

Stellungnahme zur öffentlichen Anhörung am 16. Oktober 2000  
"Folgen der genetischen Diagnostik"

## **Genetics, Data Protection and Non-Discrimination;**

### **Some Reflections from an International (Human Rights) Law Perspective**

Position Paper prepared for the Public Hearing of the  
Study Commission on the Law and Ethics of Modern Medicine on  
'Consequences of Genetic Diagnostic'

Berlin, 16 October 2000

Aart C. Hendriks, LL.M., M.Pol.Sc., Ph.D.  
Health Research and Development Council (ZON)  
PO Box 84 129  
NL-2508 AC The Hague  
The Netherlands  
tel. + 31. 70. 306 8205  
fax: + 31. 70. 306 8207  
e-mail: aart.hendriks@zon.nl

# Genetics, Data Protection and Non-Discrimination; Some Reflections from and International (Human Rights) Law Perspective

Aart C. Hendriks<sup>\*</sup>

*The more you know, the more you have doubts*  
Johann W. Goethe (1749-1832)

## 1 Introduction

Thanks to progress in the field of human genetics we now know that many – if not most – human traits and features are intrinsically interrelated with one's hereditary composition. Genetic information is increasingly collected and used for all kind of health-related purposes.<sup>1</sup> While potentially valuable for diagnosis, early intervention and medical treatment, it is also known that the collection and use of genetic information can pose a threat to the exercise and enjoyment of human rights, particularly when this information is collected and used for non-clinical purposes. In this respect, many commentators seem to be particularly concerned about the (*ab*)use of genetic information in the labour and insurance market.<sup>2</sup>

Although the collection and use of genetic information outside the clinical setting is still limited, there is strong evidence to believe that the advances in genetic research will sooner or later result in more comprehensive data collection systems and the selection of individuals on the basis of genetic traits, notably as a result of affordable and more pervasive testing. This raises the question how society, and notably States, should respond to this human rights challenge.

Before embarking on this question it should be recalled that there is clear evidence that heredity is not equivalent to destiny, particularly not since the expression of genes generally requires significant input from the environment. This calls into question the appropriateness, validity and, last but not least, legitimacy of genetic traits as (co-)determinants in decision-making processes, with the legitimacy being dependent on such factors as relevance, necessity and proportionality.

This paper confines itself to examining the meaning of two crucially important human rights applicable to the collection and use of genetic information, being the right to privacy – which includes the entitlement to data protection and the corresponding duty for the State to introduce appropriate safeguards<sup>3</sup> – and the right not to be discriminated against. Some

---

<sup>\*</sup> Aart C. Hendriks, LL.M., M.Pol.Sc., Ph.D. is secretary of the programme on health law evaluation, Health Research and Development Council (ZON), The Hague, The Netherlands.

<sup>1</sup> Cf. O.M. Arnardóttir, D.T. Björgvinsson & V.M. Matthíasson, 'The Icelandic Health Sector Database', *European Journal of Health Law* 1999, p. 307-362.

<sup>2</sup> M.A. Rothstein & B.M. Knoppers, 'Legal Aspects of Genetics, Work and Insurance in North America and Europe', *European Journal of Health Law* 1996, p. 143-161 and A. Hendriks, 'Genetics, Human Rights and Employment. American and European Perspectives', *Medicine and Law* 1997, p. 557-565.

<sup>3</sup> More extensively F.W. Hondius, 'Protecting Medical and Genetic Data', *European Journal of Health Law* 1997, p. 361-388.

current privacy and non-discrimination aspects will be – though necessarily brief – discussed.

## 2 Genetic information

As a result of progress in medical research we are now able to involve medical and genetic information<sup>4</sup> in all kind of decisions, both within and outside the clinical setting. This information can, for example, be used as evidence in criminal investigations, to assist prospective parents with respect to procreational decisions and serve as a tool for employers and insurers to make risk assessment and exclude ‘bad risks’ before entering into a contractual relation with a job or insurance applicant.

### 2.1 *How to obtain genetic information*

There are, generally speaking, four ways of obtaining genetic information from an individual:

1. Performing a genetic test;
2. Requiring an individual to release all of his or her medical records. This can, for example, be done by requesting an individual to complete medical history forms and/or by relying on the duty to disclose;
3. Using medical and genetic information that is already available, for example by studying health insurance claims; and
4. Using medical and genetic information that is otherwise available, for example by studying the prevalence of genetic diseases in a given family.

In the absence of codes of conduct and other private arrangements, individuals largely depend on the law to protect them against the improper collection and use of such information. The (any) law seeking to regulate this domain should therefore address all four methods of ‘data collection’.

### 2.2 *Treating genetic information the same or separately?*

Different from ‘conventional’ medical information, genetic information is – mostly – not purely individual but also contains information about – and may have repercussions for – the individual's relatives. This raises the question whether the collection and use of genetic information should be regulated separately from the use of conventional medical information. From a medical perspective it seems difficult to draw a sharp line of distinction between genetic and non-genetic information. Still, many scholars believe that there are good reasons to treat genetic information differently. The reason to distinguish between genetic and non-genetic medical information has to do with their different social consequences.<sup>5</sup> Personally I find it hard to believe that the difference in social consequences would imply that genetic information should be subjected to a separate legal regime. It seems, at least in my view, more logical to make the scope and type of legal protection dependent on such factors as the availability of information, the (predictive) value of the information and the degree to which the collection and use of such information is prone to abuse. There are no reasons to believe that individuals would only need protection against infringements of their rights as a result of the collection and abuse of genetic information. Or, as Bartha Knoppers has pointed out, the

---

<sup>4</sup> Medical information is generally used as a generic term covering genetic information. Cf. Article 1 of Recommendation No. R (97) 5 of the Committee of Ministers of the Council of Europe on the Protection of Medical Data: ‘The expression “medical information” refers to all personal data concerning the health of an individual. It refers also to data which have a clear and close link with health as well as genetic information.’

<sup>5</sup> M.A. Rothstein & B.M. Knoppers, ‘Legal Aspects of Genetics, Work and Insurance in North America and Europe’, *European Journal of Health Law* 1996, p. 143-161, 155.

formulation of a genetic-specific approach entails the risk of inefficiency and, in addition, is likely to be unable to distinguish between genetic risk of predisposition, carrier status and disease status. Even though Knoppers concedes that a genetic-specific approach may adequately respond to some immediate problems, she does not believe that this approach embodies a long term solution.<sup>6</sup>

Yet in many countries, as well as in a number of international organisations, there appears to be a trend to disassociate genetic information from other types of medical data. In this respect, reference can be made to Austria (Act on Gene Technology), Belgium (Law on Insurance Contracts) and France (Bioethics Law). Reference should also be made to the European Convention on Human Rights and Biomedicine (Biomedicine Convention), which contains a special provision on predictive genetic tests:

‘Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.’

A different – and in my view correct<sup>7</sup> – approach has been adopted by the Netherlands.<sup>8</sup> In this country, genetic information is perceived as just one form of medical information, which only sometimes justifies a different treatment regime. This is, for example, reflected in the Medical Examinations Act, a law which restricts the use of pre-employment and pre-insurance medical examinations.

### 2.3 *The role of medical professionals*

It should be noted here that most public and private bodies are not themselves in a position to use and interpret genetic information, due to a lack of specific knowledge and professional training. They commonly heavily rely on the expertise and advice of medical professionals, that is to say persons who, by training and profession, are qualified and entitled<sup>9</sup> to carry out genetic tests and/or to interpret genetic information. The law and medical ethics are generally very critical about the role of medical professionals acting on behalf of a ‘third party’, particularly when ‘sensitive’ information – such as genetic information – is being used to interfere with the individual’s right to self-determination or to deny individuals access to essential means of societal participation, such as employment, housing and health care (insurance).<sup>10</sup>

The threats the improper collection and use of genetic (and medical) information pose to the exercise and enjoyment of human rights may require States to take all appropriate measures – including the adoption of legislative and administrative measures – to guarantee that the uni-

---

6 B.M. Knoppers, ‘Confidentiality in Genetic Testing: Legal and Ethical Issues in an International Context’, *Medicine and Law* 1993, p. 573-582, 578.

7 I realise that this may sound utterly nationalistic.

8 Dutch Health Council, *Heredity and Society*, The Hague, 1989 (report no. 89/31).

9 Article 3.2 of Recommendation No. R (97) 5 of the Committee of Ministers of the Council of Europe on the Protection of Medical Data: ‘In principle, medical data should be collected and processed only by health care professionals, or by individuals and bodies working on behalf of health-care professionals. ...’

10 A.C. Hendriks & J.K.M. Gevers, ‘(Pre-)employment medical examinations and the law, with particular reference to the European Union’, *European Journal of Health Law* 1994, p. 229-264.

versal values, embodied in the corpus of human rights law, be adequately protected and promoted. Two of these rights will be looked into in greater detail below.

#### **4 Privacy**

The right to privacy is a fundamental human right, solidly embedded in international human rights law as well as in national constitutions, legislation and jurisprudence. Although it is difficult to give a precise definition to the term ‘privacy’ this right is generally understood as the entitlement of individuals to live their own lives free from outside intrusion. As such, this right offers protection against the arbitrary or unlawful ‘disclosure and improper discovery by third parties of facts relating to physical conditions, health or personality.’

The right to privacy is implicated whenever an individual’s personal decision-making and integrity are at stake. This right is covered by a number of international human rights instruments, including the Universal Declaration of Human Rights (UDHR),<sup>11</sup> the International Covenant on Civil and Political Rights (CCPR)<sup>12</sup> and the Convention on the Rights of the Child (CRC),<sup>13</sup> and, on a regional level, the European Convention on Human Rights (ECHR)<sup>14</sup> and the American Convention on Human Rights (ACHR).<sup>15</sup> In addition, the right to privacy figures prominently in the Biomedicine Convention,<sup>16</sup> a new treaty which seeks to complement the ECHR in an effort to protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.<sup>17</sup>

Efforts have also been made to design international legal standards exclusively geared to the protection of particular aspects of privacy, such as the European Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Data

---

11 Article 12: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to protection of law against such interferences or attacks.

12 Article 17: 1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

2. Everyone has the right to the protection of the law against such interference or attacks.

13 Article 16, para. 1: No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honor and reputation.

14 Article 8: 1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others.

15 Article 11: 1. Everyone has the right to have his honor respected and his dignity recognized.

2. No one may be the object of arbitrary or abusive interference with his private life, his family, his home, or his correspondence, or of unlawful attacks on his honor or reputation.

3. Everyone has the right to the protection of the law against such interference or attacks.

16 Article 10 (Private life and right to information).

1. Everyone has the right to respect for private life in relation to information about his or her health.

2. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.

17 Cf. H.D.C. Roscam Abbing, ‘The Convention on Human Rights and Biomedicine: An Appraisal of the Council of Europe Convention’, *European Journal of Health Law* 1998, p. 377-387.

Protection Convention) and Directive 95/46/EC of the EC on the Protection of Individuals with regard to the Processing of Personal Data and on the Free Movement of such Data.<sup>18</sup>

Reference should be made here to the human rights literature, where it has been argued that the zones of freedom covered by the term privacy can be subdivided into *physical* and *informational* zones of privacy. The physical zone encompasses respect for a person's physical integrity, home and correspondence, whereas informational privacy entails protection against the unauthorised collection, storage, use and disclosure of personal information. This distinction, which was originally developed by Westin<sup>19</sup> and which was subsequently recognised by the German Constitutional Court<sup>20</sup> and other national and international (quasi-)judicial bodies, is of great importance.

Respect for the right to informational self-determination brings us to the issue of data protection, including the protection of genetic data. The key issue of data protection is to establish safeguards against possible abuse of personal (and genetic) information by others. Louis Joinet, who was appointed as UN Special Rapporteur on data protection, originally suggested that data likely to be abused should not be gathered at all, or – at least – that human rights standards should apply in full:

“[D]ata likely to give rise to unlawful or arbitrary discrimination, especially information on racial or ethnic origin, colour, sex life, political opinions, religious, political or other beliefs ... should not be compiled ... [or] only within limits prescribed by the International Bill of Human Rights and the other relevant instruments in the field of protection of human rights and prevention of discrimination.”<sup>21</sup>

Concern about the unauthorised collection and storage of personal data by public authorities impelled the Council of Europe to create special safeguards. According to the Council of Europe, health related data – which would include genetic information – ought not to be collected, or collected only for restricted purposes, because they are ‘as such likely to lead to encroachments on individual rights and interests.’<sup>22</sup> Therefore the before-mentioned Data Protection Convention contains a special provision, Article 6, stating that:

‘Personal data revealing racial origin, political opinions or religious or other beliefs, as well as personal data concerning *health* or sexual life, may not be processed automatically unless domestic law provides appropriate safeguards. The same shall apply to personal data relating to criminal convictions’ (emphasis added).

More recently, the Committee of Ministers of the Council of Europe adopted

---

<sup>18</sup> According to this Directive, EU Member States are obliged to bring into force legislation to comply with this Directive at the latest at 24 October 1998. Only a minority of the Member States (Denmark, Greece, Italy, Portugal and Sweden) kept this deadline.

<sup>19</sup> A.F. Westin, *Privacy and Freedom*, London: The Dodly Head 1970.

<sup>20</sup> Judgment of the German Constitutional Court (*Bundesverfassungsgericht*) of 15 December 1983, 1 BvR 209/83, *NJW* 1984, 419.

<sup>21</sup> L. Joinet, *Study of the relevant guidelines in the field of computerized personal files*, Final report by the special rapporteur, UN Doc. E/CN.4/Sub.2/1983/18 (30 June 1983).

<sup>22</sup> Explanatory report on the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data, Council of Europe, Strasbourg, 1981, para. 43.

Recommendation No. R (97) 5 on the Protection of Medical Data. Article 4.9 of this recommendation provides that for reasons other than health protection, health care, judicial procedures and criminal investigations, the processing of genetic data should only be permitted in cases of overriding interest and subject to appropriate safeguards defined by law.

It follows that the collection and use of genetic (and, in general, medical) information is only permitted once special requirements are met and in case of adequate safeguards against abuse. In fact, it is increasingly recognised that the data subject (a person whose data are being collected) must be in a position to learn of the existence of a data collecting system and, in case data from him or her are indeed being collected, must be given accurate and full information and access to the data relating to him or her, and the right to verify the accuracy with a view to, if necessary, to rectify, erase or block the data collecting process.

As mentioned before, genetic information is not only obtained by performing genetic tests or by other ways of actively collecting data, but may also be revealed ‘spontaneously’, notably as a result of the duty to disclose. There is, however, no consensus on the issue to what extent and under what conditions individuals are required to release genetic information. Non-disclosure of already available genetic information can lead to anti-selection in, for example, the underwriting of insurance contracts and runs counter to the idea of symmetry of information. A broad interpretation of this duty undermines, however, the protection offered by the right to privacy and is at odds with efforts to curb genetic testing as a precondition for access to societal goods. A broad interpretation of the duty to disclose may also deter individuals from seeking early medical advice,<sup>23</sup> and therefore runs counter to the aspirations enshrined in the right to health.

Here it should be noted that the duty to disclose only refers to *relevant* information. Given the many uncertainties that are associated with most forms of genetic information it seems that the criterion ‘relevant’ is to be interpreted narrowly. There are good arguments to believe that the right to privacy entails safeguards against the unnecessary or otherwise unjustified disclosure of genetic and medical information. There is only a duty to disclose such information when an individual knows or could reasonably understand that the other party would obviously need such information to form a well-reasoned opinion on the terms of a possible contract.<sup>24</sup> The right to privacy thus seeks to protect individuals against overrating the scope of the duty to disclose.

## 5 Non-discrimination

The principle of non-discrimination is to a certain extent the corollary of equality. Non-discrimination reflects the idea that no one should be subjected to unfair or less favourable treatment because of personal characteristics which, in the given context, are irrelevant.

Non-discrimination law is particularly concerned with redressing structural disadvantage and counterbalancing the underlying power inequalities in society, as a result of which people with some personal characteristics – such as an ‘unfavourable’ genetic constitution – encounter more difficulties in enjoying equal rights and opportunities than others.

---

<sup>23</sup> Nuffield Council on Bioethics, *Genetic Screening – Ethical Issues*, London: Nuffield Council of Bioethics, December 1993.

<sup>24</sup> Cf. CoJ EC 13 October 1993, *CMC Motorradcenter GmbH v. Pelin Baskiciogullari*, case C-93/92.

The right not to be discriminated against constitutes a fundamental human right and is laid down in various human rights documents, including the UDHR,<sup>25</sup> the ICCPR,<sup>26</sup> the ICESCR,<sup>27</sup> and, on a regional level, the ECHR,<sup>28</sup> the revised European Social Charter (ESH)<sup>29</sup> the ACHPR<sup>30</sup>, the ACHR<sup>31</sup> and the Inter-American Economic Rights Protocol.<sup>32</sup> Here special reference should be made to the Biomedicine Convention. According to Article 11

‘Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.’

So far, the Biomedicine Convention is the only international treaty explicitly referring to genetic heritage as a ground for non-discrimination.

---

25 Article 2: Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Furthermore, no distinction shall be made on the basis of political, jurisprudential or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation or sovereignty.

Article 7: All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection without discrimination in violation of this Declaration and against any incitement to such discrimination.

26 Article 2 para. 1: Each State Party to the present Covenant undertakes to respect and ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Article 26: All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, property, birth or other status.

27 Article 2 para 2.: The States Parties to the present Covenant undertakes to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

28 Article 14: The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

29 Article E: The enjoyment of the rights set forth in this Charter shall be secured without discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national extraction or social origin, health, association with a national minority, birth or other status.

30 Article 2: Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status.

Article 18 para 3: The State shall ensure the elimination of every discrimination against women and also ensure the protection of the rights of the woman and the right as stipulated in the international declarations and conventions.

Article 28: Every individual shall have the duty to respect and consider his fellow beings without discrimination, and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance.

31 Article 1 para. 1: The States Parties to this Convention undertake to respect the rights and freedoms recognized herein and to ensure to all persons subject to their jurisdiction the free and full exercise of those rights and freedoms, without discrimination for reasons of race, colour, sex, language, religion, political or other opinion, national or social origin, economic status, birth or any other social condition.

32 Article 3: The States Parties to this Protocol undertake to guarantee the exercise of the rights set forth herein without discrimination of any kind for reasons related to race, color, sex, language, religion, political or other opinions, national or social origin, economic status, birth or any other condition.



Even though the term discrimination is derived from *discriminare*, meaning treating differently, discrimination is to be distinguished from differentiation. Differentiation does not automatically lead to discrimination. Differentiation – or the failure to differentiate<sup>33</sup> – only constitutes discrimination in the absence of an objective and reasonable justification. In fact, with respect to medical and genetic information there are many instances where differentiation is required to obtain equal opportunities. Treating healthy and ill people the same would be as discriminatory as refusing access to ill people. It is therefore important that the prohibition to discriminate is not merely interpreted formally, but substantively (meaning that attention should also be paid to the outcome of a treatment and the promotion of equal opportunities).

The latter does not imply that there is no need, or that it would be impossible, to offer adequate protection against discrimination on grounds of genetic heritage or health. To the contrary. As noted before, there is growing evidence that people increasingly run the risk of unjustifiably facing exclusion and a denial of equal opportunities because of their health or genetic traits, a risk the law should offer protection against.

This leaves us with the question whether it is really necessary to include medical or genetic information (or, as in the Biomedicine Convention, genetic heritage) as an explicitly mentioned forbidden ground for discrimination. One might argue that these grounds are already covered by non-discrimination instruments containing a non-exhaustive list of prohibitive grounds for discriminations. From studying the case law under these instruments it follows, however, that these provisions do not necessarily offer the required level of protection against genetic and health discrimination. These instruments typically contain a – seemingly illustrative – non-exhaustive list of forbidden grounds for discrimination supplemented by the open-ended criterion ‘or other status’.<sup>34</sup> Now that medical or genetic information is usually not listed in these instruments, protection against genetic discrimination is dependent on the way courts and (quasi-)judicial bodies interpret and apply the criterion ‘other status’. From their case law it becomes clear that courts and (quasi-)judicial bodies make a sharp distinction between listed grounds on the one hand and non-listed on the other. Listed grounds are assumed to correspond with suspect classifications, that is to say classifications which immediately raise the suspicion of discrimination. This implies that it commonly suffices for a plaintiff to deliver *prima facie* proof of discrimination after which the court will shift the *onus* of proof on the defendant. In case of a discrimination complaint based on a non-listed ground,<sup>35</sup> courts and (quasi-)judicial bodies commonly require the plaintiff to deliver all proof and tend to apply a very aloof scrutiny test, leaving a large margin of appreciation for the defendant to decide what constitutes justified differentiation. In these cases the plaintiff has to prove that the distinction made by the defendant did not serve a legitimate goal, that the relationship between the goal and the means was disproportionate or that the differentiation was otherwise unreasonable, and that the differentiation did not fall within the margin of appreciation of the defendant. It is only in

---

33 ECHR 6 April 2000, *Thlimmenos*, not published yet.

34 See e.g. Article 2 UDHR; Article 2 § 2 ICESCR; Articles 2 and 26 ICCPR; Article 14 ECHR; Article 2 ACHPR and Protocol No. 12 to the ECHR.

35 Courts and (quasi-)judicial bodies in charge of the supervision of non-discrimination treaties and provisions usually require plaintiffs to indicate on which ground they allegedly have been discriminated against. Not all grounds are recognised as deserving protection against discrimination. Cf. *Debrecezeny v. The Netherlands*, 1995.

exceptional cases that these discrimination complaints yield success in court.<sup>36</sup>

The conclusion is, that the protection non-discrimination law offers to genetic discrimination is to a large extent dependent on the substantive way non-discrimination provisions are interpreted and the explicit recognition of health and/or genetic traits as an enumerated prohibitive ground for discrimination. There are therefore good reasons to include these grounds in future non-discrimination instruments, both on the national and international level.

## 6 Conclusions

In many countries the typical response to potential human rights violations is to prohibit certain practices. Confronted with the challenges posed by the collection and use of genetic information, many countries have indeed responded in this ‘repressive’ way. This can be illustrated by looking at the way countries responded to the treat of genetic testing to access to insurances. Some countries, like Austria and Norway, have imposed a ban on genetic testing in the context of insurance. In other countries, like Belgium and France, the legislature has decided to restrict the insurer's possibility of obtaining and using previous test results. Still in other countries, like the Netherlands, the law restricts the insurer's possibility of collecting and using genetic data which is already known without genetic testing (e.g. through family anamnesis).

This paper has demonstrated, however, that the collection and use of genetic information is not necessarily illegitimate. The law should, however, offer adequate protection against all forms of collection and use which do not meet the (strict) criteria of relevance, necessity and proportionality. It appears that privacy and non-discrimination laws can complement each other in this field.<sup>37</sup>

---

<sup>36</sup> In some cases, however, courts consider a non-listed ground to be part of a listed ground. Cf. Broeks v. the Netherlands, 1987 (differentiation on the basis of breadwinnership constitutes discrimination on the basis of sex), Dekker v. Stichting Vormingscentrum voor Jong Volwassen Plus, 1990 (differentiation on pregnancy constitutes discrimination on the basis of sex) and Toonen v. Australia, 1994 (differentiation on the basis of sexual orientation constitutes discrimination on the basis of sex).

<sup>37</sup> This comprehensive approach also underlies the ‘Medical Examinations Preceding Employment and/or Private Insurance: A Proposal for European Guidelines’ Report of a Committee of Experts, Council of Europe (1999), *European Journal of Health Law* 2000, p. 147-172.