THE USE OF GENETIC TESTS BY THE INDIVIDUAL LIFE INSURANCE INDUSTRY IN SOUTH AFRICA

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Genetic Counselling

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DECLARATION

I, Noelene Kinsley declare that this research report is my own work. It is being submitted for the degree of Masters of Science in Medicine in the branch of Genetic Counselling in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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Signature

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Date

ABSTRACT

The life insurance industry's ability to access genetic test results has raised public concern regarding loss of privacy and discrimination. The insurer requires access to genetic test results to reduce the impact of individuals changing their insurance purchasing behaviour based on a predictive genetic test result, of which the insurer is unaware (anti-selection). In South Africa, industry guidelines have been established to reduce the risk of genetic discrimination whilst enabling insurance companies' access to this information for appropriate assessment of insurance risk. This study was the first to investigate the use of genetic tests by the life insurance industry of South Africa and their compliance with the guidelines, in order to identify behaviour that could result in genetic discrimination or unexpected risk exposure for the insurer. A structured interview process was conducted with 13 companies (8 insurance companies and 5 reinsurance companies), representing the individual life insurance industry. The interview guide was structured in a manner to gain insight into the companies' approach to using genetic information, including genetic test results, in defining the policy terms of an individual's life insurance contract. This study found that the companies' responses to genetic information, particularly genetic test results, were demonstrated to be aligned with the regulatory guidelines. Irregularities in their processes were noted and these could lead to discrimination or increased risk exposure for the insurance company. These resulted from inconsistencies noted in the companies' understanding of the genetic disease mechanisms of a medical condition, which is used to interpret the genetic information to assign risk. In conclusion, this study identified the need for a consistent approach to the interpretation of genetic information which would reduce the risk of genetic discrimination. This may be established through the support of specialist genetic services.

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ABBREVIATIONS

ABI	Association of British Insurers
ASISA	Association for Savings and Investments South Africa
ASISA Standard	ASISA Standard on Genetic Testing
BrCa	Breast cancer
CE	Council of Europe
CIB	Critical illness benefit
CMO	Chief Medical Officer
CVD	Cardiovascular disease
DNA	Deoxyribonucleic acid
FDR	First degree relative
FH	Family history
FHMH	Family history and medical history
GAIC	Genetics and Insurance Committee in the UK
GINA	Genetic Information Non-discrimination Act
GT	Genetic test (positive for a mutation)
HD	Huntington disease
HGC	Human Genetics Commission
HP	Haemophilia
IBOC	Inherited breast and ovarian cancer
IFSA	Australian Investment and Financial Services Association Limited
LOA	Life Offices' Association
LOA Code	LOA Code of conduct: Genetic Testing
MUSC	Medical Underwriting Standards Committee
Ombudsman	Long-term Insurance Ombudsman
PMA	Personal Medical Attendant's report

RNA	Ribonucleic acid
Interview Guide	Interview Guide for Insurer/Reinsurer
UK	United Kingdom
UNESCO	United Nations Educational, Scientific and Cultural Organization
USA	United States of America

GLOSSARY

TERM	DESCRIPTION
Actuarial fairness	There is a good statistical reason or basis for the classification of a risk
Actuarial relevance	Information that has been demonstrated to place an insurer in a better position to more accurately predict the risk of a life event occurring
Applicant	The individual applying for life insurance cover
Applicant's risk	The financial exposure of the insurance company should the insured experience a life event within a particular time frame from the commencement of the policy
Benefit amount (sum assured)	The monetary amount payable on the occurrence of the life event which the insurance benefit is covering
Benefit expiry age	The maximum age until which a benefit provides cover
Compulsory insurance	Individuals do not have a choice in the terms of the insurance policy and everyone is treated the same regardless of their risk profile
Critical illness benefit (also termed severe illness benefit or dread disease)	Provides financial support for financial difficulties associated with an individual being diagnosed with particular life-threatening conditions e.g. cancer.
Decline	Cover is denied
Defer	Cover is delayed for a defined period or until a specified event occurs
Disability insurance	An insurance benefit payable on disablement and to replace income if the disability renders the individual unable to work
Exclusion	A defined medical condition is excluded from being covered under an insurance policy
Family history (relevant)	A family history of members that have been diagnosed with the same medical condition that provides an indication of the risk of another family member being affected
Gene fault (mutation)	A change in the genetic material of a gene which is associated with disease

Genetic condition	A heritable medical condition caused by a change in the genetic information (DNA, RNA, chromosomes and other regulatory factors). These conditions can be divided into two broad categories based on their genetic inheritance, these are: single-gene and multifactorial
Genetic determinism	An individual's genetic make-up defines everything about them. Genetics is deemed as the only cause of all 'problems', over which the individuals has no control
Genetic discrimination	An asymptomatic individual, or their family, is treated differently from people considered to have a 'normal' genotype based on their actual or presumed genetic differences or characteristics
Genetic disease mechanisms	For the purpose of this study refers to mode of inheritance, penetrance, level of expressivity of the disease and age of onset
Genetic information	Information about an individual's genetic tests or the genetic tests of the individual's family members, and the manifestation of the disease or disorder in family members, including the request or receipt of genetic services or participation in clinical research that includes genetic services, for both the individual and their family members
Genetic test	"The direct analysis of DNA, RNA or chromosomes for the purposes of determining inherited predisposition to a particular disease or group of diseases"(LOA, 2001)
Insurance company or Insurer	The company that provides insurance
Insured	The individual for whom protection for the insured event is provided
Legislative prohibition	A restriction on the actions of the insurer, governed by law
Life cover benefit (death benefit)	An insurance benefit payable on death
Load	Increase in the standard premium rates based on an increase in the applicant's risk profile compared with the risk pool

Moratorium	A voluntary agreement between insurers that specifies that for a defined time period they agree not to request certain information
Multifactorial	Inheritance controlled by many genes (polygenic) with small additive effects and the impact of environment
Principle of mutuality (equity)	Individuals are pooled together based on shared risk profiles, and everyone within a specific pool will pay similar premiums
Penetrance	The number of people that carry a specific mutation that express the disease
Premium	Payment made to the insurance company by the insured for the life insurance cover provided
Policy of insurance (insurance policy)	The legal contract detailing the terms of the provision of insurance
Prophylactic treatment	Treatment that can prevent or limit the spread of a disease
Reinsurance company	Financial institution that provides insurance to insurance companies
Single-gene disorder (monogenic)	A medical condition controlled by the action of a single gene locus
Principle of solidarity (equality)	Premiums are a fixed percentage of an individual's income and the benefits and benefit amounts are predefined, regardless of the individual's needs and risk profile
Standard rates	The premium rate based on the risk profile of all individuals within a specific risk pool
Standard underwriting requirements	Information received at application stage prior to the insurance company performing any evaluation of the applicant's risk
Term policy	The insurance cover is provided for a defined period of time
Underwriting	Risk classification of an applicant
Underwriting decision	The contractual terms applied to the policy of insurance based on the risk profile of the individual
Voluntary insurance	Individuals have the choice in terms of when to purchase insurance, the type of insurance benefits they require and the benefit amount.
Waiting period	A defined period of time prior to financial protection being afforded

Whole of life	The insurance cover is provided for the whole of the insured's life or until benefit expiry age

Please note: Terms are italicised when used in the text

Chapter 1: Introduction and Literature Review

The science of human genetics has progressed significantly in the past two decades, and especially since the completion of the Human Genome Project in 2001. Increased knowledge of genetics has provided new opportunities to elucidate disease mechanisms, improve diagnosis, predict disease, and develop new treatments. These proposed benefits are often overshadowed by the public's fear of loss of privacy if their *genetic information* becomes available, specifically to employers and *insurance companies*. The use of *genetic test*s in these settings impacts on the legal, social and ethical aspects of communities (Taylor, Treloar, Barlow-Stewart, Stranger, & Otlowski, 2008). It is therefore important to establish how *genetic test*s are used in these environments and assess whether the resulting actions justify the public's fears. To determine how *genetic test*s are used in the individual life insurance industry of South Africa is therefore of value and is the focus of this study.

1.1 What is insurance?

Insurance provides financial protection on the unpredictable occurrence of a specified event (insured event) in exchange for a payment amount, or *premium* (Malpas, 2008).

The different types of *insurance* are distinguished by the 'insured event' that they cover. *Insurance* can provide financial protection for the loss or damage of assets e.g. motor vehicle insurance or on the occurrence of a 'health event' such as accessing health care services, or a 'life event' for example chronic illness, disability or death. Health insurance provides financial protection on the occurrence of a 'health event', and life insurance provides the insured protection for a 'life event'.

1.1.1 Life insurance benefits

There are three main types of life insurance benefits or products based on specific life events, these are:

- *Life cover* (death benefit) – payable on death, to provide dependants with financial security
- *Disability insurance* – payable on disablement and to replace income if the disability renders the individual unable to work
- *Critical illness benefit* (also known as severe illness and dread disease) – provides for financial difficulties associated with diagnosis of a life-threatening condition e.g. cancer or severe trauma.

The exact terms and conditions of these benefits differ per *insurer* as do the costs of accessing these benefits.

1.1.2 Insurance funding structures and premium calculations

Theoretically, the *premium* amount should be proportional to the *applicant's risk*. This risk is the financial exposure of the *insurance company* should the *insured* experience a life event within a particular time frame (Knoppers, Lemmens, Godard, Joly, Avard et al., 2004). If this method were used to calculate premiums it would make accessing *insurance* too expensive. Therefore, *insurance* is funded by the *insurer* pooling individual premiums together and investing this lump sum. Insurance benefits are then paid from this invested amount (Malpas, 2008).

There are two options for funding structures that can be used by the insurance company. The structure selected is defined by whether the *insurance* cover is provided on a *compulsory* or voluntary basis. With *compulsory insurance* everyone who is *insured* is treated the same regardless of their risk. This is known as the principle of '*solidarity*' or

equality. Everyone pays the same percentage of income or a fixed amount, for a predefined *benefit amount*, regardless of their personal financial needs and circumstances (Pokorski, 1997; Bennett & Smith, 2007). Thus the premiums are structured on affordability. Examples of this type of *insurance* include: employer provided benefits (group benefits), Workmen's Compensation Fund, the National Health Service in the United Kingdom (UK) and private medical schemes in South Africa.

Voluntary insurance allows individuals to be more selective and choose when to purchase *insurance*, define the benefits they require as well as the *benefit amount*s. With voluntary insurance individuals are grouped together into risk pools based on their individual risk (Knoppers et al., 2004). Individuals within a single risk pool will therefore all have a similar risk profile and the premiums they pay will be similar. This is the principle of '*mutuality*' or equity (Pokorski, 1997).

1.1.3 The process of risk assessment of an application

Equity is achieved by the *insurer* assigning individuals to a particular risk pool based on various factors that influence their risk, such as age, gender, occupation, income, education and health status. This process of risk selection and classification is called *underwriting*. The resulting risk classification enables the *insurer* to define the contractual terms of the *policy of insurance*, known as the *underwriting decision*. The different terms include; providing the policy at *standard rates* (the rate for all individuals within a specific risk pool), applying terms and conditions to the policy due to increased risk exposure (a *waiting period*, *exclusions*, or a *loading* of the standard rate) or *decline* the cover. Internationally, the percentage ratio of policies provided on these terms is 90% to 95% for *standard rates*, with about 4% for terms and 1% *declined* (Pokorski, 1997; Low, King, & Wilkie, 1998;Knoppers et al., 2004).

Risk classification is based on the information received by the *insurer*. The *insurer* uses this information to make a 'just' and 'fair' decision (Pokorski, 1997; Knoppers et al., 2004; Dodge & Christianson, 2007). This risk classification or discrimination is based on the principle of '*actuarial fairness'*, meaning that there is a sound actuarial basis to classify the risk. *Underwriting* information therefore needs to be *actuarially relevant* and by having access to the information, an *insurer* will be in a better position to more accurately predict the risk of a life event occurring. The information can only be deemed relevant when an association has been established between it and the occurrence of an event e.g. the risk of death increases with age based on statistical evidence (Daykin et al., 2003). Therefore the greater the predictive value of the information, the greater and more accurate the risk assignment. This *actuarial relevance* is not always easy to define especially when considering the use of *genetic information*.

1.2 Use of genetic and non-genetic information for underwriting

For the insurance industry the distinction between genetic and non-genetic information is vague (Pokorski, 1997). This is illustrated in their definition for *genetic information* which is the "information about an individual's *genetic test*s or the *genetic test*s of the individual's family members, and the manifestation of the disease or disorder in family members" including "the request or receipt of genetic services or participation in clinical research that includes genetic services, for both the individual and their family members" (Coalition for Genetic Fairness, 2008) and their "family history, physical examination and past treatment" (Pokorski, 1997).

Genetic information is currently available to *insurer*s through *family history*, blood tests, medical history and medical examinations (American Academy of Actuaries, 1998). Examples of non-genetic tests that provide *genetic information* include ultrasound for polycystic kidney disease, cholesterol tests and blood pressure readings. Family medical

history has been used for more than a century by *insurer*s, and mortality ratings for hereditary factors have been established since 1932 (Pokorski, 1997; Raeburn, 2002).

The use of *genetic information* is not new or unique to *insurance*, and to date there have been no reports of discrimination in its use (Morrison, 2005). Therefore, it is reasonable to assume that the shift in the general public's perception that the use of this information can now be harmful, is due to a new awareness of genetic testing and availability of *genetic test*s.

The public seems to fear that making *genetic test*s available to *insurer*s will lead to *genetic discrimination* which will limit access to *insurance*, impact existing insurance policies, affect medical *underwriting*, remove privacy of medical information and affect claims and affordability of cover (Christianson, 2007). Besides accessing *genetic test* results, it is argued that if *insurer*s can request a *genetic test*, an individual may be forced to have a test that could potentially provide them with information they do not want to know (Laurie, 2000). *Insurer*s would like access to *genetic test* results to protect themselves against being exposed to the cost of unexpected risks, to maintain competitiveness, for future uncertainty and to remain in business (Christianson, 2007).

1.2.1 The life insurance industry's interpretation of a genetic test

*Genetic test*s have been deemed as unique and different from other tests in terms of the depth of information they reveal about an individual (Hall & Rich, 2000). In the realm of *insurance* the use of *genetic test*s has received special attention compared with other *underwriting* information.

In the literature there are many ways in which a *genetic test* has been defined for the insurance industry. Some definitions are all encompassing including "all products of any

gene" (Knoppers et al., 2004) while others are more specific: "the presence of a variation noted at the level of the DNA, RNA or chromosomes that is predictive of a disease or disorder" (LOA, 2001).

A number of these definitions would include tests currently used by *insurer*s e.g. a cholesterol test. As a *genetic test* is considered as being unique, it is then preferable to define it based on its unique features. Internationally, various non-statutory committees addressing this issue have stated that the aim of a *genetic test* is "to examine the structure of the chromosomes or detect abnormal patterns in the DNA of specific genes. It does not apply to non-genetic medical tests for example blood or urine tests for cholesterol, prostate, cancer, liver function or diabetes" (Morrison, 2005).

1.2.2 Establishing the value of a genetic test to the life insurance industry

*Genetic test*s that are useful to an *insurer* are defined by their predictive and/or therapeutic value, but the number of these tests currently available is limited (Harper, 1997).

The value of the *genetic test* can be defined by *genetic disease mechanism*s specific to the genetic disorder being tested such as: mode of inheritance, *penetrance* (i.e. the number of people that carry a *gene fault* who express the disease), level of expressivity of the disease and age of onset. The mode of inheritance is used to categorise *genetic condition*s into two broad categories, these are: *single-gene* (monogenic) genetic disorders, where the disease results from a change in a single gene; and *multifactorial* genetic disorders, where the inheritance of disease is controlled by many genes with an additive effect (polygenic) and is affected by the environment (Harper, 1997).

Other factors that are of importance to the value of a test include preventability of the condition and cost effectiveness of the test (ease by which a *mutation* is identified for an

individual from a specific population) (Turnpenny & Ellard, 2005; Burger, 2008). Table 1.1 shows how one *genetic mechanism*, the mode of inheritance, confers the value or relevance of the *genetic test* for the *underwriting* process.

Table 1.1 :Genetic inheritance and relevance to *insurer*s (modified from Harper, 1997)

Genetic Inheritance Pattern	Relevance of the genetic test result to the life insurance	Examples
Autosomal dominant	Diseases with late-onset and progressive course Very relevant to insurers	Huntington disease, other late onset neurodegenerative disorders, adult polycystic kidney disease, familial cancer syndromes, Marfan syndrome and familial hypercholesterolaemia
Autosomal recessive	Usually early onset Carriers are usually healthy Usually of little relevance to insurers	Cystic fibrosis, sickle cell anaemia
X-linked	Risk to males only Disease presents early Female carriers are usually healthy Little relevance to insurers	Haemophilia
Chromosomal abnormality	Usually early onset Carriers are usually healthy Usually Not relevant to insurers	Down syndrome, translocations
Multifactorial disorder	Common disorders Level of predictability is low Currently little actuarial relevance	Diabetes, Alzheimer's and cardiovascular disease

Genetic test results are not the only valuable indicator for life insurance risk assessment as other factors influence the development of a genetic illness (Pokorski, 1997). This phenomenon is illustrated by comparing a gene test result for Huntington disease (*HD*) and inherited breast and ovarian cancer (IBOC) (*BRCA1*). For Huntington disease, if a region of the *HD* gene displays a number of repeats in the genetic code greater than 40, it can be said that the individual has a 99.9% probability of developing the disease. However this

predictive ‘diagnosis’ cannot provide an accurate indication of ‘timing’ for this late-onset condition, and onset can range from the age of 25 to 65, and beyond these parameters (Warby, Graham, & Hayden, 2007). The identification of a *mutation* in the *BRCA1* gene confers a probability of 40% to 80% that an individual will develop breast cancer, thus displaying a variable *penetrance* (Evans, Kerr, & Lalloo, 2006), and a 30% to 60% risk of developing ovarian cancer, suggestive of variable expressivity (Evans, 2006). The individual that has a *mutation* that denotes a predisposition towards cancer can alter their risk of developing cancer by accessing *prophylactic treatment*, such as a bilateral mastectomy. This action can reduce their risk of developing breast cancer by 90% (McGilllivary, 2006). These examples demonstrate that *genetic tests* do provide risk information but their interpretation differs substantially, as do the management options.

There are also *genetic test*s that *insurer*s can use that may favourably affect an individual’s risk profile (Malpas, 2008). Negative test results for highly predictive *genetic test*s denote that the individual is not at risk of developing the disorder and an individual’s risk profile can be improved through preventative measures in response to a positive predictive test, where available.

The value of *genetic test*s is to assess the risk of a disease, and hence it is important to address the concerns of the *insurer*s and the public relating to the use of *genetic test*s by the insurance industry.

1.3 Concerns relating to the use of genetic tests by the life insurance industry

1.3.1 Genetic discrimination

The main fear of the *insured* population regarding the insurance industry's use of *genetic tests*, is *genetic discrimination*. *Genetic discrimination* occurs "when an asymptomatic individual or their family is treated differently from people considered to have a 'normal' genotype based on their actual or presumed genetic differences or characteristics" (Billings, Kohn, de Cuevas, Beckwith, Alper et al., 1992; Taylor et al., 2008). Applicants may receive adverse terms on their insurance policy based on their genetic status, but if these decisions are proven to be actuarially fair, then this cannot be considered as discrimination. The presumed impact of *genetic discrimination* is that individuals who would usually be deemed as healthy are no longer considered so because of their genetic or risk status, based on the *insurer*s' understanding of the *genetic condition* (Ashcroft, 2007). It is postulated that this level of *genetic discrimination* could potentially create a "new intermediate health category" of neither healthy nor ill, a "genetic underclass", the "healthy ill", or the "genetically impaired" (Bennett & Smith, 2007). In this scenario it is assumed that these individuals would not be able to access *insurance* and that the information would affect existing policies and benefits.

The public's fears are not just limited to accessing *insurance*, but also that their social right to access genetic testing or participate in clinical research is affected based on the consequence of discrimination. These fears are founded on an assumption that the information a *genetic test* reveals is unique and different (Hall & Rich, 2000). The effect of placing *genetic test*s into a unique category from other tests could lead to *genetic determinism* (geneticisation), where an individual's genetic make-up defines everything about them. This implies that genetics is the only cause of all 'problems', and the individuals have no control over the effects thereof. This reasoning leads to a limited distinction between *genetic discrimination*, where people are treated differently based on their genetic

status, and *genetic determinism*, where an individual's genetic status over which they have no control, makes them different (von Hoyweghen, Hortsman, & Schepers, 2007). The impact of defining a *genetic test* as unique is counterproductive as it does not protect an individual but potentially provides a platform for discrimination.

Proof of *genetic discrimination* is limited, especially as the industry is not certain how prevalent it is, how to measure it, and what its true effect is (Bennett & Smith, 2007). Studies performed to date have been deemed as anecdotal, criticised for inflating the level of discrimination, and for using inappropriate sampling methods (Hall & Rich, 2000). Conversely, it has even been suggested that the phenomenon does not exist (Hall & Rich, 2000). The lack of credible data may be because *genetic test*s are only relevant to about 1% of the *insured* population and there is limited use of genetic testing services. The latter is probably due to the cost of genetic testing, lack of awareness of these services and the limited number of *genetic test*s available (Joly, Knoppers, & Godard, 2003; World Health Organisation, 2006).

In a North American study of individuals being tested for Huntington disease, 41.6% of the individuals personally paid for their tests to prevent *insurers* from obtaining and using the resulting information (Oster, Dorsey, Bausch, Shinaman, Kayson & Oakes, 2008). A survey of breast cancer testing genetic service centres in Europe reported that patients would not undergo testing because of fear of the *insurer*'s response (Morrison, 2005). In a UK study, 26% of individuals at risk for breast cancer declined testing for fear of discrimination. Contrary to their fears, of those who were tested, more than 80% had no difficulty obtaining health insurance (Peterson, Milliron, Lewis, Goold, & Merajver, 2002).

Recently in an Australian study, 916 individuals with a family history or *genetic test* for a late onset genetic disorder (95% had a predictive *genetic test*) were contacted to determine their

perception of the response to *genetic information* in the *insurance* market. Of the participants, 42% had experienced incidences of *genetic discrimination* by *insurer*s, including refusal of life insurance, cover offered at special rates and increased *load*ings on insurance policies. Of these participants who had experienced *genetic discrimination*, 90% had genetic information pertaining to neurodegenerative disorders viz. Huntington disease (HD), spinocerebellar ataxia (SCA) and familial cancers (Taylor et al., 2008).

These findings were confirmed by Canadian researchers who recently reported that 40% of their study population, which consisted of tested and untested asymptomatic people at risk for Huntington disease, reported some form of *genetic discrimination*, and reported that the insurance industry represented 29.2% of these cases. The insurance companies were more likely to discriminate in response to a family history of Huntington disease than to a *genetic test* (Bombard, Veenstra, Friedman, Creighton, Currie, Paulsen et al., 2009)

These studies are suggestive of *genetic discrimination*, but they do not assess whether the insurers behaved differently based on genetic information in comparison to other risk information, which is the basis used to define this discrimination.

1.3.2 Anti-selection

The main reason for *insurer*s wanting access to a *genetic test* result is to reduce the impact of individuals changing their *insurance* purchasing behaviour based on a predictive *genetic test* result which they have concealed from the *insurer* (Knoppers et al., 2004).

Insurance policies are structured on an element of 'utmost faith' meaning that *insurer*s need the same information that the *applicant* has so that there is no imbalance in risk perception. Asymmetry occurs when the *insurer* has restricted access to information either by legislation or failure of disclosure by the *applicant*. The latter is termed 'adverse selection' or 'anti-

selection' and occurs when an individual intentionally obtains insurance cover with knowledge of the increased risk of an insured event occurring but without providing the *insurer* with that information. The motivation for their actions is to take financial advantage of the *underwriting* process (Actuarial Standards Board, 1989; National Society of Genetic Counselors, 2006).

Anti-selection affects the *insurer*s' ability to maintain the financial stability of the insurance pool, and results in people purchasing more cover than necessary, submitting claims earlier than expected and selectively choosing when to buy *insurance* (Pokorski, 1997). Thus *insurer*s pay out more claims than expected because of the additional undisclosed risk. In extreme situations this could lead to the collapse of the insurance company, or to remain profitable, *insurer*s will have to charge higher premiums for everyone.

Although adverse selection has been proven to be a definite phenomenon, it has not been convincingly demonstrated in the context of an *insurer*'s access to *genetic test*s. The results from two studies that investigated the effect of *BRCA* testing on *insurance* purchasing behaviour were inconclusive (Zick, Smith, Mayer, & Botkin, 2000; Armstrong et al., 2003;). Another study reported that individuals who tested positive for the Apolipoprotein E gene (associated with Alzheimer's disease), changed their *insurance* purchasing behaviour by almost a factor of 6 in comparison to those that were not tested, indicating that a risk of anti-selection does exist (Zick, Mathews, Roberts, & Cook-Deegan, 2005).

Contrary to the *insurer*s' fears of anti-selection, one author was of the opinion that the feared effect of anti-selection is inflated because *insurer*s protect themselves against this risk by including the cost thereof in the premiums (le Grys, 1997). The standard *premium* calculation incorporates a financial buffer against the effect of anti-selection in the first five years of the policy, thereafter an *insurer* will be able to provide for the risk financially. This

premium rate is however only sufficient for the current number of *genetic test*s available, and this calculation would need to be reviewed if *genetic test*s for more common diseases become available (Viswanathan, Lemaire, Withers, & Armstrong, 2007).

1.3.3 Importance of addressing these concerns

As described, there is little evidence of *genetic discrimination* or adverse selection however these remain genuine fears for the respective parties. The topic is emotive, as access to *insurance* is deemed a social right. Proof of public fear exists and although considered irrational, it needs to be addressed (Joly et al., 2003). The consequences of not addressing these fears may result in individuals accessing *genetic test*ing and management through sources that do not provide appropriate genetic and medical support services (Murthy, Dixon, & Mossialos, 2001). A balance between the needs of the *insurer*s' and the applicants' is required (Godard, Raeburn, Pembrey, Bobrow, Farndon et al., 2003).

Responses to these fears have been variable; some writers conclude that *genetic information* should not be disclosed to *insurer*s, that doctors need to prevent this information from getting out, unless they have consent; and that genetic counsellors should tell patients of the insurance risks. Medical practitioners have suggested that patients purchase *insurance* prior to testing and certain support groups have requested that doctors set up two records for their patients, only one accessible to the *insurer* (Pokorski, 1997). The Australian National Health and Medical Research Council recommended that, prior to testing, patients should be informed by the genetic counselling services of the implications that a *genetic test* will have on their ability to purchase *insurance* (Lynch, Doherty, Gaff, Macrae, & Lindeman, 2003).

*Insurer*s have strict guidelines regarding what information may be deemed 'relevant' for *underwriting*, and actuaries are "trained to distinguish between appearances and fact"

(American Academy of Actuaries, 1998). None of the commentaries have taken these facts into consideration, and the attitudes towards *insurer*s have tended to be hostile (Raeburn, 2002). Contrary to public opinion *insurer*s are aware that a positive test for a gene *mutation* does not always translate into disease. Furthermore, the fear of life insurance companies cancelling policies based on new information received is unfounded as an insurance contract does not make allowance for this action (American Academy of Actuaries, 1998).

In 2000, participants at a workshop organised by the European Society of Human Genetics Public and Professional Policy Committee identified the various issues pertaining to the use of *genetic information* and testing by the insurance industry. Key recommendations were that a definition for predictive *genetic information* and *genetic test*s needs to be established; an interpretation of the predictive *genetic test* results is required for risk categorisation in mutuality costed insurance policies; an opinion of anti-selection is needed; the effect on risk assessment by the type of insurance product should be established; the lack of genetic services (such as genetic counselling) needs to be addressed, and reduced testing because of fears of discrimination needs to be investigated (Godard et al., 2003).

1.4 Regulation of the use of genetic tests by the insurance industry

Governments, specialists in the disciplines of health policy, genetics and insurance, and other interested parties have investigated ways to limit or prevent the negative effects of the use of *genetic test*s by *insurer*s. Their solutions have included the introduction of various legal, regulatory or industry focused models.

1.4.1 Regulatory policy models

International solutions to the *insurer*s' use of *genetic test*s are founded on three industry specific policy models: 1) *legislative prohibition*; 2) *moratorium;* or 3) status quo (Bennett & Smith, 2007). Another approach has been to strengthen privacy policies restricting access to information and to enforce rigorous control and regulation as to the availability of *genetic test*s (Knoppers et al., 2004).

1.4.1.1 Legislative prohibition

The motivation behind *legislative prohibition*, or restriction of *insurer*s' access to *genetic test*s, was to protect all parties involved. *Genetic discrimination* is therefore prevented, providing freedom for individuals to undergo genetic testing (Hall & Rich, 2000). The risk of *legislative prohibition* is that it can reinforce 'genetic exceptionalism' and increase the risk of 'anti-selection' (Lemmens, Joly, & Knoppers, 2004). This model may be chosen as a result of the complexity experienced in identifying the *actuarial relevance* of *genetic test* results. However, as the *insurer*s' understanding of the science increases, this approach will need to be reconsidered (Bennett & Smith, 2007).

1.4.1.2 Moratorium

A *moratorium* is a voluntary agreement between *insurer*s that specifies that for a defined time period they agree not to request *genetic test*s or use the results. Thus it provides the public with a sense of comfort, and it allows time for actuarial validation of *genetic test*s and their use in the insurance industry (Lemmens et al., 2004; Bennett & Smith, 2007).

Both the *moratorium* and legislative models do not make allowance for *genetic test*s that are already proven to be of *actuarial relevance*. The effectiveness of these models can be enhanced by incorporating a proportional approach, where access to information is permitted

based on specific provisos. These provisos may include specific benefit or *premium* amounts that define under which circumstances specific *genetic test*s may be considered for a particular policy. The value and relevance of the *genetic test* would be defined by an independent regulatory body (Lemmens et al., 2004).

1.4.1.3 Status quo

The reason for maintaining status quo, or to not have a policy, may be to determine the 'true effect' of allowing *insurer*s access to *genetic test*s. From the public's perspective, this could be seen as 'leaving the door open' for discrimination, although the policy makers consider people to be protected under human rights and privacy laws (Lemmens et al., 2004).

To understand the public's viewpoint, a study was performed using a citizen jury whom were given the task to select the policy model best suited to their needs. They chose the legislation model because they distrusted *insurer*s to act in accordance with a voluntary agreement or to treat individuals without prejudicing them based on business needs. Legislation seemed to meet the need for trustworthiness as it is enforceable by law (Bennett & Smith, 2007).

1.4.2 International approach to the regulation of the insurance industry's use of genetic tests

Each of these models, or combinations of them, are represented worldwide. This was illustrated in a comparative study of 44 countries (Lemmens et al., 2004). The two most common options were; the combination of a *moratorium* and guidelines, and legislation with guidelines. The solutions selected seem to be based on international trends and in response to the concerns, policies, insurance structures and debates specific to that country. The different approaches are illustrated in solutions used by the United States of America (USA), the United Kingdom (UK), Europe and Australia.

1.4.2.1 United States of America

The USA has adopted the status quo approach to life insurance and each state can act according to what they deem necessary (American Academy of Actuaries, 2002). Although the Genetic Information Non-discrimination Act (GINA) was passed in May 2008, it only applies to health *insurer*s and employers. The protection afforded by GINA does not apply to life insurance companies (Coalition for Genetic Fairness, 2008).

1.4.2.2 United Kingdom

In the UK the 'Concordant and Moratorium on Genetics and Insurance' pertains to the life insurance industry and was developed by a team including government participants, the Genetics and Insurance Committee (GAIC), the Association of British Insurers (ABI), and the Human Genetics Commission (HGC) (Raeburn, 2002). The guidelines state that individuals may not be treated differently by *insurer*s based on their predictive *genetic test* results, and that the clinical and *actuarial relevance* of a specific predictive *genetic test* would be assessed and approved by the GAIC. On approval, *insurer*s and *applicant*s should have equal access to information (Genetics and Insurance Commission (GAIC), 2005). The Moratorium states that *applicant*s need only disclose results of a *genetic test* if the insured amount is above a certain value. For these tests, *insurer*s may request results of the test but may not require that a test be performed. They may request family history, but not a *genetic test* result from a family member and *applicant*s may volunteer to provide favourable test outcomes to override a decision based on family history. The only predictive *genetic test* approved to date is for Huntington disease and only for life insurance policies with a benefit value greater than £500,000 (Genetics and Insurance Commission (GAIC), 2000). Of existing life insurance policies 97% are below this *benefit amount* (Genetics and Insurance Commission (GAIC), 2005).

1.4.2.3 European Union

No single approach is used by the member countries of the European Union, but many have established their legislation based on the Convention on Human Rights and Biomedicine, Oviedo, held by the Council of Europe (CE). This Convention states that "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited." (Council of Europe (CE), 1997). A *genetic test* is predictive of a genetic disease and can only be performed for health and research purposes subject to appropriate genetic counselling. The test is used to identify the presence of a disease-causing *mutation* (Lemmens et al., 2004). This legislation does not protect individuals that have already had a *genetic test* and therefore it is used in conjunction with the UNESCO 'Universal Declaration on the Human Genome and Human Rights' which states that "No one shall be subjected to discrimination, based on genetic characteristics, that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity" (UNESCO International Bioethics Committee, 1997; Lemmens et al., 2004).

1.4.2.4 Australia

In Australia, the Investment and Financial Services Association Limited (IFSA) defined guidelines were voluntarily agreed to by all registered life *insurer*s. These guidelines, the IFSA 'Genetic Standard Policy' were established to ensure that: everyone has access to life insurance, risk classification can freely evolve, *insurance* is priced affordably, the industry remains viable for a long time and *insurer*s remain accountable and transparent (IFSA, 2005). The agreement provides similar guidelines as those defined by the UK. In addition, they state that no preferential *underwriting* is permissible based on a *genetic test* result and *insurer*s must consider the value of *prophylactic* screening and treatment when assessing risk (IFSA, 2005).

1.4.3 Effectiveness of regulating the use of genetic tests by the insurance industry

Individual countries have based their decisions on their unique needs. To date the value of the various models have not been investigated. In the USA, an in-depth study was performed in the health insurance industry, prior to the inception of GINA, to determine whether legislation affected the risk of *genetic discrimination* (Hall & Rich, 2000). At the time of their study each state had independently implemented either guidelines or prohibitary legislation, and the authors compared states with dissimilar laws to establish whether legislation had an impact on behaviour. Based on their observations, they concluded that prohibitary law affected *insurers*' attitudes towards the social concerns relating to the use of *genetic test*s. Although advantageous, the authors' concern was that these laws have heightened both geneticists' and consumers' perception of the risk of discrimination without sufficient substantiating proof of its existence. They could not comment on the effect on *genetic discrimination* as they could not prove its prior existence.

These international responses provide a foundation to assess the process and approach of South Africa, whilst not ignoring South Africa's unique demographics and needs.

1.5 The South African Life Insurance Industry

South Africa has an estimated population of 48.7 million people from different racial groups: blacks 79.4%, whites 9.24%, mixed ancestry 9% and Indians 2.94% (Statistics SA, 2008). Overall the unemployment rate is 23.5% of the 30,6 million employable people (Statistics SA, 2009). In the context of private *insurance* this portion of the population would not be considered able to access these benefits, due to affordability. They are however granted financial protection through state managed welfare benefits which include disability grants.

For the employed population of South Africa, and those with the financial means, *insurance* benefits can be accessed through group schemes, such as membership of a union, funeral benefit schemes or employer provided benefits. Alternatively individuals may obtain *insurance* in their private capacity.

In South Africa the group and private health (medical aid) insurance are community rated, similar to solidarity funding, and the option for these *insurer*s to discriminate against an *applicant* is limited. The sector of the South African insurance industry that may discriminate against *applicant*s for *underwriting* purposes is the individual life insurance industry, and they would therefore be in a position to benefit from the use of *genetic test*s.

The individual life insurance industry in South Africa has a substantial annual premium income but the number of *insured* individuals in South Africa constitutes only 14% of the insurable population (FinMark Trust, 2009). Hence there is a potential for growth in the number of *insured* individuals, and if this occurs, it would result in many people being exposed to medical *underwriting*. The impact of the *underwriting* process can therefore potentially affect a large portion of the South African population.

1.5.1 South African Life Insurance Industry: Legislation and Regulation

The Long-term Insurance Act (the Act) defines the legal framework for the establishment and business practices of a life insurance company in South Africa (Republic of South Africa Government Gazette, 1998). The Act does not provide a foundation for *underwriting* practices and the *insurer*s' right to discriminate is attained through the Constitution and other legislation, such as the Privacy Act (Caciumaru, 2007).

The Life Offices' Association (LOA) was formed to provide an environment to address the interests and concerns of both the life insurance industry and the *insured* public. This is an

association of registered long-term insurance companies conducting business in South Africa and its purpose was to educate the public, negotiate with the authorities and enable life *insurer*s to regulate their industry. The latter was achieved through the introduction of the LOA Codes of Conduct (LOA Website, 2007), a set of principles to which the LOA member companies voluntarily prescribe. The LOA Codes of Conduct consists of 23 chapters, covering various aspects of the business of long-term insurance provision and offers a guide for best practice (LOA Website, 2007).

1.5.2 Regulation of the South African life insurance industry's use of genetic tests

In November 2001, the LOA released the 'Code on Genetic Testing' (LOA Code) (LOA, 2001). The LOA Code's stipulated purpose was to reduce the risk of adverse selection and *genetic discrimination* in the use of *genetic test*s by the South African life insurance industry. The guidelines in the LOA Code were established in consultation with the Australian IFSA consultation paper, the British ABI code of practice and a Masters degree thesis, completed at the University of Johannesburg, entitled "Underwriting guidelines for genetic testing with special reference to relevant ethical aspects" by Dr M van der Walt.

The definition of a *genetic test* as stipulated in the LOA Code was detailed in section 1.2.1., Pg. 5. The LOA Code provides guidelines as to an *insurer*'s use of *genetic test*s. The goal of the LOA Code is to ensure affordable and appropriate *premium*s by allowing *insurer*s to have access to results of *genetic test*s. These *genetic test*s had to be performed prior to application for *insurance*, and the results should be underwritten in the same manner as any other information received. The *insurer* may not request that a *genetic test* be performed, may not request the results of a *genetic test* performed after commencement of the *policy* or use a *genetic test* result to reduce *premium*s lower than *standard rates* (LOA, 2001).

To achieve these goals the LOA Code defines the role of the insurer and key people within the company. The insurer is to ensure limited access by staff members to genetic test results, their staff will be trained to have an understanding of the Code and their compliance will be monitored and details of all applicants that had genetic testing will be stored in a separate database. A senior underwriter will be responsible for genetic information and the chief medical officer will keep the company informed of developments in genetic testing, provide training regarding genetics, consult with specialists regarding genetic testing cases and provide advice for complex cases (LOA, 2001).

At the end of 2008, the LOA disbanded and was incorporated into the Association for Savings and Investments South Africa (ASISA). This association represents the majority of asset managers, collective schemes managers and life insurance companies in South Africa. Their function is to engage with policymakers, regulators, intermediaries and consumers (ASISA Website, 2009).

In 2009, ASISA's Medical Underwriting Standards Committee (MUSC) reviewed the Code and in April 2009 released the "ASISA Standard on Genetic Testing" (the Standard). The amendments were that an *insurer* is obligated to review the terms of a *policy* if an *applicant* provides the results of a predictive *genetic test*, and when assessing an individual's risk profile the *insurer* should take the value of specialist surveillance, medical intervention and successful treatment into consideration (ASISA Website, 2009).

Although these standards are not legally binding, support for the various parties is provided through the Long-term Insurance Ombudsman (the Ombudsman) whose function is to mediate disputes between *insurer*s and the *insured* including cases where there is a concern of *genetic discrimination* or adverse selection (Long term insurance ombudsman, 2008).

1.6 Motivation for this study

The value of any form of guideline, regulation or legislation is determined by whether it achieves its stated goals. In the context of the insurance industry's use of *genetic test*s, the goal of any regulation established would be to reduce the risk of '*genetic discrimination*' whilst providing *insurer*s with the opportunity to manage their risks effectively and appropriately. These goals are specifically stated in the British, Australian and South African guidelines (Genetics and Insurance Commission (GAIC), 2005; IFSA, 2005).

The effectiveness of these polices has been poorly researched and is complicated by the lack of evidence of both *genetic discrimination* and anti-selection. Such an investigation would need to establish whether *insurer*s have aligned their business practices to the recommended guidelines and, if they have, the effect that this has had on their ability to discriminate based on *genetic information* and their risk of being exposed to anti-selection.

As there is little documented proof of *genetic discrimination*, a way to measure this phenomenon is to identify individuals that have been treated differently based on *genetic information*. This can be achieved by comparing *underwriting* practices and outcomes associated with different types of *underwriting* information, including both genetic and non-*genetic information*. The assessment of the existence of *genetic discrimination* can be further strengthened by specifically comparing the different outcomes based on different forms of *genetic information* e.g. *genetic test* versus family history (Hall & Rich, 2000). In all instances the *actuarial relevance* of the *genetic test* must be taken into consideration and the *insurer*s must have aligned their business practices with the LOA Code.

This type of investigation has not been done in South Africa. Two studies have considered these aspects; one relating to the risk of adverse selection and the other *genetic discrimination* (Kotze, Schoorn, & Coetzer, 2004; Caciumaru, 2007). The one was an

informal survey establishing the *insurance* purchasing behaviour of individuals when receiving a positive genetic predisposition result for cardiac disease. The author concluded that there is a potential risk of adverse selection (Caciumaru, 2007). The limitations of this study were that the number of interviewees was small, the process was informal, the level of knowledge was unknown and the predictiveness of such a *genetic test* was not established.

The other was a review of the use of *genetic test*s in the South African insurance industry (Kotze, Schoorn, & Coetzer, 2004). The authors suggested that the fear of *genetic discrimination* in healthy individuals is unfounded. Their reasoning was that predictive *genetic test*s were of value especially if preventative measures were available e.g. people diagnosed with specific factor V Leiden *mutation*s could take suitable precautions to minimise the risk of clotting. They concluded that there are only a few genetic disorders of relevance and that the LOA Code provides appropriate protection for the *insured*.

In neither of these studies was the South African individual life insurance industry's use of *genetic test*s explored. The researcher felt that a study investigating the *underwriting* practices and the potential risks of '*genetic discrimination*' or 'anti-selection' would be valuable and this was the reason this study was undertaken. The results would provide insight into the effectiveness of current regulation and the protection afforded to the public and the insurance industry. This is important to assess as the LOA Code was modelled on international guidelines which may not be optimal for South Africa because of the unique insurance market due to its demographics.

1.7 Aim

The aim of this study was to investigate the South African life insurance industry's response to the use of *genetic test*s in providing an individual life insurance policy, and to assess the associated risks of *genetic discrimination* and anti-selection.

1.7.1 Objectives

The objectives of this study were:

- To identify the insurance industry's *underwriting* response to the use of *genetic information*, which encompasses *genetic test* results and family history, and non-genetic information, such as a personal medical history and health status.
- To determine the effect of the use of such *genetic information* by the insurance industry on the *underwriting decision*.
- To assess the *insurer*s' knowledge of the LOA Code of Conduct on Genetic Testing
- To verify the authenticity of the reported *underwriting* approaches and decisions with regards to the use of *genetic information*, by comparing reported standard practices with the responses from hypothetical cases.
- To investigate the effectiveness of the regulations in limiting adverse selection and *genetic discrimination* as a result of the insurance industry using *genetic information*.
- If necessary to recommend changes to the *underwriting* process in response to *genetic information* and thereby enhance the effectiveness of the LOA Code of Conduct on Genetic Testing

Chapter 2: Materials and Methods

2.1 Introduction

This study was a cross-sectional, comparative, descriptive analysis of the use of *genetic test*s by the life insurance industry of South Africa. Knowledge of genetic concepts and principles, *underwriting* practices (including *underwriting* requirements and decisions), insurance *policy* terms and conditions and alignment of company practices with industry regulations were investigated.

The life insurance industry refers to life insurance companies, *reinsurance* companies and an industry regulator, the Ombudsman. Reinsurance companies were included as they provide the life insurance company with financial protection for risk that the *insurer* is unable to cover. Important to this study is that the re*insurer*s provide the life insurance industry with standards for *underwriting* practices and they are considered the 'specialists' within the life insurance industry

Using a structured interview guide, data were collected by conducting interviews with participants from life insurance and reinsurance companies.

2.2 Setting of the study

This was a national study and the interviews were conducted at the head offices of the respective companies or where the participants were situated. Two interviews were conducted in Cape Town, eight in Johannesburg, one in Centurion and one in Pretoria.

Data collection commenced in January 2009 and was finalised by May 2009.

2.3 Study process

The design of the study was as follows:

- Identification of the sample population of insurance and reinsurance companies, and a suitable participant from each of the respective companies
- Obtain the approval of the company representative to participate in the research project
- Conduct an interview with the participant using the interview guide
- Computerise responses
- Analyse data
- Draw conclusions relevant to the aim of the study

2.4 Selection of the sample population

The sample population for this study was defined as the life insurance industry of South Africa, incorporating life insurance companies, reinsurance companies and the regulatory bodies to the industry.

2.4.1 Selection of sample population - life insurance companies

A list of registered South African life insurance companies was compiled from those listed on the Insurance Gateway website, a centralised web source of information relating to insurance in South Africa (Insurance Gateway Website, 2009) and the LOA website (LOA Website, 2007).

Insurance companies included in this study had to meet the following criteria: they needed to be registered as a long-term insurance company; to provide private life insurance to individuals; and to provide life insurance benefits such as life cover, income disability and

critical illness. The company had to perform their own *underwriting* (financial and medical) and be a member of ASISA (previously the LOA).

Insurance companies were excluded if their business only provided funeral cover or group risk benefits because these are costed on the solidarity basis; accidental death or *disability* cover as these policies seldom require medical *underwriting*; and credit insurance as acquisition of this type of *insurance* is not voluntary.

A list of all the insurance companies, their insurance benefits and the decision regarding eligibility for this study is summarised in Appendix A. Ten out of 33 insurance companies met the inclusion criteria and were selected to participate in this study: 1LifeDirect, AltRisk, Assupol, Discovery Life, Liberty Life, Metropolitan Life, Momentum Life, Old Mutual, Professional Provident Fund (PPS) and Sanlam.

2.4.2 Selection of sample population - reinsurance companies

In this study the reinsurance companies selected to participate were chosen for having provided support to individual life insurance companies in South Africa for more than five years. These are General Reinsurance Africa (Pty) Ltd, Hannover Re Africa, MRoA Munich Re, RGA SA and Swiss Re SA.

2.4.3 The Long-term Insurance Ombudsman

The regulatory body included in this study was the Long-term Insurance Ombudsman (the Ombudsman) because of his function as a mediator between the insurance industry and the consumer. Any complaints relating to adverse selection and *genetic discrimination* would be referred to the Ombudsman (Long term insurance ombudsman website, 2008).

2.5 Construction of the instrument, information sheet and consent forms

2.5.1 Interview Guide

The instrument for the interview was an interview guide, 'Interview Guide for *Insurer*/Re*insurer*' (the interview guide), attached as Appendix B. It was modelled on a schedule of questions used in a previous study with similar objectives, performed in the health insurance industry in the USA (Hall & Rich, 2000), The questionnaire was obtained directly from the authors.

The interview guide was used to interview both insurance and reinsurance companies and adjusted to their business practices. Responses from the reinsurance companies were not required for questions A2 and A3 as they do not provide benefits directly to the public. Their business practices are structured on those of the insurance companies they insure.

The interview guide consisted of three sections and the questions were constructed to meet the specific objectives of the study, namely: *underwriting* practices, compliance with industry regulations and *underwriting* behaviour in response to hypothetical case studies. The objectives for each section, and the information used to attain these goals, are detailed below:

2.5.1.1 Section A: Underwriting Practices

These questions were constructed to gain an understanding of a company's *underwriting* practices, including their standard underwriting requirements and their underwriting response to the kind of *underwriting* information received for different benefit types, relating to a specific medical condition.

With a prior experience in insurance underwriting the researcher has the knowledge that the standard underwriting requirements are based on protocols that define what information is required from the applicant up front. These requirements are based on the age of the applicant, the benefit type and the benefit amount requested and usually includes the application form, medical reports and blood tests.

The different life insurance benefit types are life cover, income disability (comprising both a lump sum *disability benefit* and a monthly income benefit) and a severe illness benefit (also termed as a *critical illness benefit*).

The medical conditions selected were based on their genetic pattern of inheritance. This *genetic mechanism* played an important role in defining the relevance of *genetic information* for an *insurer*'s assessment of risk (as detailed in Table 1.1) (Harper, 1997). The four medical conditions used were: Huntington disease (HD), a late-onset neurodegenerative autosomal dominant disorder with 100% *penetrance*; familial breast cancer (BrCa), an autosomal dominant disorder with variable *penetrance*; haemophilia (HP), an X-linked disorder that presents in childhood; and cardiovascular disease (CVD), a *multifactorial* condition.

2.5.1.2 Section B: Compliance with regulations

The questions in this section addressed the company's level of understanding and compliance with the LOA Code (excluding the amendments to the LOA Code detailed in the ASISA Standard, as of April 2009).

2.5.1.3 Section C: Underwriting behaviour of the company

This section consisted of hypothetical cases constructed to assess the participant's ability to apply the *underwriting* protocols, as detailed in Section A, to

practical cases. The goal of this section was to determine the participant's level of compliance to *underwriting* protocols in practice and their understanding of genetic disorders.

Probing statements were used during the interview process. The purpose and motivation for each question and the probing statements are detailed on the attached interview guide (Appendix B).

2.5.1.4 Establishing that the interview guide is understandable

The clarity of the questions and the length of time required to complete the interview process was discussed and approved by the researcher's supervisors prior to commencing with the study. No pilot was performed because of the small sample size.

2.5.2 Information Sheet

The 'Research Project Information Sheet' was designed to provide the participants with details about the research project including the study aims, objectives and methodology, the criteria used to identify the participant as an eligible representative for the company, a brief description of the information and documentation required (copies of the company's *underwriting* protocol and application form) from the participant and how confidentiality was achieved (Appendix C). All selected insurance and reinsurance companies were assigned a unique numerical code for confidentiality.

2.5.3 Consent Forms

Two consent forms were required for this project. The "Consent to Participate in an Interview" (Appendix D) form was the participants' consent to participate in the research project and to an interview. The "Recording Consent Form" (Appendix E) was for the participants to consent to a voice recording of the interview.

2.6 Procedure for data collection

2.6.1 Invitation to participate in this research project

The representatives from the companies were required to be individuals whose function involved the development, establishment and management of *underwriting* practices, who acted as facilitators in the *underwriting* process, especially for complex cases, and who had the authority to make decisions pertaining to 'special' *underwriting* cases. These representatives included the company's chief medical officer, specialist underwriters, chief underwriters and senior underwriters. Representatives were identified based on these criteria, contacted telephonically and invited to participate in this research project. Representatives who had verbally agreed to consider participation in this study were provided with an electronic copy of the 'Research project information sheet' (Appendix C) and the 'Consent to Participate in an Interview' (Appendix D) forms. Their agreement to an interview was confirmed on receipt of a signed copy of this form. The representative was then contacted to make an appointment for the interview.

2.6.2 Interview process and data collection

To provide the participant of the company with an opportunity to prepare for the interview, a copy of the interview guide was forwarded at least one day prior to the appointment. At the appointment, and prior to commencing with the interview, the participant was asked to consent to having the session audio recorded. Consent was confirmed by signing the 'Recording Consent Form' (Appendix E). The interviews were conducted by the researcher using the interview guide, and the participants' responses were documented and audio recorded. On completion of the interviews, the participants were asked to provide a copy of the company's *underwriting* protocols. For insurance companies, a copy of their application form, benefit definitions and description of the capital disability and *critical illness benefit* (CIB) were also requested. The reasoning for the latter was

because the interview guide did not assess details about the benefits and their complexities. Any differences in these definitions can directly impact underwriting practices, as the risk exposure to the insurer is defined by the life events that are covered under a specific product. If required the application form may have been used to verify the standard underwriting requirements and practices of the insurer.

2.6.3 Obtaining information from the Long-term Insurance Ombudsman

The Ombudsman was contacted to establish whether cases reporting *genetic discrimination* or adverse selection had been referred to him. If such cases existed, their *underwriting decision* would need to have been made by using *genetic information*, including *genetic test* results, family history or a combination of family history and medical information. The application date for these respective cases had to be after 1 January 2002 as the LOA Code was only released in November 2001. The Ombudsman's office referred the researcher to their website as all their cases are reportedly stored, detailed and are accessible from there.

The Ombudsman website (http://www.ombud.co.za) has three sections that could potentially contain information detailing relevant cases, these were: "Topics and Cases", "Annual Reviews" and "Newsletters".

The "Topics and Cases" section (http://www.ombud.co.za/topicsandcases.asp last updated date unknown: accessed 08/06/2009) consisted of 25 topics. Of these 25 topics only 12 were selected for all analysis as they had relevance to the theme of this study. These topics were: anti-selection (exclusions and non-disclosures), disability, dread disease, exceptions, *exclusion*s and *waiting period*s, fairness, good faith, life policies, LOA, non-disclosure and pre-existing. These topics contained cases which were reviewed by the researcher to determine whether the resulting actions were as a consequence of non-disclosure or *genetic discrimination* relating to a family history or *genetic information*.

Annual reports from the Ombudsman's office were reviewed for each year from 2003 to 2008. The reports were scanned using key words to identify cases that represent anti-selection or *genetic discrimination*, these were: 'non-disclosure', 'adverse selection', 'anti-selection', 'discrimination', 'family', 'gene' (which would highlight all words with gene as the root word) and 'inherit' (another root word). The Ombudsman's newsletters (http://www.ombud.co.za/newsletter.asp) were reviewed using the same search criteria.

2.7 Storage of data collected

2.7.1 Data storage using spreadsheets

All consent forms are in hard copy and have been filed and stored according to the stipulations of the Human Research Ethics Committee (Medical). Data generated from the interviews, the application forms and the capital *disability benefit* and *critical illness benefit* definitions and descriptions were summarised and stored in a spreadsheet using Microsoft Excel®.

2.7.2 Storage of voice recordings

The voice recordings were electronically downloaded and stored at the Division of Human Genetics, University of the Witwatersrand, using the Digital Voice Editor 2 programme.

2.8 Data analysis

This research project is a cross-sectional comparative descriptive analysis with a small sample size (13). The in-depth data from the interviews were not amenable to statistical quantitative methods of analysis, apart from sample totals and percentages. The analysis, therefore, involved comparing responses from different companies and identifying areas of agreement and disagreement for various data sets. The different data sets included responses to the questions in the interview guide from the *insurer*s and

*reinsurer*s. In the interview guide a summary of the analysis performed for each question is detailed.

For the purpose of this study the practices of the reinsurance companies are considered as the industry standard. The results for the reinsurance companies were only reported on if the insurance companies' practices did not align with that of the *reinsurer*s' i.e. the industry standard, or if the actions of the reinsurance companies needed to be considered because of the impact on the functioning of the industry.

2.9 Ethics approval

Prior to commencing with the collection of data for this study an ethics application and research proposal were submitted to the Human Research Ethics Committee (Medical) for research clearance. Approval was obtained (protocol number M081038 dated 12/12/2008) and the respective certificate is attached in Appendix F.

The results and discussion of this research will be presented in Chapter 3.

Chapter 3: Results and Discussion

This chapter provides a summary of the data gathered during the interviews with the participants of the insurance and reinsurance companies. As the complete dataset obtained was too large to report on, the information was summarised and trends observed are reported. The results have been structured to follow the *underwriting* process from application stage to the *underwriting decision*, and do not follow the order of the questions in the interview guide. The specific questions that pertain to a section have been detailed. For reporting purposes the number of companies that align with a particular response will be expressed as the numerator of a fraction with the denominator being 8 for *insurer*s, 5 for the reinsurance companies and 13 for all participants. The discussion regarding the interpretation and analysis of these results has been included in this chapter for continuity.

3.1 Participants in the study

This section reports on the sample population, and establishes the eligibility of the participating companies and the level of homogeneity between them (questions A2 and A3 of the interview guide), to allow for optimal comparative analysis.

3.1.1 Study sample

The study sample consisted of 13 of the 15 eligible companies invited to participate, which included 8 life insurance companies and all 5 reinsurance companies. The participating life insurance companies were representative of the different company profiles related to the number of people they insure and the specialised products they provide. Of the 13 companies, 12 representatives were interviewed, and 1 reinsurance company provided written responses to the questions in the interview guide.

Two insurance companies declined to participate. One is among the top three largest insurance companies in South Africa, and the other is a relatively new insurance company that provides insurance benefits through the internet. Their participation would have been valuable as the larger company represents a large percentage of the *insured* population, and the new insurance company conducts their business in a unique manner (automated online application process) and it would have been useful to see the effect hereof on the *underwriting* process.

3.1.2 Occupations of the representatives

The positions held by the insurance company representatives interviewed included: 2 specialist underwriters, 2 underwriting managers, 2 underwriting operation managers, a national underwriting manager and a chief medical officer (CMO). For the reinsurance companies the participants included: 4 senior underwriters and a CMO.

3.1.3 Summary of the interviews

The interviews were conducted on the companies' premises and the average duration was 1 hour.

3.1.4 Confirmation of the eligibility and uniformity of life insurance benefits of the participants

The eligibility of the participants and their comparative value was confirmed by identifying the products they provide and underwrite, and that these products were similar in their definition.

All the insurance companies provided the benefits central to this study i.e. life cover, *disability benefit*s (capital and monthly) and a *critical illness benefit* (CIB). At application stage, all the companies performed *underwriting* for these benefits. The reinsurance

companies do not have their own products but align their practices with the insurance companies they insure, and therefore align with the participating insurance companies.

Differences that existed in the benefit definitions for the companies were identified by comparing their responses to question A3 of the interview guide to the benefit definitions and descriptions received from 7 of the 8 insurance companies.

The benefit definitions were largely consistent. Two major factors were identified that could influence the *underwriting* processes of the companies; these were the time period for the provision of the life insurance products and the type of CIB. There are two options available for the time period that cover is provided. One is *whole of life*, where cover is provided for the whole of the *insured*'s life or until *benefit expiry age*. The other is a *term policy*, where the cover is provided for a defined period of time e.g. 10 years. Only one *insurer* did not offer the latter option. Concerning CIB, this benefit was classified into two types, the core CIB and comprehensive CIB. The core CIB provides cover for four defined conditions; stroke, coronary artery bypass graph (CABG), heart attack and cancer. Only 3/8 of the *insurer*s offered this benefit. The comprehensive CIB provides cover for predefined medical conditions for all body systems. Differences noted for comprehensive CIB were in the conditions covered but these criteria are to be standardised across all the insurance companies by 1 September 2009 (ASISA, 2009a).

The responses confirmed that the companies were similar for criteria important to this study, such as benefits provided, benefit definition and *underwriting* practices.

3.2 The South African insurance industry's interpretation of genetic information

This study evaluated the *underwriting* approach of the insurance industry in response to the use of a *genetic test*. It was important to know the companies' definition of a *genetic test* as this would directly influence their *underwriting* practices. Based on this reasoning, it was of equal importance to establish the definition of a *genetic condition*, especially in relation to a *genetic test*. As one author commented "a mutant gene is not a disease" (Godard et al., 2003). The information used for this analysis was based on the responses to questions A1 and A6.

3.2.1 Definition of a genetic test

For this study the relevant definition of a *genetic test* was that stipulated in the LOA Code, "The direct analysis of DNA, RNA or chromosomes for the purposes of determining inherited predisposition to a particular disease or group of diseases"(LOA, 2001). Most of the companies' (10/13) definitions aligned with this definition and the remaining three related their definition to a study of gene products as a predictor of disease. This is not incorrect but for the purposes of this study their definition did not align with the LOA definition. Therefore prior to commencing with the interviews these participants were asked to use the definition detailed in the LOA Code.

3.2.2 Definition of a genetic condition

The participants were asked for their definition of a *genetic condition* to gain insight into their perception of the genetic disease processes and the value of a *genetic test*.

For this study a *genetic condition* was referred to as a heritable medical condition caused by a change in the genetic information (DNA, RNA, chromosomes and other regulatory factors). These conditions can be divided into two broad categories based on their

genetic inheritance, these are: single-gene (monogenic) or *multifactorial* (Turnpenny, 2005).

The participants found it difficult to provide an exact definition for a *genetic condition* because of the many variables that exist. Most of the participants defined a *genetic condition* as a heritable disorder (11/13), and considered them to be *monogenic* (4/13), *multifactorial* (4/13) or inclusive of both (5/13). When asked to provide a list of the *genetic condition*s specifically detailed on their application forms, the common examples provided by the *insurer*s were: diabetes, high blood pressure, heart disease, stroke, cystic fibrosis, liver disorders, polycystic kidney disease (PCKD), cancer, Alzheimer disease, porphyria, bleeding disorders and Huntington disease.

From their examples the participants appeared to understand that many medical conditions have a genetic basis. What was unknown was whether they understood that the *genetic mechanism*s of these conditions were not necessarily similar or fully elucidated. It was not clear whether they understood that *genetic test*s are only available for a limited number of conditions, and the level of prediction offered is restricted to the depth of knowledge of the genetic basis.

3.2.2.1 When a positive genetic test result denotes the presence of a genetic condition

Due to the *insurer*s' interpretation of a *genetic condition*, it was important to determine what defines a genetic condition in relation to the presence of a positive *genetic test*. At application stage the individual is required to disclose all relevant information to the *insurer* in order to assess their risk profile. This includes any pre-existing medical conditions, which in the context of insurance, is any medical or physical condition that the *applicant* has suffered from, has known about, received treatment for or has consulted a medical specialist for in the past. It was unknown under what circumstances the

companies' considered a positive *genetic test* result to be a medical condition in the context of this definition. This needed to be established because any misunderstandings could lead to perceived *genetic discrimination* or unintentional non-disclosure at application stage. Question A8 required that the participants confirm in which of three situations, an individual with a positive *genetic test*, would be considered as having a pre-existing condition. The results are detailed in Table 3.1.

As expected, all the participants considered a symptomatic individual with a positive *genetic test* (A8.2) to have the *genetic condition*. The responses for presymptomatic individuals were not as consistent. For an individual with a positive *genetic test*, who had received no treatment, 7/13 companies considered the condition to be pre-existing. Those that disagreed either considered it not to be pre-existing or were not certain but commented that they would base their decision on the predictability of the *genetic test*. The latter was a valuable comment as the greater the predictive value of the *genetic test* the greater the certainty that the individual will be affected by the condition.

Table 3.1: Conditions that define a positive genetic test as a pre-existing condition

Conditions	Pre-existing Condition								
	Yes		No		Unknown		Either		
	Insurers	Reinsurers	Insurers	Reinsurers	Insurers	Reinsurers	Insurers	Reinsurers	Factors
Question A8.1. ***Positive genetic test with no treatment or preventative management***	5	2	2	1		1	1	1	Yes - BRCA or HD and No to CVD - predicatbility of test. Dependent on inheritance pattern and penetrance
Question A8.2. ***Positive genetic test with treatment for the condition***	8	5							
Question A8.3. ***Positive genetic test with preventative management only***	7	3	1	1		1			

Likewise, for an *applicant* with a positive *genetic test* who had undergone preventative treatment, most of the *insurer*s (7/8) and *reinsurer*s (3/5) considered this to be a pre-existing condition, but one company was uncertain. This uncertainty regarding when to

define a presymptomatic individual, with a positive *genetic test* as affected, increases the risk of non-disclosure and *genetic discrimination*.

3.2.2.2 Required disclosure of genetic information at application for a life insurance policy

The lack of consensus about when an asymptomatic individual was considered as having the condition raised concern, as an *applicant* may unknowingly withhold information that they do not think is relevant to their application, and this may be interpreted by the *insurer* as non-disclosure. It was important to determine whether an *applicant* is afforded sufficient guidance and opportunity to disclose all information necessary. *Insurer*s were asked to provide a copy of their application form to assess whether the questions are constructed in such a manner that the individual would know to disclose that a *genetic test* had been performed. Application forms were provided by 6 of the 8 *insurer*s. The questions in the application forms were assessed and the outcome was that the questions in the application forms prompted the applicant to disclose when a *genetic test* result is available. It is therefore reasonable to consider that an applicant has knowingly withheld this information if they do not mention the availability of these tests.

3.2.2.3 Risk of genetic discrimination for presymptomatic individuals

A positive *genetic test* for an individual presymptomatic for a condition is a criterion used to detect *genetic discrimination* (Hall & Rich, 2000). Among the companies there was no consensus as to when a presymptomatic person with a positive *genetic test* is considered to have the condition. This illustrates an increased risk for the *insurer* to act in a manner that may be perceived as discriminatory. No distinction was made on the genetic basis of the condition, which can be predictive of the condition occurring (single gene disorders) but variable based on *penetrance*, or indicative of susceptibility only (*multifactorial*) (Godard et al., 2003). These outcomes suggest that a risk for the establishment of a new

subclass of *applicant*s, the “healthy ill”, exists (Bennett & Smith, 2007). It was therefore of value to establish the *underwriting* practice of *insurer*s in response to *genetic test*s to determine the effect on the individual’s ability to access cover.

3.3 Underwriting practices and protocols

This section focuses on the initial phase of the *underwriting* process, when information to assist with risk assessment is requested by the *insurer*. To determine whether *insurer*s behave differently in response to *genetic information* versus non-genetic information, their *standard underwriting requirements* were established (using the responses to question A4). These were then compared with the requirements needed in response to *genetic information* received (question A5). Any differences between the *underwriting* requirements needed in response to genetic and non-genetic information that could not be demonstrated to be of *actuarial relevance*, could indentify an area of risk for *genetic discrimination*.

3.3.1 Underwriting requirements in response to all types of information

The *standard underwriting requirements* are the initial information received at application stage prior to the insurance company performing any evaluation of the *applicant’s risk*. For all the participating companies these requirements were the same and included a completed and signed application form, an HIV test and a cotinine test (for non-smokers). Most of the *insurer*s (6/8) would request additional requirements in response to information received and the presence of relevant *underwriting* risk factors such as: benefit type, *benefit amount*, *applicant*’s medical history (as disclosed on the application form), family history and *applicant*’s age. The relevance of these factors was defined by their relationship to a specific medical condition. Additional requirements may include medical reports, medical examinations, questionnaires or additional pathology tests.

3.3.2 Underwriting requirements in response to genetic information

To establish the companies' *underwriting* approach to *genetic information*, the companies were asked (question A5) to detail the additional *underwriting* requirements needed in response to a family history (FH) or a *genetic test* result (result not provided), for a medical condition, separately. The conditions used were Huntington disease (HD), breast cancer (BrCa), haemophilia (HP) and cardiovascular disease (CVD). Their response options included: no additional information, additional information, additional information based on risk factors, the risk factors used, and the type of additional information required. A detailed summary of the *underwriting* practices for all the companies is provided in Appendix G. These results were then assessed to determine if they differed from the standard *underwriting* protocols.

3.3.2.1 Underwriting approach to a relevant family history for a medical condition

The *underwriting* requirements in response to a FH of a medical condition were in keeping with the standard practices. This was expected as the use of a FH is not new to the *underwriting* process. Additional *underwriting* information was requested based on risk factors such as a relevant FH of the condition and the *applicant*'s age, medical history and state of health. A family history where different members have been diagnosed with the same medical condition can be used to assess the risk of other family members being affected. If this risk is deemed to be high, then in the context of insurance the individual is said to have a strong or *relevant family history* for the respective disease. Criteria used to define a *relevant family history* included the relatedness of the affected individuals to the *applicant* and their age at diagnosis or death.

3.3.2.1.1 Underwriting risk factors

The criteria for the two main risk factors, relevant FH and age of the *applicant*, in relation to the examples of medical conditions used in this study have been summarised in Table 3.2.

Table 3.2: Detail of the underwriting risk factors provided by the participating companies in response to medical conditions

Medical condition	Age of Applicant		Family history		Other Risk Factors
	Age	Effect on requirements	Relatedness	Age of diagnosis/death of relative(s)	
Huntington Disease	Greater than a defined age (45, 50 or 55 years)	Waive requirements	-	-	-
Breast Cancer	> 50years	Waive requirements	>1 first degree relative (FDR)	Less than a defined age (40, 50, 55, or 60 years)	Gender (males excluded by 2 insurers); benefit type (CIB as it provides cover for cancer); prophylactic treatment
Haemophilia (affected)	-	-	-	-	Gender (males only)
Cardiovascular disease	Less than a defined age (30, 35, 40 or 50 years)	Reduce the stringency of requirements	>1 relative	Less than a defined age (45, 50, 55 or 60 years)	-

It was noted that there was little uniformity among the *insurer*s in the criteria used to define the risk factors. This was particularly evident when considering factors such as the age of the *applicant* and the age of diagnosis for family members relevant to a FH.

For example, the age of the *applicant* affects the type of *underwriting* information required for HD. If older than a specific age then the requirements are less onerous. It is not clear how *insurer*s determined at what age individuals are at a significantly reduced risk to develop HD, but for *insurer*s this age ranges from 45 to 55 years. It is assumed that this age is perceived to be the maximum age of risk for HD, and that the *applicant* is less likely to develop HD after this defined age. This may be based on the fact that the average age of onset for HD has been described to be between 35 and 44 years. However it is of significance that 25% of cases have an onset age over 50 years (Warby et al., 2007).

Inconsistencies in the ages used to define relevant risk factors were also noted in the criteria for a strong FH, relating to the *applicant*'s current age and age of diagnosis of BrCa and CVD. A FH of HD can be used to determine the potential age of onset in a presymptomatic individual yet FH risk factors are not considered for HD (Warby et al., 2007).

3.3.2.1.2 Additional underwriting information required in response to a relevant family history

The additional information requested would be more onerous should the family history meet the criteria detailed in Table 3.2 and included a personal medical attendant's report (PMA), medical report, medical examination and/or a questionnaire, and pathology tests, as per the *standard underwriting requirements*. The purpose of these would be to obtain insight into the individual's medical history and state of health. Details of the requirements are provided in Table 3.3.

Table 3.3 : Detail of the additional underwriting information requested in response to a family history

Medical condition	Reason for requesting a PMA/Medical report/Medical examination/Questionnaire	Pathology Test
Huntington disease	Determine whether genetic test performed	Would not request that a genetic test be performed
Breast cancer	Obtain detail of cancer history and/or screening history e.g. mammograms	Would not request that a genetic test be performed
Haemophilia (Affected)	Disease management, treatment and complications	Would not request that a genetic test be performed. Request disease related tests; full blood count, partial thromoboplastin time, erythrocyte sedimentation rate (ESR) and /or clotting factors
Cardiovascular disease	Medical history and status; resting and effort electrocardiogram (ECG)	Would not request that a genetic test be performed. Request disease related tests; cholesterol and/or glucose

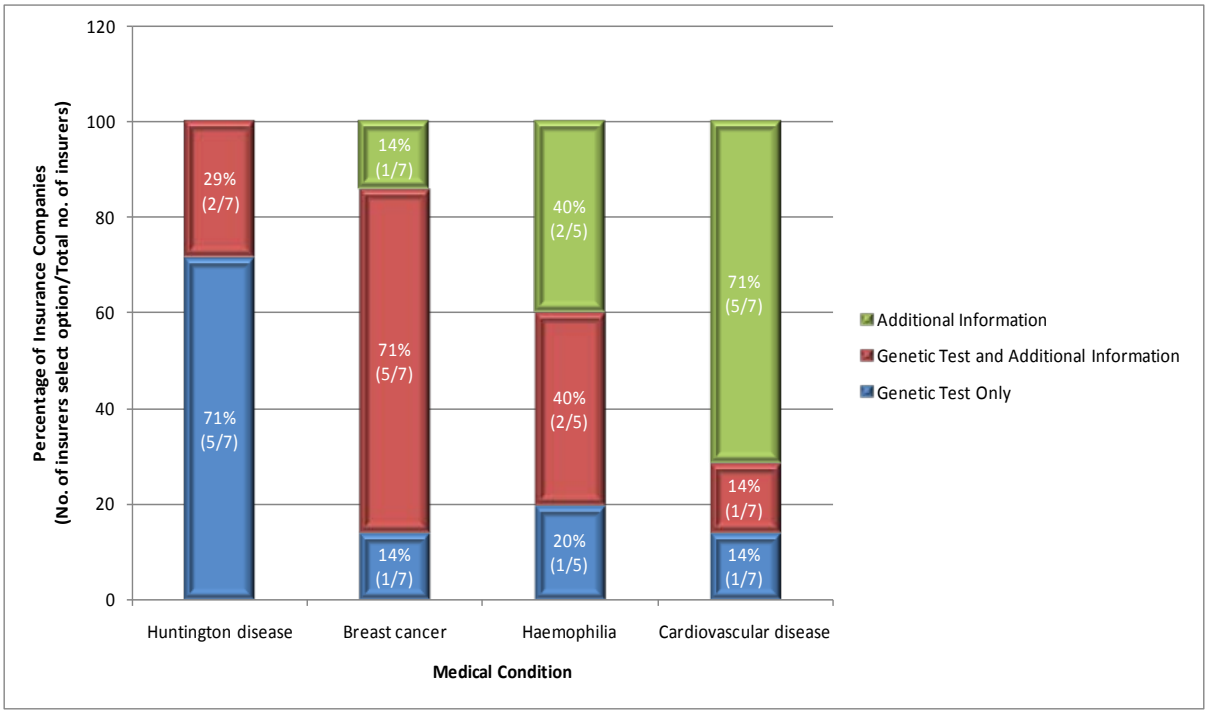
Overall, the type of additional information requested was to obtain more information relating to the medical condition. All the companies aligned with the LOA Code as they did not request that a *genetic test* be performed for *underwriting* purposes. Many *insurer*s refrained from enquiring directly whether a *genetic test* had been performed, and would trust that they would be informed thereof based on information detailed in the PMA.

The *underwriting* response to a family history does not appear to prejudice the *applicant* as the standard requirements were applied. The researcher feels that to reduce the risk of anti-selection, *insurer*s should align their criteria for *underwriting* factors so that *applicant*s will not be able to 'shop-around' for the most lenient approach. This does not impact on their market competitiveness as this does not affect their product design. The

opposite also applies in that by consolidating the definitions it will prevent *insurer*s from interpreting the relevance of a family history differently which could prejudice the *applicant*.

3.3.2.2 Underwriting approach to a genetic test result

Although family history (FH) is a criterion not new to the *underwriting* process, the availability of a *genetic test* result is, and it was important for the researcher to assess whether the companies' approach differed in response to this information. These responses have been summarised in Figure 3.1.



Please note: In reporting on haemophilia the response of two insurance companies were excluded as they had considered the applicant as unaffected, and no additional information was required

Figure 3.5: Genetic test result: Underwriting response for specific medical conditions

In most instances, the additional *underwriting* requirements in response to a *genetic test* result were the same as that for a high risk FH. The only difference to FH was when a copy of the *genetic test* result was requested. The predictive value of a *genetic test* was expressed by the need for information in addition to the test result to make an *underwriting decision*.

The *insurer*s' responses accurately reflected the predictive nature of the respective *genetic test*s and the importance of considering the inheritance pattern of the disease, as has been previously discussed in section 1.2.2, Pg.6. All *insurer*s considered the HD gene test to be the most predictive, and the gene test for BrCa less so, as they would require additional information for risk assessment. It is known that the level of prediction differs between the HD and BrCa *genetic test*, based on *penetrance* as HD is fully penetrant whereas BrCa is not. The positive result from a BrCa gene test confers a risk of 40% to 85% of developing breast cancer. If the *gene fault* is unknown in the family, then a negative test does not alter the risk of BrCa making a relevant FH more important in risk assessment (Petrucelli, Daly, & Culver, 2007). Thus additional information including detail of disease screening and *prophylactic* treatment was important to assess risk.

The *genetic test* results for HP and CVD were shown to be of little value to the *insurer*s, as additional information relating to symptoms of these diseases was more relevant for the assessment of risk. The risk profile for an individual diagnosed with an early-onset condition such as HP was based predominantly on the severity of the condition and any related complications. This was the same for a *multifactorial* condition such as CVD. Many genes have been identified which confer a susceptibility to CVD, but each with a very small contribution to risk and overall they do not equate to a high percentage of risk (Janssenns, Gwinn, Bradley, Oostra, van Duijn et al., 2008). Therefore the standard tests and requirements relating to lifestyle and medical status are of greater predictive value.

This was summed up in a comment by one of the underwriters, who, with reference to the use of cholesterol tests and medical history for CVD risk assessment stated, “There isn’t an alternative available yet...for us the jury is still out (re genetic tests)...there isn’t statistical evidence...”.

One *insurer* differed from the others in that all the *genetic test*s were considered to be predictive of risk, and stated that they would base their decision on this information alone. The reasoning was that individuals will access preventative care, should they test positive. This demonstrates a poor insight into the *genetic mechanism*s of disease.

In summary, the *underwriting* requirements in response to non-genetic and *genetic information* were similar, except when a highly predictive *genetic test* result was available. The value of the *genetic test* seemed to be based on the participants’ adequate understanding of the predictive value of the tests related to the inheritance of the *genetic condition*s. However, one *insurer* did not share this understanding.

3.3.2.3 Underwriting approach to a rare genetic condition

The medical conditions used as examples in the interview guide, although rare, represent topics that are often encountered within the health profession, in the general press and the insurance industry. It was important to determine whether the companies’ *underwriting* approach towards *genetic information* remained fair and consistent in response to an unknown *genetic condition* (Question A6.2).

When asked for their response to an unknown *genetic condition*, the insurance companies all agreed that they would seek advice on how to proceed. This included checking the reinsurance *underwriting* manual(s), referring to their senior underwriter, CMO and/or their reinsurance company. Only a few CMO’s have genetic experience as

detailed in Appendix J. Some mentioned that they would contact the pathologists or specialists who had made the diagnosis.

Based on the responses from the *insurer*s, it was evident that the reinsurance companies provide specialist support to the insurance industry. Therefore details of whom they would contact for advice were considered. The *reinsurer*s' responses were that they would consult with their CMO, their international offices and/or international specialists. It is evident from these responses that the *insurer*s are likely to respond to unique *genetic information* in an appropriate manner.

The LOA Code and the ASISA Standard both confirm that they would provide support to the industry regarding the use of *genetic test*s for risk assessments, yet none of the *insurer*s mentioned this option.

3.4 Underwriting decisions

It has been demonstrated that the *underwriting* approach towards *genetic information* aligns with the standard practices of the insurance companies, except when the *insurer* has been informed that a predictive *genetic test* result is available (refer to section 3.3.2.2, Pg.48). All these responses were also shown to conform to the guidelines as detailed in the LOA Code. It was therefore important to establish how this *genetic information* was used to make an *underwriting decision*. The decision making process incorporates other factors that affect the *applicant's risk* profile (age, occupation, health history), the benefit options selected and the *benefit amount*, in addition to the *underwriting* information received.

3.4.1 Underwriting decisions based on information received regarding a specific genetic condition

In question A7, *insurer*s and *reinsurer*s were asked to provide their *underwriting decision* for a specific benefit, based on the type of underwriting information received for a medical condition. The medical *underwriting* information included; *genetic information*, a family history (FH) and a positive *genetic test* (GT). The non-genetic information included a medical history of the disease (symptomatic or asymptomatic) (MH) and a combination of both a family history and a medical history of the disease (symptomatic or asymptomatic) with no diagnosis in the application form (FHMH). The examples of medical conditions used in the study were in keeping with those detailed in section 3.3.2. The choice of *underwriting decision*s were: *standard rates* (SD), to increase or *load* the *premium* (load), to *defer*, to *decline* the benefit (decline), to apply an *exclusion* on the *policy* for the specific medical condition (exclusion) or to offer a *term policy*. Their responses were analysed to assess what effect the type of *underwriting* information received, the *genetic condition* or the benefit type had on the *underwriting decision*.

The representatives sometimes provided more than one *underwriting decision* for each type of information received, because they had incorporated risk factors into their decision making process, such as those detailed in section 3.3.2.1.1. Therefore the total number of responses for each type of *underwriting* information received could exceed the number of companies participating, but the total for a specific *underwriting decision* would not exceed the total number of participating insurance (8) or reinsurance (5) companies.

3.4.1.1 Underwriting decisions for a specific genetic condition

For each medical condition, the insurance companies' *underwriting decision*s were compared for each benefit type. This provided insight into the impact that the information had on the decision which was based on the risk exposure for a particular benefit. The

results are discussed separately for each medical condition, and histograms (Figure 3.2, Figure 3.3, Figure 3.4., and Figure 3.5) summarise the results. Appendix H provides the *insurer*s detailed responses for each medical condition.

3.4.1.1.1 Huntington disease

Huntington disease is an autosomal dominant, late-onset neurodegenerative disease. There is a 50% chance for offspring from an affected parent to have inherited the *mutation*. If the disease causing *mutation* is identified in an individual there is a 99.9% risk of developing the disease, showing virtually full *penetrance*. The symptoms of this condition include progressive functional neurological impairment and mental disturbances including severe depression and personality changes (Warby et al., 2007). Due to these symptoms, the likelihood that an affected individual would be eligible for a disability and/or CIB is high. Death occurs within 15 to 20 years from onset of the symptoms, thus the age of mortality is dependent on when these symptoms first occur. Due to the age of onset being variable, the presence of HD will only affect the standard mortality calculations should the age of onset be more than 15 to 20 years prior to average mortality age. A summary of the *insurer*s *underwriting decision*s for HD is detailed in Figure 3.2. and in Appendix H.1.

For HD, the *life cover benefit* provided the greatest opportunity for an individual to access cover, for which the most favourable terms were afforded for when there was only a FH of HD and these were to *load* or offer a *term policy*. For the other forms of *underwriting* information received, the common decision was to *decline* the *life cover benefit*, probably because the information provided was perceived to be more predictive of disease. As expected, these decisions were influenced by risk factors such as the age of the *applicant*. If the *applicant* was older than a defined age, the terms applied were more favourable, confirming the assumption of reduced risk for the *insurer* as discussed in section 3.3.2.1.1., Pg.45.

The favourable response to a FH for a *life cover benefit* was unusual as internationally the terms applied to a FH are to *decline* the benefit whereas for a GT the *policy* would be *load*ed or offered as a *term policy*, regardless of benefit or insurance type (Hall & Rich, 2000; Bombard et al., 2009). It is unknown why the results differ. It may be that these study results were in response to life cover only and perhaps the *insurer*s are more willing to carry this risk compared to disability and CIB.

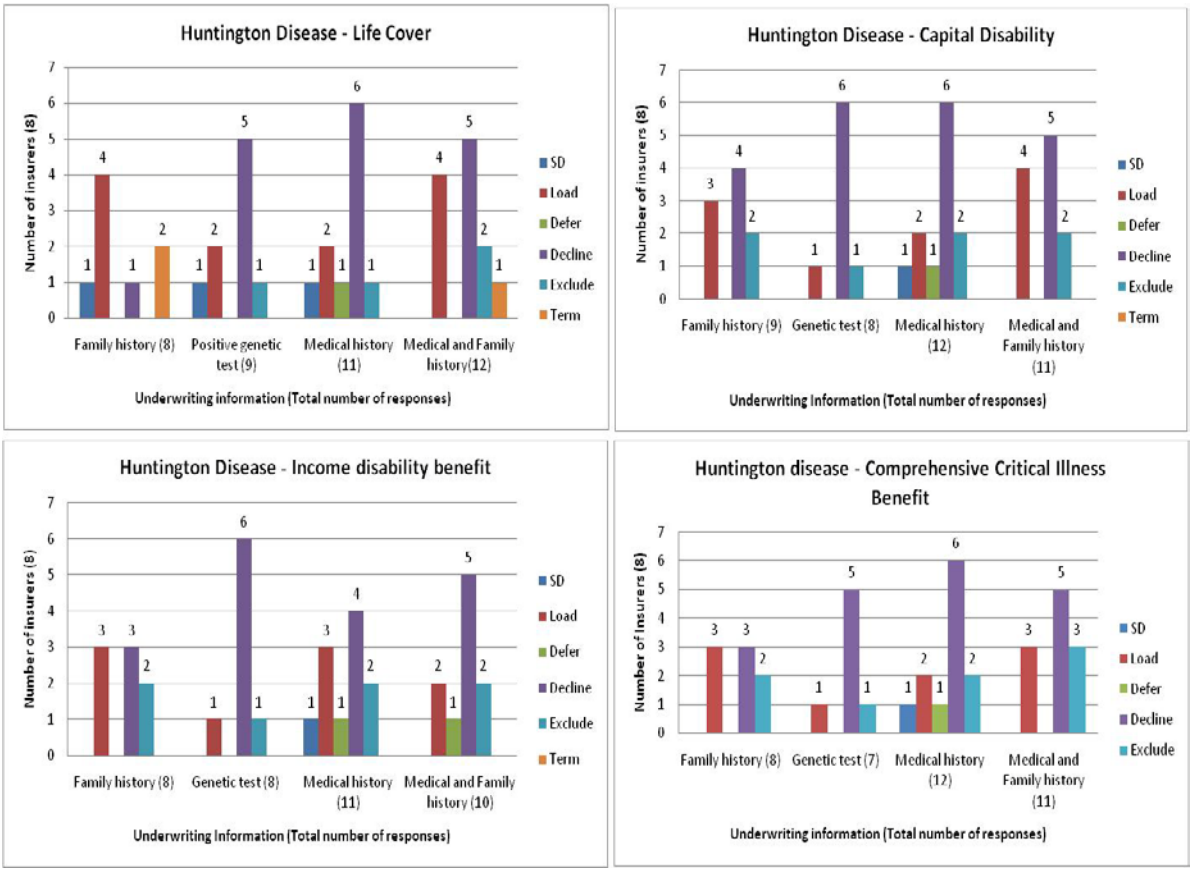


Figure 3.2 : Insurers underwriting decisions for Huntington disease

The standard *underwriting decision* for both the *disability benefit*s and the comprehensive CIB was to *decline* cover, regardless of the type of *underwriting* information used. When the *applicant*'s age was considered favourable then *policy* terms were applied - to *load* a *disability benefit* and apply an *exclusion* to the comprehensive CIB. *Standard rates* were

seldom offered, confirming that HD is viewed as a seriously debilitating illness. The core CIB was declined except for in response to FH, even though this benefit does not provide cover for HD.

The *insurer*s' response to a *genetic test* for HD confirmed its predictive value as decisions were defined by whether the result was positive or negative. This is considered to be the correct approach provided that the testing was performed by a reputable genetic service, as there are criteria that will determine the testing procedure for the individual at risk. These include; confirmation of the disease in the family, the population group that the individual is from (determines which gene to test), the gene (there are two genes associated with Huntington-type disease i.e. HD1 and HDL2) and the *mutation* (the results vary in their level of prediction, such as the number of repeats noted in the *HD* gene) (Warby et al., 2007).

An alternative to declining benefits was to offer a *term policy*. Two of the 7 *insurer*s provided this option, but for a *life cover benefit* only. According to a participant from one of the *reinsurer*s, the insurance companies in New Zealand may not *decline* cover based on a positive diagnosis of HD. Therefore the alternatives they provide are to apply a *load*ing or offer a *term policy*.

The *underwriting* response to HD is in keeping with the disease process, its inheritance pattern and the predictive value of the *genetic test*. Thus people with a family history of HD would find it difficult to obtain life insurance in South Africa. The *insurer*s respond favourably to a negative HD *genetic test* result and the researcher feels that this may be viewed as coercion for an individual to be tested. Alternate benefit options should be explored for individuals requiring financial protection, such as those reported for New Zealand.

3.4.1.1.2 Breast cancer

Familial breast and ovarian cancer syndromes represent 5 to 10% of all breast cancers (Petrucelli et al., 2007). The most common genes associated with these syndromes are *BRCA1* and *BRCA2*. *Mutation*s found in either of these genes confer a risk of 40% to 85% of breast cancer, hence *penetrance* is variable. Importantly, these *mutation*s also predict the risk of ovarian cancer with a risk which ranges from 10% to 60% (Evans, Kerr & Lalloo, 2006; Evans, 2006). A negative *genetic test* in an individual from a family where the *mutation* in one of these genes has been identified, negates the individual's risk of hereditary cancer, yet a negative test in a family where the *gene fault* has not been identified does not. A summary of the *insurer*s *underwriting decision*s for BrCa is detailed in Figure 3.3. and Appendix H.2

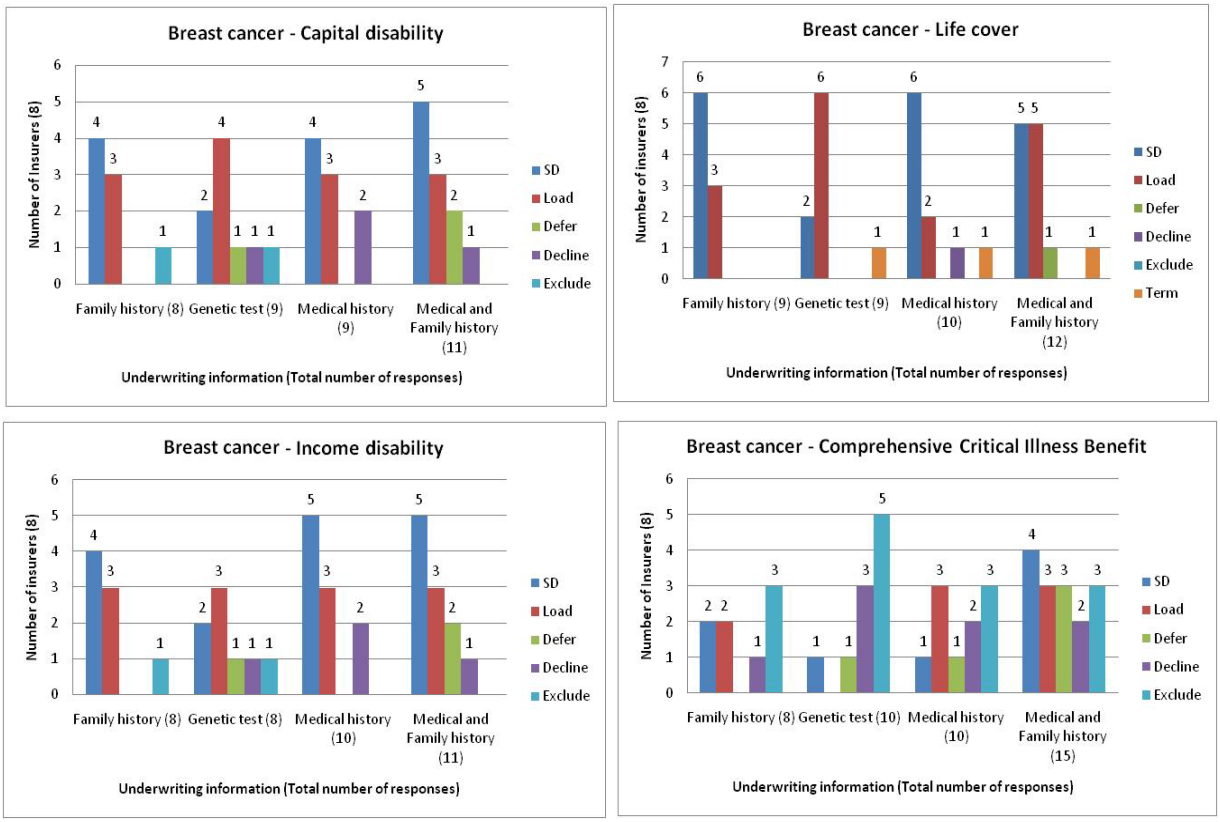


Figure 3.3 : Insurers underwriting decisions for breast cancer

The *standard underwriting requirements* played a major role in the decision making process for BrCa, and these included cancer history (regardless of whether the tumours were benign or malignant), results from screening tests such as mammograms, histology results from biopsies, *prophylactic* surgery, time of diagnosis, cancer treatment, period of remission and age of *applicant*. Two of these, cancer screening and *prophylactic* treatment, align with the ASISA standard on genetic testing which stipulates that *insurer*s should take this information into consideration when assessing risk (ASISA, 2009b) . Only one company requested information relating to prophylactic treatment.

The insurance benefit with the most favourable terms for BrCa was the *life cover benefit*, where for all types of *underwriting* information, except GT, the benefit was offered at *standard rates*. This pattern was repeated for the *disability benefit*s and CIB. Terms were applied when risk factors like a relevant FH of BrCa existed, and as noted for HD, the *disability benefit*s were *load*ed and an *exclusion* was applied to the CIB.

In the process of making an *underwriting decision* most companies considered the results from a cancer screening test, such as a mammogram, but they did not appear to take note of the benefits of *prophylactic* surgery, as detailed in section 1.2.2, Pg.8. A mastectomy was the *prophylactic* treatment considered by one *insurer*. For this *insurer, standard rates* are offered for all benefits if the *applicant* has a GT, MH or a FHMH of BrCa, no history of cancer and has had *prophylactic* mastectomy. If no *prophylactic* mastectomy was performed, then terms would be applied. This protocol highlights the value of a FH when assessing risk and that these individuals would also benefit from *prophylactic* treatment (Petrucelli et al., 2007). Thus the definition of a *relevant family history* is of utmost importance. One of the underwriters even commented that "preventative measures are to her advantage" but interestingly this *insurer*'s *underwriting* practice does not consider *prophylactic* surgery.

An important observation is that none of the insurance companies considered the associated risk of ovarian cancer. The researcher thought that the *insurer* that considers *prophylactic* mastectomy in their *underwriting* process may be vulnerable due to the unaccounted risk of the *applicant* developing ovarian cancer.

The *underwriting* information that attracted the least favourable *underwriting decision* was a GT, suggesting that *insurer*s' believe that a GT is more predictive of risk than a FH, MH or FHMH. This is an unexpected outcome compared to previous observations (section 3.3.2.2) and the reasons for this are unknown. The researcher feels that the consequence of these reported behaviours could result in an individual deferring genetic testing to obtain favourable terms for a *policy* based on FH only.

3.4.1.1.3 Haemophilia

HP is an early-onset X-linked condition (Turnpenny & Ellard, 2005). A *genetic test* result for HP carries little value for risk assessment because the diagnosis is made on symptoms and the individual will be symptomatic. The only information that affects the *insurer*s' decision process is the individual's medical history. A summary of the *insurer*s *underwriting decision*s for HP is detailed in Figure 3.4. and Appendix H.3.

The insurance companies responded with *underwriting decision*s that pertained to affected and unaffected individuals. The responses relevant to this study were for individuals affected with HP, thus all the decisions were made by considering the standard risk factors, including the individual's health status and complications associated with HP. The *life cover benefit* was provided at *standard rates* if the affected individual was well managed and had no complications. The terms applied for a personal disease history were to *load* or offer a *term policy*. In response to other forms of *underwriting* information, the most common decision applied was first to *load*, and then less frequently to provide the benefit at *standard rates* or *decline* the *policy* based on the risk factors.

This pattern of *underwriting decision-making* was observed for both of the *disability benefit*s and the comprehensive CIB. The only difference was for the core CIB, where one *insurer* offered the benefits at *standard rates* and the other *load*ed the *premium*s. The reason for this varying response was unknown especially as the benefit does not provide for haemophilia.

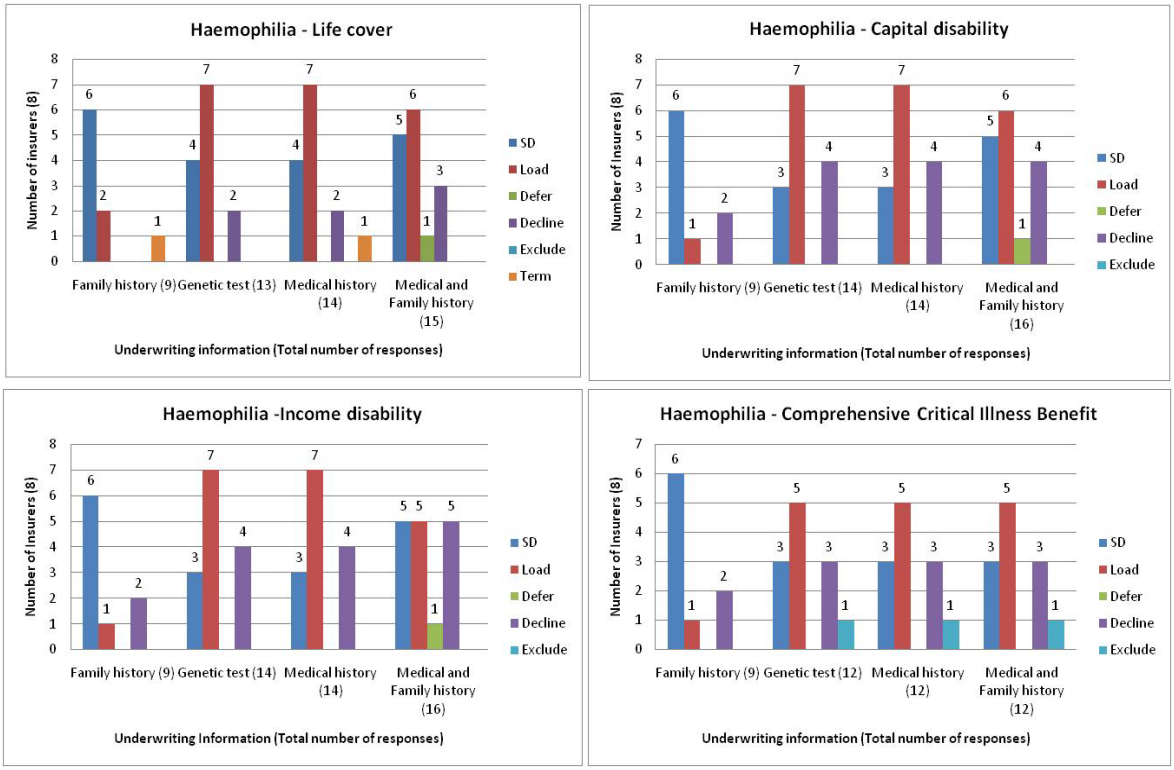


Figure 3.4 : Insurers underwriting decisions for Haemophilia

The benefits that were relevant to an affected individual with HP were disability and CIB, as both provide cover for complications associated with HP such as functional impairment resulting from joint bleeds.

3.4.1.1.4 Cardiovascular disease

CVD is a *multifactorial* disease where the predictive value of the *genetic test*s available is reported to be limited (Janssenns et al., 2008) and risk assessments are currently based on the medical status of the individual. CVD is a common medical condition known to affect many South Africans, where in 2000, 16.6% of total deaths were attributed to CVD (Bradshaw, Groenewald, Laubscher, Nannan, Nojilana et al., 2003). Therefore it is understandable that adverse terms are applied to all benefits should the risk of this disease exist. A summary of the *insurer*s *underwriting decision*s for CVD are detailed in Figure 3.5. Appendix H.4.

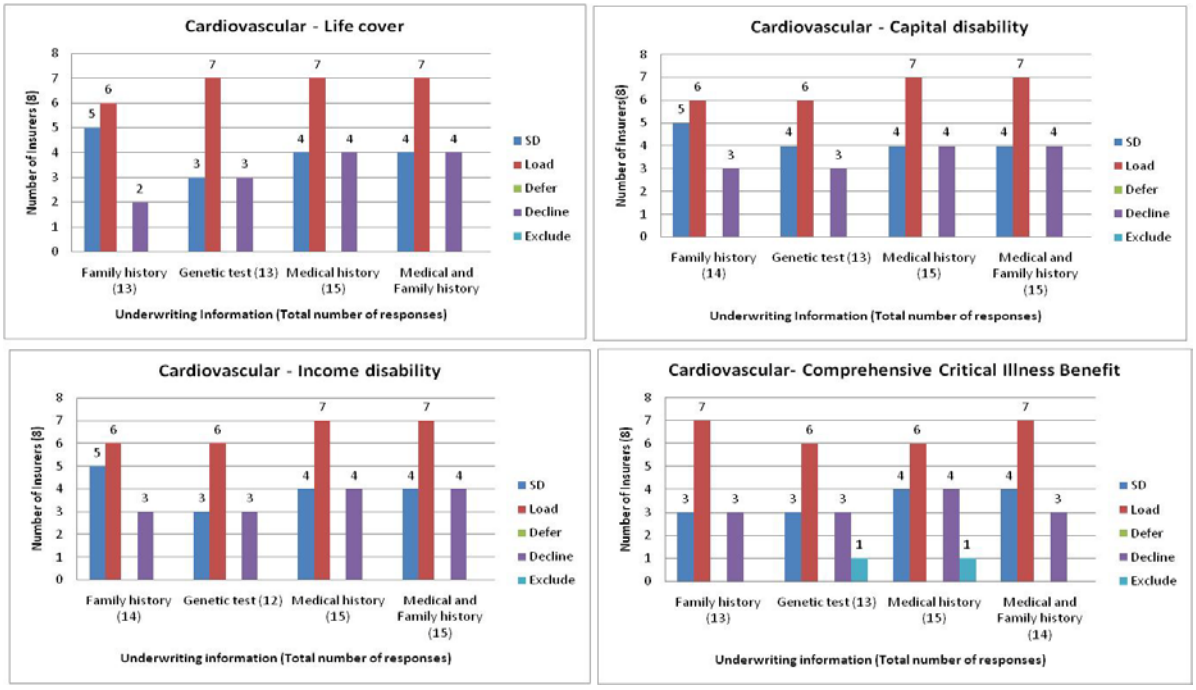


Figure 3.5 : Insurers underwriting decisions for cardiovascular disease

The decision making process in terms of CVD was founded on the *underwriting* risk factors such as the strength of the FH, the individual's personal CVD risk factors such as the *applicant*'s age (greater than 45 years), medical history and health status at application stage i.e. cholesterol levels, ECG results, and behavioural risk factors e.g.

smoking status. In response to a high risk profile for CVD the *underwriting decision* was either to *load* or *decline* the insurance *policy* based on severity. The decisions were not affected by the type of information received nor the benefit type, but by the health status of the individual and the associated risk factors.

3.4.1.2 Comparison of underwriting decisions for different types of life insurance benefits

Differences in the most common *underwriting decision*s for each benefit type across the four medical conditions were identified and the outcomes are summarised in Table 3.4. All the trends of the underwriting decisions have not been discussed because of the influence of other factors in the decision making process as detailed in section 3.4.

Regardless of the benefit type or the information received, the medical condition with the most adverse *underwriting decision*s was Huntington disease. This confirms the *insurer*s' awareness of the associated debilitating symptoms of the disease and the high predictive value of the *genetic test*. It also highlights that these individuals may not be able to access life insurance.

The most favourable *underwriting decision* for all benefits and medical conditions was in response to a FH. This was an unexpected outcome especially for a relevant FH, as one author commented "most high risks relevant to life insurance are revealed in family history" (Godard et al., 2003). Therefore it is important that the criteria used to define a relevant FH are appropriate for the specific condition otherwise it may increase the risk of exposure of the *insurer*. Likewise, because the criteria for a relevant FH were shown to differ for companies, that the chance of risk exposure for the *insurer* through the *applicant* 'shopping around' for lenient *underwriting* was increased and it would therefore be beneficial if the criteria were uniform for all *insurer*s.

Table 3.4: Common underwriting decisions for the different life insurance benefits for the different medical conditions

Benefit Type	Underwriting Information Received	Common underwriting decision for specific medical condition			
		HD	**BrCa**	**HP**	**CVD**
Life cover benefit	***Family history***	L	SD	SD	L
	Positive Genetic Test	D	L	L	L
	Medical History	D	SD	L	L
	Family and Medical History	D	SD/L	SD/L	L
Capital disability benefit	***Family history***	D	SD	SD	L
	Positive Genetic Test	D	L	L	L
	Medical History	D	SD	L	L
	Family and Medical History	D	SD	L	L
Income disability benefit	***Family history***	L/D	SD	SD	L
	Positive Genetic Test	D	L	L	L
	Medical History	D	SD	L	L
	Family and Medical History	D	SD	L	L
Comprehensive CIB	***Family history***	L/D	E	SD	L
	Positive Genetic Test	D	E	L	L
	Medical History	D	E	L	L
	Family and Medical History	D	E	L	L

Note: L – Load; D-Decline; SD-Standard rates; E – Exclude; HD – Huntington disease; BRCA – Breast cancer; HP – haemophilia; CVD – cardiovascular disease

The *underwriting* responses are mostly appropriate for the information received but there are exceptions as described for FH e.g. breast cancer. It was evident that the type of information received does affect the *underwriting decision* and, as previously noted, variables related to the presence of risk factors need to be taken into consideration

throughout the decision-making process. The researcher suggests that these risk factors should be defined and consolidated in accordance with specialist knowledge available to protect the *insurer*s. Currently, these definitions are not consistent across the companies.

3.4.2 Reconsideration of an adverse underwriting decision in response to a negative genetic test result

A large portion of this study focused on the *underwriting* response to a positive *genetic test*. Of equal importance was to determine the *underwriting decision* in response to a negative *genetic test*, especially after an adverse *underwriting decision* had been made (question A10). The responses would also confirm the companies' perception of the predictive value of the *genetic test*. Their responses are summarised in Table 3.5

Table 3.5: Insurance and reinsurance companies underwriting responses to negative genetic test results

Condition	Adjust Underwriting Decision				Underwriting Decision	Decision Unknown
	Yes		No			
	Insurer	Reinsurer	Insurer	Reinsurer		
HD	8	5			7/8 insurers and 5/5 reinsurers would apply standard rates	1
BRCA	8	5			7/8 insurers and 5/5 reinsurers would apply standard rates. However one reinsurer commented that if the family history is strong they would load the policy	1
CVD		2	8	3	Rate according to other factors such as ECG, cholesterol. One reinsurer would consider the genetic test results but in conjunction with standard medical information	

All of the participants agreed that they would reassess any previous adverse *underwriting decision* on receipt of a negative *genetic test*, provided that the predictive value of the *genetic test* was informative.

This response aligns with a clause in the ASISA Standard on Genetic Testing which states that "The applicant may ask the *insurer* to review any adverse *underwriting decision* based on a relevant predictive genetic test result" (ASISA, 2009b) and that the

individuals are not granted *premium*s that are less than the standard rate (LOA, 2001; ASISA, 2009b).

Of interest, was the interpretation of the predictive value of the *genetic test*. The interpretation of the HD *genetic test*s was the same as previously noted. However, the BrCa test was incorrectly considered as highly predictive as many *insurer*s would make a decision without considering other risk factors. This indicates that the *insurer*s do not understand that a negative *genetic test* for BrCa does not necessarily reduce the risk of BrCa where a family *mutation* has not been identified. In these circumstances other risk factors, such as the relevance of the FH, should still be considered. Many *insurer*s and *reinsurer*s would not use a CVD *genetic test*, and this would be appropriate because these *genetic test*s are of little predictive value. However one *reinsurer* commented that they would use the *genetic test* result to finalise a decision, thus alluding to a belief that this test has high predictive value.

This variance in the interpretation of the predictive value of a *genetic test* is concerning, as the risk assessment is directly affected by the level of prediction afforded by the test. The value of a *genetic test* is also influenced by other factors such as the population group of the *applicant*, the gene analysed for the disease causing *mutation*s, the association of this gene with the respective medical condition, the fault detected by the gene analysis, the interpretation thereof and the availability of the tests (Godard et al., 2003). These factors are not taken into consideration by the *insurer*s.

When evaluating the use of a *genetic test* for the purpose of insurance *underwriting* it is important to consider the above factors. The role of ASISA is to obtain information relating to the validity of the tests being used and to have a list of those that should not be used (ASISA, 2009b). The researcher contacted ASISA and requested details of the criteria used by them to evaluate the tests and for the respective list of these tests. Their

response was that the information was not available. It is therefore unknown what criteria are used to assess the value of a *genetic test* for the industry, what tests are considered useful and which ones should not be used.

The researcher thinks that it would be valuable for the insurance industry to have specialist advisors to interpret these test results, because of their complexities, and that the value of genetic services in this process should not be underestimated.

3.5 Underwriting behaviour in response to hypothetical case studies

The participants were provided with hypothetical case studies (section C) for three medical conditions, HD, BrCa and CVD. Each case had questions relating to the *underwriting* practices of the company as established through section A of the interview guide). The companies' responses were then reviewed to assess their *underwriting* behaviour in comparison with their standard protocols and theoretical *underwriting decision*s (as summarised in section 3.4). These questions also provided insight into the *insurer*s' knowledge of the medical condition and the *genetic information*, and their ability to apply this to the case. Their responses have been summarised in Tables 3.6, 3.7 and 3.8, and the number of companies' whose responses align with their specific *underwriting* protocol is expressed as a fraction.

3.5.1 Hypothetical case study I: Huntington disease

For details of this case study please refer to hypothetical case I in the interview guide (Appendix B). This case study was regarding two brothers, both over the age of 30 years. They were both applying for life insurance benefits. Their father had been diagnosed with HD at the age of 55 years and the one brother had a medical history of tremors and memory loss that his doctor ascribed to stress. The responses to questions 1 to 9 relating to this case are detailed in Table 3.6.

Table 3.6: Results from hypothetical case study I: Huntington disease

Question	Align with the company's standard protocol	Detail of response	Other
Q1. Additional requirements FH of HD	7/8 and 4/5	PMA Availability of HD genetic test result	None requested genetic test
Q6. Additional requirements FHMH	7/8 and 5/5	Information regarding symptoms (tremors, memory loss and stress)	1/8 previously required additional information, but now base decision on FHMH and decline
Q2. Underwriting decision FH of HD	6/8 and 3/5	Decline or apply a term policy	Changes to decision - favourable to applicant
Q7. Underwriting decision FHMH of HD	6/8 and 2/5	Decline or defer	An alternate option to decline was to defer or offer terms (3/8)
Q4. & Q8. Underwriting decision positive genetic test with FH or FHMH of HD	8/8 and 5/5	Decline(6/8 and 5/5)/Load (1/8)/Exclude (1/8)	Alternate option (2/8 and 1/5) was to offer a term policy
Q5. Underwriting decision negative genetic test FH of HD	8/8 and 5/5	Standard rates except 1/8	1/8 now load for FH, previously would have offered standard rates
Q9. Underwriting decision negative test FHMH of HD	8/8 and 3/5	Terms for symptoms	2/5 offer standard rates
Q3. Adoption	-	-	All would disregard FH. 1/5 would not comment as an 'ethical' issue.

The responses from the insurance and reinsurance companies generally aligned with their standard *underwriting* practices. The medical status of the individual played an important role as is evident in the different response to questions 6, 7 and 9 for the brother displaying symptoms compared with questions 1,2 and 5 (see Table 3.6). Changes to the standard *underwriting decision* were to the advantage of the client, but the motivation for these was unknown.

The known predictive value of a HD *genetic test* was confirmed and expressed by all companies declining cover for a positive test and most offering *standard rates* for a negative test for the asymptomatic brother. For the brother with symptoms the response was to rate the symptoms, even if a negative *genetic test* existed.

A risk of *genetic determinism* (section 1.4.1, Pg.13) , or even discrimination was identified in the responses of two *reinsurer*s, who would offer the *applicant* cover at *standard rate*s because the test was negative i.e. inferring that if the genetic status is normal then the symptoms are inconsequential. The researcher feels that although the test proves that the symptoms are not as a result of HD, these symptoms and their cause should still be investigated because of the impact of these on the individual's risk profile.

One *insurer* stated that they would apply a *load*ing for a FH even though the *genetic test* was negative. This suggests a limited understanding of the inheritance pattern for HD and for the ability to convert the definitive *genetic test* result into a risk.

All *insurer*s appeared to understand that HD is a heritable condition as they would disregard the FH of HD if the *applicant* was adopted. The only difference was a comment from a *reinsurer* who stated that this is an 'ethical' issue. Unfortunately they did not provide further insight into their thought process.

It can be concluded from this case that the behaviour of the companies aligned with their protocols, and *applicant*s could be reassured that they would be treated in accordance with the stipulated processes for HD.

Based on their responses, individuals' with a positive family history for HD are unlikely to be able to access life insurance cover, especially disability and CIB. The benefit application would either be deferred until a predictive *genetic test* result is available, or *decline*d. *Applicant*s over a defined age, such as 45 years, may access insurance cover and *policy* terms will be applied such as a *premium load*ing or an *exclusion*. In response to a positive *genetic test* result, most *insurer*s will *decline* access to cover. Favourable alternate options may be provided dependent on the *applicant*'s age, but the cover will be provided as a *term policy* or with a *load*ing. Overall the *insurer*s will provide insurance cover at *standard rates* to individuals with a negative HD *genetic test* result.

The participants' depth of understanding relating to HD was of interest, as it is a rare disorder, and one underwriter stated that in the 36 years he had been in the industry he had only been exposed to two cases of HD. Their decision making process for other more common but more complex conditions was less aligned among the *insurer*s. This suggests that their knowledge is based on guidelines specifically developed for HD and not on an understanding of the *genetic disease mechanism* for HD. Therefore it would be valuable to ensure that an understanding of the inheritance pattern and interpretation of *genetic test* results for HD exists, through appropriate training or detail in the *underwriting* manuals, to provide the *insurer*s with a greater understanding and ability to interpret *genetic information* received.

3.5.2 Hypothetical case study II: Breast cancer

For the details of this case study please refer to hypothetical case II in the interview guide (Appendix B). This case was of a 35 year old woman applying for life insurance

with a *relevant family history* of breast and ovarian cancer. At application stage she informed the *insurer* that she had performed cancer screening tests i.e. mammograms, and a *BRCA1* test. The questions were structured to assess the *insurer*s knowledge of the association between ovarian and breast cancer in terms of hereditary cancer syndromes. Their detailed understanding of the *genetic mechanism*s was assessed through the inclusion of both the *BRCA1* and *BRCA2* genes in the case, and the value of having identified the *mutation* within the family. The responses to questions 1 to 5 relating to this case are detailed in Table 3.7.

In general, the *underwriting* responses for this case study indicate that the insurance companies would align with their standard practices, and any differences were to the advantage of the client as they would not hastily provide a decision, but rather wait for all relevant information before assessing the risk.

Their decision making process became less certain when the information received was more complex. Two of the questions specifically mentioned the genes associated with the familial breast and ovarian cancer syndrome, *BRCA1* and *BRCA2*. The information provided was that the individual had a negative *BRCA1* test with a family history of *BRCA2* gene *mutation*. Therefore a *BRCA1* test would not be informative for this family. Instead of standard responses, most of the participants were uncertain as how to proceed. Almost half of the companies (6/13) made the correct assumption which was to base their requirements and decision on the FHMH and not on the *genetic test* result. However, of concern is that some (3/13) were prepared to provide an *underwriting decision* based on the negative *BRCA1* test. Only two (2/13) responded by stating their uncertainty as how to proceed.

Table 3.7: Results from hypothetical case study II: Breast cancer

Question	Align with the company's standard protocols	Detail of response	Other
Q1. Underwriting requirements FH and test result for BrCa	8/8 and 5/5	PMA, mammogram results; *BRCA1* results	1/8 investigated risk of ovarian cancer i.e. pap smears
Q2. Underwriting decision FH and test result for BrCa	Capital Disability: 5/8 and 5/5 Critical Illness Benefit: 5/8 and 5/5	Dependent on risk factors e.g. cancer history, mammogram results, relevance of FH, prophylactic treatment, age of applicant. Common underwriting decisions; load disability and apply an exclusion to CIB	Changes to decision - favourable to applicant. 3/8 deferred awaiting test result; 1/8 considered prophylactic treatment
Q3. Underwriting decision *BRCA1* positive	4/8 and 3/5	Standard rates/ Load / Exclude / Decline	Most decisions based on mammogram results and medical history. Changes to decisions – not favourable
Q4. Additional underwriting requirements *BRCA1* negative in *BRCA2* positive family	No specific standard requirements but compared responses with Q1., responses to a FH with genetic test result available (4/8 and 2/5)	Other responses: Did not know what to do (2/8); Defer until BRCA2 test result available(2/8); 1/5 discuss the issue with their CMO and 2/5 use the negative *BRCA1* result	1/8 required an up to date *BRCA1* test if the previous test was performed more than 2 years prior

Only one *insurer* made reference to the risk of ovarian cancer and requested detail of cancer screening tests performed, specifically a pap smear. The current standard

screening tests using pap smears or cancer biomarkers such as CA125 have a limited screening efficacy and therefore are not optimal for defining risk (Evans, 2006).

These responses highlight a poor knowledge into the detailed genetics relating to inherited breast cancer, as does the comment from one *insurer* requiring an 'up-to date' *genetic test*. Of concern was that many of the companies would offer a decision without a good understanding of the information received. Based on their responses to question 4, the *insurer*s also used the genetic testing information of other family members which the LOA Code specifically prohibits. In this case study it is unknown how the company was informed thereof and it could be argued that this information was provided with the consent of the other family members.

The inheritance of BrCa is complex and the assignment of risk even more complicated. As hereditary breast and ovarian cancer represent a small percentage of BrCa cases it is possibly unreasonable to expect the *insurer*s to have this knowledge, although it does identify the importance and value of referral of such cases to appropriate specialists.

3.5.3 Hypothetical case study III: Cardiovascular disease

For the details of this case study please refer to hypothetical case III in the interview guide in Appendix B. This case study used a *multifactorial* condition which was selected to ascertain the *insurer*s understanding of the predictive value of a *genetic test* for this type of condition. This was important because these tests are known to have little value in interpretation of risk but are available commercially. Therefore the possibility exists that an *applicant* may provide this information and it is valuable to determine the *insurer*s' response to this type of information. The responses to questions 1 and 2 are detailed in Table 3.8.

Table 3.8: Results from Hypothetical Case study III: Cardiovascular disease

Question	Align with standards	Other
Q1. Underwriting requirements CVD FH and genetic test profile	8/8 and 2/5 requirements as for a FH 2/8 and 1/5 genetic test results	1/5 no longer required a genetic test result which was their standard; 2/5 would get CMO to interpret
Q2. Underwriting decision CVD FH and genetic test profile	8/8 and 4/5 decision based on medical information; 1/5 decision based on medical information and genetic test	1/5 stated if medical history leads to a borderline decision, use genetic test to force a decision

The responses to this case study relating to CVD were in agreement with the standard protocols for the various companies. The feedback showed that none of the companies were aware that these types of tests are currently available from a limited number of private companies. The overall outcome indicated that fewer companies required the results of the *genetic test*, confirming the previous observation that these tests are, correctly, not considered as having a predictive value.

One *reinsurer* said they would consider this information as relevant in extreme situations, but these were not defined. This response raises concern about the company's understanding of the predictive value of the test. Thus creating doubt as to whether there is a means to define whether a predictive test is of value or not in assisting the *reinsurer* to assess risk.

The *insurer*s were not aware of the availability of the *genetic test*s that are marketed to the general consumers. A basic awareness and understanding of the value of these tests to the insurance industry for risk assessment purposes should exist and be provided in training. It is important to have access to this type of information and to the appropriate specialists to interpret the predictive value of a test for risk assessment.

3.5.4 Summary of the underwriting approaches to hypothetical cases

Overall the hypothetical cases illustrated that in practice, the *insurer*s and *reinsurer*s would, in most instances, apply their standard *underwriting* protocols. Some concerns arose when subtleties relating to the *genetic condition*s were introduced, and the responses seemed to indicate a poor detailed understanding. This highlights the importance of introducing training to increase knowledge with regards to *genetic condition*s and the interpretation of *genetic information*. It also indicates the importance of being able to access expert advice or refer complex cases to the appropriate specialists. This would ensure that the *insurer*s will be able to make decisions on specialist advice and allow for optimal risk analysis whilst reducing the opportunity for discrimination.

3.6 Cases of genetic discrimination and anti-selection based on genetic information

As one of the objectives of this study was to investigate the risk of *genetic discrimination* and adverse selection, the existence of these phenomena in the context of *genetic information* was explored.

3.6.1 Identification of cases by the insurers/reinsurers of anti-selection based on genetic information

The companies were requested (question A9) to provide examples of cases where anti-selection was identified to be due to the non-disclosure of a *genetic condition* based on a family history, a *genetic test*, a medical history or a combination of these. Of the insurance companies only 5 of the 8 had analysed their records for such cases, but only two could provide details of relevant cases.

Regarding the specific cases reported, one *insurer* reported a claim for kidney disease, where the doctor's report for the claim revealed a strong medical history of polycystic

kidney disease which was not disclosed at application stage. The *premium* for this *policy* was *load*ed retrospectively. The other was a claim for breast cancer for which the *insured* claimed within 8 months from the date that the cover commenced. The claims investigation revealed a strong family history, which had not previously been disclosed. They paid the claim but applied a *load*ing to the relevant benefit for the strong family history.

Only one reinsurance company knew of a case relating to cardiovascular disease where the individual had not disclosed a strong family history. Another *reinsurer* made a comment that they were of the opinion that non-disclosure was occurring, particularly in the realm of breast cancer. Their explanation was that the most common condition claimed for soon after *policy* inception was breast cancer and that in their experience it accounts for 70% of CIB claims. These comments are of interest but do not confirm non-disclosure of *genetic information* as only a small percentage of breast cancer cases are due to an inherited breast and ovarian cancer syndrome.

Although the fear of adverse selection exists, only three cases were reported by the companies. This leads to the question whether non-disclosure of *genetic information* does exist or is it just not identified? The practices of the insurance companies suggest that it is unlikely that a large number of cases would be missed because of the comprehensive application process.

3.6.2 Cases referred to the Long-term Insurance Ombudsman for anti-selection or genetic discrimination

No cases were identified that had been referred to the Ombudsman's office specifically for non-disclosure or *genetic discrimination*. Of interest was a section in their Annual Reports that details the number of cases referred to the Ombudsman resulting from non-disclosure, not just based on *genetic information*, and what percentage of these cases

were ruled in favour of the *insured* i.e. cases where the *insurer*'s actions had been shown to be incorrect. A summary of these findings is detailed in Appendix I.

From 2003 to 2008 the number of cases reported to the Ombudsman for non-disclosure of all types of information had steadily reduced, perhaps indicating that *applicant*s are more aware of the information to be disclosed at application stage and implications of non-disclosure. The percentage of cases where the Ombudsman's ruling favoured the *insured* varied over the years, but remained consistent at about a quarter of cases referred. Although contradictory to the previous observation, this could be due to a discrepancy in what *insurer*s and the Ombudsman consider as useful information to assess the *applicant's risk* profile.

3.7 Compliance with the LOA Code of Conduct: Genetic Testing

The companies' compliance with the LOA Code was evaluated throughout the interview process and these have been reported on. Section B of the interview guide specifically focused on the companies' compliance with the administrative practices and functions stipulated in these guidelines. The LOA Code defines the role of the underwriter and the CMO in the process of accessing *genetic test*s, and hence compliance to these roles was investigated, in particular, the role of the CMO, which included the provision of training regarding genetics, advice on complex cases regarding a *genetic condition* and network with medical professionals. The outcomes are summarised in Appendix J.

In general, the companies align with the guidelines of the LOA Code. Although none has a specific genetic underwriter, they would refer genetic cases to their senior underwriter or their CMO, as confirmed in Section 3.3.2.3., Pg 50. The role of the CMO was established and includes provision of training in genetics and access to genetic specialists for their expertise. Although the CMOs are highly specialised, only one was a medical geneticist. This is a reasonable outcome as the use of *genetic information* in the

insurance industry forms a small sector of their responsibilities. Most companies rely on the reinsurance companies for training in genetics and their only exposure has been information provided in the standard underwriting training courses.

Cases where a *genetic test* result is available can be referred to the Medical and Underwriting Standard Committee of ASISA, but none of the companies made this comment. These responses identify the importance of the insurance industry being able to access medical specialists in the field of genetics for specialist support. The researcher suggests that specialist training should be provided to increase the basic understanding and interpretation of genetic principles for the use of this information in the context of life insurance.

The next chapter provides the conclusion drawn from this study with recommendations

Chapter 4: Conclusions

This study is the first in South Africa to report on the appropriateness of the *underwriting* approach to the use of *genetic test*s by the life insurance industry of South Africa. Another aim of this study was to identify behaviours that could lead to *genetic discrimination* or an increased risk for anti- selection.

Genetic test results may be accessed and used by the life insurance industry of South Africa for risk assessment in accordance with the principles of the LOA Code on Genetic Testing (now the ASISA Standard) (LOA, 2001; ASISA, 2009b). The insurance industry's response to the use of *genetic test*s was evaluated by following and assessing the *underwriting* procedure from the application stage to the *underwriting decision* and their compliance with these guidelines

4.1 Underwriting approach to genetic and non-genetic information

From this study, the researcher demonstrated that the insurance industry's *underwriting* approach to information relating to a *genetic condition* was generally aligned with their standard *underwriting* practices. Any change to this practice was based on the availability of an appropriate *genetic test* result. The use of these tests was generally based on the predictive value in relation to the medical condition and the presence of the symptoms.

4.1.1 Impact of the inheritance pattern on the underwriting approach

Haemophilia, an early-onset condition, and cardiovascular disease a *multifactorial* condition were two of the four examples of *genetic condition*s used in this study. For both these conditions there was little value in the use of a *genetic test*, because the presence of the disease symptoms or indicators, and the severity of the complications associated with the disease were more indicative of risk. This fact was recognised by the majority of *insurer*s and

therefore the *underwriting* procedure for these conditions was consistently and appropriately determined by the analysis of the individual's health status.

This differed for the other two medical conditions used, breast cancer and Huntington disease, which for this study represented late-onset autosomal dominant conditions, one with full *penetrance* and the other with reduced or variable *penetrance*. Information valuable for risk assessment would be needed to predict the occurrence of these disorders in a presymptomatic individual, and would include *genetic test* results, a strong family history or a disease screening test. The information used was based on the level of predictability it afforded. Inconsistencies were noted in the *insurer*s' perceived value of the information and the interpretation thereof, particularly when considering the *underwriting* responses to breast cancer.

4.1.2 Impact of a family history on the prediction of risk for underwriting

It was shown that on notification of a family history or a *genetic test* result for a medical condition, the *insurer*s' response was generally to request additional information (see Appendix G). The type of information required was defined by the presence of risk factors associated with the condition, in particular the age of the *applicant* and the presence of a strong family history.

4.1.2.1 Age of the applicant as an underwriting risk factor

The age of the individual was used to classify the *applicant* into a high or low risk category for the specific disease. For Huntington disease, less information was required to assess an individual's risk of developing this disorder if they were older than a defined age. This age differed from 45 to 55 years between *insurer*s. Presumably, the rationale behind this ruling is that the average age of onset for Huntington disease is 33 to 45 years, but importantly 25% of affected individuals will start their symptoms after the age of 50. This difference in the

definition of risk factors was again demonstrated for cardiovascular disease where the age used for risk assessment ranged from 30 to 50 years.

The researcher is concerned that the *Insurer*s may still be exposed to an increased risk even by applying these *underwriting* standards. This is because inconsistencies in the definitions of these risk factors exist between companies and not all available information was used to define the standards. With the differing definitions, *applicant*s have the opportunity to select an insurance company with the most favourable underwriting practices and may gain access to cover with no further investigations. Where another company may have assessed them further and identified an increased risk. Therefore the age of the *applicant* relevant to risk, needs to be consolidated between companies. For HD, this risk can be reduced by considering the family history. Although not definitive it can predict the expected age of onset for an *applicant* and thus the subsequent risk exposure to the *insurer*. The researcher feels that each case will require individual assessment and consultation with genetic specialists.

4.1.2.2 Relevant family history as an underwriting risk factor

A *relevant family history* was used by the insurance companies to predict the risk of the *applicant* developing the disorder and they used variables to define what constitutes a 'relevant' family history. These variables differed between the companies for breast cancer and cardiovascular disease and were not defined for a family history of Huntington disease. A *relevant family history* of breast cancer was defined by the *insurer*s as a family where more than one first degree relative was diagnosed with breast cancer below a certain age. This age differed between companies and ranged from 40 to 60 years. The inconsistency in the relevant age of diagnosis was also observed in the variables that define a *relevant family history* of cardiovascular disease. It is unclear to the researcher why a *relevant family history* of Huntington disease has not been defined or even considered. This information, when

used in conjunction with the age of the *applicant*, would be useful to the *insurer* to assess the individual's risk in terms of age of onset, as detailed in section 4.1.2.1.

The *insurer*s' perception of the predictive value of a 'relevant' family history also seemed to vary. Initially, they stated that they would not make an *underwriting* decision on family history alone, but would require additional information, suggesting that a family history alone is not predictive of risk. However, in a separate section, when asked their *underwriting* response to a *relevant family history*, they did so without needing additional information, inferring that a family history alone was predictive of risk. Another illustration of their uncertainty of the predictive value of a family history, is that the terms applied to a *policy* for a family history were more favourable compared to those in response to other forms of *underwriting* information, such as a *genetic test* or a medical history. The researcher felt that this could suggest that a family history is considered by the insurance companies to be more predictive of risk than another form of information. This may not always be accurate as it will be determined by the *genetic mechanism*s of the medical condition, such as inheritance and *penetrance*, as well as the criteria used to define a *relevant family history*.

The possible outcome of these observations is that by having different definitions for a *relevant family history* an *applicant* may choose a company with the least stringent *underwriting* terms and this could lead to insurance companies being exposed to unexpected risk. Likewise the *applicant* is at risk of being treated differently by the same *insurer* or another *insurer* because of their varying interpretation of a *relevant family history*, and the researcher suggests that this may be a form of discrimination. This identifies the need to standardise these definitions.

4.1.3 Impact of a genetic test on the prediction of risk for underwriting

When *insurer*s are notified that a *genetic test* result is available their *underwriting* response is to request the same standard information as that required to assess a family history. The *genetic test* result is only required if the test is considered of high value in predicting the occurrence of the disease.

The need for information in addition to the *genetic test* result to make an *underwriting decision* is indicative of the predictive value of the test. In this study the insurers' responses to the Huntington disease *genetic test* was consistent, and reflected the fact that the presence of the genetic *mutation* in this condition is virtually 100% predictive of disease in a presymptomatic individual.

The researcher found that the *insurer*s' responses to a *genetic test* for breast cancer were not as consistent, confirming the nature of the test is not as predictive as that for HD. This was to be expected as it is known that the genetic *mutation*s associated with hereditary breast cancer do not confer a 100% risk (Evans et. al., 2006). This difference in predictability was mirrored in the inconsistent responses of the *insurer*s to the breast cancer *genetic test*. Initially the *insurer*s would request the test result and additional information to make a decision, suggesting that the predictive value is not 100%. However, when asked for their *underwriting decision* with regard to a positive *genetic test*, their response was based on the test result alone, which would be correct, provided that the *gene fault* was known for the family. The *insurer*s' responses to a negative *genetic test* was used to determine if their interpretation of the predictive value of the *genetic test* had changed. All the *insurer*s provided more favourable *underwriting* terms based on a negative test result alone, suggesting that these *genetic test*s are 100% predictive, and that their perception had changed. Again, this is only true if the genetic *mutation* is known for the family.

These inconsistencies were further highlighted in their response to the hypothetical case study. In the initial question, more than half of the *insurer*s would base their decision on a combination of both screening tests and *genetic test* results. However, their responses changed when the complexities of the *genetic mechanism*s for a hereditary breast and ovarian cancer syndrome were included - then the *genetic test* result was the only factor used to make a decision. The researcher interpreted this as an uncertainty in their understanding of the predictive nature of these *genetic test*s and superficial knowledge.

The inconsistencies in the response to *genetic information* revealed that the *genetic mechanism*s, genetic testing and importance of a family history for hereditary breast and ovarian cancer syndrome were poorly understood. Breast cancer is more common than Huntington disease, as 5-10% of cases are genetic. Therefore it is important to know how to interpret family history and/or *genetic test* for accurate risk assessment. This highlights the industry's need for training to increase their knowledge regarding genetic disorders and to have access to specialists for advice. It also revealed a potential risk for *genetic discrimination* as the same *insurer* may offer different terms based on the identical *genetic information*.

4.1.4 Impact of preventative care on the prediction of risk for underwriting

The insurance industry's *underwriting* response to presymptomatic individuals at risk for breast cancer who had *prophylactic* treatment, was not proportionate to the impact this has on reducing the *applicant's risk*. For an individual at risk for breast cancer, with a strong family history or a positive *genetic test*, a bilateral mastectomy has been shown to reduce the risk of developing cancer by 90% (Evans, 2006). The response to preventative or *prophylactic* treatment was shown to be inconsistent as only one company considered the inherent value of this treatment. In contrast, as part of their standard *underwriting* process all *insurer*s would reward individuals at risk for CVD for beneficial lifestyle changes such as

weight loss. The researcher proposes that this action alone could be deemed as a form of *genetic discrimination*.

Even for the one *insurer* that would offer *standard rates* to an individual that had undergone *prophylactic* surgery, such as a mastectomy, the *insurer* would still be exposed to the associated risk of a claim for ovarian cancer. Unlike with breast cancer, the standard screening tests currently used, trans-vaginal ultrasound, pelvic examinations and tests for cancer markers, are not optimal to detect the early stages of ovarian cancer which would allow for prevention and reduction of cancer risk for the individual. Therefore, for certain families, a true indication of reduced risk would be the combination of a mastectomy and oophorectomy. The latter can reduce the risk of ovarian cancer by 96% (Evans, 2006). These complexities once again highlight the need for specialist support in the interpretation of risk for individual cases.

4.2 Inconsistencies identified in the underwriting approach to genetic information

This study has shown that the insurance industry's *underwriting* approaches to *genetic condition*s are not always consistent. These inconsistencies present an issue in that the same information can be interpreted by the various *insurer*s as a different risk i.e. an individual with a strong family history but for whom no genetic fault was identified may be considered as a standard risk by some companies and at an increased risk because of family history by others. These discrepancies appeared to result from an inability to interpret the predictive value of the information, based on a limited understanding of the *genetic mechanism*s of the medical condition and the type of *mutation* analysis performed. Using

these factors to interpret the predictive value of the information is complex and requires specialist genetic support.

4.2.1 Potential for anti-selection and genetic discrimination based on underwriting inconsistencies

As demonstrated, these discrepancies denote a potential for increased risk exposure and *genetic discrimination*. *Insurer*s are vulnerable for exposure to increased risk or anti-selection through inconsistencies in their definitions of risk factors used to evaluate family history, their interpretation of a family history and *genetic test* results. Similarly, the inconsistencies in the definition and interpretation of risk factors can also be perceived as discriminatory, as *insurer*s respond differently to the same information. The unpredictability in the interpretation of a *genetic test* may also be considered as discriminatory, as it was noted to vary between *insurer*s and for the same *insurer* under different circumstances. The *applicant* can therefore be provided with different *underwriting* terms based on the same *genetic information*. This disparity in treatment may be thought to be as a result of the *genetic information* and not necessarily the inconsistencies in its interpretation, and therefore be thought to be a form of *genetic discrimination*.

4.2.2 Potential risk of genetic discrimination based on the insurance industry's perceptions of presymptomatic individuals

Most companies were shown to consider a presymptomatic individual with a positive *genetic test* as having the condition regardless of whether they had received *prophylactic* treatment. Because a correlation between the predictive value of the *genetic test* and the association of the medical condition with a presymptomatic individual exists this interpretation was not always correct as the predictive value of the *genetic test* would need to be considered. From this observation the researcher was concerned as throughout the study adverse *underwriting* terms were applied to a *policy* for a positive *genetic test*. Based on the *insurer*s' perception

of presymptomatic individuals, the resulting *underwriting decision* may not always be justifiable. For *insurer*s, misconceptions may exist in the interpretation of a *genetic test* in relation to the existence of a condition and the value of preventative treatment. Their response is also indicative of a form of genetic determinism. Their responses contradict the conclusion drawn in a previous paper that the risk of discrimination is small due to the effectiveness of preventative care in reducing risk of disease (Kotze et al., 2004).

These findings highlight the publics' concern that by making *genetic test*s available to *insurer*s their actions could result in limited access to *insurance*, different medical *underwriting* protocols and affect the affordability of cover (Christianson, 2007). However, these outcomes would be acceptable if the actions of the insurers are proven to be actuarially fair and based on effective interpretation of the genetic information.

4.2.3 The relationship between these inconsistencies and the value of the current support available to the insurance companies

The insurance companies' response when requiring assistance with the use and interpretation of a *genetic test* result, was to either consult with their CMOs or their reinsurance companies, yet only one CMO was a genetic specialist. The support offered by the reinsurance companies was in accordance with their *underwriting* standards, established in consultation with their international experts, and it would be reasonable to assume that this would enable the insurance companies to make appropriate risk assessment decisions. From the inconsistencies noted, the researcher considered that these were as a result of these manuals not being consulted prior to the interviews that the insurance companies were unable to translate the information provided into their risk assessment process or that insufficient information is available for appropriate risk assessment. Of concern is that the responses from the reinsurers did not always align with the predictive nature of the genetic

test and they may lack the knowledge to provide specialist support in response to genetic information.

Even if this information is available and appropriate for risk assessment, its value to all sectors of the South African population is unknown. The reason for this is that much of the genetic research has been based on European populations, and it is well known that these findings do not automatically apply to all races and ethnic groups (Bamshad, Wooding, Salisburg, & Stephens, 2004). As South Africa has such a diverse population, where the majority race originates from sub-Saharan Africa, these recommendations may be of little value.

Insurance companies need to be able to access expert advice specific to the unique needs of South Africa.

4.3 Insurance industry's knowledge of the 'LOA Code of Conduct: Genetic Testing'

The LOA Code (ASISA Standard) on genetic testing was established to reduce the risk of *genetic discrimination* whilst providing the *insurer*s with the opportunity for appropriate risk assessment. For this study it was important to consider whether these goals have been achieved and the first step would be to ascertain whether the *insurer*s comply with the LOA Code principles. Most of the *insurer*s were highly knowledgeable of the LOA Code and were compliant with its principles, especially in relation to their various administrative functions and roles, the definition of a '*genetic test*' and the manner in which a *genetic test* result may be accessed. They seemed to falter in the interpretation of valid *genetic test* results and their referral to the LOA/ASISA for guidance. It is uncertain whether ASISA was in a position to provide this support as the information was not readily available when requested.

4.3.1 Effectiveness of the regulations in limiting anti-selection and genetic discrimination

The *insurer*s' actions with regards to obtaining specialist support did not fully align with the processes suggested in the LOA Code or the ASISA Standard. They stated that they would contact their CMO or reinsurance company for assistance in the interpretation of *genetic test* results and none mentioned the LOA (ASISA). The LOA Code makes allowance for the use of the CMO and that the CMO in turn can contact the specialists, but it does not mention the reinsurance companies.

The LOA Code states that a subcommittee of the LOA was available to provide support in the interpretation of *genetic test* results and the factors that determine their validity. This support continues to be available through ASISA, theoretically. In addition the ASISA Standard also states that the Medical Underwriting Standards Committee (MUSC) would evaluate the *genetic test*s currently available and compile a list of genetic tests that are considered valuable to the insurance industry for *underwriting* purposes.

When ASISA was requested to provide detail of the tests deemed to be valid for the insurance industry, the criteria used to assess these and the manner in which the results should be interpreted, they were unable to provide this information. What is unknown is whether this information exists and therefore whether specialist support is provided by ASISA. With this knowledge it is also unknown whether the inconsistencies noted in the interpretation of *genetic information* by the insurance industry can be attributed to this lack of available support. Currently for the insurance companies, there appears to be limited support in the use and interpretation of *genetic information*, and the support offered is not available when requested.

The effectiveness of the regulations in limiting anti-selection and genetic discrimination could not be assessed as the existence of these factors could not be proven and all the provisions of the Code were not available.

This highlights a need for available access to specialist support for the interpretation of *genetic information* and perhaps the reassessment of the goals in the ASISA code to ensure that the various parties are able to fulfil their functional roles.

4.4 Recommendations

Areas of risk for anti-selection and *genetic discrimination* in the *underwriting* process of *genetic information* have been identified. To ensure the appropriate use of *genetic information* in the future, changes can be implemented to establish protocols pre-emptively that will reduce this effect. This is important as currently the industry is not exposed to many *genetic test*s but the number of tests available is continuously increasing as is the complexity of their interpretation. The following recommendations are based on the findings of this study.

- Inconsistencies identified in the *underwriting* approach to *genetic information* need to be addressed by the insurance companies. These include the different interpretations of a family history and the predictive value of a *genetic test*.
- The insurance companies need to establish a uniformity in their *underwriting* practices, particularly their definition of *underwriting* risk factors such as a *relevant family history*.
- Basic support for the use of *genetic information* should be provided through the companies' CMOs, the *reinsurer*s and ASISA. The researcher recommends that this process could be used to identify cases that need to be referred for specialist support and risk analysis.

- The researcher proposes the establishment of a genetic service team for the insurance industry.
- Based on these negotiations the genetic academic departments should establish teams of experts that would be available for specialist consultation by the insurance industry. The function of these teams would include:
    - Evaluate unique *underwriting* cases by providing an interpretation of the *genetic information*
    - Assess and define the predictive value of current and new *genetic test*s to the insurance industry.
    - Work with actuaries to establish the actuarial value of the *genetic test*s by using actuarial models to assist this process (Daykin et al., 2003; Knoppers et al., 2004)
    - For all cases this team will need to consider all the complex variables associated with *genetic condition*s such as the demographics of South Africa
- The researcher proposes that genetic counselling services be used in the process of genetic testing.
- Alternate products need to be developed to address unique needs

Genetic services are valuable to the *underwriting* process as factors such as the interpretation of the family history, validity of the *genetic test* and interpretation of the *genetic test* results would be established prior to risk assessment, thereby assisting the *underwriting* process whilst protecting the privacy of other family members.

These latter points illustrate the value of the various disciplines working together in a holistic manner, as is summarised in the comment, “Social circumstances of affected families would benefit more if geneticists and *insurer*s worked together” (Raeburn, 2002).

4.5 Limitations

There were a number of limitations identified in this study:

- The focus of this study was to gain insight into the insurance industry's understanding of *genetic information*. The interviewees' understanding was affected by their level of prior knowledge. Certain of the responses seemed to be more theoretical than a reflection of the interviewees own understanding and knowledge.
- Only one participant from each company was interviewed, and their responses may not have been a true reflection of the company's *underwriting* approach.
- The participants mentioned that they used *underwriting* risk factors in the decision-making process, but it is unknown to what extent these were used and this may have affected the results
- A pilot study would have been useful to identify areas that needed to be amended to enable a more thorough assessment of the underwriting process
- The examples of *genetic condition*s used in this study are well known, therefore it may have been more appropriate to use less well known examples to determine the *insurer*s' deeper level of understanding.
- A large portion of this study was based on the LOA Code which changed to the ASISA Standard during the research period. At the time of this study the information requested from ASISA was not available and many conclusions were based on this outcome. This may not be completely accurate as there may have been administrative limitations due to the change in the structure of the organisation.
- There was little analysis of the support provided by the reinsurance companies. Greater insight into the *insurer*s *underwriting* processes may have been obtained if the recommended *underwriting decision*s from the reinsurance underwriting manuals were used for comparative purposes.

- This study did not consider that perhaps the information used by the interviewees was limited by the questions asked at application stage. Many companies required questionnaires specific for the *genetic condition* or family history. A summary of the questions asked and the interpretation of the information received may have provided more insight into the *insurer*s' understanding of *genetic information* and prediction of risk.

4.6 Future research and considerations

The following should be considered for further research to provide greater insight into the use of *genetic information* by the insurance industry:

- An evaluation of the use of *genetic information* in the provision of healthcare in the private health insurance sector of South Africa would be important.
- The focus of research has been on *genetic test*s alone. It would be valuable to compare the predictive value of family history, medical history and status and *genetic tests*, for the different types of *genetic condition*s, to enhance the *underwriting* practices of the insurance companies.
- This study focused on the *insurer*s' perspective of their behaviour in the use of *genetic test*s, and therefore it would be valuable to interview affected families to understand their experiences and whether they align with these practices.
- There is a need for a formalised independent validation of *genetic test*s made available to the general population and regulation of the companies that offer these services.
- Consideration of ways for geneticists, other health care professionals and *insurer*s to work together to establish best practices with the least risk of anti-selection or *genetic discrimination*.

4.7 Summary

From the analysis of the life insurance industry's *underwriting* approach to *genetic information* and *genetic test*s it can be concluded that the insurance companies' response to *genetic information* was generally in alignment with their standard practices. Due to the complexities associated with genetic disorders inconsistencies were identified in the companies' approaches. These inconsistencies could potentially increase risk exposure for the *insurer*s and reveal opportunities for *genetic discrimination*. The irregularities appear to be based on the insurance companies' limited understanding of *genetic mechanism*s and other factors that affect the predictive nature of the complex information received. The researcher feels that the support currently available is either insufficient or inaccessible. The results of this study highlight the need for the insurance industry to access specialists who have the expertise to assist in converting *genetic information* into a predictive risk for life insurance *underwriting* purposes.

Appendix A: Summary of insurance companies considered for this study and selection of candidates

Insurance Company	Source of Information	Business	Eligibility
1LifeDirect Insurance	www.1lifedirect.co.za	Direct individual life underwriting	Yes
African Life	www.africanlife.co.za	Underwritten by Sanlam	No
Alexander Forbes Life	www.alexanderforbes.com	Short-term insurance, credit life and group risk	No
Algoa Insurance Company	www.aicinsurance.co.za	Group riskand absenteeism management	No
All Life	www.alllife.co.za	HIV management	No
AltRisk	www.altrisk.co.za	Individual life copver	Yes
Assupol	www.assupol.co.za	Individual Life Insurance (low income earners)	Yes
AVBOB Life	www.avbob.co.za	Funeral cover	No
Capital Alliance	www.capitalalliance.co.za	Underwritten by Liberty Life	No
Channel Life	www.channellife.co.za	Group riskbenefits	No
Clientele Life	www.clientellife.co.za	Group risk benefits	No
Constania Life	Telephonic contact	Credit life, accidental cover and funeral cover	No
Discovery Life	www.discovery.co.za	Individual Life Insurance	Yes
Hollard Life	www.hollard.co.za	Provided by other insurance companies	No
Liberty Life	www.liberty.co.za	Individual life insurance	Yes
Lion of Africa Assurance	www.lionlife.co.za	Funeral Life	No
Medscheme Life	Telephonic contact	Group risk	No
Metropolitan Life	www.metropolitan.co.za	Individual life insurance	Yes
Momentum Life	www.momentum.co.za	Individual life insurance	Yes
Nedgroup	www.boelife.co.za	Credit life	No
Nestlife	www.nestlife.co.za	Group risk	No
New Era Life Insurance	www.neweralife.com	Health and funeral cover	No
Old Mutual	www.oldmutual.com	Individual life insurance	Yes
Outsurance Life Insurance	www.outsurance.co.za	Credit Life and underwitten by Momentum Life	No
Professional Provident Society (PPS)	www.pps.co.za	Individual life insurance	Yes
Prosperity Life	www.pfa.co.za	Funeral and group risk	No
Real People Insurance Company	Telephonic contact	Funeral cover	No
Regent Life Insurance	www.regent.co.za	Aviation, credit life, funeral, motor, property, av	No
Rentmeester	www.liberty.co.za	Underwritten by Liberty Life	No
Safrican Life	www.safrican.co.za	Underwritten by Channel Life, funeral cover	No
Sage Life	www.sage.co.za	Underwritten by Momentum Life	No
Sanlam Life	www.sanlam.co.za	Individual life insurance	Yes
Union Life	www.unionlife.co.za	Funeral cover	No

Appendix B: Interview Guide for Insurers and Reinsurers

TO BE COMPLETED BY RESEARCHER ONLY

Date of interview:

Insurance company:

Interviewee and position held:

Telephone or face-to-face appointment:

Interview conducted by:

Time commenced:

Time ended:

Identifier Code:

INTERVIEW GUIDE FOR INSURERS/REINSURER

Identifier Code No.:

Please note that it is assumed that if there is no response to a question that you were unable to respond based on your company not having a defined protocol, process or practice for the respective scenario.

SECTION A: GENERAL UNDERWRITING QUESTIONS PERTAINING TO GENETIC INFORMATION

1. Please describe what you consider a genetic test to be.

   Purpose: To determine the participants understanding of what a genetic test is relating to the definition in the Code. To determine the participant's perception of the predictive value of a genetic test.

   Probing statements: DNA/chromosomes, biochemical, a combination and predictive value.

2. For which of the following individual life insurance products do you perform individual medical underwriting on the applicant?

   Purpose: To confirm that company does meet the eligibility criteria for this study and that they perform underwriting for all benefits.

Life Cover Benefit	☐	Lump Sum Disability Benefit (i.e. Capital Disability)	☐
Monthly Income Benefit (i.e. PHI)	☐	Severe or Critical Illness Benefit	☐

3. Define the criteria that a policyholder will need to meet to become eligible for a benefit payment under the following benefits:

Purpose: To establish if any differences exist between the companies in their benefit definitions and descriptions because of the impact that this may have on underwriting practices. The benefit definitions were summarised by using probing statements specific to the different benefits, to ensure that optimal comparisons were made.

3.1. Life Cover Benefit

Probing statements:

- Payment on death?
- Term policy (the insurance cover provided is for a limited period of time. This limits the insurers' risk exposure, especially of value for late-onset medical conditions)

3.2. Lump Sum Disability Benefit

Probing statements

- Own/any occupation
- Physical impairment
- Functional impairment
- Combination of occupation and/or functional impairment and/or physical impairment.

3.3. Monthly income benefit

Probing statements:

- Defined based on ability to perform own/any job/ occupation
- Waiting period options (the time from the event until the commencement of benefit payments). It plays an important role as the shorter the waiting period the greater the risk exposure for the insurer. Options for waiting periods include 7 days, 1 month, 3 months, 6 months, 12 months and 24 months.
- Payment from day 1: With a 7 day waiting period there is an option for the benefit payment to commence from the first day of disablement. If this option is selected insurers are exposed to a greater risk.

3.4. Severe Illness Benefit (SIB) or Critical Illness Benefit (CIB)

Probing statements:

- Core CIB
- Core CIB payment (100% or severity)
- Comprehensive CIB
- Comprehensive CIB payment (100% or severity).

4. Do your standard underwriting requirements include the following:

Purpose: To obtain the underwriting protocol or standard underwriting practice of the company. Use this as a foundation to assess whether their underwriting behavior changes based on information received and do these practices align with the industry standards (reinsurance companies' practices).

4.1. Application form

Always	☐	Dependent on sum assured	☐
Dependent on benefit	☐	Dependent on both sum assured and benefit	☐

4.2. Medical reports from personal medical attendant

Always	☐	Dependent on sum assured	☐
Dependent on benefit	☐	Dependent on both sum assured and benefit	☐

4.3. Pathology tests

Always	☐	Dependent on sum assured	☐
Dependent on benefit	☐	Dependent on both sum assured and benefit	☐

Please provide a list of the standard pathology tests required.

_____

_____

_____

_____

5. Tick or complete the box which best describes the level of analysis of information, when the response is as follows:

   Purpose: To determine the company's underwriting behaviour in response to the type of underwriting information received for a specific medical condition. Assess whether this complies with the LOA Code in terms of the use of genetic test results. Furthermore identify other factors that may influence the underwriting process

   Probing statements: Responses needed to be provided per benefit type i.e. life cover benefit, capital disability benefit, monthly income benefit and CIB.

Information provided at underwriting stage (Response)	Underwriting Procedure				
	a)Noted without requesting additional information	b)Request additional information	c) What additional information (b) will you require?	d) Request additional information in view of the presence of other factors.	e) What are the additional factors which combined with disease information (c) increases risk?
Family history of Huntington disease					
Family history of breast cancer					
Family history of haemophilia					
Family history of cardiovascular disease					
Genetic test for Huntington disease					
Genetic test for breast cancer					
Genetic test for cardiovascular disease					
Genetic test for haemophilia					

Please note: A genetic test refers to a test performed on the DNA, RNA or chromosomes, and does not include biochemical test results.

6. Please provide your understanding of a genetic condition and list all the genetic conditions specifically detailed in your application form:

   Purpose: To determine whether the representative considers a genetic condition to be monogenic or multifactorial, and the association with inheritance i.e. would they consider a family history. Check that the conditions provided align with their understanding

   Probing statements: Monogenic, multifactorial, combination of monogenic and multifactorial, inheritance

   6.1. What would the next step be in the underwriting process should any of these conditions be present or where there is a high risk of their occurrence based on the applicant's response?

   Purpose: To establish the company's response to a genetic condition and determine whether they would request a genetic test or underwriting requirements not aligned with the underwriting protocol. Furthermore, whether the risk of an adverse underwriting decision was increased based on a lack of information.

   6.2. If the applicant provides additional personal medical history information detailing a genetic condition not included on the application form, what would the next step be in the underwriting process?

   Purpose: To establish the company's response to a rare genetic condition and determine whether they would request a genetic test or underwriting requirements not aligned with the underwriting protocol. Furthermore, whether the risk of an adverse underwriting decision was increased based on a lack of information. Determine who provides them with specialist support regarding genetic tests and do their actions align with the LOA Code.

7. What would your underwriting decision be on receipt of the different forms of medical underwriting information in respect of the different medical conditions (use the abbreviations specified below):

   Purpose: To determine the impact/value of different forms of underwriting information. Assess whether their interpretation is justifiable or whether their actions create an opportunity for discrimination. Does their use of a genetic test align with the LOA Code?

Probing statements: Responses needed to be provided per benefit type i.e. life cover benefit, capital disability benefit, monthly income benefit and critical illness benefits. Insurers were asked to consider other factors that would influence their decision process.

Genetic Condition	Source of information			
	Family history with no diagnosis in the applicant (FH)	Positive genetic test in the applicant (GT)	Medical history of symptoms pertaining to condition in the applicant (MHx)	Family and medical history of condition with no diagnosis in the applicant (FHMH)
Huntington disease (HD)				
Breast Cancer – *BRCA* (BrCa)				
Haemophilia (HP)				
Cardiovascular disease (CVD				

The key of the various underwriting decisions needed to complete the table:

SD – Standard rates

Load – Increase in premium

Exclude – Exclude condition/disease

Decline – Decline

8. Do you regard an individual with a positive genetic test as having a pre-existing condition if:-

Purpose: In the insurance context a 'pre-existing condition' refers to a medical condition that an individual may have known about or sought medical attention for in the past. It addresses two issues: is an asymptomatic individual considered as having a 'condition' if they have a positive genetic test, and the company's understanding of a the predictive value of a genetic test.

8.1. They are not receiving any treatment or preventative management Yes ☐ No ☐

8.2. They are or have been on treatment for the condition Yes ☐ No ☐

8.3. They have received preventative management Yes ☐ No ☐

9. Have you had a case of adverse selection as a result of non-disclosure of a genetic condition i.e. genetic test results, positive family history and/or positive medical/clinical history?

Purpose: To determine the existence of adverse selection

Yes ☐ No ☐

If yes please complete the following table:

Genetic condition	Date of Application	Information source i.e. genetic test, FH or clinical history	Date of diagnosis	Financial impact

10. In the event that an applicant provides you with proof of a negative genetic test what effect would this information have on the underwriting decision? What, If any, would the new underwriting decision be?

Purpose: Confirm whether their actions align with the LOA Code and if their decision is appropriate based on the predictive value of the information received for a specific condition.

Probing statement: The companies were asked to respond based on the medical conditions used in examples, Huntington disease, breast cancer and cardiovascular disease.

Genetic condition	The underwriting decision will be adjusted (Y/N)	The updated underwriting decision (please use the code as per question 7.)

SECTION B: GENERAL ADMINISTRATION QUESTIONS PERTAINING TO GENETIC TESTS

Purpose: All these questions relate to specific criteria detailed in the LOA Code. The reason for this is to determine whether the company is compliant with the guidelines of the LOA Code.

1. Who is the genetic underwriter for your insurer, and what is their qualification?

2. Do you have a particular protocol in terms of the storage of genetic test results received in support of a policy application? An example is a database of genetic test results.

3. If you receive a genetic test result, who do you consult with to interpret the results into information that is relevant to the underwriting process?

4. Who provides the underwriters with training in genetics?

5. Who are the medical specialists that you contact for assistance with queries relating to genetic conditions or tests?

SECTION C: HYPOTHETICAL CASES

Purpose: Section C was designed to assess the company's level of compliance with their previously defined standard underwriting practices i.e. is the theory applied in practice, and therefore is the company acting 'fairly' towards the applicant.

The following section consists of questions pertaining to hypothetical underwriting cases.

HYPOTHETICAL CASE I

John and Henry are brothers, both over the age of 30. They have both contacted your company separately to purchase individual life insurance policies. According to their application forms their father aged 55 has just been diagnosed with Huntington disease (HD). Furthermore it is noted in Henry's application form that he has had a short history of tremors and memory loss and his GP has ascribed these symptoms to stress.

Underwriting for JOHN:

1. What , if any, additional underwriting requirements would you request?

   Analysis: Compare with Section A5, family history of Huntington disease

2. Based on this information what would your underwriting decision be for an application requesting access to a disability and/or severe illness benefit i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what).

   Analysis: Compare with Section A7, family history of Huntington disease

3. What would you do if you discovered that John was adopted?

   Analysis: Determine company's understanding of inheritance

4. What would the effect be on the underwriting decision if at application stage you are informed that John had a genetic test, and he tested positive for HD?

   Analysis: Compare with Section A7, positive genetic test for Huntington disease

5. What would you do if you received a copy of a HD genetic test for John after the policy had commenced that indicated that he tested negative for HD? (The underwriting decision was initially based on the family history only)

   Analysis: Compare with Section A10, for a Huntington disease genetic test

Underwriting for HENRY:

6. What , if any, additional underwriting requirements would you request?

   Analysis: Compare with Section A5, family history of Huntington disease, should differ to Question 1 due to the history of tremors and memory loss

7. Based on this information what would your underwriting decision be for an application requesting access to a disability and/or severe illness benefit i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what) ?

   Analysis: Compare with Section A7 family history of Huntington disease, should differ to Question 2 due to the history of tremors and memory loss

8. What would the effect be on the underwriting decision if at application stage you are informed that Henry had a genetic test, and he tested positive for HD?

   Analysis: Compare with Section A7, positive genetic test for Huntington disease. If there are cases where terms have been applied, check that these have taken into consideration the medical history of tremors and memory loss

9. What would the effect be on the underwriting decision if at application stage you are informed that Henry had a genetic test, and he tested negative for HD?

   Analysis: Compare with Section A10 but should differ to Question 5 due to the history of tremors and memory loss

HYPOTHETICAL CASE II

Mary is a 35 year old with a sister of 40 years who is currently being treated for breast cancer. Mary's mother passed away at the age of 42 from ovarian cancer. In view of this family history Mary has gone for regular annual mammograms. In addition she has been for genetic counselling and has had a genetic test for three *BRCA1* gene mutations.

Underwriting for MARY:

1. What , if any, additional underwriting requirements would you request?

   Analysis: compare with section A5, BRCA test has been performed and family history of breast cancer.

2. Based on this information what would your underwriting decision be for an application requesting access to a disability and/or severe illness benefit i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what) ?

   Analysis: compare with Section A7, family history and medical information relating to breast cancer.

3. At application stage Mary provides you with the results of *BRCA1* genetic test which states that she has tested positive for the *BRCA1* mutation. Would you request additional information for underwriting purposes, and if so what would this be? Using this information, what would your underwriting decision be for accessing disability and/or severe illness benefits i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what) ?

   Analysis: Compare with Section A5, positive genetic test, and Section A7, positive genetic test.

4. At application stage for a disability and/or severe illness benefit Mary provides you with the results of her genetic test for the *BRCA1* mutations, for which she tested negative. You have been informed that both her sister and mother have tested positive for the *BRCA2* . Would you request additional

information for underwriting purposes, and if so what would this be? Using this information, what would your underwriting decision be for accessing disability and/or severe illness benefits i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what)?

Analysis: Compare with Section A5, family history of breast cancer only, and Section A7, family history of breast cancer only.

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HYPOTHETICAL CASE III

Frank is a healthy 40 year old who does not smoke, he exercises regularly and is not overweight. In Frank's application it is evident that his father, mother and brother all suffer from hypertension and/or hypercholesterolaemia. Furthermore his father has suffered two heart attacks. Frank informs you that he found a direct-to-the-consumer genetic test to ascertain his risk of developing heart disease. His results indicated that he is healthy and has a low risk of developing cardiovascular disease.

Underwriting for FRANK:

1. What , if any, additional underwriting requirements would you request?

   Analysis: compare with section A5, cardiovascular disease genetic test has been performed and family history of cardiovascular disease.

2. Based on this information what would your underwriting decision be for an application requesting access to a disability and/or severe illness benefit i.e. provide at standard rates, load the premiums, exclude the disease, impose a waiting period, decline the policy or others (please stipulate what) ?

   Analysis: compare with section A7, cardiovascular disease genetic test has been performed and family history of cardiovascular disease.

NATIONAL HEALTH
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Professor AL Christianson 011 489-9239 Professor A Krause 011 489-9219
Professor M Ramsay 011 489-9214 Professor H Soodyall 011 489-9208 Dr AB Lane 011 489-9221

Appendix C: Research Project Information Sheet

Title: The use of genetic tests by the individual life insurance industry in South Africa.

My name is Noelene Kinsley and I am a student doing my Masters in Genetic Counselling through the Faculty of Health Sciences at the University of the Witwatersrand.

A research project forms part of this Masters programme and the aim of my study is to determine how genetic tests are used in obtaining an individual life insurance policy and the associated risk of genetic discrimination and adverse selection. To meet this aim I require input from life insurance and reinsurance companies. I wish:-

- to evaluate the underwriting approach to using genetic information and the effect of this information on the underwriting decision
- to compare the underwriting guidelines and application forms of the insurer with the reported processes and decisions.
- to investigate the effectiveness of the Life Offices Association's regulations pertaining to the use of genetic testing by insurance companies in limiting adverse selection and genetic discrimination.

My project requires the completion of a questionnaire by relevant representatives of the insurance or reinsurance company and access to information detailing underwriting protocols and the respective application forms. The representative of the insurance company is a person(s) who is actively involved in defining the underwriting protocols and practices, functions as a mediator and has the authority to make decisions pertaining to 'special' underwriting cases.

You have been identified as the relevant person in your company and therefore I wish to invite you to participate in this study. Participation in this study is voluntary and you can withdraw at any time. Should you wish to discuss this matter further or if you have any

queries regarding the research process please contact me on (011) 489 9227 or 082 547 5720. Your agreement to participate in this study will be much appreciated.

Please can you confirm whether you, as a representative of your company, will participate in this study by completing the attached consent form and faxing it to (011) 489 9226/9209 or emailing it to noelene.kinsley@nhls.ac.za.

Research process:

For convenience the questionnaire will be completed in an interview setting at the respective insurers' or reinsurers' offices. The duration of the interview process is expected to be one hour. For auditing purposes an audio recording will be made of the interview, with consent from the participant. The questionnaire will be sent to the relevant individual(s) prior to the appointment to allow for preparation and for queries to be answered upfront. All information will remain confidential. Confidentiality will be achieved through the use of a random coding system, whereby each insurer or reinsurer will be issued with a unique numerical code.

All data collected will be stored under lock and key within the Division of Human Genetics, University of the Witwatersrand for a maximum period of 6 years.

You may address any queries or complaints which may arise from this research project to Prof. Cleaton-Jones, the Chair of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand. The contact number is 011 717 2635.

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Appendix D: Consent to participate in an interview

I……(Name), am currently employed in the position of ……..(Job Title) at……..(Insurance or Reinsurance Company) and hereby agree to participate in the research study titled "The use of genetic tests by the individual life insurance industry in South Africa" conducted by Noelene Kinsley, a masters student of the Faculty of Health Sciences at the University of the Witwatersrand.

I confirm that in the company I have an active role in defining the underwriting protocols and practices, I function as a mediator and I hold a position of authority to make decisions pertaining to 'special' underwriting cases.
It has been explained to me and I understand that:

- *All information provided will remain confidential*
- *All names, including that of my company, will remain confidential*
- *The completed questionnaire will only be used toward the completion of a research project*
- *The completed questionnaire and voice recording will be the property of the researcher and the institute and will not be shared with any other parties unless so agreed*
- *There is no remuneration for participating in the study*
- *Copies of the completed questionnaire and voice recording may be made available to me*
- *The company I represent will be acknowledged by the researcher, unless otherwise advised*
- *On completion the results of the study will be made available on request*

Signed…….. Date……

Telephone no.:…….. Cell No……..

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Professor IM Ramsay 011 489-9214 Professor H Soodyall 011 489-9208 Dr AB Lane 011 489-9221

Appendix E: Recording consent form

I……(Name), am currently employed in the position of ……..(Job Title) at……..(Insurance or Reinsurance Company) and hereby agree to participate in the research study titled "The use of genetic tests by the individual life insurance industry in South Africa" conducted by Noelene Kinsley, a masters student of the Faculty of Health Sciences at the University of the Witwatersrand.

I consent to a voice recording of this interview and understand that this is solely for auditing purposes.

I confirm that in the company I have an active role in defining the underwriting protocols and practices, I function as a mediator and that I hold a position of authority to make decisions pertaining to 'special' underwriting cases.
It has been explained to me and I understand that:

- *All information provided will remain confidential*
- *All names, including that of my company, will remain anonymous*
- *The completed questionnaire will only be used toward the completion of a research project*
- *The completed questionnaire and voice recording will be the property of the researcher and the institute and will not be shared with any other parties unless so agreed*
- *There is no remuneration for participating in the study*
- *Copies of the completed questionnaire and voice recording may be made available to me*
- *The company I represent will be acknowledged by the researcher, unless otherwise advised*
- *On completion the results of the study will be made available on request*

Interviewee's signature: **Interviewer's signature:**

Appendix F: Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Kinsley

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M081038**
PROJECT	The Use of Genetic Tests by the individual Life Insurance Industry in South Africa
INVESTIGATORS	Ms N Kinsley
DEPARTMENT	School of Pathology
DATE CONSIDERED	08.10.31
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.12.12 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof A Krause

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix G: Additional underwriting requirements

Table G1: Summary of the additional underwriting requirements of the insurance and reinsurance companies in response to information received for specific medical conditions

Condition	Information Received	Additional Information Requested						Factors used to define additional requirements		Detail of the additional requirements	
		Gene test		Questionnaire		Medical Report					
		Insurers	Reinsurers	Insurers	Reinsurers	Insurers	Reinsurers	Insurers	Reinsurers	Insurers	Reinsurers
Huntington Disease (HD)	Family history (FH)	0		3		5	3	***Sum assured***; ***Age of applicant***, as HD family history not considered if applicant is >45 years	**Age of applicant**, *as no additional information required if applicant above > 55 years of age.*	Personal medical attendant report (PMA) & HD Questionnaire	*PMA and query whether test has been performed*
	Genetic test result available	7	5	2		0		One would not use a genetic test result, therefore they were not included in this summary		HD Questionnaire	
Breast Cancer	Family history (FH)	0		1		7	5	2/8 insurers would ignore FH is applicant was ***male***. Information ignored if male; ***Relevant FH*** defined as >1 1st degree relative with age of diagnosis less than defined age. Age ranges from 40 to 55 years; ***Benefit type*** of importance: CIB	**Relevant FH** *defined as >1 first degree relative, with age of diagnosis <60yrs*	PMA and mammogram reports	*PMA, mammogram histology reports*
	Genetic test result available	6	4	2		5	2	One would not use a genetic test result, therefore they were not included in this summary		PMA and mammogram reports	*PMA, mammogram histology reports*
Haemophilia (HP)	Family history (FH)	0		1		4	4	***Additional requirements*** were requested for ***affected*** individuals (4/8). One insurer stated that for affected individuals required information from both male and female applicants.	***Additional requirements*** *requested for* ***affected*** *individuals only*	PMA, PTT test, and on occasion ESR and FBC.	*Factor test, medical history, any symptoms*
	Genetic test result available	3	2	2		4	2	***Additional requirements*** were requested for ***affected*** individuals (4/8). One insurer not requiring additional information stated would base their decision on the genetic test result, as the individual would have been able to follow preventative measures (1/8).		PMA, disease treatment and management, HP Questionnaire, FBC; clotting factors, ESR.	
Cardiovascular Disease (CVD)	Family history (FH)	0		0		8	4	***Relevant FH*** defined as >1 relative where age of diagnosis or death less than defined age. (ranges from 45 to 50 years); ***Applicant's age*** of reduced risk of CVD below a defined age (ranges from 30 to 50years)	**Relevant FH** *defined as the number of 1st degree relatives, age of diagnosis/death (especially if between the ages of < 55 years and 60 years*), **Age of applicant**	Cholesterol test. Increased risk with age includes a PMA and ECG.	*Requirements increase with age of applicant. ECG, cholesterol, medical history. More stringent requirements the stronger the family history.*
	Genetic test result available	2	2	0		5	4	One insurer considers the genetic test sufficient for risk assessment	**Age of applicant**, **Relevant FH**		*PMA, medical history, cholesterol, sugar, medical examination*

Footnote: *The total number of insurers for HD differs as one insurer was not certain how they would underwrite in response to a family history for HD and was therefore excluded. For Haemophilia the results only pertain to affected individuals. The insurers may have requested more than one option.

Where the total number of reinsurers or insurers is less than the total number of participants, it is because these companies did not require additional information.

Appendix H: Underwriting decisions for medical conditions

Table H1: Insurers underwriting decisions for Huntington disease

Benefit	Underwriting information	Number of responses for different underwriting decisions								Factors
		SD	Load	Defer	D	Exclude	Term	Total	Total per Benefit	
Life cover	Family history (8)	1	4		1		2	8		More lenient decisions based on an age greater than 45 and 55years in response to a FH & 55years for a genetic test. Medical information relates to symptoms.
	Positive genetic test (9)	1	2		5	1		9		
	Medical history (11)	1	2	1	6	1		11		
	Medical and Family history(12)		4		5	2	1	12	40	
Capital Disability	Family history (9)		3		4	2		9		
	Genetic test (8)		1		6	1		8		
	Medical history (12)	1	2	1	6	2		12		
	Medical and Family history (11)		4		5	2		11	40	
Income Disability	Family history (8)		3		3	2		8		
	Genetic test (8)		1		6	1		8		
	Medical history (11)	1	3	1	4	2		11		
	Medical and Family history (10)		2	1	5	2		10	37	
Core Critical Illness Benefit	Family history(2)	1			1			2		
	Genetic test (2)				2			2		
	Medical history (2)				2			2		
	Medical and Family history (2)				2			2	8	
Comprehensive Critical Illness Benefit	Family history (8)		3		3	2		8		
	Genetic test (7)		1		5	1		7		
	Medical history (12)	1	2	1	6	2		12		
	Medical and Family history (11)		3		5	3		11	38	

Please note that the abbreviations are as follows: SD – Standard rates; D – Decline

Table H2: Insurers underwriting decisions for breast cancer

Benefit	Underwriting information	Number of responses for different underwriting decisions								Factors
		SD	Load	Defer	D	Exclude	Term	Total	Total per benefit	
Life cover	Family history (9)	6	3					9		Medical history of applicant; age of applicant, if younger than specified age then are terms applied otherwise standard rates. Prophylactic treatment considered by one.
	Genetic test (9)	2	6				1	9		
	Medical history (10)	6	2		1		1	10		
	Medical and Family history (12)	5	5	1			1	12	40	
Capital Disability	Family history (8)	4	3			1		8		
	Genetic test (9)	2	4	1	1	1		9		
	Medical history (9)	4	3		2			9		
	Medical and Family history (11)	5	3	2	1			11	37	
Income Disability	Family history (8)	4	3			1		8		
	Genetic test (8)	2	3	1	1	1		8		
	Medical history (10)	5	3		2			10		
	Medical and Family history (11)	5	3	2	1			11	37	
Comprehensive Critical Illness Benefit	Family history (8)	2	2		1	3		8		
	Genetic test (10)	1		1	3	5		10		
	Medical history (10)	1	3	1	2	3		10		
	Medical and Family history (15)	4	3	3	2	3		15	43	

Please note that the abbreviations are as follows: SD – Standard rates; D – Decline

Table H3: Insurers underwriting decisions for Haemophilia

Benefit	Underwriting information	Number of responses for different underwriting decisions								Factors
		SD	Load	Defer	D	Exclude	Term	Total	Total per benefit	
Life cover	Family history (9)	6	2				1	9		Gender - male. Medical history and disease status.
	Genetic test (13)	4	7		2			13		
	Medical history (14)	4	7		2		1	14		
	Medical and Family history (15)	5	6	1	3			15	51	
Capital Disability	Family history (9)	6	1		2			9		
	Genetic test (14)	3	7		4			14		
	Medical history (14)	3	7		4			14		
	Medical and Family history (16)	5	6	1	4			16	53	
Income Disability	Family history (9)	6	1		2			9		
	Genetic test (14)	3	7		4			14		
	Medical history (14)	3	7		4			14		
	Medical and Family history (16)	5	5	1	5			16	53	
Core Critical Illness Benefit	Family history (2)	2						2		
	Genetic test (2)	1	1					2		
	Medical history (2)	1	1					2		
	Medical and Family history (2)	1	1					2	8	
Comprehensive Critical Illness Benefit	Family history (9)	6	1		2			9		
	Genetic test (12)	3	5		3	1		12		
	Medical history (12)	3	5		3	1		12		
	Medical and Family history (12)	3	5		3	1		12	45	

Please note that the abbreviations are as follows: SD – Standard rates; D – Decline

Table H4: Insurers underwriting decisions for cardiovascular disease

Benefit	Underwriting information	Number of responses for different underwriting decisions								Factors
		SD	Load	Defer	D	Exclude	Term	Total	Total per benefit	
Life cover	Family history (13)	5	6		2			13		Medical status of individual. In particular cholesterol levels and ECG results
	Genetic test (13)	3	7		3			13		
	Medical history (15)	4	7		4			15		
	Medical and Family history	4	7		4			15	56	
Capital Disability	Family history (14)	5	6		3			14		
	Genetic test (13)	4	6		3			13		
	Medical history (15)	4	7		4			15		
	Medical and Family history (15)	4	7		4			15	57	
Income Disability	Family history (14)	5	6		3			14		
	Genetic test (12)	3	6		3			12		
	Medical history (15)	4	7		4			15		
	Medical and Family history (15)	4	7		4			15	56	
Comprehensive Critical Illness Benefit	Family history (13)	3	7		3			13		
	Genetic test (13)	3	6		3	1		13		
	Medical history (15)	4	6		4	1		15		
	Medical and Family history (14)	4	7		3			14	55	

Please note that the abbreviations are as follows: SD – Standard rates; D – Decline

Appendix I: Long-term Insurance Ombudsman non-disclosure cases

Table I: Number of non-disclosure cases referred to Ombudsman and their response in favour of the life-insured

Reporting Year	Life Cover benefits		Disability benefits	
	Total number of cases	Ruling in favour of applicant (% of Total)	Total number of cases	Ruling in favour of applicant (% of Total)
2003	120	28	139	15
2004	111	18	104	17
2005	109	14	85	28
2006	106	32	39	36
2007	103	30	33	45
2008	79	24	29	24

APPENDIX J: Administrative functions in relation to genetic tests

Table J.1: Insurers administrative practices that correspond to regulations

Insurer	Genetic underwriter			Protocol to store info			Interpretation of genetic test results	Training in Genetics	Medical specialists - genetic	CMO Qualifications
	Yes	No	Qualification	Yes	No	Standard storage & confidentiality				
1	x		Chief underwriters and medical practitioners	x		Data system with defined security priviledges	CMO	CMO and Reinsurers	Medical specialists, pathologists or reinsurers.	Specialist physician
2	x		CMO	x		Data system with defined security priviledges	CMO and Genetics Department University Stellenbosch	No training needed	CMO	Clinical geneticist
3		x		x		Data system with defined security priviledges	CMO and Reinsurer	None to date	CMO and Reinsurer	Specialist physician
4		x		x		Data system with defined security priviledges	CMO	CMO	CMO	
5		x		x		Data system with defined security priviledges	CMO and Reinsurer	None. Reinsurance seminars.	CMO	Specialist physician
6	x		CMO	x		Data system with defined security priviledges	Pathologists and medical specialists	CMO	Pathologists and Geneticists	
7	x		Insurer's medical doctors	x		Data system with defined security priviledges	CMO and Reinsurer	None	CMO and Reinsurer	Cardiologist
8		x		x		Data system with defined security priviledges	Pathologists	None	None	

Table J.2: Reinsurers administrative practices that correspond to regulation

Reinsurer	Genetic underwriter			Protocol to store info			Interpretation of genetic test results	Training in Genetics	Medical specialists	CMO Qualifications
	Yes	No	Qualification	Yes	No	Standard storage confidentiality				
1		x	Senior underwriter (nursing sister extensive years of experience in insurance)	x		Data system with defined security priviledges	CMO, pathology laboratory, Internet (Google)	Nobody. Part of training course provided to insurers	No need to date but reinsurers can contact their resources in the field	Specialist physician
2		x	CMO	x		Data system with defined security priviledges	CMO	CMO and pricing actuary	Laboratories that performed the test (Lancet,Wits)	GP with extensive years of experience in the insurance industry
3		x	CMO	x		Data system with defined security priviledges	CMO and international specialists	CMO ad international specialists	CMO	Specialist physician
4		x	Underwriters aware to address genetic information with caution	x		Data system with defined security priviledges	CMO and international specialists	No specific training. Part of underwriting manual. Underwriting training has a section on genetics	CMOs	Specialist physicians
5		x	Global approach of the reinsurance company	x		Data system with defined security priviledges	CMO and reinsurer's international specialists	Internal underwriting manual	Local and global experts	

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