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THE POWER OF ‘NEVER AGAIN’**

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The International Law of Genetic Discrimination:

The Power of ‘Never Again’

Iulia Voina Motoc

The goal of this essay is to offer an approach to genetic discrimination based on international law.¹ Many studies have been written on the topic of genetic discrimination, either from a comparative law perspective or from a utilitarian perspective of medical research development. Others have tackled the problem from the perspective of social justice.² Although all of these contain elements of international law, they do not provide a comprehensive overview: hence the need for this study.³

The relationship between new technologies and the protection of human rights is complicated. In part, this is because history shapes that relationship: the legal regime of genetic discrimination is influenced by the history of genetic discrimination, specifically its use during the genocide and crimes against humanity during World War II. More controversially, it might also be argued that this history is also the reason why the legal regime relating to genetic discrimination should be analysed more thoroughly than other types of discrimination that may arise from other uses of technology.

Perhaps this can be put another way: imagine if the science underpinning eugenic thought had been right—what would our critique be then? If we could

¹ Some of these ideas were developed in UN Sub-Commission on the Promotion and Protection of Human Rights, ‘Human Rights and the Human Genome’, Preliminary report submitted by Special Rapporteur Iulia-Antoanella Motoc, E/CN.4/Sub.2/2003/36 of 10 July 2003; E/CN.4/Sub.2/2004/38 of 23 July 2004; E/CN.4/Sub.2/2005/38 of 14 July 2005. I thank Emmanuel Decaux, Francesco Francioni and Françoise Hampson for comments on early drafts, Moma Momescu for her constant help with English translation, and Hadas Leffel for research assistance and editing the text.

² See eg the account of Gulati’s social justice approach, *infra* Part 1.

³ In addition, although cases of genetic discrimination are still isolated, fear of this type of discrimination is one of the most important factors that impedes the progress of research in genetics: see Hall, ‘Patients’ Fear of Genetic Discrimination by Health Insurers: The Impact of Legal Protections’ (2000) 2(4) *Genetic Medical* 207.

not summarily dismiss eugenics as hegemony based on ignorance and as instrumentalist science, what arguments would we marshal to defeat its programme? What principled distinctions can we make between their institutionalization efforts and ours? What difference is there between their pedigree counselling and our genetic counselling? What distinction can be drawn between their race betterment agendas and our hope for alleviation of suffering through genetic therapy? Such questions are not posed to suggest that there is no difference. Rather, they are posed in order to remind us that we must consciously and deliberately respond to eugenics not only so that we avoid repeating the mistakes of the past, but also so that unwarranted fear and guilt do not render us incapable of properly appropriating and incorporating genetic information into our social structure, our policies, and our jurisprudence.⁴

The main questions that will be asked in this chapter are: What is the meaning of genetic discrimination? How can efficient legislation on privacy protection prevent genetic discrimination? What is the relationship between international law and domestic law in fields such as insurance, employment and criminal investigation and what is the best way to protect individuals? How are various groups, such as women, indigenous people and persons with disabilities, affected by or vulnerable to genetic discrimination?

In Part 1 of this chapter, the main texts in international law will be outlined. Particular emphasis will be placed on the 1997 Universal Declaration on the Human Genome and Human Rights (UDHGHR), the first international instrument in this field. This will lead into an examination of the controversies surrounding the definition of genetic discrimination. By contrast with those who argue that it is not necessary to single out this type of discrimination, I will suggest that it should be legislated for separately within the general human rights framework. Arguments referring to the recent eugenic past, as well as the fundamental principle of human dignity⁵ and the rights 'of everyone to enjoy the benefits of scientific progress and its applications',⁶ provide further support for adopting an individual approach to this type of discrimination.

⁴ Geetter, 'Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System' (2002) 28 AJLM 1.

⁵ The Preamble of the Universal Declaration of Human Rights 1948 (UDHR) refers to human dignity as 'the foundation of freedom, justice and peace in the world' and Art 1 states that 'human beings are born free and equal in dignity and rights'. There are similar references to the foundational position of human dignity in both the International Covenant on Civil and Political Rights 1966 (ICCPR) and the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR). See in addition Arts 2, 10, 11 of the UDHGHR 1997: Art 2, eg, states that '[e]veryone has the right to respect for their dignity and for their rights regardless of their genetic characteristics' and '[t]hat dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity'. On human dignity and biotechnology, see eg D. Beylveland and R. Brownsword, *Human Dignity in Bioethics and Biolaw* (2001).

⁶ See eg Art 15 ICESCR. See also Arts 17–19 UDHGHR on 'solidarity and international co-operation', including between industrialized and developing countries.

The second part of the chapter analyses the protection of genetic privacy. The 2003 International Declaration on Human Genetic Data (IDHGD) of UNESCO, which has been described as ‘a sequel’⁷ to the UDHR, provides the main international legal framework in this regard. The most sensitive issues arise when consent to genetic data use is involved. Express consent is stipulated by the IDHGD but, as H el ene Boussard explains in her chapter in this volume, there are still many issues which remain unclear, especially as regards the relationship between individual consent and the interests of third parties, and also collective consent.

Part 3 deals with how international law against genetic discrimination becomes operational in domestic law in the fields of employment, insurance and criminal investigation. In accordance with Article 23 of the IDHGD, ‘[s]tates should take all appropriate measures, whether of a legislative, administrative or other character, to give effect to the principles set out in [the] Declaration, in accordance with the international law of human rights’. To date, the European tendency has been to prohibit the use of genetic data in employment and insurance; by contrast, in the US, state legislation provides a regulatory approach with variable definitions and degrees of prohibition of genetic discrimination. Criminal investigation is another field which raises concerns about possible discrimination.⁸ DNA databases are a valuable instrument for criminal investigations and bring major benefits. Yet, as emphasized by the IDHGD, certain practices bring up rights concerns, including: retaining full DNA samples, rather than just the DNA profiles used for identification; retaining people’s records on the database without consideration of the nature of their offence and also including those who have been arrested but not charged, or those who have been acquitted; and using the database for genetic research without consent.

The last part of this chapter deals with the issue of vulnerable groups, specifically, women, children, indigenous peoples and disabled persons.

1. The Definition of Genetic Discrimination

Discoveries in genetics have opened the door to new notions of discrimination. As a result, people who are afraid of potential genetic discrimination may be discouraged from obtaining genetic information that could bring health benefits to them and their families.

⁷ A.A. Yusuf, ‘UNESCO Standard-setting Activities on Bioethics: Speak Softly and Carry a Big Stick’, in F. Francioni (ed), *Biotechnologies and International Human Rights* (2007) 85 at 91.

⁸ See, also, the chapter by Roger Brownsword in this volume discussing what he describes as the ‘revolutionary sting’: ‘[t]he revolutionary sting... is precisely that the use of modern technologies, such as biotechnology, as a regulatory instrument might transform our culture and practice of criminal justice—ultimately with profound consequences for our valuation of both legality and human dignity.’

The present environment of suspicion regarding genetics can be traced in part to the early twentieth century ‘eugenics’ movement, which utilized the classification of genetic inferiority as a rallying point. The objective of the movement was to preserve and advance genetic superiority, and it sought to achieve this by sterilizing the ‘genetically inferior’ to prevent further dilution of the gene pool, prohibiting interracial marriage, and limiting immigration. While the most horrible form of eugenics was practiced by Adolph Hitler and the Nazi Party, a variety of eugenics-related movements existed elsewhere. In 1910, a Eugenic Records Office was established in Cold Spring Harbor, New York, which trained field-workers to collect family histories from people around the country. By 1924, data on people had been entered on around three quarters of a million cards and people made inquiries to the Office about whether particular proposed marriages would be eugenically appropriate.⁹

We are once more at a point in history where there is a strong individual and public interest in genetics. To a great extent, it will be the law that will be the custodian of our values as we decide on the right uses of genetic technologies and knowledge. And, in deciding how to shape and deploy the law, it is helpful to analyse the parallels between the previous uses of genetics and those of today. An understanding of previous abuses can act as a check against future abuse.¹⁰ It can also help to facilitate anticipatory or proactive engagement with emergent or potential problems.¹¹

After the eugenics horrors during World War II, international law set out to forbid genetics-based discrimination which can lead to a gradual development of eugenics. Let us try to examine the evolution of the law and, from this, the most appropriate definition of genetic discrimination.

A. International Legal Instruments

The Universal Declaration of Human Rights (UDHR), adopted by the United Nations General Assembly in 1948, stipulates in Article 5 that ‘No one shall be

⁹ Genetic theories were used as a basis for proposals for social and legal reform: the prime thrust of the reforms was to prevent people with allegedly undesirable genes from reproducing. The Chairman of the Department of Psychology at Harvard University advocated ‘the replacement of democracy by a caste system based upon biological capacity with legal restrictions upon breeding by the lower castes and upon intermarriage between the castes’. See Geetter, *supra* note 4, at 38. The first eugenics law, enacted in Indiana in 1907, provided for the involuntary sterilization of institutionalized, non-improvable individuals who were idiots, imbeciles, rapists or habitual criminals. Twenty-nine states passed sterilization laws between 1907 and 1931. Even the United States Supreme Court at one time did not totally reject the idea of genetics-based classes of people. In 1927, the Court held in *Buck v Bell* that a Virginia law authorizing the sterilization of certain inmates with hereditary forms of insanity or imbecility was constitutional. Justice Oliver Wendell Holmes, writing for the Court, stated that ‘three generations of imbeciles are enough’ and legitimized the sterilization of Carrie Buck, an 18-year-old female. It is this potential for defining ‘normalcy’—and by comparison, inferiority—through the detection and selection of genetic propensities that illuminates the great possibility of harm resulting from genetic discoveries.

¹⁰ See Geetter, *ibid.*

¹¹ See Motoc, *supra* note 1.

subjected to torture or to cruel, inhuman or degrading treatment or punishment'. Article 7 of the International Covenant on Civil and Political Rights (ICCPR), adopted in 1966, covers similar ground but makes express mention of medical and scientific experimentation. It provides that 'No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation'. These provisions are complemented by a range of ethical guidelines concerning biomedical research, in particular the Declaration of Helsinki, which was promulgated in 1964 by the World Medical Association and has subsequently been revised several times. The Declaration has had considerable influence on the formulation of international, regional and national legislation and codes of conduct. It addresses the ethics of research involving human subjects, and it specifies ethical guidelines for physicians engaged in both clinical and non-clinical biomedical research, including rules for informed consent of subjects and ethical review of research protocols. In similar vein, the World Health Organization (WHO) International Ethical Guidelines for Biomedical Research Involving Human Subjects stipulate that all research involving human subjects should be conducted in accordance with three basic ethical principles, namely respect for persons, beneficence, and justice.¹²

In recent years, the human genome has emerged as a specific concern within international law and policy. For instance, in 1997, the General Conference of the United Nations Educational, Scientific and Cultural Organization (UNESCO) adopted the Universal Declaration on the Human Genome and Human Rights (UDHGHR), which was endorsed a year later by the General Assembly of the United Nations.¹³ Article 1 of the Declaration states that '[t]he human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity'.¹⁴ A similar sentiment is found in the Preamble to the Declaration, which emphasizes *inter alia* that:

the recognition of the genetic diversity of humanity must not give rise to any interpretation of a social or political nature which could call into question the 'inherent dignity and . . . the equal and inalienable rights of all members of the human family', in accordance with the preamble to the Universal Declaration of Human Rights.¹⁵

¹² See <http://www.cioms.ch/frame_guidelines_nov_2002.htm>. On genetic research, see further the chapter by Hélène Boussard in this volume.

¹³ In 1999, in order to facilitate the interpretation and application of the UDHGHR in domestic law, UNESCO adopted a resolution (30 C/Resolution 23) endorsing guidelines for its implementation.

¹⁴ The phrase '[i]n a symbolic sense' has provoked diverse interpretations: see eg R. Pavoni, 'Biodiversity and Biotechnology: Consolidation and Strains in the Emerging International Legal Regimes', in F. Francioni and T. Scovazzi (eds), *Biotechnology and International Law* (2006) and Yusuf, *supra* note 7, at 88–9.

¹⁵ See Preamble, para 4. See also Art 10 UDHGHR which provides that genomic research must respect the human rights, fundamental freedoms and human dignity of individuals and groups of people.

The Preamble also emphasizes that although research on the human genome has vast potential for improving the health of individuals and of humankind as a whole, such research should fully respect 'the prohibition of all forms of discrimination based on genetic characteristics'. This sentiment is bolstered by several provisions aimed at preventing genetic discrimination. Article 2(a) provides for the right of everyone to have respect for his/her dignity and rights regardless of genetic characteristics. It then states '[t]hat dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity' (Article 2(b)). Article 6 prohibits discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity. The UDHGHR also proposes strict rules for research on the human genome (see, in particular, Articles 10, 11 and 12), and endorses the principle of prior, free and informed consent (Article 5) and respect for confidentiality (Article 7). Important principles regarding solidarity and international co-operation are set down in the Declaration (Articles 17, 18 and 19). For example, Article 17 provides that states should respect and promote 'solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character. They should foster, *inter alia*, research on the identification, prevention and treatment of genetically based and genetically influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population'. In addition, in Article 18, states are directed to 'continue fostering the international dissemination of scientific knowledge concerning the human genome' and to foster co-operation, 'particularly between industrialized and developing countries'.¹⁶

Attempts to protect against genetic discrimination have also been made at the regional level, such as through the 1997 European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (the Oviedo Convention). This Convention bans all forms of discrimination based on a person's genetic make-up (Article 11) and allows predictive genetic tests only for health or scientific research purposes (Article 12). It also sets out rules for medical research and recognizes a patient's right to know (including a right *not* to know if the patient so wishes).¹⁷ Prior to

¹⁶ See also Art 19. Francioni, 'Genetic Resources, Biotechnology and Human Rights: The International Legal Framework', in Francioni (ed), *supra* note 7, at 3 notes that 'the more genetic tests and therapies are made available, the greater the gap will grow between the fortunate who have access to such tests and therapies and those who do not. This new "discrimination" would run along the fault line that separates the rich world from the less developed world' (p 21).

¹⁷ The Explanatory Report also recognizes that: '[w]hereas the term "discrimination" usually has a negative connotation in French, this is not necessarily the case in English (where one must use the expression "unfair discrimination"); it has, however, been decided to keep the same term in both languages, as it is in the European Convention of Human Rights and in the case law of the Court. Discrimination here must, therefore, in French as in English, be understood as unfair discrimination. In particular, it cannot prohibit positive measures which may be implemented with the aim of re-establishing a certain balance in favour of those at a disadvantage because of their genetic inheritance.'

ratification, each state has to bring its laws into line with the Convention. This may require a change in the law or a new law, and any such legislation must include legal sanctions and require compensation for individuals who have suffered undue harm following medical treatment or research.

It is now clear that the Oviedo Convention and the UDHGHR were the first instruments in an ongoing engagement by international law with the human genome and questions of genetic discrimination. For instance, in Resolution 2001/39 on Genetic Privacy and Non-Discrimination, the Economic and Social Commission (ECOSOC) urged states to ensure that no-one shall be subjected to discrimination based on genetic characteristics and to take measures to prevent the use of genetic information and testing leading to discrimination or exclusion against individuals, particularly in social, medical or employment-related areas, whether in the public or the private sector. A later resolution, of 21 July 2004, on the same topic, contains similar injunctions.¹⁸ In addition, the World Health Organization (WHO) International Ethical Guidelines for Biomedical Research Involving Human Subjects, which were revised in 2002, state in Guideline 18, on issues of confidentiality in genetic research, that an investigator who proposes to perform genetic tests of known clinical or predictive value on biological samples that can be linked to an identifiable individual must obtain the informed consent of the individual or, when indicated, the permission of a legally authorized representative.¹⁹

In October 2003, UNESCO adopted the International Declaration on Human Genetic Data (IDHGD). This normative instrument establishes the principles that should govern the collection, processing, use and storage of human genetic data.²⁰ Article 1(c) of the Declaration establishes an important exception: it provides that the IDHGD applies to the collection, processing, use and storage of human genetic data, human proteomic data and biological samples, *except* in the case of investigation, detection and prosecution of criminal offences and in parentage testing that are subject to domestic law that is consistent with the international law of human rights.²¹

The aims of the IDHGD are threefold: first, to guarantee the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, human proteomic data and biological samples, in keeping with the requirements of equality, justice and solidarity, while giving due consideration to freedom of thought and expression, including freedom of research; second, to set out the principles which should guide states in the formulation of their legislation and their policies on

¹⁸ See ECOSOC Res. 2004/9 on Genetic Privacy and Non-Discrimination.

¹⁹ *Supra* note 12.

²⁰ Article 2(i) defines 'human genetic data' as '[i]nformation about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis'.

²¹ See also Art 5.

these issues; and, finally, to form the basis for guidelines of good practice in these areas for institutions and individuals handling genetic data.

Article 3 is one of the most important articles in the IDHGD. It states that '[e]ach individual has a characteristic genetic make-up. Nevertheless, a person's identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom'. Article 7 also deserves mention. It addresses non-discrimination and non-stigmatization, and provides that:

- (a) Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities.
- (b) In this regard, appropriate attention should be paid to the findings of population-based genetic studies and behavioural genetic studies and their interpretations.

An interdiction of discrimination and stigmatization close to that in the IDHGD can be found in Article 11 of UNESCO's Universal Declaration on Bioethics and Human Rights (UDBHR) adopted in 2005.²² Of course, as is the case when the term 'grounds of discrimination' is used in human rights documents, further interpretation is needed. The aim of the anti-discrimination provisions outlined above is to prohibit discrimination that impacts on human rights, fundamental freedoms and human dignity. Academic literature, however, is divided on the issue of how to define genetic discrimination. One early proposal defined genetic discrimination as 'discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal" genome of that individual',²³ distinguishing it from 'discrimination based on disabilities caused by altered genes'. On this view, the criterion for genetic discrimination is whether the disease has actually occurred or not. If the disease has not yet occurred, the discrimination is termed 'genetic'; but, if the disease is expressed, it becomes another type of discrimination, most likely discrimination based on someone's health condition.

The question of whether genetic discrimination is significantly dissimilar from discrimination on the basis of general health status has been prevalent in the

²² On the UDBHR, see eg Boussard, 'The "Normative Spectrum" of an Ethically-inspired Legal Instrument: The 2005 Universal Declaration on Bioethics and Human Rights', in Francioni (ed), *supra* note 7, 97.

²³ Billings *et al*, 'Discrimination as a Consequence of Genetic Testing' (1992) 50 AJHG 476. Rothstein and Anderlik, 'What Is Genetic Discrimination, and When and How Can It Be Prevented?' (2001) 3 Genetics Med 354 use the term to describe 'differential treatment based on genetic status'. In contrast, in one of the first studies analysing occurrences of genetic discrimination, Yesley mentions that 'the quintessential feature of genetic discrimination is the use of genetic information about an asymptomatic person'.

literature. Critics of laws against genetic discrimination argue that genetic discrimination is no different from discrimination on the basis of health status and that such discrimination is essentially at the centre of the suitable management of insurance.²⁴ Some authors consider that there is no real cause to distinguish between those with a genetic predisposition to disease and those who become ill with disease, though, to a certain extent, rather than concluding that no anti-discrimination laws are essential, they see existing laws as merely a first step in the right direction: the second step, then, would be a generic law that protects people from discrimination on the basis of health status.²⁵

Another proposal is that legislation should sketch a difference between discrimination on the basis of genotype and discrimination on the basis of phenotype. It has been suggested that such a law would forbid health insurers from charging higher rates on the basis of information about unexpressed genetic traits, regardless of the source of the information. In other words 'genetic information should thus be defined broadly to encompass any . . . information that provides probabilistic information about a person's genotype . . . from genetic tests, other medical tests, family history, diagnoses of traits or conditions, or the taking of (or even making inquiries about) a genetic test'.²⁶ In order to avoid also forbidding discrimination on the basis of health status generally, Greely proposes allowing discrimination when the trait has already manifested itself in the form of illness or disability. He considers that once the genetic predisposition is evident as illness, or in the form of a medically-relevant symptom, it should not be forbidden for it to be taken into account.²⁷

A different perspective, focusing on the US context, is offered by Gulati who uses social justice considerations to make a case against anti-discrimination law focusing on genetics. He argues that genetic differentiation should not be tolerated, not because there is anything unique about genes, but because no one should be a citizen of the United States and be forced to sacrifice their economic security for the sake of obtaining necessary medical services.²⁸

²⁴ See eg Rothstein and Anderlik, *ibid*; Suter, 'The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?' (2001) 79(3) WULQ 669; Wolf, 'Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism' (1995) 23(4) JLME 345.

²⁵ See Hellman, 'What Makes Genetic Discrimination Exceptional?' (2003) 29(1) Am J of Law and Medicine 77.

²⁶ See Greely, 'Genotype Discrimination: The Complex Case for Some Legislative Protection' (2001) 149 UPALR 1483, at 1495.

²⁷ Greely's resolution of the definitional dilemma adopts the meaning originally proposed by Billings *et al*, *supra* note 23, in an early piece on genetic discrimination. In Greely's view, the definition is 'conceptually straightforward though perhaps complicated to implement'. See also Hellman, *supra* note 25.

²⁸ As long as the oppression of having to live without health insurance is limited to the working poor and others at the margin, the goal of universal health insurance will remain unrealized. However, once interests converge and the oppression threatens to afflict those in the higher socioeconomic classes, social movements for political change become possible.

Gulati advances three main points in support of his argument: first, that genetic anti-discrimination legislation, standing within a commercial health insurance system, is normatively inferior; second, that ultimately genetic anti-discrimination laws will fail and spur a social movement for a radical reorientation of the health insurance system in the United States; and finally, that genetic anti-discrimination legislation delays the formation of the social movement and in so doing helps to maintain the current commercial health system.²⁹

In my view, singling out genetic discrimination is necessary for at least two reasons. On the one hand, it is necessary from the perspective of human rights that acknowledges the increased protection that could be provided by a specific body of law. On the other hand, it appears necessary from a utilitarian perspective, as it could help to reduce fear and thereby facilitate scientific research that contributes not just to the progress of knowledge but helps to relieve human suffering and improve the health of individuals and humanity as a whole. Also, although I acknowledge what Gulati describes as the 'normative inferiority' of legislation that forbids genetic discrimination, I do not believe that genetic anti-discrimination laws will slow or stop reform of the US health system. In addition to the fact that such a development seems unlikely in practice, it would be wrong to accept the acknowledgement of a human right at the expense of another right. In sum, then, although in general in the international law of genetics, human dignity and utilitarian perspectives stand in direct contrast,³⁰ in this particular circumstance they converge.

2. The Challenge of Privacy in the Genetic Context

In the past, in the arena of genetics, most commentators, advocates and policymakers have tended to separate privacy from non-discrimination, using different approaches to tackle these issues.³¹ In my view, however, the best way to avoid discrimination of all kinds is to use a two-sided approach. First, interrupt the right to use information concerning the trait in question, whether national origin, religion, disability or genetic predisposition, where suitable and possible. This demonstrates a strict 'privacy' method. Then, forbid the use of any information obtained despite the attempt to shut down the flow of information.

In an era in which technology has enhanced the aptitude of physicians and others to gather and distribute patient data, it is of enormous significance that we protect individual privacy and the confidentiality of genetic information in the

²⁹ Gulati, 'Genetic Antidiscrimination Laws in Health Insurance: A Misguided Solution' (2001) 4 *Quinnipiac Health LJ* 149, at 168.

³⁰ For accounts of this contrast, see the chapters by Roger Brownsword and Han Somsen in this volume.

³¹ See eg the US' Health Insurance Portability and Accountability Act 1996 (HIPAA) which contains entirely separate titles and tracks for protecting privacy and protecting against inappropriate uses of medical information, including genetic information, by group health plans and health insurers.

health-care setting.³² As one scholar has stated, ‘restrictions on disclosure will become more desirable from the viewpoint of patients as medicine is able to determine distant future risks of developing diseases’ by means of genetic testing.³³ There are, however, legitimate reasons for disclosure of patient information in the absence of specific consent. Consequently the law permits and occasionally requires such disclosure, for instance when third parties may be at risk of injury due to their lack of knowledge of such information. However, although in some cases the danger may stand out as unambiguous, in many cases there will be substantial doubt and the decision about disclosure will be extremely difficult. For example, if a person tests positive for a foremost genetic trait³⁴ which carries a serious forecast, and which also carries a certain risk for first-degree relatives, would this be a basis for disclosure to such relatives even in the face of the tested person’s objection?³⁵

In the case of genetic screening at work, if the employee does consent, then such consent should be construed narrowly.³⁶ In addition, provisions should be enacted to guarantee that genetic information is not distorted. Such a stipulation might forbid employers or unions from making employment decisions based on genetic information if the genotype has no clear relation to the capability of performing the job. Further protections from misuse could prohibit employers from using the information for health benefit decisions.³⁷

The IDHGD is the most important international instrument on genetic privacy. As noted earlier, it applies to the collection, processing, use and storage of human genetic data, human proteomic data and biological samples, except in the case of the investigation, detection and prosecution of criminal offences and in parentage testing which are provided for by domestic law that is consistent with the international law of human rights.³⁸ Not surprisingly, the IDHGD places particular emphasis on the need for consent.³⁹ Article 8 indicates that

³² See Balint, ‘Issues of Privacy and Confidentiality in New Genetics’ (1998) 9 ALJST 27, at 27.

³³ Medical records are now routinely examined in the US by auditors from insurance companies to see if they fully document the services rendered and billed for by the physician. This occurs exclusive of the patient’s express permission, and thus again is a breach of privacy and confidentiality. In addition, in the hospital setting, increasing numbers of individuals regularly look at the patient’s record. See Kotval, ‘Market-Driven Managed Care and the Confidentiality of Genetic Tests: The Institution as Double Agent’ (1998) 9 ALJST 1.

³⁴ Such situations might arise with genetic testing for Huntington’s disease or hereditary breast cancer.

³⁵ See, further, the chapter by Hélène Boussard in this volume.

³⁶ See, generally, King *et al.*, ‘Workplace Privacy and Discrimination Issues Related to Genetic Data: A Comparative Law Study of the European Union and the United States’ (2006) 43 Am Bus LJ 79. For discussion of European data protection measures, see the chapter by Francesca Bignami in this volume.

³⁷ Andrews and Jaeger, ‘Confidentiality of Genetic Information in the Workplace’ (1991) 17 (1–2) AJLM 75.

³⁸ Article 1(c).

³⁹ See similarly the non-binding Charter of Fundamental Rights of the European Union, Art 3 which provides that in order to ensure the integrity of the person, it is essential that in the fields of medicine and biology: ‘the following must be respected in particular: the free and informed consent of the person concerned, according to the procedures laid down by law; the prohibition of eugenic practices, in particular those aiming at the selection of persons.’

‘[p]rior, free, informed and express consent, without inducement by financial or other personal gain, should be obtained for the collection of human genetic data, human proteomic data or biological samples, whether through invasive or non-invasive procedures, and for their subsequent use and storage, whether carried out by public or private institutions’. It also makes it clear that any limitations on the principle of consent ‘should only be prescribed for compelling reasons by domestic law consistent with the international law of human rights’.⁴⁰

Privacy and confidentiality are addressed in Article 14 of the IDHGD.⁴¹ Article 14(a) indicates that states should work to protect the privacy of individuals and the confidentiality of human genetic data linked to an identifiable person, family or group in accordance with domestic law consistent with the international law of human rights. Article 14(b) provides that:

Human genetic data, human proteomic data and biological samples linked to an identifiable person should not be disclosed or made accessible to third parties, in particular, employers, insurance companies, educational institutions and the family, except for an important public interest reason in cases restrictively provided for by domestic law consistent with the international law of human rights or where the prior, free, informed and express consent of the person concerned has been obtained provided that such consent is in accordance with domestic law and the international law of human rights. The privacy of an individual participating in a study using human genetic data, human proteomic data or biological samples should be protected and the data should be treated as confidential.

Thereafter, Article 14(c and (d) address human genetic material collected for medical and scientific purposes and Article 14(e) closes out the provision by emphasizing that human genetic data and human proteomic data should not be kept in a form which allow the data subject to be identified ‘for any longer than is necessary for achieving the purposes for which they were collected or subsequently processed’.

3. From International Law to Domestic Implementation: Insurance, Employment, and Criminal Investigation

A. Insurance and Employment

As Francesco Francioni has pointed out, insurance and employment are areas where ‘the risk of discrimination on a genetic basis is the highest and most disturbing’. And, as he goes on to explain, there is a range of questions that need to be addressed in order to prevent discriminatory practices, including ‘(1) whether

⁴⁰ For detailed analysis of the problems concerning consent in the field of genetic research, see the chapter by Hélène Boussard in this volume. See, more generally, D. Beylveled and R. Brownsword, *Consent in the Law* (2007).

⁴¹ See also Art 15 which addresses the security of genetic data.

insurers and employers may be allowed to require genetic tests as a condition of insurance or employment; (2) whether insurers or employers may require disclosure of prior genetic tests by the applicant; and (3) whether insurers or employers may give weight for business purposes to genetic information voluntarily provided by applicants'.⁴²

Legislation that regulates the use of genetic data in insurance and employment needs to be understood within the broader contexts of the right to work, the right to health and citizenship rights. In most European states, for example, health insurance is linked to citizenship rights; hence, genetic risks neither contribute to an increase in insurance rates, nor do they determine exclusion from the insurance system. It is only in the case of life, injuries or disability insurance that they may incline the balance in a certain way. In the US, however, where many people do not benefit from health insurance, the situation is different and it has been argued that focused protection against genetic discrimination is unfair when so many are excluded from health insurance on other grounds. Moreover, although the consequences are less severe when it comes to life insurance, it has also been argued that prohibiting the use of genetics in insurance underwriting, while allowing similar non-genetic risk factors to be used, is unfair.⁴³

Explicit legislation prohibiting the use of genetic testing for insurance purposes exists in Austria, Belgium, Denmark and Norway.⁴⁴ In these countries, insurers can neither request genetic testing, nor use the test results of applicants available in medical records. Norwegian law further prohibits insurers from even asking whether a genetic test has been carried out.⁴⁵ In the Netherlands, a 1997 statute on medical examinations may pose a barrier to the use of genetic testing for insurance purposes. Article 3 provides that a medical test must not cause an excessive invasion into the privacy of the individual being tested. It further provides that a medical examination cannot be undertaken if the risks of the test, as well as the risk of receiving information on an untreatable illness, prevail over

⁴² Francioni, *supra* note 16, at 22. He concludes that '[p]rima facie, the answer to these questions appears to be negative in the light of the norms contained in universal and regional instruments on bioethics'.

⁴³ Lemmens, 'Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws' (2000) 45 McGill LJ 347, at 383 argues that statutes singling out genetic susceptibility as a category, and offering it much wider protection than other similar health conditions, although intended to promote equity in access to social goods, may themselves be ineffective and to some extent even inequitable. Lemmens suggests that many policy analysts in the US have embraced anti-discrimination and privacy legislation focusing on genetics as an imperfect way of protecting an already insufficient degree of access to health care.

⁴⁴ The European Trade Union Confederation (ETUC) has called for such a prohibition to be included explicitly in a European Commission directive on the protection of workers' personal data. ETUC claims that gene testing is not yet a problem in EU workplaces and EC legislators should make sure this remains the case. It argues that tests would reduce efforts to prevent exposure to occupational hazards, in particular in the chemical field, and introduce discrimination among workers according to certain genetic characteristics.

⁴⁵ Lemmens, *supra* note 43, at 383.

the expected advantage of the test, thereby placing a disproportionate burden on the individual. The law thus embraces a proportionality test for the determination of the acceptability of genetic tests.⁴⁶ In France, the National Ethics Committee (*Comite National d'Ethique*) recommended in October 1995 that insurers should be forbidden from using any genetic information, even if applicants submit it freely. A year earlier, a law 'On respect for the human body' introduced new provisions on genetic testing and DNA identification into the French Civil Code. According to Article 16-10, a genetic report of the characteristics of a person may be undertaken only for medical purposes or for scientific research. This seems to forbid insurers from using genetic tests for underwriting purposes but it does not prevent them from obtaining genetic-test information from medical files.⁴⁷

In Austria, Denmark, Norway, the Netherlands and Belgium, genetic testing for employment purposes is illegal.

In the United States, most of the legislative activity involving issues of genetic privacy and genetic discrimination has occurred at the state,⁴⁸ as opposed to the federal, level.⁴⁹ About forty states have laws that address some aspect of genetic privacy and discrimination. Sixteen states require informed consent for a third party to perform or require a genetic test or obtain genetic information, while twenty-three require the informed consent of the subject before disclosing genetic information to a third party. Thirty-two states have passed laws

⁴⁶ *Ibid.*

⁴⁷ France, Law no 2002-303 of 4 March 2002 relating to the rights of the patients and the quality of the system of health (1) art 98: '*Les entreprises et organismes qui proposent une garantie des risques d'invalidité ou de décès ne doivent pas tenir compte des résultats de l'examen des caractéristiques génétiques d'une personne demandant à bénéficier de cette garantie, même si ceux-ci leur sont transmis par la personne concernée ou avec son accord. En outre, ils ne peuvent poser aucune question relative aux tests génétiques et à leurs résultats, ni demander à une personne de se soumettre à des tests génétiques avant que ne soit conclu le contrat et pendant toute la durée de celui-ci.*' See also Lemmens, *supra* note 43.

⁴⁸ Because of federal law preemptions, state laws do not protect the nearly one-in-three Americans who get their health insurance through their employer.

⁴⁹ On 24 April 2008, the US Senate passed the Genetic Information Nondiscrimination Act of 2008. But similar legislation has been introduced in every congress since 1995, and President George W Bush announced his backing for a law against genetic discrimination as early as June 2001. The House of Representatives is the sticking point: knowledgeable observers consider the prospects for passage of the House equivalent of this bill to be only slightly better than they were in 2003, when the Genetic Information Nondiscrimination Act of 2003 passed the Senate by a vote of 95 to 0 but never reached the House floor. See Greely, 'Banning Genetic Discrimination' (2005) 353(9) *New Eng J of Medicine* 86. The bill would prohibit health insurance plans from denying enrollment or charging premiums on the basis of an individual's or family member's genetic information. It also prohibits health insurers from basing premiums of a group health plan on the basis of genetic information of plan members or their families. The bill prohibits disclosures or collection (requesting, requiring or purchasing) of genetic information for underwriting purposes. In addition, it prohibits the use of genetic information in employment decisions and applies the same procedures and remedies as apply to other forms of employment discrimination. Following the model of the HIPAA Privacy Rule, it provides basic protections for genetic information while permitting greater protection under other federal and state measures. Congress has certainly taken notice of the issue.

concerning genetic discrimination in employment. At least thirty-four states prohibit the use of genetic information for certain health insurance purposes. Additionally, three states require actuarial justification for the use of genetic information. Thirty states restrict employers from discriminating based on genetic information, but the laws are varied and contain different definitions and loopholes.

Looking at the employment context at the federal level, there is some protection against discriminatory use of genetic information in the workplace. The existing protection, however, falls short of the comprehensive law needed to protect the rights of workers. In 1995 the Equal Employment Opportunity Commission (EEOC) interpreted the Americans with Disabilities Act (ADA)⁵⁰ as protecting a person's genetic predisposition to disease, but the interpretation did not address whether someone can be denied a job because he or she is a carrier of a recessive disorder (and the potential employer does not want to pay health costs associated with potential or actual affected children), nor did it prevent employers from requiring that potential employees undergo genetic testing. In 2002, the EEOC filed a petition for a preliminary injunction against Burlington Northern Santa Fe Railroad, looking for an end to the practice of genetic testing of all employees who filed claims for work-related injuries based on carpal tunnel syndrome. This was the first suit by the EEOC challenging genetic testing. It alleged that the employees were not told of the genetic test or asked to consent to it. Furthermore, in at least one instance, an employee who refused to give a blood sample because he suspected that it would be used for genetic testing was purportedly threatened with expulsion if he failed to provide the sample. Burlington Northern asked employees to agree to blood tests to see if they carried a genetic trait called Chromosome 17 deletion; some studies imply that a person with that attribute is more likely to experience some forms of carpal tunnel syndrome. Within days of the EEOC action, Burlington Northern agreed to stop requiring genetic testing of employees who filed claims for carpal tunnel syndrome.⁵¹

As noted earlier, at the state level there are laws that prohibit employers from discriminating against people on the basis of genetic tests but the specifics of what constitutes unlawful discrimination vary widely. Some definitions of genetic information only include the employed individual, while others include family members as well; some only protect information from genetic tests and others include family histories and other sources of genetic information. The

⁵⁰ Americans with Disabilities Act, 42 USC §12112 (1992).

⁵¹ *EEOC v Burlington Northern Santa Fe Railway Co*, No 02-C-0456 (ED Wis 2002). A similar case occurred in Hong Kong where a court ruled in favour of compensation for three persons who had been refused employment on the ground that their parents suffered from schizophrenia: see ILO, 'Equality at Work: Tackling the Challenges. Global Report under the Follow-up to the ILO Declaration on Fundamental Principles and Rights at Work'. International Labour Conference, 96th Session 2007, Report I(B), at 49.

laws vary as to whether employers may request or require genetic testing and how, if at all, that information may be disclosed or used. Most of the state laws do not protect people from discrimination based on genetic information about their family members, thereby allowing insurers to easily circumvent the reach of the laws by basing their decisions on family histories. Few of the laws would prohibit an insurer from circumventing the law by discriminating against people based not on their test result, but on the fact that they previously requested genetic services. Some laws focus on tests of DNA and RNA, others only on tests of genes or chromosomes, or on gene products such as proteins or enzymes. Some protect people from discrimination based only on genetic test results, but would not prohibit discrimination based on genetic information gathered by other means. Others define a 'genetic test' narrowly so that protections apply only to testing for the presence or absence of genes. At the federal level, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides some protection against genetic discrimination, such as barring the use of genetic information in denying or limiting health insurance coverage for members of a group plan.

B. Criminal Investigation

DNA forensics can be seen as merely the latest in a long line of biologically-based identifying law-enforcement technologies that incorporate fingerprints and serotyping. Yet, DNA has qualities that make it meaningfully dissimilar from its predecessors with respect to the human rights apprehension it raises. DNA is predictive for sensitive information such as an individual's hereditary diseases, phenotypic propensities and familial relations. Secondly, it can be amplified from minute quantities, and because it is shed in detectable quantities in the form of sloughed skin, hand smudges, hair follicles, and saliva residues, it is more abundant as a source of evidence than fingerprints and serotypes. Third, DNA profiles are partially shared with biological relatives, which means an offender's profile cannot be collected without consequentially obtaining incomplete information about non-offending relatives' profiles. Moreover, certain alleles and allele frequencies are predictive for biologically-defined racial and ethnic categories. Finally, DNA is a relatively durable material, and therefore retains its 'informational content' much longer than would other sources of biological evidence. Together, these properties qualitatively distinguish DNA samples and profiles from fingerprints and militate against convenient analogies to fingerprints.⁵²

DNA evidence raises several questions related to genetic discrimination and the protection of genetic privacy. Human rights organizations, such as Human

⁵² See Kimmelman, 'Risking Ethical Insolvency: A Survey of Trends in Criminal DNA Data-banking' (2000) 28 *JLME* 28.

Rights Genes, have recognized the important role played by DNA evidence in criminal investigations, but remain opposed to the permanent retention of all DNA samples. They argue, first, that retention brings an increasing threat to genetic privacy if information is revealed about health or family relationships, not just identity; secondly, that it creates a permanent 'list of suspects', including anyone arrested for a wide range of offences; and thirdly, that it increases the potential for discrimination (particularly against ethnic minorities) by permanently retaining samples taken before an individual is charged, even when DNA evidence is not relevant to the investigation.

Using DNA as an investigative tool also raises the issue of how to obtain a suspect's DNA. Currently there are three ways to get a DNA sample from a known suspect: voluntary submission; DNA abandonment; or a court order. Getting a DNA sample by voluntary submission is the least problematic of the three. Although obtaining a DNA sample from a person's body is considered a search, an individual may consent to a search. DNA abandonment occurs when a person discards a personal item containing DNA. Abandonment is also usually not problematic as long as the evidence was truly abandoned, and not stolen or retrieved by an illegal search and seizure. Obtaining a court order is more difficult and usually implicates a seizure clause.

In England and Wales, where DNA forensics originated, the police are authorized to collect 'non-intimate' samples (such as hair follicles) from anyone questioned or arrested for any recordable offence, which is generally defined as an offence that could lead to imprisonment. The practice of 'mass intelligence screening', colloquially known as 'sweeps' or 'bloodings', is also permitted.⁵³ The samples are linked to the person's record on the National DNA Database, which includes their DNA profile (a string of numbers obtained from part of the sequence of the DNA). The samples are stored permanently by the companies that analyse them, for an annual fee.

In the US, federal criminal DNA databanking legislation was first passed in the 1994 Violent Crime Control and Law Enforcement Act, which authorized

⁵³ Persons living near a crime scene are asked to voluntarily submit DNA samples that can be checked against a crime scene sample, allowing police quickly (if expensively) to rule out suspects. Other countries have conducted genetic sweeps as well, including Australia, Canada and Germany; the latter collected DNA from 12,000 volunteers for a single crime in 1998. Genetic sweeps raise important questions about privacy and personal integrity. According to British authorities, samples collected from volunteers are not entered into the general database but are instead compared against the profiles of a specific crime scene sample. Profiles and tissue samples are destroyed after completion of an investigation, though they may be retained until conviction. However, the notion that sweeps are voluntary is unrealistic given the coercive pressures of heavy media attention, widespread community participation, and the fact that failure to submit a tissue sample may in itself invoke police submission. The Police Federation of Australia opposed proposed legislation, requiring police to provide genetic samples for the purpose of eliminating them as a source of crime scene contamination. Concerns were expressed that such a requirement is quite different in scope from the requirement to provide fingerprints on file, in that it is capable of being used for potentially discriminatory purposes by the employer.

the FBI to establish a software system for sharing information contained in state DNA databases (the Combined DNA Identification System, or CODIS).⁵⁴ The Act provided a substantial boost to state DNA databanks and, since 1994, thirty-five new databanking statutes have been passed. The argument can be made that removal of individual identifiers prevents any harms to the offender providing the tissue sample, since third parties like employers would be unable to link a sample to an individual, and stigmatizing or medical information would not be traceable to an individual. On the other hand, release of tissue samples, anonymized or otherwise, involuntarily involves offenders in research they might not have consented to; and requiring authorization before samples are anonymized and released for research recognizes and respects the diversity of attitudes individuals may have about supporting certain types of research. Clearly, there are compelling reasons for collecting tissue samples from offenders without their consent, but there are no clear reasons why offenders should be denied the right to exercise their choice to opt out of biomedical or forensic research—in particular, research that could be objectionable on racial or social grounds. Anonymizing DNA samples for research purposes without first obtaining consent from their source does not violate any US federal regulations. It is, nevertheless, inconsistent with the recommendations of several commentators as well as the American College of Medical Genetics. One can furthermore question whether it is truly possible to anonymize tissue samples that have been collected for the contradictory purpose of maintaining identifying information.⁵⁵

Defendants have challenged the constitutionality of DNA collection as an unreasonable search and seizure under the Fourth Amendment of the US Constitution.⁵⁶ The US Supreme Court has deemed the involuntary taking of a biological sample a 'search' under the Fourth Amendment; therefore, the forced collection of DNA must fall within an exception that allows for the collection of DNA without the existence of probable cause or reasonable suspicion. One such

⁵⁴ CODIS includes a Convicted Offender Index that stores the DNA profiles of people convicted of felony sex offences as well as other violent crimes, giving law enforcement agencies a powerful tool to identify repeat offenders and link together crime scenes. CODIS also contains a Forensic Index, which compiles DNA profiles developed from evidence left at crime scenes. Matches made in the Forensic Index can link crime scenes together and identify the possibility of a serial offender. Another feature of CODIS is its Population File, an anonymous database of DNA profiles of the general population that determines the statistical significance of a match. CODIS also includes a National DNA Index System (NDIS), which enables participating agencies to exchange and compare DNA profiles on a national level. Currently, all fifty states, as well as Puerto Rico and the United States Army, participate in NDIS.

⁵⁵ See Lewis, 'The Role Genetic Information Plays in the Criminal Justice System' (2005) 47 *Arizona L Rev* 519.

⁵⁶ 'The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probable cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized.'

exception is the 'special needs exception'.⁵⁷ Most of the courts that have addressed this issue, including the US Supreme Court, have characterized the collection of a DNA sample from a prisoner or probationer as a search and seizure, but accepted that the collection is reasonable in relation to the compelling state interests of reducing recidivism and ensuring accuracy, in light of the reduced privacy expectation of prisoners and probationers, and the minimal bodily intrusion involved in the procedure.

In the US, defendants could argue that a discriminatory purpose can be inferred based on the arrest and conviction rates that vary greatly between the sexes and among different races. In some, predominantly black, neighbourhoods, up to ninety percent of adult males have been arrested. Nationally, a black person is five times more likely to be arrested than a white person. Therefore, if DNA is collected from arrestees, or even just felons, convicted of certain crimes, then a black person is more likely than a white person to be identified from DNA left at future crime scenes. But while this disparity shows a clear discriminatory impact on black males, as they will more often be subjected to DNA profiling, it does not show discriminatory purpose and statistical evidence of disparate impact, without more, is not enough. It is unlikely, however, that defendants will be able to prove discriminatory intent behind the legislation unless evidence of a discriminatory purpose is expressed either on the face of the statute or in its legislative history. Canada's law shows greater solicitude on the issue of privacy. Canada's databanking system divides crimes into two categories: primary offences, which include murder and rape, and secondary offences, which include robbery, assaults, and arson. Canadian law mandates databanking all individuals convicted of primary offences and provides provincial judges with the option of collecting tissue samples from individuals convicted of secondary offences. Together, primary and secondary offences cover a range of criminal offences similar to that of most US states: serious property crimes such as arson, sexual offences, and violent crimes against persons. Also, as is the case in the US and the UK, samples are retained indefinitely, on the premise that forensic technologies are rapidly developing. However, in contrast to the US, Canada automatically expunges records and samples from any acquitted individuals, and provides a schedule for elimination of juvenile samples and records. Finally, the Canadian databanking law does not authorize using samples collected from offenders for research of any kind, including construction of a population database from anonymized samples of those who have been acquitted.

⁵⁷ This exception allows for a search when designed to serve 'special needs, beyond the normal need for law enforcement'. Courts have utilized this exception in cases involving random drug screening in high schools and sobriety checkpoints. Unsurprisingly, defendants have argued that a DNA sample collection for a government database does not come within the special needs exception. In making this determination, courts must examine whether the purpose of the challenged search, in this case the collection of DNA, goes 'beyond the normal need for law enforcement'.

The issue of *collection* of human genetic and proteomic data is addressed in Articles 8–12 of the IDHGD, *processing* in Articles 13–15, *use* in Articles 16–19, and *storage* in Articles 20–22. As regards collection of samples for forensic medicine or in civil, criminal and other legal proceedings, Article 12 provides that ‘[w]hen human genetic data or human proteomic data are collected for the purposes of forensic medicine or in civil, criminal and other legal proceedings, including parentage testing, the collection of biological samples, *in vivo* or *post-mortem*, should be made only in accordance with domestic law consistent with the international law of human rights’. As regards destruction of samples, Article 21(b) and (c) emphasize that:

- (b) Human genetic data, human proteomic data and the biological samples collected from a suspect in the course of a criminal investigation should be destroyed when they are no longer necessary, unless otherwise provided for by domestic law consistent with the international law of human rights.
- (c) Human genetic data, human proteomic data and biological samples should be available for forensic purposes and civil proceedings only for as long as they are necessary for those proceedings, unless otherwise provided for by domestic law consistent with the international law of human rights.

As noted earlier, the IDHGD does stipulate an exception for the criminal investigations (Article 1(c)). However, it also specifies that any such exception has to be ‘subject to domestic law that is consistent with the international law of human rights’. From this optic, therefore, I would argue that time limits on the retention of records on a database could provide an important safeguard, limiting the potential for misuse by future governments. For example, records for convicted murderers and rapists could be kept permanently, but other records removed after fixed time-periods, depending on the nature of the offence.

4. Vulnerable Groups

The final issue concerning genetic discrimination to be addressed in this essay is vulnerable groups. Women, children, the disabled and indigenous peoples are amongst the groups that have been singled out as especially vulnerable to genetic discrimination. As regards the first of these, women, it has been argued that the patenting of human gene sequences represents a new enclosure of a long-accepted argument made by many pro-choice feminists and women’s health advocates, who oppose new genetic and reproductive technologies that put corporate profits over women’s health and well-being. Feminists have also raised concerns about the commodification of reproduction and human relationships that may follow from increased recourse to genetic reproductive technologies. In particular it has been argued that genetic testing and screening, both prenatally and in combination with IVF procedures, threaten new forms of discrimination

and stigmatization. Sex selection for ‘non-medical’ reasons is prohibited by Article 21 of the WHO Draft Guidelines for Bioethics, presented at the World Health Assembly in 1999,⁵⁸ Article 14 of the Oviedo Convention,⁵⁹ and Article 68 of the Report of International Bioethics Committee of the UNESCO on Pre-Implantation Genetic Diagnosis and Germ-Line Intervention.⁶⁰

One of the most sensitive issues in genetic discrimination is that of ‘experiments’, or non-therapeutic research, on children, which leads us back to the Nazi eugenics age. In order to prevent this, the UNESCO Universal Declaration on Bioethics and Human Rights (UDBHR), from 2005, dedicated a special article, Article 7, to persons who do not have the capacity to consent. The Article not only repeats the stipulations of other international documents that say that authorization for such research should be based on the best interests of the person, it also stipulates that, as a general rule, research should only be carried out where it is for the direct benefit of the health of a person who does not have the capacity to consent.⁶¹ This Article therefore lends some support to the point-of-view according to which non-therapeutic research on children should be banned altogether.

Concern about genetic discrimination and vulnerable groups has also been raised by others. Civil rights and human rights leaders, for instance, are wary of a new free-market eugenics that could stoke the fires of racial and ethnic hatred. Many environmentalists see human genetic modification as another potentially disruptive technology being approved before long-range consequences are considered. And disability rights leaders charge that a society obsessed with genetic perfection could come to regard disabled people as mistakes that should have been prevented. At the international level, the Declaration on the Rights of Disabled Persons, adopted in 1975, stipulated that ‘whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental

⁵⁸ ‘Sex is not a disease. Except for severe sex-linked genetic disorders, the use of genetic services for the purpose of sex-selection is not acceptable.’

⁵⁹ ‘The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child’s sex, except when serious hereditary sex-related disease is to be avoided.’

⁶⁰ ‘Destruction of embryos for non-medical reasons or termination of pregnancies because of the specific gender are not “counterbalanced” by avoiding latter suffering by severe disease.’

⁶¹ Article 7 IDBHR: ‘In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent: (a) authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent; (b) research should only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law, and if there is no research alternative of comparable effectiveness with research participants able to consent. Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection of the individual’s human rights. Refusal of such persons to take part in research should be respected.’

rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible'.⁶² And the recent Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly in late 2006 and opened for signature in March 2007, provides in Article 17 that '[e]very person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'. Yet, the social model of disability, which shifts responsibility away from the disabled person's biological, psychic or cognitive equipment and towards the social, institutional and physical world designed with the characteristics and needs of the non-disabled in mind, has yet to gain wide currency in many societies. A public understanding of disabilities as 'illnesses' or 'deformities' to be eradicated could become especially problematic when the eradication of difference through genetic manipulation is within reach.⁶³ It could lead to an attempt to manipulate science to carry out a form of 'disability cleansing'. To reduce this risk, it will be important to listen to what patients' associations have to say on the subject of genetics. Patients and their families have concrete expertise of their own which must be taken into account. It is also the case that some disabled people are now seeking the right to choose to have disabled children, on the basis of new genetic screening tests that are becoming more widely available. Their argument is that they should be allowed to choose children more like themselves. The issue has divided opinions amongst obstetricians and gynecologists, some of whom regard the notion of deliberately choosing an embryo manifesting genes for deafness or dwarfism as pandering to the desires of parents rather than reflecting the best interests of a future child.

'Scientists say it's just DNA. For an Indian, it is not just DNA, it's part of a person, it is, with deep religious significance. It is part of the essence of a person. To us, any part of ourselves is sacred.'⁶⁴ It is widely known that the genes of some indigenous peoples are of special interest to researchers because their relative homogeneity facilitates the search for correlations between specific genes and phenotypic traits. During the 1990s, the Human Genome Diversity Project undertook to collect DNA samples from hundreds of indigenous groups for this purpose. The project has since been disbanded, but indigenous peoples are still the subjects of genetic research⁶⁵ and they have raised serious concerns about a

⁶² GA Res 3447 (XXX), 30 UN GAOR Supp (No 34) at 88, UN Doc A/10034 (1975).

⁶³ Koh, 'Different but Equal: The Human Rights of Persons with Intellectual Disabilities' (2004) 63 Maryland L Rev 1.

⁶⁴ D. Harry and F. Dukepoo, *Genes and Genetics: What Indians Should Know About the New Biotechnology* (1998).

⁶⁵ Despite the increased measures of protection, the HapMap is still vulnerable to misuse. The public nature of the project has removed questions of individual ownership and commercialization, yet unrestricted access to the database creates an opportunity for abuse. HapMap cannot guarantee that the public will not mischaracterize results of the study and associate negative results with certain groups. Unless there are regulatory measures to enforce sanctions, groups and individuals within those groups will be unprotected against discrimination and social marginalization.

range of issues, including: the patenting and commercialization of the information derived from their samples; the lack of fully informed consent by many of those from whom samples were taken; the potential for genetic discrimination based on the identification of group differences; and the disproportionate allocation of public funds to genetic research rather than to direct health-care and prevention programmes. There is also a longstanding problem concerning individual consent and the usurpation of group identity in favour of an individualistic one that may not be reflected in the local culture. By conferring only with individual participants, researchers may diminish the authority of the group to make decisions concerning its members. This violates the draft United Nations Declaration on the Rights of Indigenous Peoples by compromising the right to self-determination and cultural independence. The challenge is to incorporate all levels of consent in a way that conforms to the cultural norms of a particular group.⁶⁶

It is also the case that very little genetic-diversity research has focused on the health of indigenous peoples. Yet, across populations, different genes may be implicated in what appears to be the same syndrome, for example as non-insulin-dependent diabetes mellitus. This means that diversity research could play a very important role in ensuring that therapeutic methods are effective in diverse populations. Another real danger is that research will neglect the genetic bases of disease among relatively isolated, traditional communities. A brief glance at the future plans of major pharmacogenomic companies shows that some of their work is relevant to the specific health concerns of indigenous peoples. To date, however, most pharmacogenomic research has been directed at cancer, asthma and allergies, cardiovascular disease and neurodegenerative conditions such as Parkinson's and Alzheimer's diseases. Hence, one of indigenous peoples' main concerns is assuring the responsiveness of pharmacogenomic research to the needs of genetically distinct but marginalized societies, so that they fully benefit from new technologies rather than remaining—insofar as genetic research is concerned—an academic sideshow.⁶⁷

5. Conclusion

General laws governing personal health information can frequently protect genetic information, even if these laws are sometimes inadequate. Nonetheless the existence of genetic information imparts new intensity to the need to protect personal health information. As a result, legislation to address specific issues relating to genetic testing may be required to complement existing legislation. In

⁶⁶ Khan, 'Colonialism Revisited: Insights into the Human Genome Diversity Project' (1999) 3 *JLSC* at 345.

⁶⁷ Barsh, 'Pharmacogenomics and Indigenous Peoples: Real Issues and Actors' (2003) 11 *Cardozo J of Int'l and Comp L* 543.

this respect, guidelines regarding genetic discrimination should be adopted at the international level. In addition, legislation related to the taking of DNA from criminal suspects and the establishment of DNA databanks relating to convicted offenders must be carefully monitored to prevent an unwarranted enlargement of its scope.

More generally, public education is necessary in order to protect genetic privacy and prevent discrimination. Governments, in particular, have a duty to explain the uses of genetic information and their possible impact on society, and to educate the public and researchers about what the results of genetic studies mean and do not mean.⁶⁸

Research should focus on individual variations within populations, not among populations. And researchers need to shape their studies and present their results cautiously. They should define the population being studied precisely. They should also explain to what extent the threat of disease can be ascribed to genetic variants and how such variants interrelate with environmental factors. Where these matters are not well understood, doubts should be acknowledged.

To conclude, mention needs to be made of one of the most important forms of discrimination that has not been discussed here: namely, discrimination that limits or forbids access to research results for the states of the South. Put crisply, although international law stipulates the obligation to solidarity insofar as the availability of genetic research results, it still has no correspondence in reality.⁶⁹

⁶⁸ See eg Art 6 IDHGD which provides that: '[s]tates should endeavour to involve society at large in the decision-making process concerning broad policies for the collection, processing, use and storage of human genetic data and human proteomic data and the evaluation of their management, in particular in the case of population-based genetic studies. This decision-making process, which may benefit from international experience, should ensure the free expression of various viewpoints.'

⁶⁹ See Francioni, *supra* note 16.