ Ibid 83.

¹⁵⁷ Radetzki, Radetzki and Juth, above n 94, 105.

¹⁵⁸ Most insurance applications are accepted at standard rates: Investment Savings and Insurance Association, 'Underwriting Guide', above n 37, 9. See above 1.2.4.

¹⁵⁹ See chapter three.

Zealand has excellent public health and welfare system by world standards. This raises the argument that private, mutually rated insurance is a luxury beyond the requirements of basic welfare.

Each type of insurance will require a different analysis as to its role in New Zealand society, because each has a different function.¹⁶⁰ This view is in line with that of Walzer, who see goods as social in nature. This means that distribution of them must be distinct, based on their social meaning.¹⁶¹ On this theory, different 'spheres' of society call for different distributive criteria. The two spheres that Walzer discusses which are relevant to the context of genetics and insurance are the sphere of money and commodities and the sphere of security and welfare. Goods in the sphere of money and commodities should be distributed according to market principles because, people choose to spend money in different ways (depending on personal preferences, ideals, and character traits). This does not mean there should be no regulation in this sphere, because the market is based on contractual liberty. Exchanges of goods in which desperation is a factor should be banned, because there is no liberty without choice.¹⁶²

The other distinct relevant sphere is the sphere of security and welfare. Goods in this sphere are regarded as essential and should therefore be distributed on the basis of need. All members of society should have access to them, not only because they are essential, but because they are also given as recognition of membership of society.¹⁶³ The theory is similar to that of Rawls, in that basic social goods should be available to everyone and distributed on the basis of need.¹⁶⁴ The question to be answered is whether people rely on insurance to provide them with these basic social goods – health care, education, food and housing.¹⁶⁵

It has been estimated that just over 50 per cent of New Zealanders have cover on their life or health, although the figure may be substantially lower.¹⁶⁶ Research

¹⁶⁰ Norman Daniels calls this the 'multifunction thesis' and compares it to the 'uniform view' that 'insurance is insurance' and should be uniformly subject to laws. See Norman Daniels, 'The Functions of Insurance and the Fairness of Genetic Underwriting' in Mark Rothstein (ed), *Genetics and Insurance: Medical Underwriting and Social Policy* (2004) .

¹⁶¹ Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (1983). See also Trudo Lemmens, 'Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws' (2000) 45 *McGill Law Journal* 347, 385; Radetzki, Radetzki and Juth, above n 94, 134.

¹⁶² This is why we have minimum wage and health and safety laws: Ibid.

¹⁶³ Ibid 387.

¹⁶⁴ See above 3.2.6.

¹⁶⁵ Radetzki, Radetzki and Juth, above n 94, 105.

¹⁶⁶ Ministry of Economic Development, *Review of Financial Products and Providers: Insurance* (2006), 13. This includes Total and Permanent Disablement Insurance and Dread Disease Insurance. There is a

suggests that New Zealanders have an expectation that ACC, benefits, work, friends and credit facilities will enable them to 'get by' in the event of a financially catastrophic occurrence..¹⁶⁷

4.3.1 Life Insurance and Related products

According to Daniels, life insurance serves two purposes: income support and the chance to preserve an estate.¹⁶⁸ Disability income insurance also provides income support.¹⁶⁹ The chance to preserve an estate is certainly not essential in our society, however income support could be so regarded. ACC and the public welfare system provide a 'safety net' for those who find themselves in the situation where the primary income earner in the family dies or is unable to work.¹⁷⁰ Private insurance can provide benefits in this situation far in excess of those that the state will provide, which has a number of benefits for the individual and society. These benefits include social stability, reduction in the financial burden on the state, the encouragement of entrepreneurship, and more efficient allocation of capital.¹⁷¹ However, these social and economic benefits do not necessarily elevate life insurance to the status of an essential good.

In the UK, the driving force behind the extensive moratorium is that life insurance is compulsory for a home loan. The ability to obtain finance for purchasing a house could be seen as an essential good, because home ownership is such an important part of participation in the community. However, most lenders in New Zealand do not require life insurance,¹⁷² meaning that this consequential justification for restricting access to genetic information is not applicable.

4.3.2 Health insurance

The debate over the use of genetic information in health insurance tends to be dominated by arguments out of the United States, where there is no public health

strong correlation between people who own one policy and those who own a number of policies, so the total number of people may be substantially less than 50 per cent.

¹⁶⁷ Ibid. See also Blackwood King Adpartners, *AIA Life Matters Survey*, commissioned by American International Assurance New Zealand (2005).

¹⁶⁸ Daniels, above n 160, 133. This analysis will also largely apply to Total and Permanent Disablement Insurance and Dread Disease Insurance, because they are both similar to life insurance in that a claim results in a large lump sum payment, and underwriting considerations are largely the same.

¹⁶⁹ Ibid.

¹⁷⁰ A number of benefits may be applicable, including the widow's benefit and the Domestic Purposes benefit, as well as increased family assistance. ACC and sickness benefits and invalids benefit are of assistance someone is no longer able to work.

¹⁷¹ Ministry of Economic Development, above n 166, 13.

¹⁷² Email from Shane Crawford to Katharine Reynolds, 4 October 2007. Shane Crawford is the Mortgage Manager for Mike Pero Mortgages in Central Otago.

care system. Most states have moved to completely restrict the use of genetic information by health insurance companies on this basis. Currently, 1.4 million New Zealanders have private health insurance,¹⁷³ with this cover being viewed as complementary and supplementary to the public health system.¹⁷⁴

In summary, although there are arguments on both sides, it is a difficult argument to make that private insurance provides access to basic social goods. There are economic and social benefits from everyone having access to private insurance, but it would be a large leap to claim that there is a social obligation to ensure access to private insurer. This is supported by the low proportion of the population who currently have private insurance. ACC, the public health system, and welfare provide a certain level of health care and income support. If this is not considered sufficient to provide people with access to basic goods then it is more appropriate that the government increase these services, as a more appropriate redistributive mechanism.

4.4 Genetic Exceptionalism

The fact that the costs of regulation are most likely lower than those in the industry claim them to be is an argument weighing in favour of regulation despite the lack of an obvious social obligation. However, a crucial objection to regulation is that differentiating between genetic information and other forms of health information is arbitrary. Restricting the use of genetic information while allowing other health information to be used in underwriting requires that we regard genetic information as fundamentally different from this other health information in the context of insurance. A number of arguments can be raised which support the conclusion that genetic information is fundamentally different, and that therefore 'genetic exceptionalism' is justified:

- (i) The predictive nature of genetic information;
- (ii) The familial nature of genetic information – it is transmitted to offspring and can reveal information about other family members;
- (iii) Genetic information is especially personal and intimate.

¹⁷³ Health Funds Association of New Zealand, *Health Insurance Statistics June 2007* (2007).

¹⁷⁴ Ministry of Economic Development, above n 166, 14.

It is generally considered that none of these properties justifies treating genetic information as different from other health information, even in combination.¹⁷⁵

The predictive nature of genetic information is not unique. Many types of health information are predictive in nature. HIV status, smoking status, cholesterol levels and liver function tests are all predictive of future disease to a certain extent. In addition to this, a lot of genetic information is not predictive.¹⁷⁶

The familial nature is likewise not specific to genetic information. Genetic constitution is not the only thing a parent passes on to their child. Social position and education levels may be 'passed on' when you consider that people have a higher probability of occupying the same social class and having similar levels of education to their parents.¹⁷⁷ There are also other types of health information which are informative about family members, for example sexually transmitted diseases.¹⁷⁸

The suggestion that genetic information is especially personal and intimate has its basis in ideas of genetic essentialism. Genetic essentialism is a view of human beings as essentially consisting of their genes.¹⁷⁹ Another formulation of the idea is genetic determinism, which is the belief that human health and behaviour are pre-determined by our genetic makeup.¹⁸⁰ If these premises are true, there would be no denying that genetic information is special.¹⁸¹ However, we know that for most people, their life is not controlled by their genes. Genes do play a part in our lives, but the effect of our physical and social environment is much larger.¹⁸² In addition to this, there are other aspects of our lives which are regarded as especially personal and intimate but which are not afforded special protection. An example of this is mental health problems.

Even in combination, these factors do not appear to weigh in favour of genetic information being treated as different from other types of health information. HIV status, for example, shares all of these characteristics. It is predictive, has familial consequences, and is considered personal and private.¹⁸³

¹⁷⁵ Radetzki, Radetzki and Juth, above n 94, 118. See also Holm, 'Should genetic information be disclosed to insurers? Yes', above n 131; Ashcroft, above n 131.

¹⁷⁶ Holm, 'There is Nothing Special About Genetic Information', above n 131.

¹⁷⁷ Ibid 100. See also Radetzki, Radetzki and Juth, above n 94, 118.

¹⁷⁸ Radetzki, Radetzki and Juth, above n 94, 118.

¹⁷⁹ *Essentially Yours*, above n 26, 142

¹⁸⁰ Ibid 143.

¹⁸¹ Holm, 'There is Nothing Special About Genetic Information', above n 131, 98.

¹⁸² Ibid 99.

¹⁸³ Radetzki, Radetzki and Juth, above n 94, 118.

If we accept that the distinction between genetic information and other health information cannot be drawn, this means that any regulation must be of *all* health information. Section 48 of the HRA recognises that differentiating people on the basis of their health is acceptable in private, voluntary insurance. If genetic information is not significantly different from other health information, then regulating its use would be drawing an arbitrary distinction, creating inconsistency in the law.

4.5 Deterrence

The effect of deterrence¹⁸⁴ on both individual and public health outcomes is a strong argument in favour of regulation, notwithstanding the arguments in favour of no regulation. As with the phenomenon of adverse selection, it can be debated how real the problem of deterrence really is. The severity of the problem is obviously likely to be dependent on the generosity of the public health and welfare systems.¹⁸⁵ If people feel that the state could not adequately provide for them and their family should something happen to them, then they are more likely to consider the impact of having a genetic test on their ability to obtain insurance.¹⁸⁶ This is not to say that generous public health and welfare systems will completely eliminate deterrence. In Sweden, which has a very generous social insurance system, genetic counsellors have made reports of genetic testing being halted due to concerns about insurance.¹⁸⁷

Submissions to the Australian Law Commission for *Essentially Yours*¹⁸⁸ also emphasise that deterrence is a real problem.¹⁸⁹ Health professionals submitted that some people hesitate to even seek advice with regard to genetic conditions for fear of difficulty with insurance in the future.¹⁹⁰ The Human Genetics Society of Australia submitted that declining a genetic test because of the potential for future insurance issues was relatively common. The Society went on to comment that the people who refuse the test are only those who get to a clinical geneticist or counsellor in the first place. The number of people who never even get to this point because of the same concerns is unknown.¹⁹¹ In contrast, the IFSA expressed the view that most people would have any test recommended by their doctor and that their research indicated no evidence of deterrence of this nature.

¹⁸⁴ See above 3.2.3.

¹⁸⁵ See Radetzki, Radetzki and Juth, above n 94, 107.

¹⁸⁶ See below 4.5.

¹⁸⁷ See also Radetzki, Radetzki and Juth, above n 94, 108.

¹⁸⁸ See above 2.4.2.

¹⁸⁹ *Essentially Yours*, above n 26, 676. See chapter three.

¹⁹⁰ *Ibid* 677.

¹⁹¹ *Ibid*.

Although the evidence regarding deterrence is varying, it should be given significant weight as an argument because the potential individual and public health effects are great. It is in the interests of insurance companies to avoid deterrence. The individual health benefits of knowing any genetic predispositions to disease will reduce mortality rates because preventative measures can be undertaken.¹⁹² However, deterrence is also a factor in other non-genetic tests such as those for cholesterol. When this is taken into account, the effects of deterrence cannot justify drawing an arbitrary distinction between genetic information and other health information.

4.6 Conclusion

Regulating a financial market such as that of insurance should be carefully balanced against the costs of regulation. Adverse selection may not be the threat to the industry it has been made out to be by insurers, but New Zealand provides a certain level of access to basic social goods through the public health and welfare systems. If this level of support is not sufficient to provide everyone with access to basic goods, increasing its funding is a more appropriate way to remedy the situation than regulating the use of genetic information in underwriting. In addition, regulation cannot be justified if we allow other medical information to be used in underwriting. The exception in s 48 of the Human Rights Act confirms that this is acceptable practice in private, mutually rated insurance.

¹⁹² Dr Margaret Otlowski, 'Implications of Genetic Testing for Australian Insurance Law and Practice' (Occasional Paper No 1, Centre for Law and Genetics, 2001), 44.

CHAPTER FIVE

Minimising the Problems Raised by the Use of Genetic Information in Underwriting

If the use of genetic information in underwriting is permitted, two issues need to be addressed: the risk of irrational discrimination and the risk of deterrence. Both of these risks can be minimised by improving transparency in the underwriting process, which would encourage public confidence in the industry. Independent oversight of genetic information in insurance would help to prevent irrational discrimination in the first instance by assisting underwriters in risk classification, and would go further in promoting public confidence. These approaches should be combined with public and industry education which fosters an attitude towards genetic testing as a positive way to improve our health. Combining this education with the practical approaches to reducing irrational discrimination will help to reduce the possibility of deterrence.

The best way for these changes to be implemented is through industry policy and agreement with government, a more practical option than legislation, and more in line with the current approach to regulation both in New Zealand and overseas.

5.1 *The Issues to be Addressed*

5.1.1 Irrational Discrimination

An Australian study published this year which analyses data collected between 1999 and 2003 showed that most underwriting decisions where there was disclosure of a positive genetic test were reasonable.¹⁹³ The study analysed 234 insurance applications in which genetic test results were disclosed. Although most of the underwriting decisions were thought reasonable, several cases involving hereditary breast and ovarian cancer tests were considered to require 'further investigation'.¹⁹⁴

¹⁹³ Otlowski et al, 'Industry Study', above n 29, 367. This may show an improvement in industry practices following a study in 2001 which found that there were issues of genetic discrimination in the Australian life insurance industry, Kristine Barlow-Stewart and David Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250. Health insurance in Australia is community rated so this was not a subject of the study.

¹⁹⁴ There were a total of 15 adult onset conditions for which genetic test results has been disclosed, but only five for which a positive genetic test was the only underwriting consideration with regards to that particular condition. Otlowski et al, 'Industry Study', above n 29, 377.

This is unsurprising given that the BRCA1 and BRCA2 tests were the only tests disclosed for complex multifactorial diseases. One particular case involved a blanket exclusion of any type of cancer, following a positive BRCA1/BRCA2 test. The decision was questioned by clinical geneticists consulted by the author, who considered that the positive test only justified excluding breast, prostatic and colorectal cancer.¹⁹⁵ The numbers in the study were small and there were limitations on the data collected, due to possible underreporting by insurance companies, so it can be assumed that there were still more cases which were not reported.

Although there have not yet been any complaints to the Human Rights Commission regarding genetic discrimination,¹⁹⁶ this does not mean such discrimination has not occurred in New Zealand, and certainly does not mean that preventative measures need not be taken. As the use of predictive tests for multifactorial disorders increases, the frequency of misguided underwriting decisions will also likely increase.¹⁹⁷ The issue should be addressed sooner rather than later, especially considering advances in genetics in the last year.¹⁹⁸

5.1.2 Deterrence

Deterrence from taking a genetic test for fear of not being able to obtain insurance has adverse welfare consequences for both individual and the community at large.¹⁹⁹ However, very few genetic tests can be considered 100 per cent accurate in predicting whether a disease will present itself clinically, so most cannot reasonably be used to justify an offer of insurance on terms which are not affordable to the applicant.²⁰⁰ Encouraging a public perception of genetic testing as helping to inform decisions about our health could reduce the chance of deterrence, especially when combined with public confidence that genetic test information will not be used in a manner any different from other health information.

¹⁹⁵ Ibid 386.

¹⁹⁶ Email from Robert Hallowell, above n 68.

¹⁹⁷ See 'Do Not Ask or Do Not Answer', above n 32, 77; 'Serious Disease Genes Revealed', above n 32. 'Serious Disease Genes Revealed' BBC News Online (<<http://www.bbc.co.uk>>, 6 June 2007)

¹⁹⁸ See above 1.1.7.

¹⁹⁹ See above chapter three.

²⁰⁰ See above 1.1.7. Huntington's disease is the only disease for which a genetic test is considered 100 per cent predictive of eventual onset.

5.2 *Should Genetic Status be Expressly Included as a Prohibited Ground of Discrimination in the Human Rights Act?*

Genetic status is not expressly included as a prohibited ground of discrimination in the HRA, so there is an argument that none of the restrictions in s 48 apply.²⁰¹ It is likely that genetic status would fit within the definition of disability,²⁰² but the issue as to whether it should be expressly included needs to be addressed, so that there would be no doubt that discrimination on the basis of genetic status is subject to the controls in ss 44 and 48.

In jurisdictions where genetic discrimination in insurance is prohibited, there have been difficulties of definition and scope and there is no one universal approach.²⁰³ Whether the HRA should be amended to include genetic discrimination as an express prohibited ground is a wide ranging policy issue beyond the scope of this paper.²⁰⁴ The recommendations contained in this chapter proceed on the basis that there will be no amendment to the HRA.

5.3 *Legislation or self-regulation?*

Legislative regulation of the insurance industry is light-handed in New Zealand. This has resulted in a strong self-regulatory attitude within the industry, and has led to a generally stable and well managed market.²⁰⁵ There are currently proposals for reform of the regulatory framework for the insurance market, as part of a general review of non-bank financial products and providers, but these proposals do not involve any supervision of or controls on the underwriting process.²⁰⁶ Although self-

²⁰¹ See above 1.2.5.

²⁰² See above 1.2.5 **Error! Reference source not found..**

²⁰³ See above 2.1

²⁰⁴ Human Rights Commission, 'Discussion Paper', above n 52, 14. This is because it would apply to all areas of life covered by the HRA.

²⁰⁵ Ministry of Economic Development, above n 166, 13. This approach to regulation is common to the UK and Australia, see Chapter Two. See also New Zealand Law Commission, 'Life Insurance Report', above n 71; New Zealand Law Commission, 'Preliminary Paper', above n 69.

²⁰⁶ Hon Pete Hodgson, 'Non-Bank Finance Sector Review' (Press Release, 13 May 2005). See also Ministry of Economic Development, above n 205; New Zealand Law Commission, 'Life Insurance Report', above n 71; New Zealand Law Commission, 'Preliminary Paper', above n 69.

regulation has drawbacks,²⁰⁷ regulation of the underwriting process by legislation would be a drawn out process and would be out of line with the approach in Australia and the UK.²⁰⁸ An agreement between the government and the industry, similar to the Concordat and Moratorium on Genetic Testing²⁰⁹ in the UK, would create publicity which would provide the industry with a strong commercial incentive not to flout its own rules. In Australia, the IFSA has entered into a memorandum of understanding with stakeholders in the mental health sector regarding underwriting where there is a history of mental health problems.²¹⁰ An agreement of this nature is also an option, but an agreement with the government would likely create more publicity and promote awareness of the issues surrounding genetics and insurance.

The solutions outlined in this chapter should be the subject of a formal concordat on genetic testing and insurance between the government, the ISI, and the HFANZ. The concordat should be implemented through the policies and standards of the ISI and HFANZ. The appearance of cooperation and agreement between the insurance industry and the government would encourage public confidence in the industry, and promote awareness of how genetic information is relevant to insurance.

5.4 The Solutions

5.4.1 An Independent Regulatory Body

The possibility of the creation of an independent regulatory body in New Zealand was mentioned in the Discussion Paper for the Review of the Insurance Guidelines,²¹¹ and was also mentioned in the Law Commission's recent report on life insurance.²¹²

²⁰⁷ These drawbacks can be summarised as: (i) A lack of legal effect of codes of practice and guidelines; (ii) A lack of accountability of industry bodies; (iii) A lack of mechanism to monitor for and deal with breaches of policy; (iv) A lack of public awareness of industry policy: David Clarke, 'The Use of Industry Codes of Practice - are Consumers Getting a "Fair Go"' (1996) 26 *Victoria University of Wellington Law Review* 717. See also Usher, above n 36, 15-16. These drawbacks can be limited by commercial pressure to 'play by the rules' as failing to do so would create bad publicity and discourage consumer participation.

²⁰⁸ In Australia, recommendations for controls on the underwriting process were seen by the government as best implemented through industry policy: Australian Government, *Government Response to Recommendations in Essentially Yours: The Protection of Human Genetic Information in Australia* (2005), 27-31. Keeping policy in line with that in Australia is a consideration because of the high level of Australian involvement in the New Zealand industry: Ministry of Economic Development, above n 166, 17.

²⁰⁹ HM Government and Association of British Insurers, above n 99.

²¹⁰ Investment and Financial Services Association, *Memorandum of Understanding between Mental Health Sector Stakeholders (MHSS) and Investment and Financial Services Association* (2004).

²¹¹ Human Rights Commission, 'Discussion Paper', above n 52, 14.

²¹² New Zealand Law Commission, 'Life Insurance Report', above n 71, A25-28.

In the UK, the GAIC is a ‘non-statutory advisory non-departmental public body’,²¹³ with terms of reference to establish criteria for the evaluation of specific genetic tests and evaluate tests against these criteria. In addition to this, the GAIC reports to various ministers about its activities and industry compliance with its recommendations, and also functions as a consumer complaints avenue of last resort.

The idea of an independent regulatory body is appealing because it can be proactive in protecting consumers, rather than placing the onus on them to make a complaint. Such a body would encourage public confidence that genetic information is being used only when the law allows it,²¹⁴ and would help to heighten public awareness about how genetic tests are really used by the insurance industry. Industry opinion is that the decision to establish such a body should not be made until technology advances further.²¹⁵ However, taking into account the rapid advances in genetic research in the last year,²¹⁶ postponement will only go further to increasing confusion and the risk of irrational discrimination.

The size of the insurance industry in New Zealand may not justify the cost of creating such a body in New Zealand. However, the relatively slow rate at which new genetic tests are introduced would mean that running costs would remain low. Initial funding for the Human Genetics Advisory Committee in Australia was A\$7.6 million over four years, for an ‘independent expert advisory body on human genetics’. The set-up costs for a genetics and insurance advisory committee in New Zealand would be significantly lower because of its narrow focus. The public health benefits in preventing deterrence and increasing public confidence in the industry also need to be taken into account.

The committee should be composed of members representing a wide range of stakeholders. Consultation with the insurance industry and the public in major decision making would be essential in order to promote the idea that the use of genetic information in insurance should be open and transparent.

A body such as this brings with it a significant possibility of delay, therefore the industry should still be allowed to use the results of genetic tests within the bounds of s 48 before they are assessed by the committee.²¹⁷ Given that the use of genetic

²¹³ Genetics and Insurance Committee, ‘Fifth Report’, above n 101, Annex B.

²¹⁴ *Essentially Yours*, above n 26, 707.

²¹⁵ Human Rights Commission, ‘Discussion Paper’, above n 52, 15.

²¹⁶ See above 1.1.7.

²¹⁷ This was recommended in *Essentially Yours*, above n 26, 711.

information in underwriting seems mostly reasonable at present,²¹⁸ a ban on using genetic tests until approval (as is the case in the UK) would be a disproportionate restriction on applicant disclosure requirements in light of the fact that other medical information will still be allowed to be taken into consideration.

The body would take the form of a non-statutory committee affiliated with the Ministry of Health or the Human Rights Commission – a ‘genetics and insurance advisory committee’. The primary role of the genetics and insurance advisory committee would be to:

- (i) Create criteria to assess the suitability of particular genetic tests for use in underwriting.
- (ii) Evaluate tests using the procedures above and make recommendations to the ISI and HFANZ as to their use in underwriting.
- (iii) Monitor the use of genetic tests by the insurance industry in order that tests can be assessed as soon as possible after their entry into the market.

5.4.1.1 *Creating Criteria for Assessment*

These criteria would guide any decision as to whether a particular genetic test is appropriate for use in underwriting. Consultation with the insurance industry and the public will be necessary when formulating these criteria. The criteria used by the GAIC would be a useful starting point:²¹⁹

- (i) *Technical relevance* – Addresses whether the test is an accurate measure of the genetic information. This will be affected by whether the same mutation is found in all individuals with the disease, or whether many different mutations are implicated.
- (ii) *Clinical relevance* – Addresses whether a positive test result is likely to have future adverse health implications for an individual. Factors such as age of onset, penetrance and expressivity will be relevant to this assessment.²²⁰

²¹⁸ See above 5.1.1.

²¹⁹ Genetics and Insurance Committee, above n 31, Annex C. Detail as to each criteria are contained in Genetics and Insurance Committee, *Second Report from January 2002 to December 2002* (2003), Annex D. This approach is similar to the one recommended in *Essentially Yours*, where the Inquiry recommended that the proposed Australian Human Genetics Advisory Committee establish procedures to assess and make recommendations on particular genetic tests to be used in underwriting based on scientific reliability, actuarial relevance and reasonableness (above n 26, 711).

²²⁰ See above 1.1.4.

- (iii) *Actuarial relevance* – Addresses whether a positive test result justifies an increase in premiums. This will involve in-depth actuarial analysis, and will depend on the type of insurance product.²²¹ It will also take into account treatment and prevention options that might affect the risk of a claim.

5.4.1.2 Assessing Specific Tests

The criteria decided on should be used to assess the suitability of a particular test for a particular insurance product. Any recommendations made by the committee should include a description of other factors which should be taken into account when considering a positive result for a given test. In particular, preventative measures taken by the applicant should be considered, where these are actuarially significant.²²²

5.4.2 Clarification of the HRA exception

An underwriting decision which discriminates on the basis of a disability is permitted provided that it is supported by ‘reasonable statistical data’, or ‘reasonable professional opinion’.²²³ There is an additional requirement that the decision is ‘reasonable having regard to the applicability of the data or advice or opinion, and of any other relevant factors, to the particular circumstances’.²²⁴ What is ‘reasonable’ was addressed by the Federal Court of Australia in the recent case *QBE Travel Insurance v Bassanelli*.²²⁵ The case involved an application for travel insurance by Ms Bassanelli, who had breast cancer. She was not seeking cover for costs related to the cancer, but was nonetheless refused cover on the grounds that it was often difficult to distinguish between breast cancer related problems and other conditions suffered while travelling. This decision was found to be unreasonable in the Federal Court. The Court made it clear that reasonableness is an objective test – an insurer cannot simply assert that data is reasonable in order to justify a decision. In addition, the phrase ‘any other relevant factors’²²⁶ was held to require that ‘the particular

²²¹ This is because predisposition to a given disease may increase the risk of a claim for one type of insurance product but not another. Eg, a positive test for both BRCA1 and BRCA2 (which indicates a higher probability of breast/ovarian cancer) may increase the chance of a claim for income protection cover, but may not increase the chance of a claim for life insurance to the same extent. This is because treatment and prevention measures may reduce the mortality rate, but not reduce the rate of incidence of breast and ovarian cancer to the same extent (therefore the chance of not being able to work for a period remains high).

²²² See below 5.4.2.

²²³ Human Rights Act s 48(1)(a).

²²⁴ Ibid s 48(1)(b).

²²⁵ *QBE Travel Insurance v Bassanelli* [2004] FCA 396 (Australia) (*Bassanelli*).

²²⁶ Disability Discrimination Act 1992 (Cth) (Australia) s 46

circumstances of an individual who is discriminated against be addressed but not in a formulaic way'.²²⁷

It is likely that *Bassanelli* would be applied in New Zealand, because of the similarities between the Disability Discrimination Act 1992 (Cth) in Australia and the Human Rights Act. If this is the case, it would mean that insurers would not be able to 'pick and choose'²²⁸ what material they consider to be 'any other relevant factors'.²²⁹ Insurers would have to take into account the benefits of early detection and preventative measures in risk classification. Merely relying on underwriting guidelines which indicate an increased risk of claim would not be sufficient if those statistics do not take into account advances in preventative therapy and other individual circumstances. In light of *Bassanelli*, the new Human Rights Commission Draft Insurance Guidelines state:

In deciding whether treatment is reasonable, the information or data relied on should be relevant to the individual applicant. Insurers should be prepared to explain the basis for their decision.²³⁰

The commentary to the Draft Guidelines recognises that there may not be direct data in all cases, but that insurers should be prepared to explain why they have arrived at certain decisions and acknowledge the limitations of data they do use.²³¹

Bassanelli and subsequent change in the Draft Insurance Guidelines is a step in the right direction towards ensuring that underwriting decisions are fair and reasonable. Providing reasons to the extent required by a *Bassanelli* approach could be met with hesitation by the industry because it would increase costs. However, this approach would help to instil public confidence in the industry and make it easier for consumers to make complaints. Recognition of this approach would be crucial to any concordat because it emphasises the need for underwriting decisions to be transparent and fair to consumers, by taking into account all the relevant information and letting the consumer know the reasons for their decision.

The current ISI policy on genetic testing is part of the ISI Underwriting Guide, not part of the Manual of Practice Standards. Compliance with the Manual of Practice Standards is mandatory, while the Underwriting Guide is just that – a guide. The ISI is in the process of reviewing its practice standards to ensure they are relevant, and

²²⁷ *Bassanelli* [2004] FCA 396, 405 (Mansfield J).

²²⁸ Otlowski et al, 'Industry Study', above n 29, 373.

²²⁹ See also *Xiros v Fortis Life Assurance Ltd* [2001] FMCA 15 (Australia).

²³⁰ Human Rights Commission, 'Draft Guidelines', above n 54, 4.1.

²³¹ *Ibid* 4.1 (commentary).

aligned where possible with the Australian Standards.²³² Any concordat should ensure that a genetic testing policy is included in the revised standards, as is the case in Australia. The HFANZ also has a Code of Practice but their policy on genetic testing is not included in it, so this should be changed along the same lines.

5.4.3 Increasing Disclosure Requirements

Currently there is no requirement that an insurer disclose the reasons for a non-standard underwriting decision.²³³ Changing this would be the first step in establishing an open relationship between insurers and applicants, despite the costs it may impose on insurance companies. In Australia, insurance companies are required to provide applicants with written reasons for an adverse underwriting decision on request.²³⁴ A similar requirement in New Zealand, as per the approach in *Bassanelli*, would open up the relationship between the insurance company and the applicant, and encourage transparency in the underwriting process. This would enhance public confidence that decisions were being made only as permitted by the Human Rights Act.

5.4.4 Review of Decisions

Currently the only avenue for review of an underwriting decision is the Human Rights Commission complaints process. Following the recent changes, the process of making a complaint is relatively simple and consumer friendly. However, the extent to which consumers are aware of this complaints avenue is uncertain, so agreement to publicise it should be part of a concordat.

In the UK, the GAIC is used as a complaints avenue of last resort where complaints cannot be resolved by the insurance company or the ABI.²³⁵ An industry run complaints process was also suggested as an option in *Essentially Yours*.²³⁶ However, both these options are part of an overall scheme for any code of practice breach. In New Zealand, neither the ISI nor the HFANZ include their genetic testing policy in mandatory standards. This should be changed.²³⁷ Both the HFANZ and ISI members participate in the Insurance and Savings Ombudsman scheme, but

²³² Investment Savings and Insurance Association, 'Submission to the Ministry of Economic Development on the Review of Financial Products and Providers: Insurance' (2006), 9. This review has been placed on hold awaiting the outcome of the Ministry of Economic Development Review of Financial Products and Providers.

²³³ Although there is guidance that an insurer should provide reasons in the new draft guidelines issued for comment by the Human Rights Commission. See above 5.4.2.

²³⁴ Insurance Contracts Act 1984 (Cth) (Australia) s 75.

²³⁵ Genetics and Insurance Committee, 'Fifth Report', above 31, Annex B.

²³⁶ *Essentially Yours*, above n 26, 732.

²³⁷ See above 5.3.

complaints about underwriting decisions cannot be made to the Ombudsman.²³⁸ This leaves the Human Rights Commission as the only avenue of complaint. If this process is adequately publicised, it may be sufficient, because it is tailored to the needs of consumers and has the potential to result in legal proceedings if the complaint cannot be resolved. Any suggestion to expand the jurisdiction of the Ombudsman or create additional complaints procedures within the ISI and HFANZ would be met with opposition by the industry because of the potentially significant cost. A concordat should contain agreement to publicise the Human Rights Commission as a complaints avenue, and an agreement that the situation will be reviewed if it is considered by the government to be insufficient. If this is the case, further options would be setting up a complaints avenue run by the genetics and insurance advisory committee, or looking closer at the possibility of an industry based process.

5.4.5 Education

5.4.5.1 Industry Education

All people involved in the sale and underwriting of insurance should be aware of the issues surrounding genetic testing and insurance. Particular issues of importance are how genetic tests are relevant to applications, why they need to be disclosed, and how they are similar to other health information. This will reduce the potential for deterrence because of the knowledge advisers and salespeople can impart to consumers. Educating underwriters will reduce the risk of irrational discrimination.

This does not mean that all advisers or underwriters need to be experts in genetics. Training to this level would be disproportionate to the number of occasions on which genetic testing will arise in insurance application. Training to the point where those involved are aware of the issues and know when to seek further advice would be sufficient. The IFSA has published a document for insurance advisers which outlines the main points of the IFSA policy and provides further sources of information.²³⁹ Agreement for such an approach to be taken by the ISI and HFANZ, along with agreement to review training on a regular basis, will ensure that applicants are not provided with information which would deter them from undergoing a genetic test or applying for insurance. It would also ensure that underwriters would know when to seek further advice about an application involving genetic information, which would reduce the risk of irrational discrimination.²⁴⁰

²³⁸ See above n 62.

²³⁹ Investment and Financial Services Association, *Human Genetic Information: Q & A for Risk Insurance Advisers* (2006). Available at <www.isi.com.au>.

²⁴⁰ See *Essentially Yours*, above n 26, 733-738.

5.4.5.2 Community Education

Submissions to *Essentially Yours* indicate there is a significant lack of public understanding about genetics, insurance, and their relevance to each other.²⁴¹ The report suggests there is a need for community education not just by the insurance industry but also by the government and the medical community.²⁴² Discussing the possibility of such a wide educational programme in New Zealand is beyond the scope of this paper, but there are steps that can be taken by the insurance industry to minimise misunderstanding. The IFSA has published a comprehensive fact sheet for consumers about life insurance and genetic testing.²⁴³ The creation and dissemination of a similar document by ISI and HFANZ would educate consumers about how genetic testing can influence an insurance application and why it is necessary for insurers to have access to this information. Providing information as to what controls there are on the underwriting process and how their rights are being protected will help prevent deterrence. This material will also ensure that consumers are aware of tests which have been assessed by the genetics and insurance committee.

5.5 Summary

In summary, there are various ways in which irrational discrimination and deterrence can be reduced. The two main approaches suggested are:

- (i) *The creation of an independent body to assess genetic tests* – A genetics and insurance advisory committee will establish criteria to assess the relevance of particular genetic tests in the underwriting process and then apply it to individual tests.
- (ii) *A concordat between the government and industry* – The main thrust of the concordat would be the maintenance of an open relationship between the applicant and the insured, and the fair and reasonable use of genetic information in underwriting. Implementation of the agreement would be through mandatory industry policy. The main aspects of the concordat would be:
 - a. Genetic tests will be used in underwriting in accordance with the recommendations of the genetics and insurance committee.

²⁴¹ *Essentially Yours*, above n 26, 735.

²⁴² *Ibid.*

²⁴³ Investment and Financial Services Association, *Fact Sheet: Life Insurance and Genetic Testing in Australia* (2002). Available at <www.isi.com.au>.

- b. The ISI and HFANZ will regularly report the disclosure of genetic tests in insurance applications to the genetics and insurance committee so that tests can be assessed as they enter the market.
- c. Reiteration of the approach to underwriting drawn from *Bassanelli*.
- d. Insurers will provide reasons for underwriting decisions when requested by an applicant.
- e. The industry will publicise the Human Rights Commission complaints process to applicants.
- f. The ISI and HFANZ will assist insurers in educating underwriters and those involved in the sale of insurance. There should be education about the issues that arise from the use of genetic information in insurance so that they do not mislead consumers and know when to seek help.
- g. The ISI and HFANZ will create and disseminate to insurers publicity material about genetic testing and how it is used in insurance, to be passed on to consumers.

Conclusion

The use of genetic information in underwriting raises a number of ethical issues. However, these ethical concerns do not necessarily justify regulation. What they do suggest is that if the use of genetic information in insurance affects basic welfare by denying people access to basic social goods, something should be done to remedy this. New Zealand has a public health and welfare system which provides a 'safety net' of health care and income support. The relatively small number of New Zealanders who take out private insurance indicates that this 'safety net' is considered adequate to provide access to basic social goods.

If in fact private insurance is relied on for access to basic social goods, regulation still may not be appropriate. Insurance companies are neither designed for, nor well suited to, the redistribution of wealth. In addition to this, restricting the use of genetic information in underwriting while still allowing the use of other health information draws an arbitrary distinction between the two which cannot be justified. Redistribution through the public health and welfare systems is a more efficient mechanism, so an increase in funding in these areas is more appropriate than regulation.

However, this does not mean that there should not be any restrictions on the way insurers use genetic information. The difficulty in interpreting genetic information means that there is a high risk of irrational discrimination. Education for both insurance companies and consumers will reduce this risk and enhance consumer confidence in the industry. The industry should agree to make full disclosure of reasons for an adverse underwriting decision, whether the basis be in genetic information or other health information. These decisions should take into account *all* the factors which influence the risk of a claim. An independent regulatory body should be set up to assess the suitability of genetic tests and make recommendations to the industry as to their use in underwriting.

Reducing the risk of irrational discrimination will help to reduce the risk of deterrence when combined with education for the public about genetic testing and how it is relevant to insurance. If people are confident that genetic tests will be treated no differently from other health information, this will increase public confidence in the industry and reduce the risk of deterrence from taking a genetic test.

The conclusions in this dissertation rest largely on the general acceptance of medical underwriting as appropriate in private insurance, and the adequacy of the public

health and welfare systems in providing access to basic goods. New Zealand has chosen the level of support the state is willing on an equal basis – the ‘safety net’ provided by the public health and welfare systems. Perhaps the debate over the use of genetic information in insurance will spark wider debate about the level of support this ‘safety net’ provides, and whether it in fact allows everyone access to the basic social goods they need.

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