

Genetic testing and the insured's right not to know

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OPSOMMING

Genetiese toetse en die versekerde se reg om nie te weet nie

Tans heers daar onsekerheid oor die billikheid van die gebruik van die uitslae van genetiese toetsing deur versekeraars. Versekeraars gebruik die uitslae óf om versekerdes in verskillende risiko-klasse in te deel om premies te bepaal óf om dekking aan versekerdes te weier. Hierdie artikel benader die aangeleentheid deur te kyk na die betekenis van genetiese toetsing, die gebruik van die uitslae van sodanige toetse, die verspreiding of uitsluiting van die risiko deur die gebruik van die uitslae en sluit af deur 'n moontlike reg om nie te weet nie aan die versekerde te verleen, onderhewig aan die uitwerking van die Grondwet op 'n moontlike reg. Internasionale standpunte word ook in ag geneem by die oorweging van die vraag of Suid-Afrika ook 'n reg om nie te weet nie behoort te erken.

1 INTRODUCTION

The utilisation of results obtained from genetic testing by insurers in the assessment of risk and the possible infringement on the insured's constitutional rights such as the rights to equality,¹ human dignity,² freedom and security of person³ as well as the insured's right to privacy⁴ currently forms the centre of a lively and topical debate amongst academics, both locally⁵ and abroad.⁶ The AIDA⁷ World Congress held in Buenos Aires in October 2006 was themed "The influence of technological and scientific innovation on personal insurance".⁸ Part 2 of this congress was titled "The human genome project and personal insurance".⁹

1 S 9 of the Bill of Rights contained in Ch 2 of the Constitution of South Africa, 1996 (the Constitution).

2 S 10.

3 S 12(2)(b).

4 S 14.

5 See amongst others Nienaber and Van der Nest "Genetic testing for the purposes of insurance risk assessment and the constitutional right to privacy" 2004 *THRHR* 446; Low, King and Wilkie "Genetic discrimination in life insurance: Empirical evidence from a cross-sectional survey of genetic support groups in the United Kingdom" 1998 *British Medical J* 1632.

6 According to Bornstein "Genetic discrimination, insurability and legislation: A closing of the legal loopholes" 1996 *J of Law and Policy* 553, in 1996 in the United States of America 12 states had enacted legislation restricting genetic testing or the use of genetic information in the context of insurance practice and five of these states had pending legislation to update laws governing genetic testing and at least 15 more states had some proposed genetic discrimination legislation at hand.

7 International Association of Insurance Law.

8 <http://www.aida.org.za>.

9 *Ibid*.

This article aims to provide some structure to the main arguments in favour of using the results flowing from genetic testing by insurers; and against using such results as they will have an influence on the assessment of risk by insurers. Suggestions regarding the correct approach to be followed are examined, as well as the possibility of acknowledging an insured's right not to know the results obtained from genetic testing.

2 GENETIC TESTING

2.1 Introduction and definition

The Human Genome Project was introduced and co-ordinated by the United States Department of Energy and National Institution of Health 13 years ago.¹⁰ The aim of this project was to map and sequence human DNA to establish specific landmarks throughout the genome which can be used as reference points to locate any designated genes as well as the possible impact it can have on society.¹¹ The prediction of possible genetic diseases could be analysed through these tests. Genetic testing is defined as a predictive genetic test which assesses an asymptomatic person's future risk of disease.¹²

The Life Office's Association of South Africa (LOA) defines "genetic testing" as "[t]he direct analysis of DNA, RNA, genes or chromosomes for the purposes of determining inherited predisposition to a particular disease or group of diseases".¹³

A wider definition of "genetic information" is preferable:¹⁴

"Genetic information means information about inherited genes or chromosomes, and of alterations thereof, whether obtained from an individual or family member, that is scientifically or medically believed to be associated with a statistically relevant increased risk of development of disease, disorder or syndrome."

Further uses of genetic tests include the confirmation of the carrier status in a person that could make one prone to develop breast or ovarian cancer if one has mutated genes,¹⁵ identifying future health risks, predicting drug responses, assessing risk to future children as well as prenatal diagnostic testing, presymptomatic testing for predicting adult-onset disorders, and forensic or identity testing.¹⁶

Even though this project has been seen by many as groundbreaking, adverse effects also flowed from it.¹⁷

10 See also www.genomics.energy.gov for the history of this project.

11 Deoxyribonucleic acid forms the structural components that dictate hereditary characteristics. Kuschke "Data protection of the results of genetic testing and possible discrimination in insurance due to these results" 2007 *De Jure* 307.

12 Evans, Skrzytnia and Burke "The complexities of predictive genetic testing" 2001 *British Medical J* 1052 1053; Nienaber and Van der Nest 2004 *THRHR* 448.

13 The Life Office's Association of South Africa *LOA code of conduct* ch 20 on "Genetic Testing" (November 2001) 20.4 (hereinafter *LOA code of conduct*).

14 Nöthling Slabbert "Genetic privacy in South Africa and Europe: A comparative perspective (1)" 2007 *THRHR* 624.

15 Farham "Genetic testing for breast cancer" 26 August 2004. See http://health.iafrica.com/illness_condition/cancer/breast_cancer/62427.htm accessed 13 Dec 2007.

16 www.genomics.energy.gov, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml accessed 13 Dec 2007.

17 See Lenox "Genetic discrimination in insurance and employment: Spoiled fruits of the Human Genome Project" 1997 *Univ of Dayton LR* 190; and Underwood and Cadle "Genetics, genetic testing, and the specter of discrimination: A discussion using hypothetical cases" 1996–1997 *Kentucky LJ* 665.

2.2 Genetic testing and risk classification in insurance law

Risk can be defined as the possibility that a specified but uncertain event may occur or as the possibility of an undesirable change in the patrimonial circumstances of a person or the possibility of harm.¹⁸ I agree with the point of view¹⁹ that the specific meaning of risk is not clear and that it is sufficient to say that it is the possibility of harm. It is very clear from the above definitions that an element of uncertainty is evident in all possible instances of risk. In 1967 the court defined an insurance contract as

“a contract between an insurer (or assured) and insured (or assured), whereby the insurer undertakes in return for payment of a price or premium to render to the insured a sum of money or its equivalent, on the happening of a specified uncertain event in which the insured had some interest”.²⁰

From this definition one can clearly see the element of future uncertainty and that the court identified risk and included it as one of the *essentialia* of an insurance contract. This definition of an insurance contract was applied subsequently.²¹

The relevance of genetic testing can thus clearly be seen in the context of insurance law. If we categorise insurance law it can be divided into indemnity insurance and non-indemnity insurance (also known as capital insurance). Taking a closer look at capital insurance it is clear that one of the insurance policies that is used most often is life insurance. According to the LOA²² the purpose of life insurance is specifically to provide financial protection against the untimely death or disability of a person. The role that genetic testing plays in the application of an insured for life insurance and the final granting of life insurance by the insurer has become vitally important. Because genetic testing assesses a person's future risk of contracting a disease, a genetic test is a very useful aid for insurers when it comes to risk assessment and risk classification of the prospective insured. Results obtained through gene testing will indicate whether the prospective insured could be placed in a higher risk category. The relevance of this is that the premium paid by the insured will be influenced directly by the category of risk he or she is placed in. A very frank approach is that of Khan:²³

“Insurance is a business that depends on predicting health risks and setting premiums to account for them, and so insurers are very likely to be interested in gene testing for individuals.”

One of the pitfalls of genetic testing is that it merely assesses the possibility of developing a disease in the future. No certainty exists as to whether the disease will develop, when it will develop or the severity of the disease if it does develop.²⁴ Read illustrates the complexity of the results obtained from a genetic test as follows:²⁵ “The thing that people worry about is the idea of a genetic

18 Van Niekerk “Assumptions, risk and the insurance contract” 1998 *SA Merc LJ* 123.

19 Prozesky-Kuschke “Insurance and carriage” in Nagel (ed) *Commercial law* (2006) 298; Reinecke *et al General principles of insurance law* (2002) 191.

20 *Lake v Reinsurance Corporation Ltd* 1967 3 SA 124 (T).

21 *Sydmore Engineering Works (Pty) Ltd v Fidelity Guards (Pty) Ltd* 1972 1 SA 478 (W).

22 *LOA code of conduct* 20.2.

23 “Genetic testing and insurance” <http://www.cnn.com/HEALTH/bioethics/9808/genetics-part2/template.html> accessed 7 Aug 2007.

24 Nienaber and Van der Nest 2004 *THRHR* 449.

25 1999 *British Medical LJ* 273.

readout that tells you what you're going to die of. That's very largely paranoia and science fiction."

The results of gene testing illustrate the likelihood of a person with a specific gene mutation developing a disease or disorder.²⁶ Furthermore, even if a specific gene mutation is positively identified by gene testing the likelihood that the disease could occur can be influenced by a variety of environmental exposures, ways of life and the effect of other genes present and the interaction with those genes.²⁷ The influences of the environment and human behaviour make the results of gene testing even more unreliable if used by insurers to categorise insureds in possible risk areas.²⁸

Even though various uncertainties and pitfalls exist regarding gene testing and the interpretation of the results of gene testing, insurance companies have great interest in the information flowing from these results. With life insurance, insureds pay a relatively small premium into a common fund in order to safeguard financial security and stability. By doing this insurance companies spread the risk amongst policy holders in more or less the same risk category. Risk-spreading can be defined as follows:

"One of the most satisfactory general methods of creating financial security against risks therefore seems to be that of spreading the risk among a number of persons all exposed to the same risk and all prepared to make a relatively negligible contribution towards neutralising the detrimental effects of the risk which may materialise for one or more of their number. This is known as insurance."²⁹

This approach to risk-spreading highlights one of the most important fundamental rights enshrined in the Constitution, namely the right of every human being to be treated equally.³⁰ It would definitely infringe on an insured's right to equality if he or she is charged a lower premium just because material information is withheld when the risk is determined.³¹

When insurance companies use the results obtained from gene testing to spread the risk as described above, using the results has a justifiable role to play. In the event of the insurers using the information resulting from the results to reject an application for insurance or to cancel policies, it would boil down to companies limiting the risk in stead of spreading it. This would constitute an unjustifiable practice.³² A possibility to be examined in this regard is the desirability of legislation focusing on genetic discrimination specifically in the insurance law context.³³

According to the LOA³⁴ it is in the interest of affordable premiums in the event of life insurance that a policy which deals with issues raised by new genetic

26 Nienaber and Van der Nest 2004 *THRHR* 448.

27 *Ibid.*

28 Kaprio "Commentary: Role of other genes and the environment should not be overlooked in monogenic disease" 2001 *British Medical J* 1019.

29 Reinecke and Van der Merwe *General principles of insurance* (1989) 2.

30 S 9 of the Constitution.

31 Van der Merwe "*Uberrima fides* en die beraming van die risiko voor sluiting van 'n versekeringskontrak" 1977 *TSAR* 1.

32 Nienaber and Van der Nest 2004 *THRHR* 450; and Bornstein "Genetic discrimination, insurability and legislation: A closing of the legal loopholes" 1996 *J of Law and Policy* 565.

33 Lemmens "Selective justice, genetic discrimination, and insurance: Should we single out genes in our laws?" 2000 *McGill LJ* 347.

34 *LOA code of conduct* 20.4.

technology is needed. One of the various sensitive issues regarding insurance companies and genetic testing is then specifically the issue of whether an applicant for insurance can be requested by the insurance company to undergo gene testing as a part of risk assessment and classification which will also influence the premiums. During the 2006 World Congress this issue was investigated. International viewpoints on the question whether insurance companies may request insureds to undergo genetic testing can be noted as follows:³⁵

- Denmark: There is a general prohibition on insurance companies to request genetic information.
- France: Human genome tests are forbidden even with the consent of the insured.
- Germany: The German Insurance Association released a paper declaring that it would be unnecessary for an applicant for insurance to undergo a genetic test in order to enter into a contract.
- Greece: The collection and usage of sensitive data is prohibited, unless the data has been obtained with the written consent of the applicant.
- Portugal: Requesting and using genetic information as a method to refuse life insurance or to increase premiums are prohibited.

Knowledge of the results of gene testing may have extreme implications, depending on the specific outcome of the test. On the one hand, where the results of a genetic test leave the patient with possible effective intervention to treat or even prevent the disease or disorder from developing, knowledge of the results will have a positive effect on the life of the patient.³⁶ Irrespective of the fact that it will still categorise the insured in a high risk category, the insured will be in a position to take positive steps in managing the disease or disorder. For example, where a woman undergoes the tests and the results indicate that she is carrying mutated genes which could cause ovarian or breast cancer to develop, she could go for frequent screening. She could also improve her health by, for example, stopping to smoke and better her environmental behaviour.³⁷

Based on these facts the information obtained from gene testing can have a dramatically positive effect if it enables people to take preventative steps to reduce the chances of the disease or disorder from emerging.

Unfortunately the contrary is also true. According to the LOA, “[t]he psychological effects of an unfavourable result may be devastating for some people”.³⁸

Negative feelings from the knowledge of the results could also impact on a person's quality of life if he or she knows what he or she will be facing in future and that there is nothing that he or she can do to better the situation. The test for Alzheimer's disease will predict the risk of the disease but will leave the person without any preventative measures to control the realisation of the risk.³⁹ A person's financial security could also be influenced negatively by knowing that his insurability will be affected by the state of his health.⁴⁰ Further examples of both

35 <http://www.aida.org.za>.

36 Nienaber and Van der Nest 2004 *THRHR* 449.

37 *Idem* 453.

38 *LOA code of conduct* 20.5.

39 Evans, Skrzynia and Burke “The complexities of predictive genetic testing” 2001 *British Medical J* 1054.

40 Kuschke 2007 *De Jure* 306.

the short and long-term impact on a person's emotional well-being include distress, depression, guilt, a negative impact on behaviour, lowered self-esteem, goals, expectations, impact on family relationships which specifically include decisions on marriage and having children.⁴¹ I agree with Nöthling-Slabbert⁴² that the disclosure of genetic information does not only have the possible effect of stigmatisation of the insured, but could also affect his or her financial and educational situation as well as employment opportunities, application for insurance and future health care.

This is where one should examine an insured's right not to know the results flowing from gene testing. The LOA suggests that "[i]t is known that many individuals would prefer not to know their risk especially if the disease in question has no prospect of prevention or cure".⁴³

2.3 The right not to know

A person's right to know is a well known and fundamental ethical and legal principle.⁴⁴ This principle is highlighted by various legal principles and enactments.⁴⁵

Even though the LOA believes that it is inappropriate for insurance companies to request an applicant to undergo gene testing due to the possible unfavourable psychological effects that may flow from knowledge of the results, the possibility exist that more people will be willing to undergo genetic tests if they have the right not to know the results.⁴⁶ The acknowledgement of the right not to know has benefits for both the insurance company and the prospective insured. The insurance company will be able to obtain material information which will help them to make a fair risk and premium assessment; at the same time the principle of equity will apply if all people in the same risk category were to be treated equally. If the insureds have this right not to know the results of the gene testing they would probably consent to undergo gene testing more easily. Another argument in favour of the insured's right not to know is the fact that gene testing often only indicates the uncertain probability of the development of a disease or disorder.⁴⁷

The predictive power of genetic testing is on the increase. This has the effect that more people are being confronted with the fact that they are at risk of attracting a serious disease or disorder. In the event where no real and effective treatment is available to reduce the risk of contracting the disease or disorder, the possibility of acknowledging a person's right not to know the results of the genetic tests emerges.

Where a person is confronted with the discovery of a genetic condition that places him or her at a high risk of suffering a specific disease or diseases, it could have such a severe psychological effect on their lives that, to their mind,

41 Schneider "Adverse impact of predisposition testing on major life activities: Lessons from BRCA ½ Testing" 2000 *J of Health Care Law and Policy* 365.

42 2007 *THRHR* 622.

43 *LOA code of conduct* 20.5.

44 Andorno "The right not to know: An autonomy based approach" 2004 (30) *J Med Ethics* 435 available at www.jmedethics.com, accessed 10 Sept 2007.

45 Eg the Promotion of Access to Information Act 2 of 2000.

46 *LOA code of conduct* 20.5.

47 Evans, Skrzynia and Burke 2001 *British Medical J* 1053.

the purpose of their lives might have evaporated.⁴⁸ In these situations one could argue that "it may not be justifiable to take away hope from a person by exposing them to knowledge they do not want".⁴⁹ One could therefore argue that people should have a choice as to whether they would want to know the results after undergoing gene testing.

Some of the criticism against an insured's right not to know includes the following. Firstly, knowledge is seen as power. This suggests that having knowledge makes one powerful. This is true, but in those instances where the so-called power will deprive a person from living his or her life to the fullest, it can be argued that the lack of this specific power that could have a devastating effect on a person's life is indeed the power. Another objection against a person's right not to know is rooted in the doctor-patient relationship where the doctor has a duty to disclose risks to patients.⁵⁰ Furthermore, one could argue that the person who chooses the right not to know is acting contrary to his or her solidarity and responsibility towards others.⁵¹ The biggest objection in acknowledging an insured's right not to know is probably rooted in the constitutional right of freedom of expression.⁵² Madlala J stressed the importance of this right in a democratic society as follows:

"Freedom of expression is critical to an open and democratic society based on freedom and equality and without freedom of expression, openness is severely compromised and endangered. It cannot be gainsaid that freedom of expression lies at the heart of the democracy. This Court has recognised in other cases that freedom of expression is one of a 'web of mutually supporting rights'."⁵³

Andorno gives examples of how the right not to know has been recognised by various international ethical and legal instruments.⁵⁴ The European Convention on Human Rights and Biomedicine⁵⁵ states that "[e]veryone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed". The UNESCO Universal Declaration on the Human Genome and Human Rights⁵⁶ provides that "[t]he right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected".

During the AIDA Congress in October 2006 participating countries had to complete a questionnaire on various aspects of personal insurance and genetic testing. Question 5 of this questionnaire read: "Do the legislation, doctrine and/or case law in your country contemplate the applicants' 'right to not know'?"⁵⁷ International viewpoints with regard to this question are reflected as follows:

- Australia respects the insured's right not to know.
- Belgium respects the insured's right not to know.

48 Andorno fn 44 above.

49 *Ibid.*

50 This article does not examine any connection between the right not to know in the insurance law perspective and the medical environment.

51 Andorno fn 44 above.

52 S 16 of the Constitution.

53 *NM v Smith (Freedom of expression institute as Amicus Curiae)* 2007 5 SA 268 (D).

54 Andorno fn 44 above.

55 Adopted in 1997: a 10.2.

56 Adopted in 1997: a 5c.

57 <http://www.aida.org.za>.

- Colombia: The Political Constitution of Colombia respects various personality rights under which one can include the right not to know.
- Ecuador: No legislation exists but an insured's right not to know can not be restricted in law.
- France acknowledges the right not to know.
- Germany: The right not to know is included in the principle to protect one's personality and dignity.
- Italy: No legislation exists, but in terms of the Oviedo Convention the right has been inferred as an integral part of the principle of respect for human dignity.
- Spain: Legislation protects a patient's right not to know.
- Uruguay acknowledges the right not to know.

South Africa has no legislation in this regard. The opinion is that a person's rights to privacy, information, and bodily and mental integrity should not prevent an insured to use his right not to know.

It is very clear from the above examples as well as various others⁵⁸ that an explicit choice on the part of the insured is necessary for the right not to know to come into operation. This right not to know can therefore not be assumed – it must be stated expressly. The following statement that was recently placed on a blog summarises it as follows:⁵⁹ “If someone prefers not to know what reality looks like, will you insist he has to know and be unhappy about it?”

3 CONCLUSION

The acknowledgement of a right not to know highlights a person's autonomy. You are in control of your life and the choice not to know the results shows an individual's right to self determination. An individual's desire to control information about him- or herself and keep it confidential from others are included in the acknowledgement of the right not to know.⁶⁰ I agree with Andorno that this right not to know should be classified as a relative right.⁶¹ In other words, if it is necessary to disclose the results obtained from a genetic test to avoid serious harm to third parties, especially family members, the patient's right not to know can be restricted. Therefore, if compelling public interest exists to interfere with a person's right to privacy, this right can be restricted.⁶² This reasoning coincides with the well-known possible restriction of any human right provided for in the Constitution.⁶³ The following excerpt from the well-known Constitutional Court case *Bernstein v Bester NNO*⁶⁴ clearly sets out the balance between the right to privacy and the restrictive working of section 36 of the Constitution:

“A very high level of protection is given to an individual's intimate personal sphere of life and the maintenance of its basic preconditions and there is a final untouchable sphere of human freedom that is beyond interference from any public

58 Andorno fn 44 above.

59 <http://backreaction.blogspot.com/2007/08/right-not-to-know.htm> accessed 10 Sept 2007.

60 *NM v Smith (Freedom of Expression Institute as Amicus Curiae) supra* 263H.

61 Andorno fn 44 above.

62 *NM v Smith (Freedom of expression institute as Amicus Curiae) supra* 251H–I.

63 S 36.

64 1996 2 SA 751 (CC) para 77.

authority. So much so that, in regard to this most intimate core of privacy, no justifiable limitation thereof can take place. But this most intimate core is narrowly construed. This inviolable is left behind once an individual enters into relationships with persons outside the closest intimate sphere; the individual's activities then acquire a social dimension and the right of privacy in this context becomes subject to limitation."