

# Access to genetic information and the insurer's duty of genetic data protection<sup>1</sup>

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## OPSOMMING

### **Toegang tot genetiese inligting en die versekeraar se verpligting om data te beskerm**

In hierdie artikel word die impak van die ontwikkeling van menslike genetiese toetse, en die reg op inligting wat in die toetsresultate vervat word, bespreek. Die individu se gemene-regtelike en grondwetlike regte op privaatheid en sy individualiteit word deur die openbaarmaking van inligting wat hy as konfidensieel mag beskou, bedreig. Die reg op toegang tot inligting word in die lig van die relevante Grondwetlike bepalings, die Wet op Elektroniese Transaksies en Kommunikasies, die Wet op die Bevordering van Toegang tot Inligting, die Wet op Finansiële Adviseurs en Tussengangers, die Wetsontwerp op die Beskerming van Persoonlike Inligting sowel as internasionale wetgewing, die menings van skrywers en ander organisasies soos die Life Offices Association, ontleed. Die moontlikheid dat die aanwending van sodanige inligting deur die versekeraar tot genetiese diskriminasie aanleiding kan gee, word bespreek. Laastens word die statutêre verpligtinge van 'n versekeraar om data te beskerm en verantwoordelik te bestuur, kortliks ontleed.

## 1 Introduction

In this age, commonly known as the information age, more personal information is being collected, stored and used than ever before. Nationally and internationally, the need for the law to provide measures to ensure effective data protection becomes greater each day. Due to advanced digital technology and the revolution in biotechnology, there is an increasing flow of personal data across all frontiers for the purpose of data processing, automatic or otherwise, increasing the ability to disseminate information worldwide.

In the field of personal insurance, the collection of and access to personal information is paramount to the core business of insurers. The formation of centralised databases allows various role players in the insurance industry to gain access to personal information stored in these

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databases.<sup>2</sup> Previously, information pertaining to a prospective insured's and his family's medical history has played an understandably crucial role in the determination of the risk and the subsequent decision to provide insurance cover against these risks. Scientists have spent the past decades to determine why certain diseases strike specific families or specific groups of people.

The Human Genome Project,<sup>3</sup> that focuses on the genetic mapping and sequencing of human DNA<sup>4</sup> in order to determine and predict possible genetic diseases, introduced a whole new wealth of information that could be used by an insurer to determine the risks posed by a prospective insured. The Life Offices Association (hereinafter "LOA") defines "genetic testing" as "the direct analysis of DNA, RNA, genes or chromosomes for the purposes of determining inherited predisposition to a particular disease or group of diseases".<sup>5</sup> Initiated in 1990 and completed early in this century,<sup>6</sup> genetic mapping therefore reveals the "red flags" of disease, exposing the harmful roles that particular genes play in causing disorders, predispositions and the susceptibility to certain diseases.<sup>7</sup> It is important to remember that these tests often indicate only the uncertain probability, and not the absolute certainty or clear-cut prediction, of actually developing the disorder or disease.<sup>8</sup>

Genetic testing raises many new ethical, social and legal issues. Not only can the information obtained from genetic testing dramatically improve lives by having a corrective impact on family history through early treatment and lifestyle changes,<sup>9</sup> it could also impact severely on the life of the person tested, as it could open his eyes on what the future could hold for him as well as his family healthwise, and could also greatly affect his financial security due to its negative impact on his insurability. Some genetic testing requires the genetic testing of various members of a family for so-called genetic linkage tests. As the interests of various persons, not

2 At issue in South Africa at the moment is the establishment of a communal database for the sharing of claims information by South Africa's largest short-term insurers, including Santam, Mutual & Federal, SA Eagle, Auto & General, Lloyds and AIG, and the criticism that it will infringe upon the policyholder's rights to privacy: [www.bday.co.za/bday/content/direct/1,3523,885591-6078-0,00.html](http://www.bday.co.za/bday/content/direct/1,3523,885591-6078-0,00.html) (accessed on 2006-07-10).

3 Or "HGP", an international thirteen-year effort coordinated by the US Department of Energy and National Institutes of Health. See also [www.genomics.energy.gov](http://www.genomics.energy.gov) for more details on the history and scope of this project.

4 Deoxyribonucleic acid, which forms the structural components that dictate our hereditary characteristics.

5 LOA *Code of Conduct* ch 20 Genetic Testing par 3.

6 See n 12.

7 Martinez "Mapping the Future" [www.swmed.edu/home\\_pages/publish/magazine/HumanGenome/enomeproj.html](http://www.swmed.edu/home_pages/publish/magazine/HumanGenome/enomeproj.html) (accessed on 2006-09-11).

8 Evans, Skrzynia and Burke "The complexities of effective genetic testing" 2001 *British Medical Law Journal* 1053; [http://en.wikipedia.org/wiki/Privacy#Genetic\\_privacy](http://en.wikipedia.org/wiki/Privacy#Genetic_privacy) (accessed on 2006-10-11).

9 Eg for the early detection of hemochromatosis or excess iron storage in the body, that can successfully be treated pre-symptomatically which then leads to a normal life-expectancy, whereas late diagnosis and failure to treat it properly can be fatal.

only the potential insured as the primary data subject are affected, the rules, procedures and protocols relating to the protection and use of this information must be clearly defined and strictly implemented.<sup>10</sup>

## 2 Genetic Testing

Early in 2003 researchers claimed to have mapped the entire chain of human DNA, also known as the “individual’s genetic constitution” or “blueprint of life”<sup>11</sup> successfully.<sup>12</sup> The nucleus of each human cell contains the threadlike molecule of DNA that is bundled into 23 pairs of chromosomes, and each chromosome contains thousands of the 20 000 to 25 000<sup>13</sup> human genes that are interspersed between non-coding sections of DNA. This forms the biological instruction manual or “genome” of the cell.<sup>14</sup> Changes and mutations of these genes, hereditary<sup>15</sup> or acquired,<sup>16</sup> lead to diseases.

In addition to the significance and many benefits of this achievement<sup>17</sup> for which the scientists involved were awarded the Nobel prize,<sup>18</sup> the management and use or processing of the information obtained from genetic

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10 See in this regard The Life Office’s Association of South Africa *LOA Code of Conduct* ch 20 on “Genetic Testing”; [www.loa.co.za](http://www.loa.co.za); “Policies on Release of Human Genomic Sequence Data” *Summary of the Report of the Second International Strategy meeting on Human Genome Sequencing* (Bermuda 1997) that warns about the sensitivity of, and potential errors in the processes to obtain, and errors in the contents of this information, and proposes the necessary guidelines for releasing human sequence data; also Hubbard and Lewontin “Pitfalls of genetic testing” 1996 *New England Journal of Medicine* 1192 [www.ornl.gov/sci/techresources/Human\\_Genome/research/bermuda.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/research/bermuda.shtml) (accessed on 2006-09-21); Janssen *Genetic discrimination and genetic privacy in a comparative perspective* (2005) 53.

11 McKusick “The human genome organisation: History, purpose and membership” 1989 *Genomics* 385.

12 Eaton “Human Genome Project Completed” 2003 *British Medical Journal* 838; Cf Clabby “Human genome map’s a wrap” *The News & Observer* (2006-05-18), stated that the final chromosome was only successfully mapped in 2006; International Human Genome Sequencing Consortium “International Human Genome Sequencing Consortium Describes Finished Human Genome Sequence Researchers Trim Count of Human Genes to 20 000 – 25 000” 2004 *Nature* 931.

13 Previously numbers of 100 000 plus were predicted; see International Human Genome Sequencing Consortium 931.

14 Martinez “Mapping the Future” [www.swmed.edu/home\\_pages/publish/magazine/HumanGenome/genomeproj.html](http://www.swmed.edu/home_pages/publish/magazine/HumanGenome/genomeproj.html) (accessed on 2006-09-11).

15 Single causative genes could, for example, cause sickle cell anaemia or cystic fibrosis.

16 A variety of gene mutations, a particular combination of genes or the influence of environmental factors such as pollution could cause various diseases, for example congenital heart defects, familial colon cancer, diabetes, breast cancer, Down’s syndrome or polycystic kidney disease. Single mutated genes do not necessarily cause the disease, but with the right environmental influences and gene combinations, the disease develops.

17 The World Medical Association *Declaration on the Genome Project* (1992).

18 Eaton “Human genome pioneers are awarded Nobel prize” 2002 *British Medical Journal* 325.

testing, the right of privacy to the test results, as well as the duty to disclose and to protect this information has become a crucial issue.<sup>19</sup>

Scientists will be kept busy for at least the next decade to finally determine the effects and consequences of different combinations of genes and potential environmental contributions.<sup>20</sup> An increasing number of gene tests are, in the meantime, rapidly becoming available commercially.<sup>21</sup> The relevance of the different tests for purposes of insurance risk selection and risk classification has to be determined. One could, for example, ask whether a predisposition to colon cancer could be a legally justified reason to bar a person from obtaining mortgage insurance,<sup>22</sup> and whether it is necessary to allow an insurer who provides property insurance access to the records of the potential insured's entire medical predispositions.

### 3 Confidentiality of Genetic Information

#### 3.1 Right to Privacy and Identity

"The intensity and complexity of life, attendant upon advancing civilization, have rendered necessary some retreat from the world, and man, under the refining influence of culture, has become more sensitive to publicity, so that solitude and privacy have become more essential to the individual; but modern enterprise and invention have, through invasions upon his privacy, subjected him to mental pain and distress, far greater than could be inflicted by mere bodily injury."<sup>23</sup>

Defining privacy has always been notoriously problematic, as it means different things to different people.<sup>24</sup> It has been said that "privacy, like an elephant, is more readily recognised than described".<sup>25</sup>

19 It was agreed that as this project was a communal effort, the primary genomic sequence should be in the public domain and is therefore a public document and freely available, yet a specific individual's genetic test results remain in the private domain [www.ornl.gov/sci/techresources/Human\\_Genome/research/bermuda.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/research/bermuda.shtml) (accessed on 2006-09-21); see also Nienaber and Van der Nest "Genetic testing for the purpose of insurance risk assessment and the constitutional right to privacy" 2003 *THRHR* 451.

20 Casey "What Can the New Gene Tests Tell Us?" [http://ornl.gov/sci/techresources/Human\\_Genome/publicat/judges/judge.html](http://ornl.gov/sci/techresources/Human_Genome/publicat/judges/judge.html) accessed on 2006-10-09).

21 *Ibid.* For example carrier screening to determine whether a spouse carries one copy of a gene, that in combination with the other spouse's gene would cause a hereditary disease in their offspring; prenatal diagnostic testing for Down's syndrome and presymptomatic testing to predict or estimate the risk of adult-onset cancers and disorders. Mutations in two specific genes, namely BRCA1 and BRCA2 (named for BREast CAncer) have been found to cause a high risk of developing familial breast or ovarian cancer; [www.dukemednews.duke.edu/news/controversy.php?id=1733](http://www.dukemednews.duke.edu/news/controversy.php?id=1733) "Genetic Testing for Breast and Ovarian Cancer Susceptibility".

22 Newman "Genetics in the Courtroom: An Introduction" 1997 *The Judges' Journal* 1.

23 Warren and Brandeis "The Right to Privacy" 1890 *Harvard Law Review* 2.

24 *Bernstein and others v Bester* NO 1996 (2) SA 751 (CC) par 73; Roos *The law of data privacy protection: a comparative and theoretical study* (LLD dissertation 2003 Unisa) 15; Neethling Potgieter and Visser *Law of Personality* (2005) 30.

Neethling, Potgieter and Visser define privacy as

“an individual condition of life characterised by seclusion from the public and publicity. This condition embraces all those personal facts which the person concerned has himself determined to be excluded from the knowledge of outsiders and in respect of which he has the will that they be kept private”.<sup>26</sup>

Most countries have laws that regulate the unsanctioned use of private information. In South Africa the right to privacy is embodied in the common law<sup>27</sup> and in section 14 of the Constitution.<sup>28</sup> In the insurance industry problems arise when insurers do not respect the confidentiality of the personal information of the insured, or where third parties obtain unauthorised access to insurance databases, and the information is abused to the insured’s detriment.

The Constitutional Court has emphasised the interdependency between the constitutional and the common law right to privacy.<sup>29</sup> The common law right to privacy is part of a person’s *dignitas* and it is a valuable aspect of a person’s personality. The Constitution does not distinguish between the trilogy of *fama*, *corpus* and *dignitas* as far as reference to the right to dignity is concerned.<sup>30</sup>

The Court has adopted a sensible approach in saying that the scope of a person’s privacy extends *a fortiori* only to those aspects in regard to which a legitimate expectation of privacy can be harboured.<sup>31</sup> The test to determine the scope and content of the right to privacy is the “reasonable expectation of privacy” test,<sup>32</sup> which requires a subjective expectation of privacy, as well as an expectation that is recognised by society as reasonable. Also, the right to privacy relates only to the most personal aspects of a person’s existence, and not to every aspect within his personal knowledge and experience.<sup>33</sup>

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25 Young *Privacy* (1978) 2.

26 Neethling *et al* 32; *National Media Ltd v Jooste* 1996 3 SA 262 (A) 271.

27 *O’Keeffe v Argus Printing and Publishing Co Ltd* 1954 3 SA 244(C) is seen as the *locus classicus* for the recognition of a common law right to privacy in South Africa.

28 The Constitution of the Republic of South Africa s 14: “Everyone has the right to privacy, which includes the right not to have (a) their person or home searched; (b) their property searched; (c) their possessions seized; or (d) the privacy of their communications infringed”; *Grütter v Lombard* unreported SCA case no 628/05 paras 8–13.

29 *Bernstein* par 72.

30 S 9; Woolman *et al Constitutional Law of South Africa* (2005) 36-i–36-19 and 36-43; *Dendy v University of Witwatersrand, Johannesburg* 2005 2 All SA 490 (W) 497. See also *Khumalo v Holomisa* 2002 5 SA 401 (CC) par 27 “The right to privacy entrenched in s 14 of the Constitution, recognises that human beings have a right to a sphere of intimacy and autonomy that should be protected from invasion. This right serves to foster human dignity. No sharp lines then can be drawn between reputation, *dignitas* and privacy in giving effect to the value of human dignity in our Constitution”.

31 *Bernstein* par 75.

32 *Idem* paras 74 to 79 on the position in the USA, Canada and Germany.

33 *Idem* par 79.

Violation of such a right to privacy constitutes an *iniuria*.<sup>34</sup> In the first instance the compilation and distribution of data, through the disclosure of private facts about a person (the so-called processing of data)<sup>35</sup> threatens the privacy of an individual. This occurs where true facts are processed contrary to the person's will or intention.

In the second instance the acquisition and disclosure of false or misleading data also threatens the identity of a person.<sup>36</sup> Both the infringement of privacy and the infringement of identity can occur concurrently.<sup>37</sup> This emphasises the need to strictly control all facets of information management, namely the processing and use of information, as well as to prevent the abuse or unauthorised access of personal data. Unwanted exposure of personal information in an insurance context may lead to discrimination, loss of physical integrity, loss of good name, loss of dignity and intimacy, loss of benefits, stigma and embarrassment.<sup>38</sup>

Lastly, any unauthorised genetic testing, or coercion or insistence that tests are done, is also a form of *iniuria* due to the infringement of the physical integrity or *corpus* of a person.<sup>39</sup> Where non-violent infringements such as the mere painless collection of DNA is concerned, the courts have stated that "the kind of test which is under discussion here, requires a physical infringement of a person's body. It is not only an infringement of his right to privacy, but also an infringement of his right to bodily integrity. Without the victim's consent it is an assault upon him, whether it is the prick of a needle, or the removal of whichever part or content of the human body".<sup>40</sup>

### 3 2 Data Privacy

In order to address the issue of "information privacy" or "data privacy", the meaning of what "data", and also what "private or personal data" entails, must be determined. The Electronic Communication and Transactions Act<sup>41</sup> defines data as "electronic representations of information in any form".<sup>42</sup> Data is processed by a "data controller" or by or on behalf of

34 See also *Grütter v Lombard* par 13 where it was confirmed that not every intrusion upon a protectable right of personality will necessarily constitute an *iniuria*, unless the infringement constitutes a wrongful violation that is determined by considerations of legal policy.

35 See the discussion under par 4 1 n 78.

36 Neethling *et al* 37 270; Roos "Data protection provisions in the Open Democracy Bill" 1998 *THRHR* 567; *Swanepoel v Minister van Veiligheid en Sekuriteit* 1999 4 SA 549 (T).

37 Neethling *et al* 37.

38 Goldman "Health at the Heart of Files?" Brandeis Lecture delivered at the Annual Meeting of the Massachusetts Health Data Consortium (April 2001); South African Law Review Commission *Privacy and Data Protection Discussion Paper 109* Project 124 (Oct 2005) ch 2; Neethling *et al* 85 129 191.

39 Neethling *et al* 84 242.

40 *Nell v Nell* 1990 3 SA 889(T) 895; the translation is by Neethling *et al* 86.

41 Act 25 of 2002 (hereinafter referred to as "ECTA").

42 S 1 item 20.

a so-called “responsible party”.<sup>43</sup> Controllers can be classified as public or private data controllers.<sup>44</sup> Genetic information can be processed by both. Insurance data controllers are identified private data controllers, whereas the state in all its facets personifies public data controllers.<sup>45</sup>

In brief, “personal data” can be said to be data that can be linked to a specific individual, called the “data subject”.<sup>46</sup> In terms of ECTA “personal data” means personal information about an identifiable individual including physical or mental health, well-being and disability,<sup>47</sup> information relating to the medical history of the individual,<sup>48</sup> any identifying number, symbol or other particular (the question is whether this includes the absolutely unique DNA of an individual) assigned to the individual,<sup>49</sup> the fingerprints or blood type of the individual.<sup>50</sup> The Act does not refer specifically to genetic information.

In terms of ECTA, the minister may declare<sup>51</sup> certain classes of information as critical data, for which additional protection measures are prescribed.<sup>52</sup> Critical data means data that is of importance not only to the protection of national security, but also includes data that is identified as of importance for the economical and social well-being of citizens.<sup>53</sup> Should the Minister in future declare genetic information as critical, the protection of a database containing this information will require a higher degree of care.

In terms of The Promotion of Access to Information Act<sup>54</sup> and The Protection of Personal Information Bill the term “personal information” enjoys the same meaning as provided for under ECTA.<sup>55</sup> The Bill refers specifically also to “information privacy”.<sup>56</sup>

Under the EU Directive<sup>57</sup> personal data means any information relating to an identified or identifiable natural person. The right to privacy is a highly developed area of law in the EU, and can be found in article 8 of the European Convention on Human Rights<sup>58</sup> that covers the right to

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43 ECTA s 1 item 21; See The Draft Protection of Personal Information Bill (hereinafter referred to as the ‘Bill’) s 2 item 15.

44 Roos 13.

45 Neethling *et al* 268.

46 Neethling *et al* 267; ECTA s 1 item 23 defines a “data subject” as “any natural person from or in respect of whom personal information has been requested, collected, collated, processed, and stored after the commencement of this Act”.

47 S 1 item 44(a).

48 S 1 item 44(b).

49 S 1 item 44(c).

50 S 1 item 44(d).

51 S 53.

52 Ch 9 ss 52–58.

53 S1 item 13.

54 Act 2 of 2000 (hereinafter referred to as “PAIA”).

55 PAIA s 1 item 18(a)-(d); Bill s 2 item 8(a)-(d).

56 See the discussion on the provisions of the Bill under par 4 4 below.

57 EU Directive 95/46/EC.

58 The Convention for the Protection of Human Rights and Fundamental Freedoms, adopted in 1950, and also known as the “ECHR”.

respect for private life, that includes another's private and family life, his home and his correspondence. The issues on the right to privacy lead to the Convention for the Protection of Individuals with regard to the Automatic Processing of Personal Data of 1981,<sup>59</sup> that caused various member countries to adopt their own legislation in accordance with the Convention.<sup>60</sup>

### 3.3 Genetic Data Privacy

What makes genetic secrets so special?<sup>61</sup> The question arises whether the right to privacy of genetic information<sup>62</sup> should be different from the right to privacy of other information.<sup>63</sup>

Genetic information is neither unique nor distinctive in its ability to offer probabilistic peeks into our future health.<sup>64</sup> A simple cholesterol test can in some cases be a better predictor of ill-health than a genetic DNA test could.

Genetic testing also does not increase the risk, it only increases knowledge about an existing risk. The issue at hand is not about a new disease such as AIDS, SARS or bird flu, but about new and more accurate information about an uncontrollable factor or state of an individual's health. Some medical information relates to a matter of choice, for example lifestyle issues such as smoking, sexual preferences and activities, yet with genetic information there is no choice nor control.

There is no consensus on why genetic information, as a sub-class of medical information, should be classified as more sensitive in nature than any other information for example on blood type,<sup>65</sup> previous illnesses or allergies.<sup>66</sup> Two schools of thought exist on whether the information obtained by human genome testing should in principle be treated differently

59 A Convention of the Council of Europe, signed in Strasbourg on 1981-01-28. For a detailed discussion on the Directive, see Fromholz "The European Union Data Privacy Directive" 2000 *Berkeley Tech Law Journal* 471.

60 For example the *Wet Bescherming Persoonsgegevens 2000* of the Netherlands, the *New Zealand Privacy Act 1993*, and the *US Genetic Privacy Act 1995*.

61 Bregman-Eschet "Genetic Databases and Biobanks: Who controls our genetic privacy?" Nov 2006 *Santa Clara Computer & High Technology Law Journal* 1.

62 *Idem* 3. Bregman-Eschet states that the term of genetic privacy applies to the concept of privacy to genetic-related findings and refers to the use of personal data derived from one's genes.

63 Human Genetics Committee "Whose hands on your genes?" *Report HGC01/P4* (2001-02-15); [www.hgc.gov.uk](http://www.hgc.gov.uk) (accessed on 2007-02-11).

64 Bregman-Eschet Nov 2006 *Santa Clara Computer & High Technology Law Journal* 3.

65 Blood group typing is in fact a genetic test, although in general it is not seen to be invasive enough to enjoy the stricter protection advocated for other genetic tests such as chromosome testing: *Europabio Human Medical Genetic Testing: An Europabio Position Paper* (2004-05) 4.

66 Poste "Privacy and Confidentiality in the Age of Genetic Engineering" 1999 4 *Texas Law Rev & Politics* 25 28; Murray *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (1997) 60; Annas "Genetic Privacy: There Ought to be a Law" 1999 *Texas Rev Law & Politics* 9; Bregman-Eschet Nov 2006 *Santa Clara Computer & High Technology Law Journal* section II.



from information gleaned from the medical history of the family or the insured's own previous medical history. Some argue that the information is so sensitive and unique that it deserves special privacy protection, and others that there should be no distinction as there is no clear demarcation that separates genetic data from other health data.<sup>67</sup> It does though disclose more of our personal information as well as information regarding our relatives, the whole family and even unborn children, than any other information.<sup>68</sup> The debate continues.

In the United States of America, for example, to avoid dealing with the contentious issue of distinguishing between genetic and other medical information, genetic privacy legislation is based only on the premise that genetic information is different from other types of personal information and requires extra special protection.<sup>69</sup>

Neethling *et al*<sup>70</sup> state that to determine which facts regarding the genetic information of the insured are private in nature, the solution may be to leave it to each individual to decide for himself which facts are of a confidential nature, and should be excluded from the knowledge of others and kept private. The LOA requires underwriters to keep any genetic test results completely confidential, and to keep comprehensive records of any action or decision taken relating to genetic issues, and to keep the information in a coded form.<sup>71</sup> The Bill also refers to the term "biometric" which is defined as "techniques of personal identification that are based on physical characteristics including fingerprinting, retinal scanning and voice recognition".<sup>72</sup> This would, due to the general nature of the characteristics mentioned, also include DNA.

This discussion will not join the fray and address this issue further. For the discussion on the current statutory measures in place for data protection that follows under paragraph 5 below, any personal information relevant to insurance, medical, genetic or otherwise, is deemed to be of a

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67 Gostin and Hodge "Genetic privacy and the law: An end to genetic exceptionalism" 1999 *Jurimetrics: Journal of Law, Science and Technology* 21; for a discussion on the roles of family members, see also Slabbert "The (genetic) ties that bind us and the duty to disclose genetic risks to blood relatives" unpublished proceedings of the world congress on medical law, organized by the World Association for Medical Law, held from 2006-08-07 to 2006-08-11 in Toulouse, France.

68 Ronchi and Carblanc "Genetic Information" November 2001 *OECD Observer* 21; Laurie "The most personal information of all: An appraisal of genetic privacy in the shadow of the Human Genome Project" 1996 *International Journal of Law, Policy and the Family* 82-83; Annas 1999 *Texas Rev Law & Politics* 9.

69 Genetic Information Nondiscrimination Act of 2007; Annas, Glantz and Roche "The Genetic Privacy act and Commentary" [www.ornl.gov/sci/techresources/Human\\_Genome/resource/privacy/privacy1.html](http://www.ornl.gov/sci/techresources/Human_Genome/resource/privacy/privacy1.html) (accessed on 2007-01-27); the legislation specifically targets group health plans and health insurance issuers and prohibits discrimination on the basis of genetic information, and prohibits enrolment and premium discrimination based on information about a request for or receipt of genetic services, and required genetic testing.

70 30.

71 LOA ch 20 par 8 11.

72 Bill s 2 item 1.

confidential nature and labelled and deserves to be protected as confidential information. There is general uncertainty and uneasiness on whether current data protection systems are efficient enough to cover the new realities and eventualities posed by the advent of comprehensive and accurate genetic testing.<sup>73</sup>

## 4 Infringements and Limitations of the Right to Privacy and Identity

“Privacy is acknowledged in the truly personal realm, but as a person moves into communal relations and activities such as business and social interaction, the scope of personal space shrinks accordingly.”<sup>74</sup>

### 4.1 General

In general the main counter-values against control and privacy of personal information are commerce (in terms of the principle that better information leads to better markets), and truthfulness (that privacy can also be used to deceive and to defraud), yet these are not fundamental rights in themselves that compete with other constitutionally entrenched rights.<sup>75</sup>

In terms of the ECHR any restriction of a right must be “in accordance with law” and “necessary in a democratic society” in order to effectively limit or restrict the right to privacy.<sup>76</sup> These principles are in line with the general limitations clause as found in section 36(1) of our Constitution, as quoted below.<sup>77</sup>

The seven internationally-recognised principles that govern the *protection* of personal data to protect the data subject’s privacy are notice, purpose, consent, security, disclosure, access and accountability.<sup>78</sup> The three principles that govern the *processing*<sup>79</sup> of personal data, are transparency,<sup>80</sup> legitimate purpose<sup>81</sup> and proportionality.<sup>82</sup>

73 Ronchi and Carblanc “How healthy is our healthcare?” Dec 2001 *OECD Observer* 2.

74 *Bernstein* par 67.

75 Kang “Information Privacy in Cyberspace Transactions” 1998 *Stanford Law Review* 1212.

76 ECHR art 8.

77 Par 4.2.

78 As stipulated by the Directorate for Science Technology and Industry of the Organisation for Economic Co-operation and Development; see also the provisions of ECTA as discussed under par 5.2 below on the protection; Bill Ch 3 Part A combines the protection and processing principles and list eight general information protection principles namely (a) limitation of processing – ss 7–10, (b) purpose specification – s 11–13, (c) further processing – s 14, (d) information quality – s 15, (e) openness – s 16, (f) security of information – s 17–20, (g) individual participation – s 21–22, and (h) accountability – s 23.

79 Bill s 2 item 12 defines “processing” as “any operation concerning personal information, including in any case the collection, recording, organisation, storage, updating or modification, retrieval, consultation, use, dissemination by means of transmission, distribution or making available in any other form, merging, linking, as well as blocking, erasure or destruction of information”.

In order to comply with transparency and legitimate purpose, data may only be processed when the data subject<sup>83</sup> has consented to the processing, and where processing is necessary for the performance or conclusion of a contract, for compliance with a legal obligation, to protect the vital interests of the data subject, for the performance of a task carried out in the public interest or in the exercise of an official authority or for legitimate interests pursued by the data controller or third parties to whom the data is disclosed, except where the interests are overridden by the data subject's fundamental rights and freedoms.<sup>84</sup>

Data may as far as proportionality is concerned, only be processed insofar that it is adequate, relevant and not excessive in relation to the purpose for which it is processed.<sup>85</sup>

That the data may be inaccurate, incomplete or irrelevant for the purpose for which it is processed, used for a purpose other than the one for which processing was authorised, and accessed, disclosed or destroyed without proper authorisation,<sup>86</sup> are all risks inherent to the processing of personal data.<sup>87</sup>

## 4 2 South African Common Law and the Constitution

Certain restrictions of the right to privacy are acknowledged in our law. In terms of the common law, an infringement is not wrongful or unlawful if a ground of justification exists. Examples include consent,<sup>88</sup> legitimate or lawful interests of another, or where the infringement is in the public interest.<sup>89</sup>

In terms of section 36(1) of the Constitution a fundamental right may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom. All relevant factors

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80 Art 7 EU Directive n 56.

81 Art 6b EU Directive.

82 Arts 6, 8, 14 and 15 EU Directive.

83 N 45 for the definition of a "data subject".

84 Art 7 EU Directive.

85 Art 6 EU Directive.

86 Leyden "Europeans fear data loss disaster" *Channel Register* (2007-02-19) 1 reports that 58% of IT managers fear major data losses by breach of security measures; one in five businesses expect to cope with major confidential data loss due to loss of equipment and hackers. The US, Australia, Canada and the UK are in the process of enacting legislation that forces entities to disclose personal data security breaches. Development in South African legislation could follow suit. This could have the benefit of enabling persons to minimize their losses through subsequent damage control, but it could also increase the chances of succeeding with a liability claim against the company as a statutory duty or a duty of care is breached: [www.out-law.com/page-7783](http://www.out-law.com/page-7783) of 19/02/2007 (accessed on 2007-02-22).

87 Roos Abstract (LLD dissertation 2005 Unisa) published at <http://etd.unisa.ac.za/ETD-db/ETD-desc/describe?urn=etd-06012005-124300>.

88 In terms of ECTA s 51(1) for example, written consent is required; see par 5 2 n 183 below.

89 *Financial Mail v Sage Holdings* 1993 2 SA 451 (A).

must be taken into account, including the nature of the right, the importance of the purpose of the limitation, the nature and the extent of the limitation, the relation between the limitation and its purpose, and less restrictive means to achieve this purpose.<sup>90</sup> Infringements allowed by other statutes are dealt with below.

In terms of the right of access to information under section 32 of the Constitution, everyone has the right of access to any information that is held by another person and that is required for the exercise or protection of any rights. Section 32(1)(b) provides specifically for the horizontal application of the right of access to information held by another person, whereas section 32(1)(a) provides for access to information held by the state. A potential insured has a pre-contractual duty to disclose material and relevant information, and the insurer has the corresponding right to insist on the disclosure. This is also a continuous duty and corresponding right after conclusion of the insurance contract. The right of access to information can only be limited in terms of section 36 of the Constitution as discussed above.<sup>91</sup>

### 4.3 The Promotion of Access to Information Act

The Promotion of Access to Information Act is focussed on actively promoting a society in which persons have effective access to information to enable them to more fully exercise and protect all of their rights.<sup>92</sup> The Act gives effect to the constitutional right to access information.<sup>93</sup> This includes the rights of the insurer to request access to all relevant and material information held by a public or private body<sup>94</sup> in order to enable him to effectively exercise or protect any of his rights.

Rights to access information are subject to justifiable limitations aimed at the reasonable protection of privacy and of commercial confidentiality, in a manner that balances the right with any other rights, including rights found in the Bill of Rights<sup>95</sup> such as the right to privacy. The operation of section 36 of the Constitution is once again relevant to decide on the issue of whether the right to privacy enjoys precedence above the right of access to information, or *vice versa*.

Any right of access to information may be refused where the access would lead to the unreasonable disclosure of personal information of a third party, including a deceased person.<sup>96</sup>

Access must be refused where the record contains scientific information of a third party and disclosure would cause harm to the commercial or

90 For a comprehensive discussion on dignity and discrimination, see Woolman 36-19-36-25.

91 See the discussion on limitation of fundamental rights under par 4.2.

92 Preamble to PAIA; n 53.

93 S 9(a).

94 S 1 item 21 defines a "private body" as "a natural person or partnership who carries or has carried on any trade, business or profession, but only in such a capacity; or any former or existing juristic body".

95 S 9(b); see the discussion on constitutional rights par 4.2.

96 S 63(1).

financial interests of a third party,<sup>97</sup> and where the disclosure of information that was supplied in confidence by a third party would put him at a disadvantage in contractual or other negotiations.<sup>98</sup> A private body must also refuse a request for access to confidential information where the disclosure would constitute a breach of duty of confidence owed to a third party in terms of an agreement, such as the agreement between doctor-and-patient.<sup>99</sup>

It is clear that insurers will not have the right in terms of this Act to request the access of information held by a medical data bank, or a doctor for example, to exercise their rights in terms of insurance contracts.

The LOA Code of Conduct also places a duty upon insurers to ensure that as few staff as necessary will have access to the genetic information.<sup>100</sup>

#### 4 4 Draft Protection of Personal Information Bill

Project 124 of the South African Law Review Commission<sup>101</sup> lead to the Draft Protection of Personal Information Bill,<sup>102</sup> which is extremely relevant to the issue at hand. The purpose and objective of the Act is to balance the right of privacy and the right of access to information.<sup>103</sup>

The proposed Act will prohibit the processing of personal information other than in accordance with the conditions set out in the Act. Compliance will be enforced by a specialised statutory regulatory body known as the Information Protection Commission.<sup>104</sup> The commission's role would be to educate, to issue and apply codes of conduct and guidelines, to deal with complaints and also to issue an enforcement notice where necessary.<sup>105</sup>

The Act identifies processing as a lawful infringement of privacy if processing is in accordance with the law and is done in a careful and proper manner not to intrude upon the privacy of the data subject to an unreasonable extent.<sup>106</sup> It may only be processed for the purpose for which it was collected and processed in a way that is adequate, relevant and not

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97 S 64(1)(b).

98 S 64(1)(c).

99 S 65; see further Ch 5 of the Act on the procedures and requirements for third party notification and intervention when dealing with a request for access to information.

100 LOA ch 20 par 6 4.

101 The SALRC.

102 SALRC *Discussion Paper 109 on Project 124 on Privacy and Data Protection* Oct 2005; see also the Mandela Institute's Privacy and Access to Information Project <http://wwwserver.law.wits.ac.za/mi/privacy/briefing.htm> (accessed on 2007-02-07). The proposed legislation could be finalised at the end of 2007, yet most likely only early in 2008.

103 Ch 1 s 1(1).

104 Bill ch 5 Part A.

105 Ss 34–46.

106 Bill s 7.

excessive.<sup>107</sup> The purpose must be specific, explicitly defined and legitimate.<sup>108</sup> Further processing must take into account the relationship between the purpose of the further processing, the purpose for which the information was obtained in the first instance, and the nature of the information obtained.<sup>109</sup>

The data subject has to consent expressly to the processing, or where processing is necessary for the performance of a contract or agreement to which the data subject is a party,<sup>110</sup> or where processing is necessary for the upholding of legitimate interests of the responsible party or of a third party to whom the information is supplied.<sup>111</sup>

A specific and very important exemption is made to the prohibition on the processing by an insurer of any of personal information concerning a person's health.<sup>112</sup> Insurers are not prohibited from processing of data where it is necessary for (i) assessing the risk to be insured by the insurance company and the data subject has not objected thereto; or (ii) necessary for the performance of the insurance agreement, or (iii) necessary for the enforcement of any contractual rights and obligations.<sup>113</sup> The insurer has to treat the information as confidential at all times.<sup>114</sup> This is further qualified by an uncertain section that states as follows:

"Personal information concerning inherited characteristics may only be processed, where this processing takes place with respect to the data subject from whom the information concerned have(sic) been obtained, unless (a) a serious medical illness prevails, or (b) the processing is necessary for the purpose of scientific research or statistics."<sup>115</sup>

The commission may also authorise the processing of personal information if, in the special circumstances of the case, the interference with the privacy of the data subject is outweighed by public interest in a substantial degree, or where the processing involves a clear benefit to the data subject or a third party.<sup>116</sup>

#### 4 5 Life Offices Association of South Africa

In South Africa the LOA is allowed to store personal and other information in the "Life Register" pertaining to the application and available information of a prospective insured whose application for insurance cover has been denied. Any member of the LOA is entitled to access the information, although the information is kept in coded form, and only a limited number of persons have access to these records.<sup>117</sup>

107 *Idem* s 8.

108 *Idem* s 11.

109 *Idem* s 14(2).

110 *Idem* s 9(1)(a) and (b).

111 *Idem* s 9(1)(f).

112 S 29(1)(b).

113 S 29(1)(b)(i)-(iii).

114 S 29(3).

115 S 29(5).

116 S 33(1).

117 See the discussion on specifically encryption of data in accordance with the provisions of ECTA ch V par 5 2 below.

#### 4 6 Duty of the Insured to Disclose Information to the Insurer and Genetic Discrimination in Insurance

In terms of the common law, a potential insured has the duty to disclose all information material to the risk before, during and after conclusion of an insurance contract. Where the insured discloses false information that is material to the assessment of the risk, he will be liable for a misrepresentation, and where he fails to disclose material information, he will be liable for a misrepresentation made by omission, in both cases rendering the contract voidable,<sup>118</sup> irrespective of fault. It could even constitute fraud. Due to the prospective insured's intimate knowledge of all facts regarding the risk which he wants to transfer to the insurer, a legal duty requires him to disclose all relevant material information within his actual or constructive knowledge to the insurer.<sup>119</sup> This enables the insurer to decide whether he is prepared to accept the transfer of risk from the insured and to reach consensus with the insured.<sup>120</sup>

It is a fact that an omission to disclose available genetic information would definitely be to the insurer's detriment as it makes accurate risk-assessment impossible. On the other hand, the disclosure may constitute an unwanted exposure of personal information that may lead to discrimination, loss of benefits, loss of intimacy, stigma and embarrassment.<sup>121</sup>

An objective test of whether the reasonable person is of the opinion that the information is material to the assessment of the risk by the insurer, is used to determine which information is material and which is not.<sup>122</sup> The courts identified the following categories of facts as material to the risk: Facts indicating exceptional exposure to risk, facts relating to the insured's previous insurance records, for example, where applications for insurance cover were refused in the past, and lastly, subjective circumstances that in a specific case indicate a greater propensity for the realization of the risk than in other cases.<sup>123</sup> A duty to disclose information will be seen as reasonable according to the legal convictions of the community.<sup>124</sup> The misrepresentation, provided that the insured acted or omitted to act intentionally or negligently, will also justify a delictual claim by the insurer against the insured for loss suffered.<sup>125</sup>

118 Reinecke *et al* paras 174–175; Van der Merwe *et al Contract General Principles* (2005) 92–103, 121–124.

119 Reinecke *et al* paras 112, 197.

120 *Mutual & Federal Insurance Co Ltd v Oudtshoorn Municipality* 1985 1 SA 419 (A); *Anderson Shipping v Guardian National Insurance* 1987 3 SA 506 (A); *Qilingile v SA Mutual Life Assurance Society* 1993 1 SA 69 (A); *De Waal NO v Metropolitan Lewens Bpk* 1994 1 SA 818 (O); *SA Eagle v Norman Welthagen Investments* 1994 2 SA 122 (A); *Commercial Union Insurance Co of SA Ltd v Lotter* 1999 2 SA 147 (SCA).

121 Goldman 8; SALRC Discussion Paper ch 2; n 101.

122 Reinecke *et al* paras 198–200; *Liberty Life Association of Africa Ltd v De Waal* 1999 4 SA 1177 (SCA).

123 Reinecke *et al* 202.

124 *Regal v African Superslate* 1963 1 SA 102(A); see also as an analogy Slabbert "The (genetic) ties that bind us and the duty to disclose genetic risk to blood relatives" (unpublished) (see n 67).

125 Reinecke *et al* par 179–197; Van der Merwe *et al* 92–103, 124–127; *Bayer South Africa (Pty) Ltd v Frost* 1991 4 SA 559 (A) 570.

Allowing insurers access to medical records to obtain information also raises concerns about the invasion of the patient's right to privilege and confidentiality in terms of the doctor-patient relationship. It is clear that the content of a patient's records may only be disclosed with the patient's consent, and that insurers cannot place pressure on medical practitioners to supply them with a patient's personal information without the patient's co-operation. A private body may refuse a request for access to confidential information made in terms of The Promotion of Access to Information Act<sup>126</sup> where the disclosure would constitute a breach of duty of confidence owed to a third party in terms of an agreement, such as the agreement between doctor-and-patient.<sup>127</sup> Where unlimited access to medical databases is allowed, the principle of free and informed consent is endangered.

An interesting perspective that is being discussed internationally, is the acknowledgement and scope of the potential insured's "right not to know", where he can elect to allow third parties such as his medical practitioners or insurers to receive and process his personal data unknown to him, as opposed to the insurer's right to know.<sup>128</sup> Where the insured's right not to know is acknowledged as a separate right, based on the basic principle of autonomy,<sup>129</sup> and not merely where he waives his right to information, it would be unreasonable to force him to undergo a genetic examination before entering into a life insurance policy, for example.

Use or application of genetic information may not lead to discrimination and inequality. Moral concerns of unfair genetic discrimination and the disproportionate impact on a few affected individuals is increasing.<sup>130</sup>

In terms of the Constitution of the Republic of South Africa, the fundamental rights of the people in South Africa as enshrined in the Bill of Rights, affirm the democratic values of human dignity, equality and freedom.<sup>131</sup> In terms of the equality clause no person may unfairly discriminate directly or indirectly against anyone on one of more of the following

126 See the discussion under par 4 3.

127 S 65.

128 See n 1 on the AIDA Conference in Buenos Aires, where the issue on the right not to know was specifically raised and reported under Theme 2 of the Conference: "The Influence of Scientific and Technological Innovations on Individual Insurance" [www.aida.org.uk](http://www.aida.org.uk); also Laurie *Genetic privacy: A challenge to medico-legal norms* (2002) 208.

129 Laurie 208-209.

130 Report HCG01/P4 Annex B on the *HGC Information-Gathering Day on Genetics and Insurance* (2001-02-09); genetic composition forms the basis for eugenics – the self-direction of human evolution. Practical examples include selective breeding and forced sterilizations in China, modern-day reprogenetics through the creation of a genius sperm bank and so-called "designer babies", scientific racism through for example immigration control, and even genocide as happened in Bosnia and Rwanda. Genetic discrimination dealt with in insurance refers to intrinsic eugenics, where discrimination is based on a person's genetic traits that are intrinsically beneficial or detrimental to them: <http://en.wikipedia.org/wiki/eugenics> (accessed on 2006-10-09). Black "We must keep Eugenics away from Genetics" [www.Newspday.com](http://www.Newspday.com) (2003-10-15).

131 S 7(1).



grounds: race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth. Any discrimination is deemed to be unfair unless it is established to be fair.<sup>132</sup>

Genetic tests are not always highly predictive in nature. The question is whether genetic characteristics that merely indicate the possibility of a disability manifesting in future, are included under the abovementioned factors, specifically as a disability.<sup>133</sup>

One must keep in mind that where information resulting from human genome testing is used to the detriment of a potential insured, by placing him in a higher risk classification group, one could argue that he is being discriminated against, obviously where testing is not done on the other potential insured's, or where the test results are not conclusive and should not be seen to be material to the assessment of the risk. On the other hand, where the genetic information is available and indicates that the insured should fall within a higher risk class, yet this is not done, this practice discriminates against all the other insured's who fall into a lower risk category because prejudicial information about their genetic information is not known or those who do not pose a greater risk because of their more positive risk profiling. One could thus argue that by not using material information that is available, the insurer discriminates against all the other insured's.

Care must be taken to distinguish genetic distinction from genetic discrimination.<sup>134</sup> Discrimination is more than distinction and differentiation. It is an action based on prejudice resulting in the unfair treatment of people.<sup>135</sup> True genetic discrimination, also referred to as the war against the weak,<sup>136</sup> includes workplace discrimination and insurance discrimination. Internationally, new exclusions for insurance policies for injuries or deaths caused by toxic industrial compounds, the use of new technology, for example, mobile telephones, cathode rays, nuclear hazards, expanded polyurethane, electromagnetic fields, global warming (the greenhouse

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132 S 9(2), 9(3); see also Havenga "Equality in Insurance Law – The Impact of the Bill of Rights" 1997 SA Merc LJ 275.

133 Disability can in general be described as any condition that interferes with someone's ability to perform everyday tasks. According to the medical model of the World Health Organisation's *International Classification of Functioning, Disability and Health (ICF)* "disability is a problem of a person, caused directly by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals". [http://en.wikipedia.org/wiki/International\\_Classification\\_of\\_Functioning%2C\\_Disability](http://en.wikipedia.org/wiki/International_Classification_of_Functioning%2C_Disability) (accessed on 2007-05-01) the degree of accuracy to determine whether a person will in fact develop the disease, differs from one disorder to the next; see also Havenga 288–289.

134 Dignity informs equality analysis at two stages. Firstly, differentiation amounts to discrimination where the distinction is an affront to dignity, and secondly the extent to which it impairs the dignity is an indication of the fairness of the discrimination, see in general Woolman 36-26 on the right to dignity.

135 [www.wikipedia.org/wiki/Discrimination](http://www.wikipedia.org/wiki/Discrimination) (accessed on 2007-02-21).

136 *Black War Against the Weak: Eugenics and America's Campaign to Create a Master Race* (2003).

effect) and the concentration of gases in the atmosphere, are being established. It follows that exclusions may also be included in policies for life and health insurance, based on the information gleaned from results of genetic tests.

As insurance is generally voluntary and the risk of adverse selection is accepted, underwriting is actually about discrimination.<sup>137</sup> Fair discrimination is therefore necessarily part of private insurance. The insurer is entitled to classify insureds into various risk categories, and has the right of access to all relevant information to assist him with risk selection and risk classification.

No specific legislation applies to insurance that restricts or prohibits insurance cover or tariff discrimination on account of the policyholder's characteristics, his environment, ethnic background, demography and so forth. This type of discrimination already occurs in practice, during normal risk-assessment by the insurer.<sup>138</sup> The genetic predisposition to a disorder and the insurability and claims in this regard are currently seen and treated in the insurance industry the same as any other peril. Due to lack of statutory control, the matter therefore has to be dealt with in terms of the Constitution,<sup>139</sup> other statutes as well as relevant common law principles.

Commercial insurance does not entitle everyone to equally enjoy the benefit and privilege of insurance cover. Private insurers must have the right to underwrite in order to participate in the economic sphere. The problem is that there are no general systems or even guidelines, that force insurers into apply consistent practices as far as evidence-based underwriting is concerned. The evidence that is applied is usually commercial, and not set on generally-acceptable standards, ethical or otherwise. What is required therefore is the creation of a system that ensures the equitable treatment or application of available information.<sup>140</sup>

The question is basically whether the individual rights of the policyholder prevail over the financial interests of the insurer, and also whether the rights of some insured's should enjoy preference above the rights of

137 Report HGC n 129.

138 Jeffords and Daschle "Political Issues in the Genome Area" 2001 *Science* 1249; Thomas "Genetics and insurance: an actuarial perspective with a difference" [www.guythomas.org.uk](http://www.guythomas.org.uk) (accessed on 2007-02-12); Lowden "Genetic discrimination and insurance underwriting" 1992 *American Journal for Human Genetics* 901; 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 Law Journal* 1632; Broome "Legal Issues of Genetic Discrimination" *Blount Undergraduate Initiative University of Alabama* [www.bma.ua.edu/~joshua/archive/aug06](http://www.bma.ua.edu/~joshua/archive/aug06) (accessed on 2007-02-11); see also Nienaber and Van der Nest "Genetic testing for the purpose of insurance risk assessment and the constitutional right to privacy" 2003 *THRHR* 446 for a more detailed discussion on the impact of genetic testing on the insurer's right to accurate risk assessment.

139 See *Brink v Kitshoff* 1996 4 SA 197 (CC) on the impact of the Constitution on statutory insurance law.

140 HGC n 129; LOA n 5.

others, necessarily causing discrimination.<sup>141</sup> The financial interests of the insurer are not specifically protected in the Constitution. The commitment to privacy grounded in individual autonomy would have to yield when the greater good requires it.<sup>142</sup> The LOA believes it is necessary to regulate and balance the legitimate interests of the policyholders and the insurer.<sup>143</sup> The balance between the legitimate interests of the various categories of policyholders, those whose genetic information is available, and those whose information is not, is also at issue in this case.

Equity, as a fundamental principle of insurance, requires policyholders who fall within a higher risk category, to be charged higher premiums, and the lower the risk, the lower the premium. The costs must be shared fairly between all the policy holders. There should be no reason why these normal principles should not also apply to differentiate between a person whose genetic information is available and justifies a higher risk profile classification, and another whose information is not available or that is, yet does not indicate a higher risk profile.

Except for the constitutional provisions concerning unfair discrimination, no legislation or case law exists that prevents insurers identifying two risk groups: One group including policyholders who have had genetic examinations and the second group where policyholders have not. There should be no reason why such a risk identification or classification should be disallowed, provided that sufficient and effective rules, procedures and codes of conduct on the testing and on the processing of the test data are available and adhered to.<sup>144</sup>

Where there is no unfair discrimination in taking the genetic information into account for the risk assessment, the determination of insurance tariffs must be based on the fundamental principle of equity and depends upon agreement between the potential insured and the insurer. One should also keep in mind that contractual autonomy does not always limit, but also actually enhances self-respect and dignity,<sup>145</sup> and should be informed by our constitutional commitment to dignity.<sup>146</sup>

Genetic testing by insurers has the potential to lead to so-called economic eugenics.<sup>147</sup> A request by the insurer for the insured to undergo genetic testing prior to taking out life insurance for example, is not *per se* unlawful, provided that only relevant and material information gleaned from such an examination may be taken into account for the selection and classification of the risk.

Regarding the coercion of unwilling participants to undergo testing, or whether an insurer can insist that a potential insured undergoes genetic

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141 See the discussion under par 4 6.

142 Woolman 35-45.

143 LOA par 1.

144 This is also the view of the LOA.

145 *Brisley v Drotsky* 2002 4 SA 1(A) par 94.

146 Woolman 36-45(e).

147 See in this regards n 129 on eugenics in general; also "Genetic testing by insurers could lead to "economic eugenics" [www.spuc.org.uk/news/releases/2000/october12](http://www.spuc.org.uk/news/releases/2000/october12) (accessed 2007-02-07).

testing, one should once again refer to sections of the Constitution and the common law. The LOA also supports the point that insurers may not ask or coerce applicants to undergo genetic tests to obtain insurance.<sup>148</sup>

In terms of the Constitution everyone has the right to bodily and psychological integrity that includes the right to make decisions concerning reproduction, the right to security and control over their body, and not to be subjected to medical or scientific experiments without their informed consent.<sup>149</sup> In addition, the common law right to physical integrity as discussed above<sup>150</sup> also applies in this context. The Prohibition of Pre-employment HIV Testing Bill that attempts to deal with the right of an employer to request an employee or potential employee to undergo an HIV test, and the proposed move to criminalise the non-disclosure of HIV status to one's partners, may create a legal duty to undergo routine medical testing, and also place a duty of disclosure of actual or imputed knowledge, upon a person in specific circumstances.<sup>151</sup> A possible analogy may be drawn between this situation and the insurer-insured relationship on the issue of medical testing and the right of privacy to test results.<sup>152</sup>

If an insured's right "not to know" is acknowledged as a separate right, the insistence that a potential insured undergoes a genetic test, would of course also be unreasonable. There is no reason why the patient could not waive his right to receive the results, in other words waive his right to know. This does not mean that a right not to know is acknowledged as a separate right. This question arises from the possibility that the patient could request that the results be disclosed only to the patient's medical practitioner, and that the practitioner could advise him merely of the effects of the results and whether, in the practitioner's opinion, the patient should or should not take cognisance of the test results. Once again section 12(2) of the Constitution applies, namely that everyone has the right to bodily and psychological integrity that includes the right to make decisions concerning reproduction, the right to security and control over their body, and not to be subjected to medical or scientific experiments without their informed consent.

Human genome testing has now provided us with a greatly improved scientific basis for risk selection and classification relating to the health status of an individual. Genetic information must obviously not be used in isolation, but should form part of the wider family medical history data. In a positive sense, it offers the potential insured the opportunity to take proactive steps, where the test results can be of a corrective nature as to family medical history, to allow a person to pursue preventative strategies

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148 LOA par 6 1.

149 S 12(2).

150 See par 3 1 n 38.

151 1997, which is a result of the SALRC on *Aspects of the Law relating to AIDS Project 85*, specifically relating to pre-employment HIV testing.

152 It is interesting to note that from 1 April 2007 insurance companies carrying membership of the LOA will no longer apply the HIV and Aids exclusion clauses to life and disability policies ([www.busrep.co.za/index.php?fSectionId=&fArticleId=3752085](http://www.busrep.co.za/index.php?fSectionId=&fArticleId=3752085)).

to reduce the risk by negating the second trigger that is required to activate the genetic predisposition for a specific disease or disorder through lifestyle changes.<sup>153</sup> This enables him to minimize risk or loss by increasing his health-enhancing activities.<sup>154</sup> Where this ability to reduce the risk exists and is not utilised, the continued detrimental actions of the insured or lack of pro-active beneficial action could cause losses not only to the insurer, but also indirectly to other insureds. The principle of requiring an insured to prevent or decrease the risk of loss, should in my opinion not be deviated from as far as the risk-minimization based on information obtained through genome testing is concerned.

In terms of the LOA an insurer may not offer or grant an applicant premiums lower than standard rates based on the favourable result of genetic testing.<sup>155</sup>

There are increasing calls for open access to all medical information, including all genetic information, for purposes, of economic efficiency.<sup>156</sup> The right to privacy of an individual must then bow before the greater economic good. Free access also affects the principle of free and informed consent.<sup>157</sup> This once again confirms that adequate safeguards need to be put in place to protect the individual's rights in the often ruthless pursuit of constant economic growth.<sup>158</sup>

As to genetic information obtained for purposes of research, section 16(2) of the Constitution acknowledges the right of freedom of expression, which includes the freedom of scientific research. No specific formal regulations restrict diagnostic studies or research on the human genome at the moment, except for section 12(2) of the Constitution. In terms of this section everyone has the right to bodily and psychological integrity that includes the right to make decisions concerning reproduction, the right to security and control over their body, and not to be subjected to medical or scientific experiments without their informed consent. The Bill contains a general exemption from the prohibition to process personal information<sup>159</sup> for the purpose of scientific research or statistics, provided that the research serves a public interest, and the processing is necessary for the research and statistics, and the research or statistics would be impossible or involve a disproportionate effort to ask for express consent, and lastly sufficient guarantees are provided to ensure that the processing does not adversely affect the individual privacy of the data subject to a disproportionate extent.<sup>160</sup>

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153 See the brief discussion in paras 1 and 4 6 on the positive impact of genetic testing and the insured's general duty to mitigate losses.

154 Reinecke *et al* par 286; *Paterson v Aegis Insurance Co Ltd* 1989 3 SA 478 (C); *Santam Ltd v CC Designing CC* 1999 4 SA 199 (C) 211.

155 LOA ch 20 par 6 2.

156 Epstein "Regulation of Genetic Discrimination: Old Responses to New Technology" (1994 74) *BUL Review* 1; Posner "The Right of Privacy" (1978) *Gaming Law Review* 393.

157 See paras 4 2 and 4 6 on the limitation of the right to privacy.

158 Ch 20 LOA 1.

159 Bill s 24.

160 S 31(2).

Diagnostic studies on the human genome in general medical practice are merely regulated by general principles of accepted medical practice, including good clinical practice and the application of general medical ethical standards.<sup>161</sup> Medical practitioners and researchers remain bound to their common law duty of privilege of information and confidentiality towards their patients. The principles of good clinical practice include informed consent by the patients, as well as comprehensive pre-test and post-test counselling on the test results.<sup>162</sup> This could enable the insured to decide whether he wants to exercise his right not to know, as discussed above.<sup>163</sup> Unauthorised use by an insurer of information obtained from genetic research procedures, has been dealt with under the discussion on the invasion of privacy above. The statutory duty to protect information, is discussed below.

#### 4 7 Remedies for Infringement of Rights

One must keep in mind that as far as the violation of rights to privacy and identity are concerned, a distinction should be made between a constitutional infringement and a delict, and distinguish between the enforcement of a constitutional right and enforcing of a common law right.<sup>164</sup> The two may overlap, and the values of the Constitution will play a role in the determination of whether the requirements for a delictual claim have been met.<sup>165</sup>

The purpose of a constitutional remedy is to reaffirm, enforce, protect and vindicate fundamental rights, and to act as a deterrent for future violations.<sup>166</sup> The purpose of a delictual remedy is compensation, and tends to be retrospective in effect.<sup>167</sup> It is also possible to apply for an interdict to protect a right by an order to cease violating or infringing actions.<sup>168</sup> A violation of privacy or identity could lead to a claim for common law delictual damages, including not only pecuniary losses incurred, but other forms of loss suffered or incurred such as loss of good name, emotional trauma and so forth.<sup>169</sup> Constitutional damages could also, where it is

161 Ethical conduct requires (a) respect for a patient's autonomy, (b) beneficence to the patient, (c) non-maleficence, and (d) justice, including fairness and equity: Europabio 6.

162 Greenberg "Genetic Testing and Related Ethical Issues" 2005 *CME Your SA Journal of CPD: Genetics* 18; see also par 7 2 of the LOA ch 20 that where the insurer believes that an applicant does not understand the implications of genetic testing, the applicant needs to be advised of the implications of such testing with the assistance and co-operation of his medical advisor.

163 See the reference and discussion in par 4 6 and under n 127.

164 McQuoid-Mason "Invasion of Privacy: Common Law v Constitutional Delict – Does it make a difference?" 2000 *Acta Juridica* 227; Neethling *et al* *Law of Delict* (2006) 19; *Rail Commuters Action Group and others v Transnet Ltd t/a Metrorail and others* 2005 2 SA 359 (CC); *Dendy* case 494–507.

165 McQuoid-Mason in Chaskalson *Constitutional Law of South Africa* (1999) 18-2.

166 Neethling *et al* 20.

167 *The Rail Commuters Action Group* case 401; Neethling *et al* 19.

168 Neethling *et al* 212.

169 *Idem* 235–243 for a detailed discussion on the nature of delictual damages.

appropriate relief in the particular circumstances, be claimed for the breach of a constitutionally entrenched right.<sup>170</sup>

Care must be taken to comply with the two-stage inquiry required in matters dealing with a constitutional infringement, namely on whether a right has been infringed upon and whether the infringement is justifiable, and the single inquiry required in matters dealing with delict, on whether an unlawful infringement of a right has taken place.<sup>171</sup>

In addition to traditional common law remedies, and the influence of the Constitution on the implementation of these remedies, the complexities of the unique problems in this field require effective statutory intervention.

Insurers who are held liable are not necessarily without remedy. Specific insurance cover known as “data protection insurance” is available in the market for insurers to cover losses and liabilities caused by, for example, viruses or unauthorised access by third parties through hacking resulting in contamination, loss or unauthorised access and subsequent use or abuse of data. General liability insurance cover is also available to the insurer.

## 5 Statutory Measures Relevant to the Maintenance and Management of Data Held in Insurance Databases

### 5.1 General

In addition to the issues and remedies addressed above, it is important for insurers to note what their statutory duties regarding the management of their databases, and what the consequences of non-compliance are. The following statutes apply to the relationship between insurers and insured’s regarding data protection and data management, and should be read together: the Electronic Communications and Transactions Act,<sup>172</sup> the Financial Advisory and Intermediary Services Act<sup>173</sup> and the Protection of Personal Information Bill.<sup>174</sup>

Most data<sup>175</sup> so submitted is held in the form of electronically processed information. The data controllers for insurers process data relating to insurance risks posed by prospective insureds.<sup>176</sup>

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170 *Modder East Squatters v Modderklip Boerdery (Pty) Ltd; President of the Republic of South Africa v Modderklip Boerdery* 2004 6 SA 40 (SCA) 62; *MEC for the Department of Welfare, Eastern Cape v Kate* 2006 2 All SA 455 (SCA) 462–467; *The Rail Commuters Action Group case* 401; *Fose v Minister of Safety and Security* 1997 3 SA 786 (CC) 821.

171 *Bernstein* 790; *McQuoid-Mason* (1999) 18-1.

172 N 40.

173 Hereinafter referred to as “FAISA”.

174 N 42.

175 See par 3.2 on the meaning of data; a “data message” as defined under ECTA s 1 includes “a stored record”.

## 5.2 The Electronic Communications and Transactions Act<sup>177</sup>

Chapter VIII on the protection of personal information is the most relevant to address the issue on the protection of data.<sup>178</sup> A data controller may only collect, collate, process or disclose any information if he has express permission from the data subject to do so, unless the data controller is required or entitled to do so by law.<sup>179</sup> Personal information may only be requested electronically as is necessary for the lawful purpose for which it is required.<sup>180</sup> It may also only be used for that purpose.<sup>181</sup> The specific purpose must be disclosed to the data subject in writing before information is requested.<sup>182</sup> Data must be kept for at least one year after use of the information has terminated, and must then be deleted or destroyed once it has become obsolete.<sup>183</sup> Record must also be kept of any third party to whom the data was disclosed and the date on which, and purpose for which, it was disclosed.<sup>184</sup>

The only exception to these rules is that the party controlling personal information may use it to compile profiles for statistical purposes, and may freely trade with the profiles provided that it cannot be linked directly to a specific data subject. For research purposes however, the consent of the individual is required.<sup>185</sup>

Chapter V of ECTA deals with cryptography providers and the cryptography products and services for the protection of data. Two solutions may be proposed for the issue of genetic data protection. The first is that cryptography products and services are mandatory for the management of the data, and the second to classify any database containing genetic data as a critical database that enjoys greater statutory protection than an ordinary database.<sup>186</sup>

The penalties for a violation of rights to privacy are determined by statute. Under Chapter XIII of ECTA on Cyber Crime, and subject to The Interception and Monitoring Prohibition Act,<sup>187</sup> a person who intentionally accesses, intercepts or interferes with any data without permission or authority to do so, is guilty of an offence. Selling, distributing or possessing or using any device, program or component designed to overcome security measures to protect data or to protect access to data, also constitutes an offence.<sup>188</sup> Any person who performs any acts mentioned under

<sup>176</sup> Roos 13.

<sup>177</sup> Act 25 of 2002.

<sup>178</sup> Ss 50–51.

<sup>179</sup> S 51(1); s 51(6).

<sup>180</sup> S 51(2).

<sup>181</sup> S 51(4).

<sup>182</sup> S 51(3).

<sup>183</sup> S 51(5); s 51(8). See similar provisions in the US Genetic Privacy Act s 162.

<sup>184</sup> S 51(7).

<sup>185</sup> See in this regard the strict provisions of the US Genetic Privacy Act n 181 ss 2 and 132.

<sup>186</sup> Ch 9 ss 52–58; see the discussion under par 3.2 n 51.

<sup>187</sup> Act 127 of 1992.

<sup>188</sup> S 86.



section 86 in order to obtain any unlawful proprietary advantage, commits an offence.<sup>189</sup> A person who attempts, or assists or aids and abets someone, to commit the abovementioned offences, is also guilty of an offence.<sup>190</sup> The penalties prescribed are the imposition of a fine and/or imprisonment of up to either twelve months or five years, depending on which type of offence is committed. This does not however provide compensation for the loss or injury suffered by the person whose privacy was infringed upon.<sup>191</sup>

Civil damages claims are not dealt with under the ECTA.

### 5.3 The Financial Advisory and Intermediary Services Act<sup>192</sup>

This Act applies to financial products that include long-term or short-term insurance contracts or policies.<sup>193</sup> Chapter IV of the Act deals with the codes of conduct for financial service providers, such as insurers. The Act prescribes specific provisions that must be included in the codes. The most relevant provisions for the purpose of data protection of genetic information are provisions on the making of adequate disclosures of relevant material information, including disclosures of actual and potential own interests,<sup>194</sup> adequate and appropriate record-keeping<sup>195</sup> and proper safekeeping and protection of transaction documentation of clients.<sup>196</sup> Records must be maintained for a period of five years.<sup>197</sup>

Part II of the Act deals with enforcement measures.<sup>198</sup> The registrar may claim payment for *losses* suffered by any person due to the non-compliance or contravention of the provisions of the Act.<sup>199</sup> The term is not defined in the Act, and appears to include all possible losses, patrimonial and non-patrimonial, direct or consequential in nature. The court may, in addition to the claim for losses, order payment of a penalty for punitive purposes,<sup>200</sup> interest<sup>201</sup> and costs of the suit.<sup>202</sup> Any costs must be set-off against any amounts received, and the balance must then be paid out to the person who actually suffered the loss.<sup>203</sup>

The registrar may lastly declare certain business practices undesirable, especially where these practices harm the relations between the provider and clients or the general public, unreasonably prejudices a client or

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189 S 87.

190 S 88.

191 S 89.

192 Act 37 of 2002.

193 S 1 item 16(c).

194 S 16(2)(a).

195 S 16(2)(b).

196 S 16(2)(d).

197 S 18.

198 Ss 33–39.

199 S 33(2)(a).

200 S 33(2)(b).

201 S 33(2)(c).

202 S 33(2)(d).

203 S 15(3).

unfairly affects any client.<sup>204</sup> The processing of genetic information for purposes of insurance risk selection and classification could, in view of these provisions and the effect of such processing on client's right to privacy, be declared as undesirable which would then force insurers to discontinue the practice of relying on genetic information for the purpose of risk assessment and classification.

#### 5 4 The Protection of Personal Information Bill<sup>205</sup>

The Bill contains various provisions on the actual management of data. Processing of data must comply with the requirements set out above under the discussion on the access to data,<sup>206</sup> and must also be in accordance with the Codes of Conduct issued in terms of the Act.<sup>207</sup> The "explicit consent" to the processing of data on health is required.<sup>208</sup>

As to the protection of the data in the databases, records of personal information must not be kept in a form which allows the data subject to be identified for any longer than is necessary for the purpose for which the information was lawfully processed.<sup>209</sup> The party that has used the data to make a decision about the individual must retain the record for the time prescribed in law, if any, or otherwise for a period that will afford the data subject a reasonable opportunity to request access to the record.<sup>210</sup> Records must be deleted or destroyed as soon as is reasonably practicable after authorised access has terminated.<sup>211</sup>

The party responsible for the security of the data must implement appropriate technical and organisational measures to secure the integrity of the data and to protect the data against unauthorised or unlawful access,<sup>212</sup> by identifying all reasonably foreseeable internal and external threats to the data under its control, to establish and maintain appropriate safeguards, and to ensure that verifications and updating of the safeguards occur regularly.<sup>213</sup>

A written<sup>214</sup> agreement must govern the relationship between any processor who processes the information on behalf of the responsible party and the latter, that includes a duty upon the processor to establish and maintain the required security measures.<sup>215</sup>

The commission must first be notified, and must then complete a prior investigation before any information may be transferred to any third

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204 S 34.

205 Par 3 2 n 42.

206 Par 4.

207 Ch 7 ss 54–62.

208 S 24.

209 Bill s 13(1).

210 *Idem* s 13(3).

211 S 13(4).

212 S 17(1).

213 S 17(2).

214 The section includes a qualification that the agreement must be in writing "or in another equivalent form", whatever that would mean.

215 S 19.

country that does not have adequate information protection laws. A specific section on the transboundary flow of information prescribes what will be deemed to be adequate.<sup>216</sup> Once the commission has found the processing to be lawful, the transfer may continue.<sup>217</sup>

The commission must also be notified of any fully or partly automated processing of any personal information.<sup>218</sup>

The commission must be notified of the compromise of any information as soon as is reasonably possible after the compromise is discovered.<sup>219</sup> The Act specified later that it must be in the most expedient time possible and without unreasonable delay.<sup>220</sup> The person whose data is compromised must be notified in writing in the prescribed manner.<sup>221</sup> The commission must ensure that the provisions of the Act are enforced in accordance with the duties and powers conferred to it by the Act.<sup>222</sup> This includes the power to have a warrant to enter and search issued by a court of law.<sup>223</sup>

Chapter 9 of the Act deals with offences and stipulates the penal sanctions when an offence has been committed.<sup>224</sup>

Every responsible party must appoint an information protection officer who must ensure compliance with the Act and who must liaise with the Commission in all relevant matters.<sup>225</sup>

## **5 5 LOA Code of Conduct**

The LOA is allowed to store personal and other information in the “Life Register” pertaining to the application and available information of a prospective insured whose application for insurance cover has been denied. Any member of the LOA is entitled to access the information, although the information is kept in coded form, and only a limited number of persons have access to these records.<sup>226</sup>

## **6 Conclusion**

The LOA does not, with the advent of genetic testing, anticipate significant changes in the percentages of applicants who have been able to obtain life insurance.<sup>227</sup> Actuarial estimates will definitely be affected by the

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216 S 94.

217 Ch 6 Part B.

218 Ch 6 Part B ss 47–51.

219 S 20(1).

220 S 20(2).

221 S 20(4)-20(6).

222 Ch 8 ss 63–87.

223 Ss 73–79.

224 Ss 88–92.

225 Ch 6 Part B s 46.

226 See the discussion on specifically encryption of data in accordance with the provisions of ECTA ch V under par 5 2.

227 LOA Ch 20 3.

increased availability of genetic information.<sup>228</sup> It is on the other hand a real possibility that where legislation or insurance practice makes genetic testing compulsory for life or health insurance, the attractiveness of insurance would diminish and other investment and savings schemes may appear more attractive to consumers.

In view of the on-going developments in the field of genetic testing and the successes of researchers in determining the consequences of specific gene-gene and gene-environment combinations and as genomic profiling is at the moment still inconsistent,<sup>229</sup> the testing procedures, protocols, criteria and the interpretation and practical application of the results need to be strictly regulated. Law reform initiatives for the use of specifically genetic information must be implemented urgently.<sup>230</sup> The formal regulation of these issues would not be strange or new in an industry that is already heavily regulated.<sup>231</sup> In addition to data protection insurance and general liability insurance, the possibility of spreading the risks through a specific genetic re-insurance pool may also be an answer to address the concerns of the insurers.<sup>232</sup>

Where the testing is executed with the insured's informed consent,<sup>233</sup> and the results are *material* to the assessment of the risk, and where it is used *confidentially* only to assess the true risk *that factually exists*, the information should be disclosed and used just as any other information such as previous own or family medical history, dangerous occupations and personal lifestyle and activities. Access to genetic information does not increase the risk. It is just another improvement that leads to more accurate risk assessment. Genetic information that is available should be applied consistently throughout the industry, in accordance with strict protocols, standards and control, for example, in accordance with the LOA's current Code of Conduct on Genetic Testing,<sup>234</sup> or the Core Ethical Values of The European Association for Bio-industries<sup>235</sup> and only where the real effect of a specific genetic test result on the risks has been scientifically proven with absolute accuracy and certainty, should it be taken into account for risk assessment.<sup>236</sup>

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228 Thomas "Genetics and insurance: An actuarial perspective with a difference" 2001 *Response to the HGC Consultation 2*.

229 Greenberg 21.

230 See Reilly "Fear of Genetic Discrimination Drives Legislative Interest" Jan-June 1997 *Human Genome News* 8(3-4) for a discussion on the international position.

231 HGC Report.

232 HGC Report 2.

233 Par 4 6 and n 163 on pre- and post-test counselling.

234 N 10.

235 N 64.

236 This is also in accordance with the opinion of the LOA ch 20 par 4 1 that available genetic information should be allowed for the purpose of risk assessment, whereas the LOA does not support the view that insurers are entitled to request all prospective insureds to undergo genetic testing; *Cf* Havenga 289-290.