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Legal aspects of genetic testing regarding insurance and employment

National report for Belgium

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Introduction

1. Are data available about the frequency of use of “genetic testing” in insurance and employment processes? Have you observed a change over time?

There are no data available about the use of genetic testing in insurance and employment. There are also no public databases that contain data about the use of genetic testing in insurance or employment processes.

There are no data in the annual report of the national insurance ombudsman about genetic discrimination or the use of genetic testing in insurance.¹

Statistics from UNIA reveal that in 2011 there was one case lodged with that body about genetic discrimination.² However, no further information is available about the facts of that case.

2. Please briefly identify any public policies that may influence both the prevalence of genetic testing and the assumption of risk.

PART I: ARE EXISTING GENERALIST FRAMEWORKS FOR REGULATING GENETIC TESTING ADEQUATELY ADAPTED TO THE INSURANCE AND EMPLOYMENT CONTEXTS?

A. General

3. Does your jurisdiction define « genetic » information for the purpose of employment or insurance?

In Belgium there is a national law on insurance: the Insurance Act 2014.³ The section on the insurance contract has an imperative character.⁴ In this section there is a specific regulation for the use of genetic information and genetic testing in insurance. Art. 58 and 61 of the Insurance Act 2014 prohibit any use of genetic information or testing in the context of insurance. Genetic data may never be communicated.⁵ The use of genetic research and genetic information is prohibited to avoid any systematic prejudice against “the genetically weak”

¹ INSURANCE OMBUDSMAN, <http://www.ombudsman.as/nl/publications/index.asp>.

² UNIA, http://unia.be/files/Documenten/Artikels/Eerste_cijfers_2016.pdf; UNIA is an independent public institution that fights discrimination and promotes equal opportunities.

³ Insurance Act 4 April 2014, *Belgian State Gazette* 30 April 2014. (Insurance Act 2014)

⁴ Section 4, art. 56 Insurance Act 2014.

⁵ Art. 58, paragraph 1 *in fine* Insurance Act 2014.

and an improper risk selection by the insurer. The prohibition aims to secure social security equivalence between the “genetically strong” and the “genetically weak”.⁶ The legislature also intended to protect the private life and the right to privacy of the insured person and his/her family, in ascending, descending and lateral lines of relation. Genetic information about the insured person also says something about his/her family. Their right to privacy could also be threatened by the communication of genetic data.⁷

The concept of genetic information, however, is not defined by the Insurance Act 2014 or any other act. In the absence of a legal definition, the contracting parties can agree a contractual definition. The principle of contractual freedom applies. This means that everyone is free to sign a contract, to choose their contracting party and to determine the content of the agreement.⁸ Contracting parties can therefore define the meaning of relevant concepts in their agreement.⁹ Contractual freedom however, is limited by public order, good morals or provisions of imperative law.¹⁰ Provisions of imperative law are statutory provisions aimed to protect the interests of certain categories of individuals, such as the policyholder.¹¹ An imperative law cannot be deviated from by agreement. A contract that deviates from rules of imperative law is in principle null and void. The nullity is relative.¹² The parties’ contractual freedom is therefore limited by these imperative laws. Imperative laws can contain

⁶ Amendments to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, 1586/4, 6; Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 34 and 75-76; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 10; D. WUYTS, “Precontractuele spreekplicht van de verzekeringnemer en de verzekeraar” in J. ROZIE, S. RUTTEN and A. VAN OEVELEN (eds.), *Zwijgrecht versus spreekplicht*, Antwerp, Intersentia, 2013, 175; T. VANSWEEVELT, “Art. 61 Wet Verzekeringen” in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, afl. 18, 28-29; C. PARIS en V. CALLEWAERT (eds.), *Actualités en droit des assurances*, Brussels, Larcier, 2015, 22.

⁷ Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 34; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 8 and 31.

⁸ Cass. 23 December 1977, *Arresten van het Hof van Cassatie* 1978, 509; *Pasicrisie belge* 1978, I, 480; C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, “Definitie, soorten en basisbeginselen” in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-18.

⁹ C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, “Definitie, soorten en basisbeginselen” in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-20.

¹⁰ P. VAN OMMESLAGHE, “Les obligations” in *Traité de droit civil Belge*, Vol. 2, Brussels, Bruylant, 2013, 173; R. FELTKAMP, “Contract, contractsluiting, voorbesprekingen en onderhandelingen – enkele basisnoties” in R. FELTKAMP and E. JANSSENS, *Ondernemingscontracten stap voor stap*, Ghent, Larcier, 2013, 9-10; C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, “Definitie, soorten en basisbeginselen” in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-20b-II.4-21.

¹¹ R. FELTKAMP, “Contract, contractsluiting, voorbesprekingen en onderhandelingen – enkele basisnoties” in R. FELTKAMP and E. JANSSENS, *Ondernemingscontracten stap voor stap*, Ghent, Larcier, 2013, 9-10; P. WERY, “Théorie générale du contrat” in *Droit des obligations*, Brussels, Larcier, 2014, 303 and 304-305; C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, “Definitie, soorten en basisbeginselen” in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-20b-II.4-21.

¹² Cass. 15 March 1968, *Arresten van het Hof van Cassatie* 1968, 936, *Rechtskundig Weekblad* 1967-68, 2000, *Journal des Tribunaux* 1968, 289, *Pasicrisie belge* 1968, I, 884; R. FELTKAMP, “Contract, contractsluiting, voorbesprekingen en onderhandelingen – enkele basisnoties” in R. FELTKAMP and E. JANSSENS, *Ondernemingscontracten stap voor stap*, Ghent, Larcier, 2013, 10; P. WERY, “Théorie générale du contrat” in *Droit des obligations*, Brussels, Larcier, 2014, 308; C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, “Definitie, soorten en basisbeginselen” in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-21.

prohibitions, injunctions or they can limit how a contract's content can be determined.¹³ To summarize, parties are free when concluding their agreement (...) unless it is prohibited by a rule of public order, good morals or imperative law.¹⁴

Although the Insurance Act 2014 doesn't specifically define genetic information, the imperative character of section 4 and art. 61 of the Act aims to protect the policyholder against the use of genetic data. When a contractual definition is so strict that the protection of the consumer is non-existent, this is contrary to the *ratio legis*. Such a definition might then be considered as a violation of a rule of imperative law.

In the context of employment, art. 3 of the Medical Examination Act 2003¹⁵ regulates the use of genetic testing. The legislature wanted to create an appropriate and accurate legal framework for medical investigations conducted in the context of labor relations for recruitment or promotion purposes. The legislature also aimed to eliminate concerns that some companies would perform predictive genetic research or AIDS tests.¹⁶ The Act wants to protect job applicants and employees against far-reaching medical examinations and against selection and/or discrimination based on medical data (such as a genetic test or AIDS test).¹⁷ Unfortunately art. 3 also doesn't define the relevant concepts.

The only definition that will apply in Belgium from May 2018 is the one in the GDPR.¹⁸ The General Data Protection Regulation of 2016 is a new set of regulations about collecting and processing data. These regulations contain a definition of genetic data. According to the GDPR genetic data are *personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question*¹⁹

In Belgium this regulation will replace the Processing Personal Data Act. The regulation will enter into force on 28 May 2018. From that date this definition of genetic data will also directly apply in other Belgian legislation. Until then, the Belgian legislature has time to make the necessary legislative changes in order to comply with the regulation. It remains to be seen whether additional legislative measures will be taken in relation to the concept of genetic data.

¹³ P. WERY, "Théorie générale du contrat" in *Droit des obligations*, Brussels, Larcier, 2014, 306; C. VANACKERE, K. SWERTS, J. DEERNE and K. MARCHAND, "Definitie, soorten en basisbeginselen" in *Bestendig Handboek Verbintenissenrecht* 2016, Afl. 25, II.4-20b-II.4-21.

¹⁴ P. VAN OMMESLAGHE, "Les obligations" in *Traité de droit civil Belge, Vol. 2*, Brussels, Bruylant, 2013, 173; R. FELTKAMP, "Contract, contractsluiking, voorbesprekingen en onderhandelingen – enkele basisnoties" in R. FELTKAMP en E. JANSSENS, *Ondernemingscontracten stap voor stap*, Ghent, Larcier, 2013, 10.

¹⁵ Act 28 January 2003 on medical examinations carried out within the framework of employment relations, *Belgian State Gazette* 9 April 2003 (Medical Examination Act).

¹⁶ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken Senaat* 2002-03, 2-20/1, 1.

¹⁷ A. RAHME (ed.), F. HENDRICKX, O. VANACHTER and A. VAN BEVER, *Discriminatie op basis van handicap en gezondheidstoestand in de arbeidsverhouding*, Antwerp, Intersentia, 2009, 147; W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2016-17*, Malines, Kluwer, 2016, 1116.

¹⁸ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC, *OJ L*. 119, 4.05.2016, p. 1-88. (Regulation (EU) 2016/679)

¹⁹ Art. 4, 13° Regulation (EU) 2016/679.

It is problematic that the legislature didn't define these concepts. It is not clear what is meant by "genetic data", "techniques of genetic research" or "predictive genetic research".²⁰ The accurate interpretation of these concepts is important because they determine the scope of the legal regime and determine which subjects are excluded from the application.²¹

The lack of definition begs a variety of questions. Is genetic data different from medical data, and if so what is the difference?²² Does genetic data also include genetic predispositions?²³ Do "genetic research techniques" also include genetic data that are discovered accidentally during medical examinations?²⁴

Advances in genetic sciences make distinctions between what is genetic and what is not more difficult. Certain disorders, such as Huntington's disease or cystic fibrosis, are clearly genetic in nature. Other common conditions are not so easily defined. For example, distinctions are blurred when a faulty gene appears to be the cause of a classical disorder.²⁵ The distinction between genetic data and other health data therefore seems arbitrary when almost all diseases are, in part, due to genetic factors.²⁶ In this way the ban on communicating genetic data is no longer adapted to developments in medicine and the needs of insurers.²⁷

The difference between genetic data and an individual's previous medical history is not always clear.²⁸ This distinction is important as an individual's medical history must be communicated at the conclusion of the insurance agreement.²⁹ The Patient Rights Act has

²⁰ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 32; N. HAUTENNE, "Les examens médicaux liés à la relation de travail: bref commentaire de la loi du 28 janvier 2003", *Tijdschrift voor Gezondheidsrecht* 2003-04, 222; G. SCHAMPS, "Le secret médical et l' assureur: commentaire du nouvel article 95 de la loi du 25 juin 2002 sur le contrat d' assurance terrestre", *Tijdschrift voor Gezondheidsrecht* 2003-04, 141; L. WOSTYN, C. CLEPKENS and A. HUTSEBAUT, *Overhandigen medische gegevens*, Ghent, Academia, 2009, 145; D. WUYTS, "Precontractuele spreekplicht van de verzekeringnemer en de verzekeraar" in J. ROZIE, S. RUTTEN and A. VAN OEVELEN (eds.), *Zwijgrecht versus spreekplicht*, Antwerp, Intersentia, 2013, 176; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS (eds.), *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 426.

²¹ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 589.

²² K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 54.

²³ N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 248.

²⁴ K. TROCH, "Het medisch beroepsgeheim en zijn impact op de levensverzekering", *Rechtskundig Weekblad* 1993-94, 1299.

²⁵ N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 249-250; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 426.

²⁶ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 600.

²⁷ T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 426.

²⁸ D. WUYTS, *Verzekeringsfraude*, Antwerp, Intersentia, 2014, 318; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 29.

²⁹ Art. 58 jo. 61 Insurance Act 2014; D. WUYTS, *Verzekeringsfraude*, Antwerp, Intersentia, 2014, 318.

provided some clarification in this area, noting that insurance agreement statements should not be based on genetic tests that can be used to determine the risks of development of future diseases.³⁰

Sub questions a)-e)

Not applicable.

4. Does your jurisdiction recognize the « special status » of genetic data in keeping with Article 4 of the UNESCO International Declaration on Human Genetic Data?

Belgian law is aware of the sensitive and specific nature of genetic data.³¹ Abuse of genetic information for example, could lead to stigmatizing minority groups e.g. ethnic groups with common genetic defects.³² There is a focus on the predictive value of genetic data. There is also recognition of the familial character and racial or ethnic character of genetic data.³³ A survey with Flemish genetic counselors shows that the majority of counsellors think that protection of genetic data is necessary.³⁴

The Belgian legislature is aware of the sensitive nature of genetic information and has therefore introduced the prohibition against using genetic data. This is evident from parliamentary records.³⁵ In a limited way, the legislature can be seen as having recognized the special status of genetic data.

There is however no legislation or any other legally binding document that explicitly recognizes the fact that genetic data has a special status because of its predictive value, its impact on the family, its cultural significance for persons of groups and the fact that it may contain information of which the significance is not necessarily known at the time of the collection of the samples.³⁶ There is no consensus on the degree of specificity of genetic data and many authors dispute the separate treatment and the special status of genetic data.³⁷

³⁰ Report GILKINET and BROUNS to the bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/012, 107.

³¹ E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 74.

³² S. TACK and A. DIERICKX, “Nader gebruik van lichaamsmateriaal voor wetenschappelijk onderzoek: Toelaatbaarheid getoetst vanuit het recht op respect voor het privéleven (art. 8 EVRM)”, *Tijdschrift voor Gezondheidsrecht* 2008-09, 387-388.

³³ E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 74; S. TACK and A. DIERICKX, “Nader gebruik van lichaamsmateriaal voor wetenschappelijk onderzoek: Toelaatbaarheid getoetst vanuit het recht op respect voor het privéleven (art. 8 EVRM)”, *Tijdschrift voor Gezondheidsrecht* 2008-09, 388.

³⁴ E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 75.

³⁵ Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 34; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 8 en 31.

³⁶ Art. 4 UNESCO International Declaration on Human Genetic Data.

³⁷ E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 74; K. JACOBS, “Genetische informatie en verzekeringen”, *Recht en Kritiek* 1997, 28-29; A. ROUVROY, “Informations

5. Briefly, does information derived from genetic testing receive particular or distinctive legal consideration (e.g. through specific regulatory texts, state-initiated policies or voluntary codes) in your jurisdiction?

Yes.

The use of genetic data in insurance has been prohibited by law since 1992. Art. 58, paragraph 1 *in fine* Insurance Law stipulates "*Genetic data may not be communicated.*" Art. 61, paragraph 3 Insurance Act 2014 states "*The medical examination, necessary for the conclusion and execution of the agreement, can only be based on the history of the current state of health of the prospective insured person and not on techniques of genetic research to predict the future state of health.*" Art. 61 Insurance Act 2014 always applies when an person's health status is important when concluding or executing the agreement, regardless of whether it concerns life or non-life insurance.³⁸

The Belgian rule is clear: every use or communication of genetic data is completely prohibited.³⁹ The prohibition applies to any form of information about the genetic condition of the policyholder, regardless of how the insurer has obtained the information.⁴⁰ The prohibition has a wide personnel scope: it applies to the policyholder, the insured, the physician and the insurer.⁴¹ The ban is absolute and affects the communication of both favorable and unfavorable data.⁴² The prohibition will always apply, even when the policyholder agrees to use the data.⁴³

Since 2003, the use of medical examinations for the recruitment or promotion of employees is regulated by law.⁴⁴ The 2003 Act prohibits biological tests, medical examinations or oral

génétiqes et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 600

³⁸ Bill concerning insurance, *Parlementaire Stukken Kamer* 2013-14, nr. 3361/1, 39.

³⁹ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 589.

⁴⁰ C. PARIS and V. CALLEWAERT (eds.), *Actualités en droit des assurances*, Brussels, Larcier, 2015, 22.

⁴¹ F. PONET, R. RUBENS and W. VERHEES, *De Landverzekeringsovereenkomst: praktische commentaar bij de wet van 25 juni 1992*, Antwerp, Kluwer, 1993, 430; D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 32; H. CLAASSENS, "De nieuwe verzekeringswet en de medische expertise. Het standpunt van een verzekeringsjurist" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 43; N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 243; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 53; D. WUYTS, *Verzekeringsfraude*, Antwerp, Intersentia, 2014, 318; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 425.

⁴² T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS (eds.), *Handboek verzekeringsrecht*, Antwerp, Intersentia, 2016, 425.

⁴³ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Brugge, Die keure, 1994, 32; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 427.

⁴⁴ Act 28 January 2003 on medical examinations carried out within the framework of employment relations, *Belgian State Gazette* 9 April 2003 (Medical Examination Act); Report to the bill concerning medical examinations that are carried out within the framework of industrial relations, *Parlementaire Stukken Kamer* 2002-03, 2133/002, 3. The Advisory Committee on Bioethics already advised this in 2002:

information gathering to obtain information about the health of a job applicant or employee, for any reason other than to check whether he/she is suitable for a particular job. These tests and questions are only allowed to determine the current health status of the applicant or employee and not his/her future health. This means that questions about hereditary diseases are prohibited. Predictive genetic research and AIDS tests are explicitly prohibited.⁴⁵ Biological tests and medical examinations can only be requested or performed by a prevention advisor-industrial medicine of the company.⁴⁶ The law applies to labor relations that are regulated by the Employment Contracts Act or a statutory appointment. It applies to individuals who are already employed and to new job applicants.⁴⁷ Violation of the law is punishable under criminal law.⁴⁸ Those who feel the law has been breached can file a claim with the labor court to have the law applied.⁴⁹ Exceptions are possible by Royal Decree, and there can be special dispensation in individual situations to conduct (otherwise prohibited) genetic research and / or AIDS tests.⁵⁰ It is possible that certain genetic diseases affect an employee's work duties and pose a danger to himself or others. Examples include employees transporting people or goods, pilots or nurses. If it cannot be determined in any other way whether an employee could develop certain diseases, it is permitted in some exceptional cases to conduct a predictive genetic test or HIV test.⁵¹ The Royal Decree has yet to determine under which exceptional conditions examinations can take place. As long as there is no Royal Decree, predictive genetic research and AIDS tests are prohibited.⁵²

The Processing of Personal Data Act regulates the right to protection of information about a person.⁵³ Medical data, and genetic data, are also covered by this protection.⁵⁴ The processing of health data is specifically regulated.⁵⁵ Processing is in principle prohibited unless one of

ADVISORY COMMITTEE ON BIOETHICS, *Advies nr. 20 van 18 november 2002 betreffende predictieve genetische tests en HIV-tests in het kader van arbeidsverhoudingen*, 36, <https://www.health.belgium.be/nl/advies-nr-20-predictieve-genetische-tests-en-hiv-tests-arbeidsverhoudingen>; I. PLETS, "Medische onderzoeken op het werk", *Nieuw Juridisch Weekblad* 2003, afl. 33, 618.

⁴⁵ Art. 3, § 1 Medical Examination Act; I. PLETS, "Medische onderzoeken op het werk", *Nieuw Juridisch Weekblad* 2003, afl. 33, 618; E. ESSERS, "Juridische aspecten bij de werving en selectie van werknemers", *Sociale Wegwijzer* 2005, nr. 5, 14; W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2017-18, Band 1*, Malines, Kluwer, 2017, 494.

⁴⁶ Art. 3, § 3 Medical Examination Act.

⁴⁷ P. DUFAUX, "Medische onderzoeken in de arbeidsverhoudingen", *Tijdschrift voor Wetgeving* 2003, afl. 7, 314; W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2017-18, Band 1*, Malines, Kluwer, 2017, 493.

⁴⁸ Art. 9 Medical Examination Act; Art. 117 Social Criminal Code.

⁴⁹ Art. 7-8 Medical Examination Act.

⁵⁰ Art. 5 Medical Examination Act; P. DUFAUX, "Medische onderzoeken in de arbeidsverhoudingen", *Tijdschrift voor Wetgeving* 2003, afl. 7, 315.

⁵¹ Report to the bill concerning medical examinations that are carried out within the framework of industrial relations, *Parlementaire Stukken Kamer* 2002-03, 2133/002, 3; *Handelingen Senaat* 2002-03, 14 november 2002, nr. 2-241, 27; I. PLETS, "Medische onderzoeken op het werk", *Nieuw Juridisch Weekblad* 2003, afl. 33, 619.

⁵² W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2017-18, Band 1*, Malines, Kluwer, 2017, 494.

⁵³ Act 8 December 1992 on the protection of privacy with regard to the processing of personal data, *Belgian State Gazette* 18 March 1993. (Processing Personal Data Act).

⁵⁴ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 465.

⁵⁵ Art. 7 Processing Personal Data Act.

the exceptions in art. 7 § 2 of the Act applies. For example, it is permitted when the individual has consented or when the processing is necessary for preventive medicine or medical diagnosis purposes, for the provision of care or treatment or the management of health services.⁵⁶ This involves, for example, situations of multidisciplinary collaboration where a patient consults several physicians/care providers and each of them makes the patient's medical file available to the other practitioners in order to provide the patient with the best care.⁵⁷ Processing data is also permitted in the context of staff policy when the processing is necessary with a view to carrying out the specific obligations and rights of the controller with regard to labor law.⁵⁸

As far as the regulation of genetic data in the Insurance Act 2014, the Medical Examination Act and the Processing Personal Data Act goes, there is no legislation on (the use of) genetic testing and the information derived from these tests. There is no general legal framework specifically aimed at collecting and using genetic data.⁵⁹

6. Does your jurisdiction exercise extraterritorial jurisdiction over human genetic data collection, notably by multinational insurance companies headquartered there?

The Insurance Act 2014 applies to Belgian insurers, foreign insurers with an office in Belgium and foreign insurers that perform insurance activities in Belgium without having its office in Belgium.⁶⁰ This means art. 61 of the Act applies to all these insurers and Belgium has jurisdiction over any genetic data collection they might perform. The Medical Examination Act applies to labor relations regulated by the Employment Contracts Act of 3 July 1978 as well as the employment relationships governed in the regulations concerning the status of government personnel.

The GDPR will regulate the cross-border processing of data.⁶¹ This is the one-stop-shop principle. If the processing has a cross-border nature within the meaning of article 4, 23) GDPR, the supervision will be organized by the leading data protection authority. This is the supervisory authority of the main establishment, usually the head office.⁶² The head office is the place where a company has its central administration in the European Union, unless the decisions about the objectives of and resources for the processing of personal data are taken in another office that is also authorized to carry out those decisions, in which case that

⁵⁶ Art. 7, § 2, a) and j) Processing Personal Data Act.

⁵⁷ A. VIJVERMAN and E. DELBEKE, "De uitwisseling van gezondheidsgegevens uit het elektronisch patiëntendossier", *Tijdschrift voor Gezondheidsrecht* 2012-13, 110.

⁵⁸ Art. 7, § 2, b) Processing Personal Data Act.

⁵⁹ L. SCHUERMANS and C. VAN SCHOUBROECK, *Grondslagen van het Belgische verzekeringsrecht*, Antwerp, Intersentia, 2015, 628; S. DEFLOOR and H. NYS, "Patiëntengegevens en verzekeringen. Een onmogelijke relatie?" in *Over grenzen. Liber Amicorum Herman Cousy*, Antwerp, Intersentia, 2011, 496.

⁶⁰ Art. 4, § 1 Insurance Act 2014.

⁶¹ Art. 4, 23) Regulation (EU) 2016/679: "cross-border processing' means either: (a) processing of personal data which takes place in the context of the activities of establishments in more than one Member State of a controller or processor in the Union where the controller or processor is established in more than one Member State; or (b) processing of personal data which takes place in the context of the activities of a single establishment of a controller or processor in the Union but which substantially affects or is likely to substantially affect data subjects in more than one Member State."

⁶² Art. 56 Regulation (EU) 2016/679; PRIVACY COMMISSION, <https://www.privacycommission.be/nl/faq-page/10157#t10157n20069>.

establishment is the head office. The leading authority can be the only official representative for a multinational company.⁶³

7. *Where genetic testing is undertaken in a clinical medical setting or in a biomedical research setting, does the physician or researcher have a duty of disclosure to the patient or participant of the socio-legal risks associated with the testing, in particular in relation to the possible impact for insurance or employment applications?*

Based on his/her right to self-determination, the patient is entitled to information about his/her state of health.⁶⁴ This information also relates to genetic health.⁶⁵ The patient is entitled to the truth even when it concerns a serious or incurable disease and/or no curative therapy is available (anymore).⁶⁶ Health status information includes diagnosis, prognosis and health advice. In the case of genetic disorders, the prognosis can be very important for the further life planning of the patient, for example decisions about relationships, professional career and reproduction.⁶⁷ The right to information is an independent right and is not linked to a later consent and treatment.⁶⁸ It also applies to genetic disorders for which no treatment is possible or for which the patient no longer wishes treatment.⁶⁹

Besides the right to health information, the patient also has a right to informed consent prior to a medical intervention.⁷⁰ “Intervention” is interpreted broadly and applies to research activities, surgeries or treatments and any decision to refuse and continue these interventions.⁷¹ Before the patient can give his/her consent, the health care professional has an obligation to provide information about the intervention. This obligation to provide

⁶³ S. RAETS, “Alles wat werkgever moeten weten over de Algemene Verordening Gegevensbescherming (GDPR)”, *Oriëntatie*. 2016, afl. 7, 222.

⁶⁴ Art. 7, § 1 Act 22 August 2002 on the rights of the patient, *Belgian State Gazette* 26 September 2002. (Patient Rights Act)

⁶⁵ T. VANSWEEVELT and S. TACK, “Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming” in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 335; V. VANDERHULST, “De therapeutische exceptie en het recht van de patiënt op informatie, met bijzondere aandacht voor de zorg rond het levenseinde”, *Tijdschrift voor Gezondheidsrecht* 2015-16, 329.

⁶⁶ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 20 and 22; Art. 33 Code of Medical Duties; T. VANSWEEVELT and S. TACK, “Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming” in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 333; V. VANDERHULST, “De therapeutische exceptie en het recht van de patiënt op informatie, met bijzondere aandacht voor de zorg rond het levenseinde”, *Tijdschrift voor Gezondheidsrecht* 2015-16, 329 and 337.

⁶⁷ T. VANSWEEVELT and S. TACK, “Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming” in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 335.

⁶⁸ Rb. Namur 25 January 2008, *Revue générale des assurances et des responsabilités* 2009, 14530; S. TACK and T. BALTHAZAR, *Patiëntenrechten. Informed consent in de zorgsector: recente evoluties*, Ghent, Larcier, 2007, 4-5.

⁶⁹ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 20; J.J. CASSIMAN, *Wat zit er in mijn genen?*, Leuven, Davidsfonds, 2004, 189; T. VANSWEEVELT and S. TACK, “Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming” in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 336; S. CALLENS, L. BODDEZ, M. LEIRE and L. VAN LEUVEN, “De patiënt in de gezondheidszorg en medische aansprakelijkheid” in S. CALLENS and J. PEERS (eds.), *Organisatie van de gezondheidszorg*, Antwerp, Intersentia, 2015, 620; H. NYS, *Geneeskunde. Recht en medisch handelen*, Malines, Kluwer, 2016, 116.

⁷⁰ Art. 8 Patient Rights Act.

⁷¹ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 24.

information relates to all the information that is required to be able to consent in full knowledge.⁷² The law provides a summary of the minimum data to be communicated.⁷³ Given the possible major impact of the test results, all types of associated information in genetic research are of great importance.⁷⁴ A special interpretation must therefore be given to the information. In addition to the nature of the research, the existence of possible treatment methods and their risks and consequences have to be communicated. Additional relevant information includes the destination of DNA samples, confidentiality, access to the medical file, methods of managing genetic data relating to family members and third parties and information about social and societal consequences such as employment and insurance.⁷⁵

Human Rights

8. *Is protection against genetic discrimination covered under general human rights protections in your jurisdiction? If so, is genetic status expressly referenced as an included ground of discrimination, or are other categories, such as disability, interpreted to include genetic status?*

Yes.

In Belgium, there are three laws that are the legal basis for combating discrimination: the general act of 10 May 2007 to combat certain forms of discrimination⁷⁶, the act of 10 May 2007 to combat discrimination between women and men⁷⁷ and the act of 30 July 1981 punishing certain acts motivated by racism or xenophobia⁷⁸. All these regulations apply to insurance and employment relations.⁷⁹

Both direct and indirect discrimination is forbidden. Direct distinction is when someone is treated less favorably than someone else is or would be in a comparable situation on the basis of one of the protected criteria. Direct discrimination is (...) a direct distinction that cannot be justified on the basis of the provisions of the law.⁸⁰ Indirect distinction is when an apparently neutral provision, standard or action prejudices persons characterized by a particular protected criterion, compared to others. Indirect discrimination is the indirect distinction that cannot be justified on the basis of the provisions of the law.⁸¹

⁷² Art. 8, § 2 Patient Rights Act.

⁷³ Art. 8, § 2 Patient Rights Act: “*The purpose, nature, degree of urgency, duration, frequency, relevant contraindications, side effects and risks associated with the intervention, aftercare, possible alternatives and financial consequences.*”

⁷⁴ VLD, *Verslagboek genetica en samenleving: VLD-studiedag*, Brussels, 1996, 25. This is also emphasized in art. 12 of the Convention on Human rights and Biomedicine, which requires an appropriate genetic counseling in addition to informed consent.

⁷⁵ VLD, *Verslagboek genetica en samenleving: VLD-studiedag*, Brussels, 1996, 25; J.J. CASSIMAN, *Wat zit er in mijn genen?*, Leuven, Davidsfonds, 2004, 199.

⁷⁶ Act 10 May 2007 to combat certain forms of discrimination, *Belgian State Gazette* 30 may 2007. (Anti-Discrimination Act)

⁷⁷ Act 10 May 2007 to combat discrimination between men and women, *Belgian State Gazette* 30 may 2007. (Gender Act)

⁷⁸ Act 30 July 1981 punishing certain acts motivated by racism or xenophobia, *Belgian State Gazette* 8 August 1981. (Racism Act)

⁷⁹ Art. 5, § 1 and art. 4 1° Anti-Discrimination Act; Art. 5, 1° and art. 6, § 1, 1° and 5° Gender Act; Art. 4, 1° and art. 5, § 1, 1° and 5° Racism Act.

⁸⁰ Art. 4, 6° and 7° Anti-Discrimination Act; Art. 5, 5° and 6° Gender Act; Art. 4, 6° and 7° Racism Act.

⁸¹ Art. 4, 8° and 9° Anti-Discrimination Act; Art. 5, 7° and 8° Gender Act; Art. 4, 8° and 9° Racism Act.

In the context of genetic testing in insurance and employment, the general law is the most important one. The Anti-Discrimination Act creates a general framework to combat discrimination based on certain protected criteria by punishing discriminatory behavior.⁸² There is no general prohibition of discrimination for any form of discrimination, regardless of the distinguishing criterion used.⁸³

The Anti-Discrimination Act explicitly forbids the use of genetic information to discriminate. Art. 3 refers to “*a physical or genetic characteristic*”.⁸⁴ On a European level genetic discrimination is prohibited by the Charter of Fundamental Rights of the European Union.⁸⁵ The Oviedo Convention also forbids genetic discrimination but Belgium has not signed that convention.⁸⁶

Genetic discrimination, like discrimination on the basis of race or gender, is inadmissible since in both cases the discrimination is based on unchanging, inherent characteristics of persons and not on the basis of skills or qualifications.⁸⁷

Discrimination however, can be justified. Direct distinction can be justified by a legitimate goal when the means to achieve this goal are suitable and necessary.⁸⁸ Indirect distinction can be justified by a legitimate goal when the means to achieve this goal are suitable and necessary.⁸⁹

There are two general grounds for justification. First, there can be a positive action. A direct or indirect distinction based on one of the protected criteria is not discriminatory where this directly or indirectly distinguishes a measure of positive action.⁹⁰ Secondly, there can be a distinction by or pursuant to the legislation. A direct or indirect distinction based on one of the protected criteria is not discriminatory when this distinction is imposed by or pursuant to legislation.⁹¹

These general grounds for justification could be applied to genetic data. There are no specific grounds for justification related to genetic data.

9. Has discrimination on the basis of genetic status been seen to intersect with other forms of discrimination, for example on the basis of gender, family status, race, ethnic origin or national origin, for individuals belonging to groups that may be considered pre-disposed to particular illnesses (e.g. persons of African descent and Sickle-cell anemia; Tay-Sachs disease in persons of Ashkenazi Jewish heritage, etc.)?

⁸² W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2017-18, Band 2*, Malines, Kluwer, 2017, 1267.

⁸³ A. RAHME (ed.), F. HENDRICKX, O. VANACHTER and A. VAN BEVER, *Discriminatie op basis van handicap en gezondheidstoestand in de arbeidsverhouding*, Antwerp, Intersentia, 2009, 24.

⁸⁴ Art. 10 Anti-Discrimination Act.

⁸⁵ Art. 21 Charter Of Fundamental Rights Of The European Union, *OJ C 326*, 26.10.2012, p. 391-407.

⁸⁶ Art. 11 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Oviedo, 4 April 1997, <https://rm.coe.int/168007cf98>.

⁸⁷ A. ROUVROY, “Informations génétiques et assurance. Discussion critique autour de la position “prohibitionniste” du législateur belge”, *Journal des Tribunaux* 2000, 590.

⁸⁸ Art. 7 Anti-Discrimination Act.

⁸⁹ Art. 9 Anti-Discrimination Act.

⁹⁰ Art. 10 Anti-Discrimination Act.

⁹¹ Art. 11 Anti-Discrimination Act.

No. These examples are known in the literature but these situations have not really occurred in Belgium. There is no information available about the discrimination of these groups in Belgium.

10. Are discrimination in employment and discrimination in respect to insurance addressed according to the same analytical framework?

Yes.

The Anti-Discrimination Act of 2007 applies both to insurance companies and employers.

The Anti-Discrimination Act applies to the public sector and the private sector with regard to the access to and supply of goods and services that are publicly available.⁹² Agreements between private legal entities that offer goods and services, in particular insurance contracts, therefore fall under the scope of the law.⁹³ The law also applies to labour relations which includes the conditions for access to employment.⁹⁴ The anti-discrimination law aims to combat discrimination in labour relations. There is a focus on prohibiting discrimination based on a person's current or future state of health, disability and physical or genetic characteristics. The law aims to prevent selection decisions being made on the basis of these protected criteria.⁹⁵

An employer may not discriminate and exclude candidates for reasons unrelated to the function or nature of the activity⁹⁶ and insurers may not discriminate in decisions about acceptance, pricing and coverage on the basis of the criteria listed in the Anti-Discrimination Act.⁹⁷

11. Please discuss any pivotal human rights decisions from your jurisdiction regarding genetic discrimination in the insurance and/or employment contexts.

There are no published important decisions on genetic discrimination.

There are no records about genetic discrimination held by interest groups such as the national insurance ombudsman. It seems that genetic discrimination, as with a lot of other forms of discrimination, stays under the radar.

12. Overall, does the general non-discrimination framework provide a sufficient basis to address the challenges posed by genetic testing in the context of insurance or employment.

⁹² Art. 5, § 1, 1° Anti-Discrimination Act.

⁹³ B. WEYTS, "De Antidiscriminatie wet van 10 mei 2007 en verzekeringen" in J. ROGGE (ed.), *Discriminatie, geslachtsdifferentiatie en verzekeringen. Dossier 13, Tijdschrift voor verzekeringen*, Malines, Kluwer, 2007, 11; Y. THIERY, *Discriminatie en verzekering*, Antwerp, Intersentia, 2011, 142; K. BYTTEBIER and T. WERA, "Discriminatie in verzekeringen, m.i.v. discriminatie op basis van handicap en leeftijd", *Tijdschrift voor Privaatrecht* 2013, afl. 4, 2656; T. VANSWEEVELT and B. WEYTS (eds.), *Handboek verzekeringsrecht*, Antwerp, Intersentia, 2016, 23.

⁹⁴ Art. 5, § 1, 5° and § 2, 1° Anti-Discrimination Act.

⁹⁵ A. RAHME, F. HENDRICKX, O. VANACHTER and A. VAN BEVER, *Discriminatie op basis van handicap en gezondheidstoestand in de arbeidsverhouding*, Antwerp, Intersentia, 2009, 131.

⁹⁶ ADVISORY COMMITTEE ON BIOETHICS, *Advies nr. 20 van 18 november 2002 betreffende predictieve genetische tests en HIV-tests in het kader van arbeidsverhoudingen*, 4, <https://www.health.belgium.be/nl/advies-nr-20-predictieve-genetische-tests-en-hiv-tests-arbeidsverhoudingen>; I. PLETS, "Medische onderzoeken op het werk", *Nieuw Juridisch Weekblad* 2003, afl. 33, 619.

⁹⁷ Bill concerning insurance, *Parlementaire Stukken Kamer* 2013-14, nr. 3361/1, 32.

Since there are no published judgments and most genetic discrimination issues remain under the radar, it is difficult to judge if the non-discrimination framework provides a sufficient basis to address genetic discrimination. The absence of published judgments about genetic discrimination may indicate that there is compliance with the legal prohibition on genetic discrimination.

13. How does your jurisdiction protect the confidentiality of information derived from genetic testing and the privacy of the person who was subject to it? More precisely, what protection is afforded to:

a) Genetic test results contained in a patient's medical or hospital file from disclosure to or access by third parties, including employers and insurers?

Every patient has a direct right of access to his/her patient's medical file.⁹⁸ With the consent of the patient, his/her confidant or representative, staff members of care institutions and the general practitioner also have access to a patient's file.⁹⁹ The patient also has a right to receive a copy of his/her medical file.¹⁰⁰

After the patient has died, an indirect right of access is granted to the spouse, the legally cohabiting partner, the partner and relatives until the second degree. The right of access is exercised by a professional provided that the person wishing to access the medical file submits a adequately justified and specific request for access and that the patient has not explicitly opposed this inspection.¹⁰¹ After the death of the patient there is no right to copy the file.¹⁰²

The insurer has no right of access. The next of kin could however exercise their right to access with a consulting physician of the insurance company. This is not a problem when the insurance company has the same interests as the insured and the relatives. However, it can become problematic when the insurance company has a conflict of interest and wants to circumvent art. 61 Insurance Act 2014.¹⁰³ The National Council of the Medical Order has stated that it is ethically unacceptable for an consulting physician of an insurer to assist the next of kin in inspecting the file of the deceased insured with the aim of circumventing art. 61 of the Insurance Act.¹⁰⁴

The insurer is not entitled to a copy of the patient record. This is prevented by physician-patient confidentiality.¹⁰⁵ If the insurer wants a certificate or declaration for concluding or executing the agreement, the insured can request a statement from his/her doctor who can

⁹⁸ Art. 9, § 2 Patient Rights Act.

⁹⁹ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 500-502.

¹⁰⁰ Art. 9, § 3 Patient Rights Act.

¹⁰¹ Art. 9, § 4 Patient Rights Act; T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 522-529.

¹⁰² T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 541.

¹⁰³ A. VIJVERMAN, *Het elektronisch medisch dossier*, Antwerp, Intersentia, 2013, 58.

¹⁰⁴ NATIONAL COUNCIL OF THE ORDER OF PHYSICIANS, *Inzage van het medisch dossier van een overledene door de raadgevende arts van een verzekeringsmaatschappij*, 25 November 2006, www.ordomedic.be

¹⁰⁵ A. VIJVERMAN, *Het elektronisch medisch dossier*, Antwerp, Intersentia, 2013, 58; T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 546.

deliver the statement to the patient. The insured person then decides for himself whether or not to give the declaration to the insurance company.¹⁰⁶

If the insured person has died and the insurer wishes to receive a statement about the cause of death, the physician of the insured person can give a statement to the consulting physician of the insurer provided that the insured person has given his/her consent during his/her life.¹⁰⁷ This only concerns a statement about the cause of death and not a copy of the patient file. A copy of the complete file would constitute a violation of professional secrecy.¹⁰⁸

However, the insurer can try to access the patient file through other techniques. In the context of legal proceedings, he/she can request an expert's report in which the court expert will have to request the patient's file. In this way the insurer is given indirect access to the file.¹⁰⁹ The insurer may also request the court to add a relevant document to the case file if there are serious, certain and consistent suspicions that a party or a third party has a document in its possession that contains evidence of a relevant fact, for instance the patient's medical file.¹¹⁰

Finally, the insurer can also simply ask the patient for a copy of his/her medical records. The patient is entitled to a copy of his/her file, and he/she can decide if he/she wants to hand it over to the insurer.¹¹¹ However, the physician may refuse to issue a copy if he/she has clear indications that the patient has been pressurized by an insurer to obtain a copy.¹¹²

The application of art. 61 Insurance Act 2014 should always be kept in mind. The insurer may not ask for genetic information and the physician or policyholder may not disclose it.¹¹³

In addition, genetic records are generally better protected than other medical records as they remain in the genetics department.¹¹⁴

b) Genetic test results obtained in the context of biomedical research?

The general regulation concerning the processing of personal data applies. The Processing Personal Data Act aims to protect the personal privacy of every person against the processing of his/her personal data.¹¹⁵ The concept of processing encompasses wide range of activities,

¹⁰⁶ A. VIJVERMAN, *Het elektronisch medisch dossier*, Antwerp, Intersentia, 2013, 58; T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 546.

¹⁰⁷ A. VIJVERMAN, *Het elektronisch medisch dossier*, Antwerp, Intersentia, 2013, 58-59; T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 547.

¹⁰⁸ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 547.

¹⁰⁹ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 548.

¹¹⁰ Art. 877 Judicial Code.

¹¹¹ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 550.

¹¹² Art. 9, § 3, paragraph 2 Patient Rights Act.

¹¹³ Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 76; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 8 and 10; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS (eds.), *Handboek verzekeringsrecht*, Antwerp, Intersentia, 2016, 425.

¹¹⁴ E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 75.

¹¹⁵ Art. 2 Processing Personal Data Act.

such as any processing or any set of operations concerning personal data, whether or not carried out using automated processes, such as collecting, recording, organizing, storing, updating, modifying, retrieving, consulting, using, providing by means of transfer, disseminate or otherwise make available, bring together, interrelate, and shield, erase or destroy personal data.¹¹⁶ If this personal data concerns the health of a person, (...) it is referred to as health data. These are all data of a personal nature from which information can be derived regarding the previous, current or future physical or psychological state of health of the natural person who is or can be identified, with the exception of purely administrative or accounting data concerning the medical treatment or care.¹¹⁷ Genetic data that provides a picture of the health status of the patient is considered health data.¹¹⁸

In principle, the processing of health data is prohibited.¹¹⁹ Exceptionally data may be processed or exchanged in a limited number of cases.¹²⁰ Possible exceptions that can be relied on in the context of medical data are "*when the person concerned has consented to such processing in writing*" and "*when the processing is necessary for preventive medicine or medical diagnosis purposes, the provision of care or treatment to the person concerned or a relative, or the management of the health services acting in the interests of the data subject and the data are processed under the supervision of a healthcare professional*" or "*when the processing is necessary for scientific research and is carried out under the conditions established by the King by a decree deliberated in the Council of Ministers, after advice from the Commission for the protection of privacy*"¹²¹

The patient must always be informed about the recipients or categories of recipients of his/her personal data.¹²²

Biobanks are regulated in the context of laws concerning human biological products. The administrator of the biobank ensures that the consent of the donor is respected and that the material is only made available for authorized purposes.¹²³ In case of secondary use, use that goes beyond the original consent, the administrator must obtain a new permission from the original donor.¹²⁴ When the biobank discontinues its activities, the material must be

¹¹⁶ Art. 1, § 2 Processing Personal Data Act.

¹¹⁷ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 464.

¹¹⁸ J. HERVEG, *La protection des données du patient dans l'hôpital*, Waterloo, Kluwer, 2009, 20; T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 465.

¹¹⁹ Art. 7, § 1 Processing Personal Data Act.

¹²⁰ Art. 7, § 2 Processing Personal Data Act.

¹²¹ Art. 7, § 2, a), j) and k) Processing Personal Data Act.

¹²² Art. 9, § 1, d) Processing Personal Data Act.

¹²³ Art. 15, § 1 Processing Personal Data Act.

¹²⁴ T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 1275-1276.

transferred to another biobank or it must be destroyed.¹²⁵ When the biobank saves human body material, the administrator can only be a physician.¹²⁶

The National Council of the Order of Physicians also stated that the processing of genetic data and material must be done with the greatest confidentiality. Its use, even after anonymization, should be limited to the protocol for which the test subject has given his/her consent. The use of this genetic material for other purposes than those defined in the protocol, requires a new protocol and a new consent of the test subject.¹²⁷

c) Genetic information detained by, or for, an insurer or employer in case genetic testing is permitted in these contexts?

Not applicable.

14. What role does consent play in allowing genetic information contained in a medical or hospital file to be disclosed to third parties such as insurers and employers?

None. The duty of professional confidentiality prevails.

Some believe that with the consent of the patient, confidential information can be shared with third parties.¹²⁸ They argue that art. 458 Criminal Code protects the interests of the secret-owner.¹²⁹ Since duty of professional confidentiality protects the patient, he/she can renounce his/her right and give the physician permission to make the data known to third parties.¹³⁰

Legally this is not correct. The duty of professional confidentiality indeed exists to protect the individual interest. Primarily, however, it exists in the public interest and only subsidiary in the individual interest.¹³¹ Criminal law, and therefore also the duty of professional confidentiality, has a public order character and private individuals cannot deviate from this by private agreement.¹³² The patient's consent cannot exempt the physician from his/her duty

¹²⁵ Art. 17, §1/1 and § 2 Act 19 December 2008 on the acquisition and use of human body material with a view to medical application to humans or scientific research, *Belgian State Gazette* 30 December 2008. (Act on the acquisition and use of human body material)

¹²⁶ Art. 22 Act on the acquisition and use of human body material; T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 1276.

¹²⁷ NATIONAL COUNCIL OF THE ORDER OF PHYSICIANS, *DNA-onderzoek en farmacogenetica*, 17 juli 2004, www.ordomedic.be.

¹²⁸ F. VAN NESTE, "Het medisch beroepsgeheim" in A. HEYVAERT, R. KRUIHOF and T. VANSWEEVELT (eds.), *Juridische aspecten van de geneeskunde*, Antwerp, Kluwer, 1989, 191; F. PONET, R. RUBENS and W. VERHEES, *De Landverzekeringsovereenkomst*, Antwerp, Kluwer, 1993, 428; T. GOFFIN, "Toestemming in het medisch recht. Een nieuwe lezing van een oud probleem", *Rechtskundig Weekblad* 2007-08, 1316; F. BLOCKX, "Les données que les patients 'confient' à leur médecin", *Tijdschrift voor Gezondheidsrecht* 2011-12, 115; S. CALLENS, S. CAENEN and L. VAN LEUVEN, "E-Health en het omgaan met gegevens in de gezondheidszorg" in S. CALLENS and J. PEERS (eds.), *Organisatie van de gezondheidszorg*, Antwerp, Intersentia, 2015, 378.

¹²⁹ F. PONET, R. RUBENS and W. VERHEES, *De Landverzekeringsovereenkomst*, Antwerp, Kluwer, 1993, 427; F. BLOCKX, "Les données que les patients 'confient' à leur médecin", *Tijdschrift voor Gezondheidsrecht* 2011-12, 114.

¹³⁰ F. BLOCKX, *Beroepsgeheim*, Antwerp, Intersentia, 2013, 173-174.

¹³¹ I. VAN DER STRAETE and J. PUT, *Beroepsgeheim en hulpverlening*, Bruges, die Keure, 2005, 37; A. DIERICKX, J. BUELENS and A. VIJVERMAN, "Het recht op de bescherming van de persoonlijke levenssfeer, het medisch beroepsgeheim en de verwerking van persoonsgegevens" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 588-589.

¹³² Cass. 30 oktober 1978, *Arresten van het Hof van Cassatie 1978-79*, 235, *Revue générale des assurances et des responsabilités* 1980, nr. 10.272; Art. 55 Code of Medical Duties; J. STEVENS, "Het beroepsgeheim van de advocaat en dat van de geneesheer", *Tijdschrift voor Gezondheidsrecht* 2002-03, 2; C. VAN DEN

of professional confidentiality and cannot cancel the unlawfulness of the violation.¹³³ Under Belgian law, consent is therefore not accepted as justification.¹³⁴

15. How does your legal system protect the interests of family members, including those not yet born, in the protection of their genetic information?

In the absence of a general regulation on the use of genetic information, *lex specialis* provides protection in certain branches of the law. The Patient Rights Act provides protection by the fact that third parties do not have access to medical records.¹³⁵ Insurers or employers can therefore not obtain knowledge about genetic information from the prospective policyholder, which can provide information about his/her relatives.

In addition, the Insurance Act provides protection by introducing a complete and absolute prohibition on requesting and communicating genetic information in connection with the conclusion or performance of an insurance contract.¹³⁶ This ban was also introduced to protect the privacy of relatives.

The use of genetic research and genetic data was forbidden to avoid the systematic disadvantage of the "genetically weak" and improper risk selection by the insurer and to ensure the social solidarity between the genetically strong and genetically weak.¹³⁷ The prohibition also aimed at the protection of the right to privacy of the insured person and his/her family members, both in ascending and descending lines and in the sidelines. Genetic information about the insured person also says something about his/her family. This would

WYNGAERT and S. VANDROMME, *Strafrecht en strafprocesrecht in hoofdlijnen, I*, Antwerp, Maklu, 2009, 270; A. DIERICKX, J. BUELENS and A. VIJVERMAN, "Het recht op de bescherming van de persoonlijke levenssfeer, het medisch beroepsgeheim en de verwerking van persoonsgegevens" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 677-678 and 680.

¹³³ Labor Court Bergen 5 september 1980, *Informatieblad RIZIV* 1981, 151, noot R. GROSEMANS, *Journal des Tribunaux* 1980, 742, noot R. GROSEMANS, *Journal des Tribunaux du Travail* 1981, 107, *Rev.dr.pén.* 1981, 99, noot, *Tijdschrift voor Sociaal Recht* 1981, 71; M.N. VERHAEGEN and J. HERVEG, "Professionnels de la santé" in D. KIGANAHE and Y. POULLET (eds.), *Le secret professionnel*, Brussels, La Chartre, 2002, 116 and 120; L. VANHEESWIJCK, "Het beroepsgeheim en het recht van verdediging", *Nullum Crimen* 2011, 345; A. DIERICKX, "Het beroepsgeheim en de toestemming van de geheimgerechtigde" in *Liber amicorum Michel Rozie*, Antwerp, Intersentia, 2014, 186.

¹³⁴ Art 64 Code of Medical Duties; H. NYS, "Predictief genetisch onderzoek: enkele juridische aspecten", *Vlaams Tijdschrift voor Gezondheidsrecht* 1989, 239; I. VAN DER STRAETE and J. PUT, *Beroepsgeheim en hulpverlening*, Bruges, die Keure, 2005, 188; A. DIERICKX, J. BUELENS and A. VIJVERMAN, "Het recht op de bescherming van de persoonlijke levenssfeer, het medisch beroepsgeheim en de verwerking van persoonsgegevens" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 678.

¹³⁵ Art. 9 Patient Rights Act.

¹³⁶ Art. 58 *jo.* 61 Insurance Act 2014.

¹³⁷ Amendments to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, 1586/4, 6; Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 34 and 75-76; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 10; D. WUYTS, "Precontractuele spreekplicht van de verzekeringnemer en de verzekeraar" in J. ROZIE, S. RUTTEN and A. VAN OEVELEN (eds.), *Zwijgrecht versus spreekplicht*, Antwerp, Intersentia, 2013, 175; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, afl. 18, 28-29; C. PARIS and V. CALLEWAERT (eds.), *Actualités en droit des assurances*, Brussels, Larcier, 2015, 22.

also threaten their right to privacy.¹³⁸ Genetic data from relatives are therefore also covered by the ban.¹³⁹

In the context of employment the genetic information of family members is protected by the Medical Examination Act. The law says: “*The biological tests, medical examinations or oral questions to obtain medical information about the health status or genealogical information of an employee or job applicant may not be performed for reasons other than those related to the current suitability of the employee for and the specific characteristics of the vacancy*”. Examinations and questions to receive genealogical information are forbidden. Information about the health of the employees parents or ancestors can indicate certain hereditary disorders and/or predisposition for certain diseases. This information cannot be used as a criterion for selection.¹⁴⁰

What if any role does your jurisdiction provide to family members in decision-making about disclosure to third parties—notably employers and insurers—of genetic information contained in an individual’s medical or hospital file?

If the insured person is still alive, certain safeguards apply to protect the health data of the insured person. 1) The physician can only issue a statement at the request of the insured person, 2) the physician is chosen by the insured person himself, 3) the medical certificate must be required for concluding or executing the contract, 4) the physician may only issue the medical certificate to the insured person himself, 5) the declaration must be limited to a description of the current state of health and 6) the insured person can only deliver the statement to the consulting physician of the insurer.¹⁴¹ Due to the fact that the insured person must request a medical certificate himself, the insurer cannot request this. Family members cannot do this either.¹⁴²

After the death of the insured person, the insurer can also have an interest in information about his/her death. Art. 61, paragraph 4 of the Insurance Act regulates the *post mortem* certificate. The legislature also provides legal guarantees here. 1) The insurer must have the prior consent of the insured person, 2) the physician delivers the medical certificate on the cause of death and 3) it is delivered to the consulting physician of the insurer.¹⁴³ The insured must therefore have given his/her consent. The physician cannot provide the information on his/her own initiative. He/she is bound by his/her professional secrecy. Other third parties, such as the insurer, cannot give the physician permission to deliver the statement.¹⁴⁴

¹³⁸ Report VERHEYDEN to the bill on the land insurance contract, *Parlementaire Stukken Kamer* 1990-91, nr. 1586/5, 34; Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 8 and 31.

¹³⁹ C. PARIS and V. CALLEWAERT (eds.), *Actualités en droit des assurances*, Brussels, Larcier, 2015, 22-23.

¹⁴⁰ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken Senaat* 2002-03, 2-20/3, 5.

¹⁴¹ Art. 61, paragraph 1 and 2 Insurance Act 2014; S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 147.

¹⁴² S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 147.

¹⁴³ Art. 61, paragraph 4 Insurance Act 2014; S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 170-171.

¹⁴⁴ S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 174.

The question arises whether heirs and other beneficiaries can give the physician permission to disclose information. The right of the insured to relieve the physician from his/her professional secrecy could be regarded as a personal and extra-patrimonial right. The consent of third parties cannot relieve the physician from his/her professional secrecy. So, he/she may not submit a death certificate at the request of a family member.¹⁴⁵ However, they could give a substitute permission if the interests of the insured person and those of the surviving relatives coincide or at least the interests of the deceased would not be harmed.¹⁴⁶ The medical professional secret is then weighed against a certain higher importance.¹⁴⁷

Relatives can also get information about the health of the insured in a different way. Based on art. 9, § 4 of the Patient Rights Act, certain family members are entitled to access the patient's medical files through a professional practitioner. They are not entitled to a copy, but the professional can take notes from the patient file.¹⁴⁸ They can give these notes to the insurer.

Under Article 61 Insurance Act, however, the insurer may never request or use genetic information. If he/she asks relatives to disclose genetic information about their insured family member, he/she violates art 61.

16. Does your jurisdiction recognize individuals' right of access to information regarding their health or medical status that might be available to insurers or potential employers? Does it recognize the same right to family members?

Yes

Art. 9, § 2 Patient Rights Act gives the patient a direct right to access his/her patient's medical file. This right to access is a complete right to access which means it applies to all the data and documents that are part of the file.¹⁴⁹ Still, there are two exceptions on this right to access. The patient does not have access to the personal notes of the physician and to data of third parties.

The patient not only has the right to access the content of his/her medical file but also the right to know who accessed his/her medical file. First of all, based on art. 8 ECHR the patient has the right to know who collected data about him.¹⁵⁰ Second, art. 10, § 1 Processing Personal

¹⁴⁵ Antwerp 16 February 2005, *Rechtskundig Weekblad* 2007-08, 33; Antwerp 22 October 2014, *Tijdschrift voor Gezondheidsrecht* 2014-15, noot T. VANSWEEVELT; S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 174; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, afl. 18, 37.

¹⁴⁶ B. WEYTS, "De informatieplicht van de kandidaat-verzekerde en de afgifte van het medisch dossier in het raam van een levensverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1997-98, 331; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, afl. 18, 37.

¹⁴⁷ B. DUBUISSON, "Secrets, mensonges et confidences conclusions", *Revue de droit de l'ULB* 2000, 348; S. DEFLOOR, *Het gebruik van medische informatie in private verzekeringen*, Antwerp, Intersentia, 2014, 174-175.

¹⁴⁸ T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, afl. 18, 38.

¹⁴⁹ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 494.

¹⁵⁰ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 495.

Data Act states that the person proving his/her identity, has the right to obtain from the controller of the processing whether there has been processing of data concerning him, the purposes of the data processing and the categories of recipients to whom the data were provided. Applied to a patient's medical file, this means that a patient has the right to know who has consulted his/her medical files.¹⁵¹

An employee or job applicant also has a right to be informed about the personal data concerning him/her that will be processed. Art. 10, § 1 of the Processing Personal Data Act applies to the application files.¹⁵² The Privacy Commission explicitly states a right to direct access to the processed personal data. Everyone has the right to receive, in a comprehensible form, a copy of the processed data, as well as any available information about its origin.¹⁵³

Family members do not have the same rights.

17. Does your legal system recognize that individuals and their family members have a right not to know about their genetic information? If so, how does this right play out in the context of insurance and employment?

Yes.

The patient has the right to say that he/she doesn't want to know certain information about his/her health.¹⁵⁴ Every patient has the right to say that he/she doesn't want to be aware of his/her genetic information. No one can oblige him to receive certain information. When the patient invokes this right, the practitioner must respect this. The duty to inform becomes a duty to not inform.¹⁵⁵ This right, like the right to information, is based on the right to physical integrity, self-determination and privacy.¹⁵⁶ By invoking his/her right not to know, the patient waives his/her right to health status information.¹⁵⁷ The right to self-determination can therefore also be formulated negatively as the right not to know its genetic profile. The right not to know also largely coincides with the right to free and informed consent.¹⁵⁸ By refusing

¹⁵¹ T. VANSWEEVELT, "Rechten met betrekking tot het patiëntendossier" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 496.

¹⁵² T. DE BOCK and I. VANDERREKEN, "Enkele (nieuwe) juridische grenzen aan het wervings- en selectieproces", *Oriëntatie* 2003, nr. 11, 243.

¹⁵³ PRIVACY COMMISSION, *Informatienota over de bescherming van persoonsgegevens in België*, https://www.ou.nl/documents/40554/187634/Belgische_regelgeving_bescherming_van_persoonsgegevens.pdf/b1e5f2f1-eeb4-4a8b-a44c-500da473015c.

¹⁵⁴ Art. 7, § 3 and art. 8, § 3 Patient Rights Act; Art. 10, paragraph 2-3 Convention on Human rights and Biomedicine.

¹⁵⁵ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 22; P. CRAEYNEST and M. COKELAERE, *Onze genen. Handboek menselijke erfelijkheid*, Leuven, Acco, 2007, 295.

¹⁵⁶ W. DIJKHOFFZ, "Het recht op informatie en geïnformeerde toestemming", *Tijdschrift voor Gezondheidsrecht* 2003-04, 105; R. D'HAESE, "Medische contracten in het licht van het recht op eerbied voor de fysieke integriteit. De *informed consent*-vereiste als raakpunt", *Tijdschrift voor Belgisch burgerlijk recht* 2010, 435-436; T. VANSWEEVELT and S. TACK, "Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 342.

¹⁵⁷ L. CASSIERS and E. VERMEERSCH (eds.), *Erfelijkheid: genetische tests en maatschappij*, Leuven, Garant, 2000, 60-61; T. VANSWEEVELT and S. TACK, "Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht, II*, Antwerp, Intersentia, 2014, 342 and 385.

¹⁵⁸ J.J. CASSIMAN, *Wat zit er in mijn genen?*, Leuven, Davidsfonds, 2004, 193 and 199.

a genetic investigation, he/she determines whether genetic information is created.¹⁵⁹ Patients regularly rely on this right in the context of genetic research. The classic example is Huntington's disease. The patient can choose not to know his/her carrier status because there is no cure or because this knowledge will influence his/her or her future life.¹⁶⁰

Since genetic information about a patient also gives information about his/her family members, they have the right to say that they don't want to know this information because they don't want to know if they have a genetic risk. Everyone has the right to say that he/she doesn't want to be informed about his/her current or future health.

In the context of insurance and employment the fact that everyone has the right not to know his/her genetic passport is an argument to prohibit the use of genetic information.¹⁶¹

The right not to know is connected with the right to self-determination. For further information see question 18.

18. Please discuss and evaluate any other rights or principles, recognized in your legal system, that are relevant to the use of genetic testing in the context of insurance or employment (e.g. autonomy, self-determination).

In addition to the right to privacy, other personality rights are also affected when people ask to share genetic information. A person's right to self-determination is threatened when he/she cannot freely choose whether he/she wants to receive certain information or not.¹⁶² Everyone has the right to get information about his/her state of health. Genetic information is also part of this right to information, even when curative therapy no longer exists.¹⁶³ But a patient always has the right to decide that he/she does not want to receive certain information. The right to self-determination can therefore also be formulated in a negative way as the right not

¹⁵⁹ L. CASSIERS and E. VERMEERSCH (eds.), *Erfelijkheid: genetische tests en maatschappij*, Leuven, Garant, 2000, 60; J.J. CASSIMAN, *Wat zit er in mijn genen?*, Leuven, Davidsfonds, 2004, 193

¹⁶⁰ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 22; W. DIJKHOFFZ, "Het recht op informatie en geïnformeerde toestemming", *Tijdschrift voor Gezondheidsrecht* 2003-04, 105; H. NYS, *Recht en bio-ethiek. Wegwijs voor mensen in de gezondheidszorg*, Leuven, Lannoo, 2010, 50; S. PANIS, *Stamcellen en recht : een juridische analyse van wegneming tot gebruik*, Antwerp, Intersentia, 2015, 401.

¹⁶¹ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken Senaat* 2002-03, 2-20/4, 3; *Handelingen Senaat* 14 November 2002, 2-241, 29; M. HILLEN, "Verzwijging van erfelijkheidsgegevens bij het aangaan van verzekeringsovereenkomsten", *Ars Aequi* 1991, 971; H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213; K. TROCH, "Het medisch beroepsgeheim en zijn impact op de levensverzekering", *Rechtskundig Weekblad* 1993-94, 1298, voetnoot 212; T. VANSWEEVELT and S. TACK, "Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht*, Volume II, Antwerp, Intersentia, 2014, 342.

¹⁶² K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 137.

¹⁶³ Bill concerning the rights of the patient, *Parlementaire Stukken Kamer* 2001-02, nr. 1642/001, 20; Art. 33 Code of Medical Duties; V. VANDERHULST, "De therapeutische exceptie en het recht van de patiënt op informatie, met bijzondere aandacht voor de zorg rond het levenseinde", *Tijdschrift voor Gezondheidsrecht* 2015-16, 329; T. VANSWEEVELT and S. TACK, "Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht*, Volume II, Antwerp, Intersentia, 2014, 335.

to know one's genetic profile.¹⁶⁴ Based on this right not to know, no one can be forced to undergo genetic research. The decision to undergo a genetic examination must be taken in full freedom, without pressure from someone else such as an insurer.¹⁶⁵ When this investigation precedes issuing an applicant with necessary insurance, this free consent is under pressure. Exercising pressure to undergo a hereditary examination to qualify for insurance may constitute a disproportionate infringement of the right of self-determination of the person concerned. In the context of hereditary research, this also means that having to undergo non-voluntary research, can infringe one's private life, particularly because a person can be confronted with serious health risks for which there is no prospect of prevention or treatment.¹⁶⁶

However, there is the nuance that the right to self-determination is also limited by the law itself. The policyholder is also prevented from communicating positive results to the insurer when he/she wants to.¹⁶⁷

Part II

Rights and obligations of insurers and employers

19. How does the insurance industry justify collecting genetic information?

1. Insurance technical aspects

Insurers argue that they should have the possibility to differentiate premiums.¹⁶⁸ The premium and the risk have to be balanced on the basis of the actuarial principles. If insurers do not have all the relevant information, the premium for a certain risk cannot be estimated well and be adapted to the situation.¹⁶⁹ It is based on the principle: equal situations must be treated equally

¹⁶⁴ T. VANSWEEVELT and S. TACK, "Het recht op gezondheidstoestandinformatie en geïnformeerde toestemming" in T. VANSWEEVELT and F. DEWALLENS (eds.), *Handboek Gezondheidsrecht*, Volume II, Antwerp, Intersentia, 2014, 342.

¹⁶⁵ M. HILLEN, "Verzwijging van erfelijkheidsgegevens bij het aangaan van verzekeringsovereenkomsten", *Ars Aequi* 1991, 971; H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213; K. TROCH, "Het medisch beroepsgeheim en zijn impact op de levensverzekering", *Rechtskundig Weekblad* 1993-94, 1298, voetnoot 212.

¹⁶⁶ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213.

¹⁶⁷ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 127.

¹⁶⁸ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 133; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509.

¹⁶⁹ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 134; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509-510.

and unequal situations must be treated unequally.¹⁷⁰ This is actuarial fairness. The prohibition goes against this principle.¹⁷¹

The fact that insurers may not take genetic information into account may have important consequences. When a person has a hereditary condition, he/she would in principle pay a higher premium for life insurance on death and a lower premium for life insurance. Since the insurer cannot make use of this information due to the prohibition, he/she will take into account the possibility that a policyholder has a genetic disorder.¹⁷² Instead of a standard rate with additional premiums for those who pose a higher risk, a general rate is used, taking into account the greatest risks, with the possibility of negotiating a lower premium.¹⁷³ All policyholders pay the same premium that is higher, based on the average risk. Policyholders with a good risk will then switch to an insurer that differentiates on the basis of genetic information to receive a lower premium. Policyholders with a bad risk go to an insurer that does not differentiate on the basis of genetic information. In that case, the premium will still be lower than when it is differentiated. This insurer will mainly attract bad risks. As a result, he/she will get more claims with more or higher reimbursements. To compensate for this, the premiums are raised, which causes even more "good risks" leaving the pool. This creates a vicious circle.¹⁷⁴

From a territorial point of view, the ban may also result in good risks taking out insurance in countries where the premium is determined taking into account the genetic profile. Bad risks that don't receive insurance in their own country can, however, come to Belgium to get insurance, as a result of which the insurance policies are becoming more and more expensive.¹⁷⁵

¹⁷⁰ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 133; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509.

¹⁷¹ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 137.

¹⁷² K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 134; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509-510.

¹⁷³ J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 146.

¹⁷⁴ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 33; K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 133-134; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 55, voetnoot 5; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509-510; E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 98.

¹⁷⁵ J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 146.

Insurers therefore state that if they are no longer able to differentiate premiums, their competitive position on the free market will be jeopardized.¹⁷⁶ Private insurance is a service that, in contrast to social security, can only be used by paying a fee that is proportionate to the risk that is proposed.¹⁷⁷

In the context of insurance, the possibility that a risk will materialize must also be uncertain. When it is certain that a disease will occur the risk is in principle not insurable. This is sometimes expressed as: a burning house cannot be insured.¹⁷⁸

From the point of view of the insurers it can also be argued that the prohibition does not take into account the fact that the developments in genetics have virtually no influence on the element of chance.¹⁷⁹ The element of chance is the same as with other medical data as there is uncertainty about the development of most disorders. The risk assessment based on genetic and classical medical data must therefore be the same. Since the influence on the element of chance is limited, the same actuarial and legal principles can be applied.¹⁸⁰

2. Asymmetric information and self-selection

The most important argument on which insurers rely is that of self-selection or anti-selection. The insurer is in a weaker position when concluding an insurance contract. He doesn't have the same information as the policyholder. In the context of insurance, however, it is important that both parties have equal information.¹⁸¹ To solve this problem, the spontaneous obligation to provide information applies to the policyholder. However, due to the fact that genetic data do not have to be communicated, an information asymmetry arises again between the parties and the insured has an advantage on the insurer.¹⁸²

The policyholder knows, consciously or unconsciously, more about his/her genetic risks than the insurer.¹⁸³ Due to the fact that the insurer does not receive information about genetic risks and the resulting asymmetry, there is a risk of self-selection or anti-selection.¹⁸⁴ Self-selection

¹⁷⁶ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 133; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509.

¹⁷⁷ J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 145.

¹⁷⁸ EMERITIFORUM, *Genetische informatie, private verzekeringen en rechten van de mens - een stand van zaken in recht en praktijk*, Leuven, KU Leuven, 2012, 3.

¹⁷⁹ N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 248.

¹⁸⁰ N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 252 en 253.

¹⁸¹ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 21.

¹⁸² K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 21 and 33; A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 597; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 511-512.

¹⁸³ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 21; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 55.

¹⁸⁴ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 212; K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K.

means that prospective policyholders who realize that they have a high risk and expect this risk to materialize in the future, will be more likely to take out insurance. Those with a low risk are less likely to take out insurance.¹⁸⁵ Especially when the policyholder decides for what amount he/she wants to be insured, this can be a problem.¹⁸⁶ Policyholders who know that they are genetically disadvantaged can obtain an unjustified advantage based on their prior knowledge by taking out insurance policies at very high amounts at the expense of the community. The premium is based on the average risk, whereby a relatively low premium is determined and the losses for the insurer are distributed among all policyholders.¹⁸⁷ This can lead to an increase in the amount of the reimbursements, which increases the premiums, leaving the policyholders with "good risks" leaving the pool.

Self-selection allows the policyholder to take out insurance against high amounts while being protected by the right to remain silent or even the right to lie.¹⁸⁸ To avoid genetic discrimination, it must be assumed that the policyholder has an unjustified advantage based on his/her prior knowledge.¹⁸⁹ Solidarity should not go so far that a policyholder can abuse his/her knowledge and let the community pay for it.¹⁹⁰ The solidarity obligation applies to the community and the social security system, and should not rest on private insurers.¹⁹¹

JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 141; A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 588; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 55; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 425.

¹⁸⁵ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22; A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 588; P. RAEYMAEKERS, *Genen en gezondheid*, Amsterdam, Natuur en techniek, 2001, 137; T. VANSWEEVELT and B. WEYTS, "Medische informatie" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 425.

¹⁸⁶ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22.

¹⁸⁷ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 33; K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22 and 33; P. RAEYMAEKERS, *Genen en gezondheid*, Amsterdam, Natuur en techniek, 2001, 137.

¹⁸⁸ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 597.

¹⁸⁹ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 212.

¹⁹⁰ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22.

¹⁹¹ L. CASSIERS and E. VERMEERSCH (eds.), *Erfelijkheid: genetische tests en maatschappij*, Leuven, Garant, 2000, 31.

Insurers cannot protect themselves in any way against this risk of self-selection unless they are allowed to ask questions about and segment on the basis of genetic data.¹⁹² The ban is therefore deemed unbalanced and unacceptable and must be changed.¹⁹³

3. Discrimination

The legislature wanted to avoid genetic discrimination and ensure that people with a genetic disorder were not faced with difficulties when concluding an insurance contract because of this abnormality. However, a prohibition of discrimination does not only mean that equal cases are treated equally. Uneven cases must also be treated unequally.¹⁹⁴

Discrimination occurs when people who are in the same factual circumstances are treated differently. Individuals who are in a different situation and are treated differently are therefore not discriminated against if the difference in treatment is not based on an opinion about the person's superior or inferiority because of a certain characteristic. Individuals who have the same genetic abnormality and have to pay a higher premium than people who do not have this abnormality are therefore not discriminated against. The difference in premium is justified by an objectively observable difference.¹⁹⁵

In purely technical-actuarial terms, discrimination is therefore no argument to prohibit the use of genetic information.¹⁹⁶ By segmentation, unequal treatment and discrimination are prevented.¹⁹⁷ Actuarial equality is therefore perfectly compatible with genetic discrimination when the criteria that are used are not arbitrary but objective. If the increased premium corresponds to the increased risk because of his/her genetic characteristics, there is no problem from an actuarial point of view.¹⁹⁸

¹⁹² H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 216; K. TROCH, "Het medisch beroepsgeheim en zijn impact op de levensverzekering", *Rechtskundig Weekblad* 1993-94, 1299; D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 33-34; T. VANSWEEVELT and B. WEYTS, "Het belang, de kenmerken en situering van het verzekeringsrecht" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 47.

¹⁹³ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 34.

¹⁹⁴ J. VELAERS, "De "objectieve en redelijke verantwoording" als ultieme toetssteen van ongelijke behandeling in verzekeringszaken" in C. VAN SCHOUBROECK and H. COUSY (eds.), *Discriminatie in verzekeringen*, Antwerp, Maklu, 2007, 93; T. VANSWEEVELT and B. WEYTS, "Het belang, de kenmerken en situering van het verzekeringsrecht" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 47.

¹⁹⁵ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 143.

¹⁹⁶ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 143; R. SALOMONS, "Erfelijke gegevens en verzekering" in H. COUSY and C. VAN SCHOUBROECK (eds.), *Liber Amicorum Hubert Claassens*, Antwerp, Maklu, 1998, 167.

¹⁹⁷ T. VANSWEEVELT and B. WEYTS, "Het belang, de kenmerken en situering van het verzekeringsrecht" in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 47.

¹⁹⁸ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 594.

4. Scientific progress

Finally, account must be taken of the fact that genetics is still evolving.¹⁹⁹ This progress is obviously positive. In the context of insurance law, however, this can cause problems regarding the prohibition. When so many diseases turn out to have a genetic origin, what is allowed to be communicated to the insurers about the state of health of the policyholder?²⁰⁰ In principle, frequently occurring illnesses must therefore be excluded from the obligation to notify if they have a genetic origin. There is a risk that the protection will then shift from the genetic risks to all medical data in general. This will undermine the underwriting freedom of insurers.²⁰¹

What are the main objections?

1. Consequences for research and health care

The use of genetic data for insurance purposes could have a negative impact on the willingness of individuals to carry out genetic testing out of fear of communicating the results to the insurer, even if it could provide life-saving information.²⁰² Individuals who bear responsibility for the future are being punished. They must reveal their negative results and be disadvantaged in contrast to persons who did not take their responsibility. This can ensure that ultimately no one wants to take his/her responsibility: "ignorance is bliss".²⁰³ It can even ensure that family members of a policyholder who knows that he/she has a certain condition, no longer want to be tested out of fear of the consequences in the context of insurance.²⁰⁴ This therefore has implications for scientific research. It is argued that when no one wants to be examined anymore, the genetic truth disappears to the background.²⁰⁵ In this way, the right to require genetic testing not only creates an obstacle to access insurance, but also to access health care.²⁰⁶

The (non) willingness to test can also have consequences for the health of the population. Hereditary diagnoses can be used to make early diagnoses and the patient can adjust his/her behavior so that the illness is inhibited or even prevented. In certain cases no prevention is

¹⁹⁹ D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 29.

²⁰⁰ L. SCHUERMANS and C. VAN SCHOUBROECK, *Grondslagen van het Belgische verzekeringsrecht*, Antwerp, Intersentia, 2015, 216, voetnoot 51.

²⁰¹ I. VAN HOYWEGHEN, "Taming the wild life of genes by law? Genes reconfiguring solidarity in private insurance", *New Genetics and Society* 2010, nr. 4, 444.

²⁰² H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 212-213; D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 29; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 52; L. JORDE, J. CAREY and M. BAMSHAD, *Medical genetics*, Philadelphia, Elsevier, 2015, 318.

²⁰³ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 24; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 517-518.

²⁰⁴ G. EVERS-KIEBOOMS and M. WELKENHUYSEN (eds.), *Die ziekte in mijn familie, krijg ik die later ook? Predictieve genetische tests*, Tielt, Lannoo, 2005, 27.

²⁰⁵ B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 518.

²⁰⁶ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 212-213; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 52.

possible but on the basis of this knowledge the patient can make important decisions, for example on reproduction.²⁰⁷ The long-term consequences can also be detrimental. When someone has knowledge of the fact that he/she is a carrier, he/she can act on this and after a while this can ensure that a deviation occurs less or even disappears.²⁰⁸ (...)

2. Value of genetic information

Scientific progress has ensured that the predictive value of genetic data has increased significantly. In the future, this knowledge will only increase and we will probably discover many genes that are the basis of certain disorders.²⁰⁹ In the future, it is likely that every individual will be fully screened for the most common genetic disorders.²¹⁰ The desire to use this information will therefore only increase.²¹¹

However, genetic information does not always offer complete certainty. The predictive value of the information is only certain in a limited number of cases. Usually it only gives the chance - a probability - of a certain disease developing.²¹² Many genetic disorders are multifactorial or multi-genetic. It may not be clear what the seriousness of the disease will be or when (if ever) the disease will manifest itself. In the context of research for autosomal dominant disorders, there is certainty or high probability that the condition will manifest later in life, for example Huntington's disease. But even in those cases there remains uncertainty about when the disease will manifest itself and to what extent.²¹³ Genetic predispositions should therefore not affect the assessment.²¹⁴

²⁰⁷ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 23.

²⁰⁸ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 24.

²⁰⁹ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 209.

²¹⁰ S. VANDEKERCKHOVE, "Ziekte voorspellen", *De Morgen* 26 October 2017, 8.

²¹¹ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 209; D. CASSIMAN, J.J. CASSIMAN and P. DEGRYSE (eds.), *Adam en Eva en andere verhalen over genetica*, Oostkamp, Stichting Kunstboek, 2000, 68.

²¹² A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 595; J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 143-144; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 28-29.

²¹³ G. EVERS-KIEBOOMS and M. WELKENHUYSEN (eds.), *Die ziekte in mijn familie, krijg ik die later ook? Predictieve genetische tests*, Tiel, Lannoo, 2005, 24; N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 252; A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 586 and 595.

²¹⁴ N. JEGER and P. CAUWENBERGH, "Individuele levensverzekeringen "overlijden" en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst", *Tijdschrift voor Gezondheidsrecht* 1996-97, 254.

The importance and value of genetic information is therefore somewhat overestimated.²¹⁵ For example, if the presence of BRCA1 / 2 is confirmed, the risk for the insurer hardly increases. The follow-up of the patient is better in that case and prevention is getting better and better.²¹⁶

3. Genetic discrimination

One of the legislatures' reasons for introducing the ban was to avoid genetic discrimination. If genetic data is used as a selection criterion, it is feared that this would lead to an ever-increasing differentiation between policyholders because of their individual predisposition. This would lead to increasing individualization in terms of insurability and insurance conditions. This creates the danger of genetic discrimination.²¹⁷ This could eventually lead to a dichotomy in society between the "genetic good" and the "genetically weaker".²¹⁸

4. Personality rights

Genetic data are highly personal data. They are immutable, do not age and are an integral part of a person's life from birth. When they are made public, this is a serious violation of the personal privacy of the person.²¹⁹ Insurers who use genetic tests as a negative recruitment tool therefore violate the privacy of the individual.²²⁰

In addition, the obligation to undergo a genetic test, that then shows an untreatable genetic condition, can be a psychologically heavy burden that violates the physical integrity.²²¹ This

²¹⁵ J. REMANS, *De boom van goed en kwaad*, Leuven, Acco, 2005, 156-157; EMERITIFORUM, *Genetische informatie, private verzekeringen en rechten van de mens - een stand van zaken in recht en praktijk*, Leuven, KU Leuven, 2012, 4.

²¹⁶ EMERITIFORUM, *Genetische informatie, private verzekeringen en rechten van de mens - een stand van zaken in recht en praktijk*, Leuven, KU Leuven, 2012, 4.

²¹⁷ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 212; K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 24; S. DEFLOOR and H. NYS, "Patiëntengegevens en verzekeringen. Een onmogelijke relatie?" in *Over grenzen. Liber Amicorum Herman Cousy*, Antwerp, Intersentia, 2011, 498.

²¹⁸ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 139; G. EVERS-KIEBOOMS and M. WELKENHUYSEN (eds.), *Die ziekte in mijn familie, krijg ik die later ook? Predictieve genetische tests*, Tielt, Lannoo, 2005, 27; P. CALCOEN, *Genetic information, private insurance and human rights*, Emeritiforum KU Leuven, Leuven, 29 November 2012, <https://www.kuleuven.be/emertiforum/em/Forumgesprekken/2012-2013/291112>.

²¹⁹ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 137; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 513-514; P. CALCOEN, *Genetic information, private insurance and human rights*, Emeritiforum KU Leuven, Leuven, 29 November 2012, <https://www.kuleuven.be/emertiforum/em/Forumgesprekken/2012-2013/291112>.

²²⁰ K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 52; G. EVERS-KIEBOOMS and M. WELKENHUYSEN (eds.), *Die ziekte in mijn familie, krijg ik die later ook? Predictieve genetische tests*, Tielt, Lannoo, 2005, 27.

²²¹ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 137, 140-141; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 517; P. CALCOEN,

is also a violation of privacy.²²² It is unfair to confront a person with such new information that is unchangeable for the rest of his/her life.²²³ It would therefore be irresponsible for insurers to be able to impose such research for their own economic purposes and thereby expose policyholders to psychological risks.²²⁴

5. Contractual freedom

In the context of non-compulsory insurance contracts, everyone is free to choose whether or not to conclude the contract.²²⁵ When the conclusion of the insurance is linked to the condition that the policyholder shares genetic information, he/she has the free choice whether or not to conclude the contract. The policyholder must decide for himself whether he/she wants to give up his/her privacy for insurance or not.²²⁶ Based on the right to self-determination, a person has the right not to be subjected to an investigation in which he/she didn't consent.²²⁷ He/she can always refuse to undergo this examination.²²⁸

The question, however, is whether there is freedom and free choice.²²⁹ The policyholder is not always in a position to refuse, as a result of which the free permission comes under pressure.²³⁰ For example, obtaining a mortgage loan is often linked to the conclusion of a life insurance. The free choice of the borrower is therefore limited. Many people are not able to buy or build a home without a loan. The choice to take out insurance or not is therefore limited: if he/she doesn't take out the insurance, he/she cannot obtain a loan.²³¹ In such cases, the policyholder will probably still provide information to close the insurance while he/she

Genetic information, private insurance and human rights, Emeritforum KU Leuven, Leuven, 29 November 2012, <https://www.kuleuven.be/emertiforum/em/Forumgesprekken/2012-2013/291112>.

²²² H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213.

²²³ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 141; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 517.

²²⁴ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 141.

²²⁵ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22-23; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 513-514.

²²⁶ B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 513-514.

²²⁷ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213.

²²⁸ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 137.

²²⁹ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 22-23; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 513-514.

²³⁰ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 213; A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 600.

²³¹ B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 513-514.

would have preferred to keep this information.²³² It is therefore often, morally or financially, mandatory to take out insurance and to give up part of his/her privacy.²³³ When pressure is exerted on the policyholder to undergo a heredity test in order to qualify for insurance, this implies a disproportionate infringement of the right to self-determination.²³⁴ A certain legislative paternalism is therefore justified to protect the policyholder, even against himself.²³⁵

6. Suspicions

If genetic data is allowed to be communicated voluntarily, certain policyholders will communicate this information and others will not. The fact that no information is shared can arouse suspicion with the insurer that there is a genetic disorder. As a result, the policyholder is then categorized in a higher risk category. This creates a domino effect: when certain policyholders decide to share their data, the others are forced to follow. The protection given by the legislation to the policyholder by the right to private life and free consent is not sufficient to provide effective protection against discriminatory practices.²³⁶

7. Consequences for relatives

Another reason why people cannot be nonchalant about the use of genetic data is the fact that this information also has an impact on people other than the policyholder. The privacy and physical integrity of third parties are also involved.²³⁷ The genes are the basis of the human body. We inherit them from our parents and transfer them to our offspring.²³⁸ A lot of genetic information is therefore the same within one family. The genetic code of a person indirectly provides information about his/her family members. There is a realistic possibility that a relative is a carrier of the same abnormal gene.²³⁹

²³² K. JACOBS, “Genetische informatie en verzekeringen”, *Recht en Kritiek* 1997, 22-23.

²³³ B. DESMET, “Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste”, *Jura Falconis* 2005-06, nr. 4, 513-514.

²³⁴ H. NYS, “Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen”, *De Verzekering* 1992, 213.

²³⁵ A. ROUVROY, “Informations génétiques et assurance. Discussion critique autour de la position “prohibitionniste” du législateur belge”, *Journal des Tribunaux* 2000, 600.

²³⁶ A. ROUVROY, “Informations génétiques et assurance. Discussion critique autour de la position “prohibitionniste” du législateur belge”, *Journal des Tribunaux* 2000, 601.

²³⁷ H. NYS, “Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen”, *De Verzekering* 1992, 214; K. JACOBS, “Verzekeringen en genetica” in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 138; S. TACK and A. DIERICKX, “Nader gebruik van lichaamsmateriaal voor wetenschappelijk onderzoek: Toelaatbaarheid getoetst vanuit het recht op respect voor het privéleven (art. 8 EVRM)”, *Tijdschrift voor Gezondheidsrecht* 2008-09, 388.

²³⁸ K. JACOBS, “Is zwijgen wel goud? Een spanningsveld tussen beroepsgeheim en recht op informatie” in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 95; B. DESMET, “Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste”, *Jura Falconis* 2005-06, nr. 4, 514; P. CALCOEN, *Genetic information, private insurance and human rights*, Emeritforum KU Leuven, Leuven, 29 November 2012, <https://www.kuleuven.be/emertiforum/em/Forumgesprekken/2012-2013/291112>.

²³⁹ K. JACOBS, “Is zwijgen wel goud? Een spanningsveld tussen beroepsgeheim en recht op informatie” in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader*

Genetic research therefore has consequences for relatives. Test results also provides information about the family members in the ascending, descending or lateral line of the patient. Their right to privacy can be threatened.²⁴⁰ Moreover, such knowledge on the part of the insurer can ensure that the relatives experience difficulties in accessing insurance.²⁴¹ However, this bias is not always correct. It is possible that a certain disease disappeared for many generations within a certain family, but suddenly reappears.²⁴²

8. Actuarial aspects

Proponents of the use of genetic information rely mainly on actuarial arguments. For example, they refer to the risk of self-selection to justify the use of genetic information. However, this argument is debatable. Genetic research indicates only exceptionally a certainty or high probability. Usually these are only predispositions.²⁴³ When a large number of persons with a predisposition take out insurance against high amounts but only a few develop the disease, this is in favor of the insurer.²⁴⁴

The danger of self-selection is more limited and needs to be qualified. Self-selection is based on the assumption that policyholders can assess their position on the market and use this information in an economically rational way. However, policyholders rarely know the market and can hardly assess their position on that market. The fact that they can calculate their actuarially correct premium is therefore unrealistic. Psychological factors also have an influence and ensure that a person doesn't behave rationally and leaves the pool when he/she thinks he/she is paying too much.²⁴⁵ Moreover, the majority of the population has no knowledge about its genetic risk profile. The danger of self-selection therefore cannot play out.²⁴⁶

In addition, there is propitious or auspicious selection. This counters the idea that good risks tend to leave the pool when the premiums rise. Those at high risk are often those who do not take out insurance and those at low risk are often risk averse and willing to pay a high

voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 95.

²⁴⁰ Report MONSET to the bill on the land insurance contract, *Parlementaire Stukken Senaat* 1991-92, nr. 306/2, 31.

²⁴¹ H. NYS, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen", *De Verzekering* 1992, 214; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 514.

²⁴² P. CRAEYNEST and M. COKELAERE, *Onze genen. Handboek menselijke erfelijkheid*, Leuven, Acco, 2007, 195.

²⁴³ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 595; J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 143-144; T. VANSWEEVELT, "Art. 61 Wet Verzekeringen" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 28-29.

²⁴⁴ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 598.

²⁴⁵ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 140.

²⁴⁶ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 141.

premium. There is therefore a negative correlation between the extent to which policyholders are risk averse and their expectation of loss.²⁴⁷

Is the release of genetic information then socially desirable? Persons with "bad genes" are disadvantaged and will probably no longer be able to take out insurance or only at a high premium. They are deprived of the opportunity to provide financial security for their family in the event of premature death. Isn't this the purpose of an insurance policy, to enable a person to financially support his/her family if he/she dies prematurely? In addition, he/she can die prematurely as a result of another illness or accident that is not related to his/her genetic disorder.²⁴⁸ Insurers often argue that they will still offer insurance but with higher premiums. The question is whether they will actually offer insurance when it concerns, for example, Huntington's disease. Insurers are not charities and want to make a profit. They will therefore not cover very bad risks.²⁴⁹

Moreover, we can wonder whether genetic information can be used as a criterion to assess risks. For the evaluation of risks no criteria may be used that are not pertinent actuarially.²⁵⁰ A "normal genome" is not an objective reality. It does not exist.²⁵¹

Insurers say their competitive position on the market is at risk if they cannot differentiate the premiums. To this end, a vicious circle could arise.²⁵² This is easily avoided when all insurers are prohibited to differentiate on the basis of genetic information.²⁵³ When no insurer can use genetic information, no one has an advantage and they are equally confronted with claims related to genetic disorders.²⁵⁴

²⁴⁷ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 140.

²⁴⁸ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 24; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 515.

²⁴⁹ B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 515.

²⁵⁰ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 595.

²⁵¹ A. ROUVROY, "Informations génétiques et assurance. Discussion critique autour de la position "prohibitionniste" du législateur belge", *Journal des Tribunaux* 2000, 600.

²⁵² D. FRERIKS, "De verzekeringswet van 25 juni 1992 en het medisch beroepsgeheim" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 33; K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 133-134; K. TROCH, "Art. 95 Wet Landverzekeringsovereenkomst" in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 55, voetnoot 5; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 509-510; E. GOESSENS, *Solidariteit en concurrentie in de private verzekering: een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 98.

²⁵³ K. JACOBS, "Genetische informatie en verzekeringen", *Recht en Kritiek* 1997, 21; B. DESMET, "Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste", *Jura Falconis* 2005-06, nr. 4, 510.

²⁵⁴ K. JACOBS, "Verzekeringen en genetica" in E. GULDIX, J. STUY and K. JACOBS, *Het gebruik van genetische informatie: het ethisch en juridisch kader voor het maatschappelijk gebruik van geïndividualiseerde genetische informatie*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 134.

As was mentioned under question 18, self-determination is also one of the objections against the collection and use of genetic information.

How do employers in your jurisdiction justify collecting genetic information as part of the recruitment process?

In order to defend the use of predictive genetic research within the framework of labor relations, the protection of the health and safety of the employees concerned is cited. A similar argument is sometimes used in companies, in order to justify some examinations, that they want to protect the employee against possible specific reactions to dangerous products.²⁵⁵

What are the main objections?

Genetic testing in labor context is ethically unacceptable. It is impossible to determine based on predictive genetic research whether an employee meets the required conditions for a particular job. The tests cannot determine with certainty the risk that an employee will contract a disease during his/her career.²⁵⁶ The scientific value is not yet proven. The discovery of a damaged gene does not necessarily mean that that person will get a certain disease at an age when he/she is otherwise still able to work.²⁵⁷ In view of this and the potentially important consequences for the employee's life, a prohibition is designated.²⁵⁸ It is unacceptable that on the basis of often uncertain tests, whose quality of predictability has not yet been scientifically proven, someone is refused a job or promotion. If the employee performs the job well or is suitable for a position, he/she must be able to exercise it, regardless of all kinds of predictive tests.²⁵⁹

These practices would result in people being excluded from the labor market without taking into account the actual suitability of the worker for the job for which he/she is applying. This would be based on analyzes whose predictive value is usually statistical and not individual in nature, without taking into account current or future treatment of any predicted disease. It would also ignore the adaptability of employees when they get a disease in their further professional career.²⁶⁰

The conducting of genetic tests also provides an instrumentalisation of the employees: employees are not instruments but people.²⁶¹

The prohibition will combat discrimination in employment based on the health status of the employee. The “weaker” are protected by law.²⁶²

²⁵⁵ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken* Senaat 2002-03, 2-20/1, 2.

²⁵⁶ *Handelingen* Senaat 2002-03, 14 November 2002, nr. 2-241, 27.

²⁵⁷ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken* Senaat 2002-03, 2-20/1, 2.

²⁵⁸ Report DE ROECK and VAN RIET to the bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken* Senaat 2002-03, 2-20/4, 11.

²⁵⁹ *Handelingen* Senaat 2002-03, 14 November 2002, nr. 2-241, 29.

²⁶⁰ Report to the bill concerning medical examinations that are carried out within the framework of industrial relations, *Parlementaire Stukken* Kamer 2002-03, 2133/002, 3.

²⁶¹ *Handelingen* Senaat 2002-03, 14 November 2002, nr. 2-241, 27.

²⁶² Report to the bill concerning medical examinations that are carried out within the framework of industrial relations, *Parlementaire Stukken* Kamer 2002-03, 2133/002, 5.

The health data of the employee are strictly personal and it is not appropriate for the employer to have access to it.²⁶³

Employees have the right not to be informed. The employer may not have more information than the individual concerned. Therefore, all tests that are not related to the skills of the person concerned should be prohibited.²⁶⁴ It is unacceptable that an employer is given the right to be informed, especially if the employee does not wish to make this information known or does not want to know himself. Privacy is necessary, especially in terms of health and the future, especially for the employee in question.²⁶⁵

In addition, the psychological risk must be taken into account: knowing that illnesses can occur in later life can lead to a loss of independence, to a change in the individuality development of the individual.²⁶⁶

20. Are insurers specifically allowed to ask questions about an applicant's genetic status, or to require genetic testing prior to granting insurance coverage? Please, specify the conditions and clarify the moment at which this information may be requested. What are the sanctions for contravening these rules? If you have relevant data, please indicate whether the regulatory framework yields high compliance.

During the recruitment process, are employers specifically permitted to ask questions of job applicants regarding their genetic status, or to require genetic testing prior to employment? Please specify the conditions (e.g. specific safety-sensitive jobs) and clarify the moment during the hiring process at which this information may be requested (e.g. only after an offer of employment has been made conditional on successfully passing a medical examination?).

Since the absolute prohibitions, insurers and employers are in no way allowed to ask questions about an applicant's genetic status or to require genetic testing prior to granting insurance coverage or employment. In the context of the Medical Examination Act of 2003 there is still no Royal Decree that sets out exceptions that allow to carry out genetic tests or AIDS tests in an employment context.²⁶⁷

21. Where genetic testing is permitted for insurance purposes, including employer-provided insurance, does your regulatory framework distinguish between a) The nature of insurance to be underwritten b) The monetary value to be insured, c) The kind of testing/result (e.g. predictive versus diagnostic) d) The type of uses considered appropriate for information derived from the genetic testing (e.g., in insurance: assessing rates/caps; excluding some conditions/rejecting coverage)

Not applicable.

²⁶³ Report to the bill concerning medical examinations that are carried out within the framework of industrial relations, *Parlementaire Stukken Kamer* 2002-03, 2133/002, 5.

²⁶⁴ Report DE ROECK and VAN RIET to the bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken Senaat* 2002-03, 2-20/4, 3.

²⁶⁵ *Handelingen Senaat* 2002-03, 14 November 2002, nr. 2-241, 29.

²⁶⁶ Bill concerning the medical examinations that are carried out within the framework of labor relations, *Parlementaire Stukken Senaat* 2002-03, 2-20/1, 2.

²⁶⁷ W. VAN EECKHOUTTE, *Sociaal Compendium Arbeidsrecht met fiscale notities 2017-18, Band 1*, Malines, Kluwer, 2017, 494.

22. *Where an insurer is allowed by law to use genetic testing, is retention of the samples after the insurance-related decision has been made permitted? If so, for how long can the samples be kept? Is the insurer permitted to undertake further, future testing (in case tests for new conditions are developed for instance)?*

Where an employer is permitted by law to undertake genetic testing as part of the recruitment process, can the samples be retained by the testing agency (e.g. medical intermediary) after the hiring decision has been made? If so, for how long can the samples be kept? Is the employer permitted to undertake further, future testing (in case tests for new conditions are developed for instance)?

Not applicable.

23. *Where the law permits an insurer or employer to require genetic testing, does the insurer or employer have any obligations to manage the psychosocial risks to the person associated with the testing, or learning the results of the testing (e.g. psychological harm; disclosure of facts about close family relationships, such as non-paternity; stigmatization; intra-family conflict...)?*

Not applicable.

Rights and obligations of the insurer in relation to a job applicant, the insured employee, and close family members

24. *Does your jurisdiction require voluntary disclosure on the part of an insurance applicant where results of DNA testing are contained within their existing medical records? If such an obligation exists, is it imposed only at the application stage?*

Does your jurisdiction require disclosure of genetic information or any prior genetic testing by the job applicant to a potential employer?

Since the prohibition in art. 61 Insurance Act 2014 is absolute, the insurance applicant is not required nor allowed to disclose results of DNA testing. By determining that genetic data cannot be communicated, the legislature gave the insurance applicant a possibility to conceal the possibility that he/she is a carrier of a defective gene.²⁶⁸ Not being allowed to share information also means that the information should not be shared.²⁶⁹ There is therefore not only a right but also a duty to withhold this information.²⁷⁰

The same applies for job applicants. Since there are no exceptions that allow genetic tests or AIDS tests to be carried out in an employment context, job applicants are not required to disclose genetic information.

²⁶⁸ K. JACOBS, “Genetische informatie en verzekeringen”, *Recht en Kritiek* 1997, 31; T. VANSWEEVELT, “Art. 61 Wet Verzekeringen” in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 28-29.

²⁶⁹ H. NYS and K. VERSCHUEREN, *De toepassing van genetica. Rechtsbescherming bij de toepassing van genetica in en buiten de gezondheidszorg*, Brussels, Federale Diensten voor Wetenschappelijke, Technische en Culturele Aangelegenheden, 1994, 96; T. VANSWEEVELT and B. WEYTS, “Medische informatie” in T. VANSWEEVELT and B. WEYTS, *Handboek Verzekeringsrecht*, Antwerp, Intersentia, 2016, 425

²⁷⁰ E. GOESSENS, *Solidariteit en concurrentie in de private verzekering : een juridische en beleidsmatige analyse van hun rol, methodes en begrenzing*, Dissertation, Leuven, 2016, 106.

25. What are the consequences of failing to disclose the results of prior genetic testing or other genetic information?

If a job applicant refuses or fails to disclose past genetic testing to an employer, is the employee liable to disciplinary measures including potentially the termination of employment (e.g. for “dishonesty”)?

The insurance applicant cannot be sanctioned for this concealment. When there is a prohibition to communicate data, there can be no question of concealment or fraud.²⁷¹ The same applies to the job applicant.

Conclusion

26. Do you consider that the risks and benefits associated with genetic testing in the insurance and employment context are currently appropriately distributed through your jurisdiction’s regulatory framework?

The current regulatory framework in Belgium offers the most comprehensive protection for the consumer. Employers and insurers are in no way allowed to ask about genetic data or to require genetic testing prior to granting insurance coverage or employment.

The legislature wants to offer maximum protection.²⁷² The absolute prohibition is *de facto* an acceptance obligation for the insurer with regard to genetic data.²⁷³ As a result of this prohibition, genetic information has been placed outside the market.²⁷⁴ In this way Belgium has something close to comprehensive legislation for the protection of consumers against the misuse of genetic information.²⁷⁵

However there are some fundamental critiques.²⁷⁶ The current regulations should be analyzed and evaluated to see if the existing regime is still the most appropriate solution, and to see if the risks and benefits associated with genetic testing could be more appropriately addressed.

²⁷¹ D. WUYTS, *Verzekeringsfraude*, Antwerp, Intersentia, 2014, 318; T. VANSWEEVELT, “Art. 61 Wet Verzekeringen” in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 28-29.

²⁷² N. JEGER en P. CAUWENBERGH, “Individuele levensverzekeringen “overlijden” en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst”, *Tijdschrift voor Gezondheidsrecht*. 1996-97, 241-242; B. DESMET, “Genetisch onderzoek en verzekeringen. De wet van de (genetisch) sterkste”, *Jura Falconis* 2005-06, nr. 4, 528.

²⁷³ K. TROCH, “Art. 95 Wet Landverzekeringsovereenkomst” in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2003, afl. 8, 53-54.

²⁷⁴ A. ROUVROY, “Informations génétiques et assurance. Discussion critique autour de la position “prohibitionniste” du législateur belge”, *Journal des Tribunaux* 2000, 593-594.

²⁷⁵ J. REMANS, *De boom van goed en kwaad*, Leuven, Acco, 2005, 156.

²⁷⁶ H. NYS, “Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen”, *De Verzekering* 1992, 209-219; N. JEGER en P. CAUWENBERGH, “Individuele levensverzekeringen “overlijden” en erfelijkheidsonderzoek: een kritische analyse van de artikelen 5 en 95 van de wet van 25 juni 1992 op de landverzekeringsovereenkomst”, *Tijdschrift voor Gezondheidsrecht* 1996-97, 239-256; K. JACOBS, “Genetische informatie en verzekeringen”, *Recht en Kritiek* 1997, 32; A. ROUVROY, “Informations génétiques et assurance. Discussion critique autour de la position ‘prohibitionniste’ du législateur belge”, *Journal des Tribunaux* 2000, 585-603; J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 143; T. VANSWEEVELT, “Art. 61 Wet Verzekeringen” in *Verzekeringen: artikelsgewijze commentaar met overzicht van rechtspraak en rechtsleer*, 2015, Afl. 18, 29; M. FONTAINE, *Droit des assurances*, Brussels, Larcier, 2016, 211-212.

27. *What if any recommendations would you formulate address genetic testing in insurance and employment context in an equitable and efficient manner?*

As noted above, some criticisms should be addressed. For instance, definitions are important to define the scope of the regulation - but current definitions are insufficient. To make appropriate recommendations, a complete evaluation is needed. Belgium could, for example, consider whether regulations similar to those in The Netherlands would be more appropriate to achieve a more equitable and efficient regulation.

A general regulation on the use of genetic research and testing would be useful, especially to ensure that the protection of genetic data is addressed in an equitable and efficient manner. This would also enable adequate protection in the context of insurance and employment.

28. *Is there a fruitful role for transnational, including international, action in the governance of genetic testing in insurance and employment?*

Transnational, European and international action is very important in this context. The Council of Europe's Committee on Bioethics is already actively working on the subject of genetic testing. Recently, it published a recommendation on the processing of personal health-related data for insurance purposes. This included data resulting from genetic tests, and states that insurers are not allowed to use genetic data in the context of insurance contracts.²⁷⁷ The Oviedo Convention is also an important instrument to guide member states. However, Belgium has not (...) signed the convention.

29. *Are there other themes or issues of central importance to your jurisdiction that were not covered by this questionnaire?*

In Belgium, lack of enforcement is a problem in the area of genetic testing in an insurance context. In the context of employment, there are criminal sanctions. In the context of insurance, there are no sanctions when the prohibition is violated.²⁷⁸ There is therefore incomplete protection against abuse. It is only at a corporate level that the insurance company can be sanctioned by the inspection body FSMA (Financial Services and Markets Authority).²⁷⁹ Otherwise, the legislation does not set out any sanction of any kind. We could ask ourselves how we can prevent the insurer from using genetic data. When, for example, a policyholder passes on a favorable result, how can the insurance company be prevented from granting a premium reduction?²⁸⁰

²⁷⁷ Recommendation CM/Rec (2016)8 of the Committee of Ministers to the member States on the processing of personal health-related data for insurance purposes, including data resulting from genetic tests, 26 October 2016.

²⁷⁸ R. DEBERDT, "Het medisch beroepsgeheim en de orde van de geneesheren" in J. VAN STEENBERGE (ed.), *Medisch beroepsgeheim en verzekeringen*, Bruges, Die keure, 1994, 82.

²⁷⁹ D. WUYTS, *Verzekeringsfraude*, Antwerp, Intersentia, 2014, 319-320.

²⁸⁰ J.L. FAGNART, *Droit privé des assurances terrestres: principes généraux*, Waterloo, Kluwer, 2011, 145-146.