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HUMAN GENETIC MANIPULATION AND THE RIGHT TO IDENTITY: THE CONTRADICTIONS OF HUMAN RIGHTS LAW IN REGULATING THE HUMAN GENOME

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Abstract

This paper analyses an overlooked tension between the right to personal identity and the collective right to human identity in the context of human rights law as it applies to prospective human genetic modification. While the right to personal identity may justify a valid interest in the modification of one's individual genome, the collective right to identity defends a global interest in the preservation of the human genome.

Taking this tension into account, the article identifies a number of contradictions and problematic issues in the current international legal regulation of the human genome that undermine the right to personal identity. These are the cases of the notion of the human genome as common heritage of humanity and the unfounded idea of species integrity, among others.

The article also argues that the Universal Declaration on the Human Genome and Human Rights (UDHGHR) and the Oviedo Convention, together with the UNESCO Bioethics Committee, adopt a "geneticist-identity framework" which favours a conception of human identity solely based on genetic components. By prohibiting any change to the constitution of that shared genetic inheritance, those international legal instruments place an unjustified brake on the possibility for human genetic modification. This, as the article explains, is at odds with the "personality-identity framework" of the European Convention on Human Rights Law (ECHR), which privileges a narrative and developmental idea of individual identity.

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1. Introduction

This article examines the inadequacies of the existing international legal framework concerning prospective technologies applied to human genetic modification. The analysis is pursued from a “right to identity” perspective. In this light, the paper draws attention to the current imbalance between the individual and the collective interests involved in the regulation of the human genome. Hence, the article finds an unjustified and disproportional prioritisation given to the idea of a collective, static and heritable genetic identity (framed in a rather deterministic fashion). This position overlooks the value and interest of individual identity by prohibiting any changes to the individual human genome under the cover of an absolute need to preserve a collective human genome which is deemed as the fundamental basis of human identity. This article thus argues in favour of a more balanced approach and proposes a legal view that takes into account the right to personal identity (and not only collective one) in the use of prospective technologies in the field of human genetic engineering. For that purpose, the paper identifies a number of flaws and problems in the international legal framework that regulates the human genome. These flaws demonstrate how the idea of a humanity-wide collective interest in the preservation of the human genome is poorly grounded and constructed.

Before advancing to the *problematique* in question and to the substantive arguments put forward in this article, there are a couple of remarks and assumptions that need to be clarified.

1.2 *The Nature and Assumptions of the Argument*

Regarding the nature of the argument presented in this article, it must be remembered that, given the present state of genetic technologies, the contradictions identified in this paper relate to genetic manipulations foreseeable in the future. The argument delivered here is primarily theoretical and prospective. The reasoning developed here does not rely on the extent of genetic modification technologies available now. Instead, it focuses on prospective technological developments of the future. Despite their theoretical and prospective nature, those arguments carry significant and pragmatic implications for the current regulatory framework and they question some of the existing assumptions, principles, and rules that currently govern the regulation of the human genome. This is the case for the notions of the human species and of what could be called a collective right to human identity.

Regarding the assumptions of the argument, it is equally pertinent to bear in mind the type of human genetic manipulation that is targeted in this article.

Taking into account the vastness of the field of genetic engineering and its numerous implications on human and personal identity, this article focuses its discussion upon the possibility of (voluntary) genetic modification in human adults.¹ The paper,

¹ Although unquestionably important for the theme of identity, practices such as genetic screening, cloning techniques, reproductive technologies and pre-implantation diagnosis (which allow for the selection of individuals before birth) will not be discussed. This article does not consider persons “created” or “designed” through reproductive cloning, as these cases go beyond the scope of the paper’s analysis.

therefore, focuses on adult people choosing to engage into genetic manipulation and avoids delving into complex problems of autonomy, self-determination and informed consent. Furthermore, the article departs from the assumption that these genetic modifications affect not just the somatic cells of the treated individuals but also their germ cells, and that these modifications, therefore, are transmissible to subsequent generations.²

Other important theoretical assumptions relate to health and safety risks and the scrutiny of public debate. The paper assumes that these genetic interventions can be (in a foreseeable future) successfully and safely performed without causing unintended health problems or risks. The article also departs from the assumption that these technologies have passed the test of public discourse, have undergone rigorous assessment of its potential impacts, and have explicit, public approval.³

In addition, it should be noted that the criticisms regarding the communitarian conception of common genetic heritage should be seen within the individual – collective identity rights dialogue and not extrapolated to questions concerning human genes patenting and other issues of commercialisation and intellectual property rights.

Before exposing these arguments and considering how they relate to the right to identity, the introduction of the right to identity within the current international law of human rights needs to be explained.

2. Human Rights and the Right to Identity

The international legal framework of human rights has rather recently “uncovered” the right to identity and launched it into the international legal arena. Besides its explicit reference in the UN Convention on the Rights of Child,⁴ which expressly recognises the right to identity, the latter has been recurrently invoked in the case law of the European Court of Human Rights in Strasbourg (ECtHR), namely through jurisprudential interpretation of the right for respect of one’s private life, as set out in Article 8 of the Convention.⁵ Despite not being specifically mentioned in any of the

² Genetic manipulations satisfying these conditions are not possible at present. Insofar as it has been attempted to date, adult gene therapy affects only the somatic genome, and not the germline. This article, nevertheless, adopts a forward-looking approach by examining how the possibility of changing an individual’s germ cells may alter humanity’s shared genetic inheritance and contravene the UDHGHR.

³ M Frankel, “Inheritable Genetic Modifications and a Brave New World: Did Huxley Have It Wrong?” (2003) 33/2 *The Hastings Center Report* 31-36, at 36. These two exposed assumptions are, moreover, in line with the report issued by the American Association for the Advancement of Science (AAAS) on inheritable genetic modification. See MS Frankel and AR Chapman, *Human Inheritable Genetic Modifications* (Washington, DC: American Association for the Advancement of Science, 2000). Frankel also concluded that “no genetic modifications affecting the germ line, whether intentional or inadvertent, should be undertaken until technology’s safety, efficacy, and social implications had been subject to widespread public discussion”. See M Frankel above, at 31.

⁴ Art 8(1) stipulates “the right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference”. For the inclusion of Article 8 as a result of a proposal by Argentina, see S Detrick, *The United Nations Convention on the Rights of the Child: A Guide to the “Travaux Préparatoires”* (Dordrecht: Martinus Nijhoff, 1992).

⁵ The full text of art 8 is:

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

articles of the European Convention on Human Rights (ECHR), the Court in Strasbourg has derived a right to identity from the “right to one’s private life”, enshrined in art 8 of the ECHR (in a similar way as to the right to privacy).⁶

2.1 Right to Genetic Identity

In light of new technological developments, namely in the field of genetics, the international legal framework of human rights has also had the benefit of re-conceptualising the right to personal identity.⁷ The new approach to the right to personal identity is based upon existential and developmental meanings of identity. Identity is not looked at as a sum of different elements, representative of one’s identity and subject of being misrepresented and falsified, but as a narrative, an individual inner story that each person needs to build, develop and rewrite over time in order to define the meaning of their lives.⁸

A paradigmatic example is the reference to the concept of genetic identity, which constitutes a significant advance in the conceptualisation of the right to identity. Despite its clear focus on the genetic components, it is important to note that the relevance and weight attributed to the concept of genetic identity (as the right to identity encompassing genetic characteristics) has not been extrapolated (at least theoretically). Genetic attributes are seen as only a part (albeit important) of someone’s identity, not equating to the whole of the identity itself. Moderation and balance in dealing with this concept prevents engaging with a sort of “genetic

2. There shall be no interference by a public authority with the exercise of this right except such as 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.

⁶ The ECtHR has “consistently viewed Article 8’s protections expansively and interpreted the restrictions narrowly”, so that now there is a right to personal autonomy, identity and integrity even if not explicitly stated in the Convention’s text but interpreted by the ECtHR from “the right to respect one’s private life”. J Marshall, *Personal Freedom through Human Rights Law?: Autonomy, Identity and Integrity under the European Convention on Human Rights*, International Studies in Human Rights, 98 (Leiden: Martinus Nijhoff, 2009), at 31.

⁷ Human genetics, in fact, can be seen “as the ‘new’ engine of the modern construction of human rights”. H Boussard, “Individual Human Rights in Genetic Research: Blurring the Line between Collective and Individual Interests”, in T Murphy (ed), *New Technologies and Human Rights* (Oxford: OUP, 2009), at 246.

⁸ This “autobiographical” characterisation of identity, conceptualised in human rights law, represents a welcome addition (and evolution) to the administrative-oriented meaning of identity, as configured by domestic private law. While the latter had the State as point of departure, setting up the identity elements that would characterize and individuate each individual; now, and within the human rights perspective, the individual is the starting point, stipulating and deciding which identity elements he or she wants to be described and recognised by. For more detailed notes on the history of the conceptualisation of the right to identity, see N De Andrade, “Right to Personal Identity: The Challenges of Ambient Intelligence and the Need for a New Legal Conceptualization” in S Gutwirth et al (eds), *Privacy and Data Protection. An Element of Choice*. (Dordrecht: Springer, forthcoming 2011). It is the idea of identity as a narrative process, a life-time exercise of creating and recreating one’s own story, which explains the Court’s open and progressive stance in establishing sexual identity rights (namely in the cases of sex change) and as in allowing access to information about one’s origins and past experiences (also considered important aspects of one’s identity). For a more detailed analysis, see J Marshall, see note 6 above, at ch 7.

essentialism” or “genetic reductionism” which reduces the human person to a mere expression of his or her genetic architecture. Consequently, the definition of personal identity, as professed by human rights, strives to balance the influence of genetics alongside the role of the environment and social conditioning in the formation of one’s identity. In this regard, the wording of Article 3 of the International Declaration of Human Genetic is particularly relevant, as it refers to the “person’s identity” encompassing not only the genetic components of each individual, but also the “complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others”.⁹

The right to genetic identity, moreover, has recently acquired considerable importance in the face of the risks and threats of genetic manipulation. As genes are shared to a lesser or greater extent by all human beings,¹⁰ the question of re-engineering or manipulating those genes implicates not only the interests of the individual human person but also the interests of groups and future generations. As a result, family, specific communities and potentially all of humanity’s interests are at stake in the field of human genetic manipulation. Given the peculiar dual nature of genes, as well as the intricacies and subtleties of the international legal framework of human rights in the field of genetics, it is necessary to acknowledge the double vest in which the human person is protected by the correspondent body of human rights. Accordingly, the human rights legal framework in the field of genetic engineering protects the human person not only as an individual per se, but also as a depository of the genetic heritage of the human species.

Therefore, “the protection of genetic identity appears as the new rationale of the right to identity (the genetic identity of the individual) and the right to the uniqueness of the individual (the genetic identity of the human species)”.¹¹ In the conceptualisation of the right to identity endorsed by this perspective, and given the collective dimension of the human genome, it is interesting to note that the right to identity no longer protects personal identity in the sense of “who am I”, but in the sense of “who will my descendants be”. The rationale behind this particular manifestation of the right to identity is no longer shaped by the need to protect one’s self-perception (who am I to myself) or the perception of myself forged by a second-person (who am I to others),¹² but “who am I” according to the genetic characteristics of the human species. Here, the individual is protected as part of the whole, as representative of an important community, i.e. humanity. As such, “the individual is protected as a depository of the

⁹ Contrary to this moderate and laudable definition of identity, the bias towards the collective idea of identity and integrity of the human species contradicts this extra-genetic notion of personal identity, focussing solely upon genetic criteria in defining and upholding the collective entity at stake, the human species.

¹⁰ As the constituent building block of all organic life, genes are shared by family relatives and, to a larger degree, by all human beings. Each of us does not only share part of our genomes with parents, siblings and other family members, but also with any other human being. In this light, it has been argued that the human genome is simultaneously universal and individual S Barbas, *Direito Do Genoma Humano* (Coimbra: Almedina, 2007), at 14. This notion represents not only the set of genomes of all past, present and future human beings, but also the genome of a specific and determined individual.

¹¹ H Boussard, see note 7 above, at 249.

¹² These two identity perspectives, named *idem/ipse* identities, have been advanced in philosophy by P Ricœur, *Oneself as Another* (Chicago: University of Chicago Press, 1992).

genetic heritage of the species and the right to genetic identity protects the interests of future individuals and of the human species over time”.¹³

Nevertheless, the manner in which the right to identity conciliates the individual and collective interests implicated in the protection of the human genome is unbalanced and unarticulated. The right to genetic identity stands in a conceptual quagmire when one looks at the competing individual and collective interests regarding human genetic modification. In this respect, the connection between the right to genetic identity, on the one hand, and the right to genetic integrity and the right to a non-modified genetic heritage, on the other, is problematic. This connection, as this article will attempt to demonstrate in the following sections, uncovers several intricate problems, erroneous assumptions and negative implications. In contrast to the legal situation portrayed within the scope of the general Human Rights Conventions (such as the ECHR), the international human rights legal instruments in the field of genetics expose a rather unarticulated and problematic right to genetic identity, framed between individual and collective conflicting interests, and with an unclear relation to the right to integrity and the regulation of the human genome.

The following section gives a brief analysis of the international law of human genetic manipulation. It analyses the current regulation of the human genome, encompassing its designation as Common Heritage of Humankind, as well as the so-called right to a non-modified genetic heritage.

3. The International Law of Human Genetic Manipulation: The Regulation of the Human Genome

The underlying objective behind the international law of human genetic manipulation and the regulation of the human genome¹⁴ is the protection of the genetic identity of both the human individual and the human species.

Among the different legal constructions that have emerged in order to protect the genetic identity of the human species,¹⁵ the most intriguing ones are the so-called Right to Genetic Integrity and the Right to a Non-Modified Genetic Heritage.

Within the context of gene therapy, the right to genetic integrity impedes the modification of the genetic code of the individual. This right was originally termed in the 1982 Recommendation of the Parliamentary Assembly of the Council of Europe on Genetic Engineering as the “right to a non-modified genetic heritage”. Aware of the dangers posed by “the use of new scientific techniques for artificially recombining genetic material from living organisms, referred to as ‘genetic engineering’” (point 1),

¹³ H Boussard, see note 7 above, at 259.

¹⁴ The human genome is the term used to collectively describe all of the (approximately 30,000) genes found in humans. It constitutes the complete DNA sequence for a human, comprising all of the genetic materials that make up an individual person. In this way, the definition of the human genome encompasses not only the full set of genes of each individual, but also the entire range of genes constituting the human species.

¹⁵ Boussard lists four legal constructions connected to the protection of genetic identity: 1) the prohibition of practices contrary to human dignity, in particular the prohibition of reproductive human cloning (art 11); 2) the right to genetic integrity and the right to a non-modified genetic heritage; 3) the right to a unique identity (which is related to the embryo) and 4) the principle of non-discrimination. H Boussard, see note 7 above.

the Parliamentary Assembly decided to enshrine a novel human right: “the right to inherit a genetic pattern which has not been artificially changed” (point 4.a). Deriving it from the rights to life and to human dignity, this right was not framed in absolute terms, contemplating an exception for therapeutic applications (gene therapy). Through that recommendation, the protection of the human genome was deemed as a fundamental step in ensuring respect for human dignity in both its individual and collective aspects.

Moving to the present and observing the current Regulation of the Human Genome, two international instruments assume particular relevance: the Universal Declaration on the Human Genome and Human Rights (UDHGHR)¹⁶ and the Oviedo Convention on Human Rights and Biomedicine (Oviedo Convention).¹⁷

Following the same lines of the 1982 Recommendation, the Oviedo Convention emphasises the protection of the dignity and identity of all human beings (art 1), allowing only interventions which seek to modify the human genome for preventive, diagnostic or therapeutic purposes (art 13).¹⁸ The UDHGHR, while stating in its first article that the human genome “underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity”,¹⁹ contributes to the international legal framework by declaring the human genome as the Common Heritage of Mankind.

These international instruments are committed to ensuring the preservation of the human species by defending it from scientific and technological practices that may violate its integrity and common identity. By preventing possible modifications to the human genome, these instruments seem to have the objective of ensuring that humans remain humans in light of scientific advancements.

The regulatory legal framework of the human genome is, nonetheless, deeply flawed and inconsistent, and it hides a number of problems and erroneous assumptions. The next section provides a detailed analysis of these flaws, problems and assumptions.

¹⁶ The UDHGHR was adopted by the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 1997. Presented as a companion instrument in the field of genetics to the 1948 Universal Declaration of Human Rights, the UDHGHR served as the building block for the UNESCO 2003 International Declaration on Human Genetic Data (IDHGD) and the 2005 Universal Declaration on Bioethics and Human Rights (UDBHR).

¹⁷ This Convention presents the particularity of being the only legally binding instrument (for state parties), having “a special authority to create new human rights or interpret positive rights (i.e. rights enshrined in human rights treaty or customary international law) in genetics”. H Boussard, see note 7 above, at 247.

¹⁸ Art 13, Interventions on the Human Genome:

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aims are not to introduce any modification in the genome of any descendants.

¹⁹ The UDHGHR also establishes in its first article that the human genome is, in a symbolic sense, the heritage of humanity. I shall return to this important point.

3.1 The Flaws and Problems of the Current International Legal Regulation of the Human Genome

The underlying general problem cutting across the following list of flaws concerns the unresolved tension between individual and collective interests, namely the current imbalance between an alleged human species identity and every other individual identity. These flaws and problematic issues demonstrate how the right to personal identity has been undermined by a collective right to the preservation of an alleged human identity.

3.1.1 The Relationship between the Right to Genetic Identity and the Right to Genetic Integrity

The first problem refers to the lack of uniformity across the different legal instruments regarding the articulation between the right to identity and the right to genetic integrity.

The recognition of a person's right to a non-modified genetic patrimony was initially formulated as a right to genetic identity.²⁰ An example of this correspondence can be found, for instance, in a 1993 proposition for a European Parliament resolution on the right to genetic identity, which stated that the right to genetic identity covered the right to a non-modified genetic heritage.²¹

The situation is different in today's legal framework. The Oviedo Convention, although it explicitly refers to the protection of the integrity of human beings (art 1), does not enshrine a general right to genetic integrity. Along the same lines, the final version of the UDHGHR, despite some hesitation occurring during its drafting phase, does not make any reference to the integrity of genetic heritage and limits itself to forbidding a restricted number of practices which are contrary to human dignity. This document, rather than focussing upon the idea of integrity, insists upon the link between human genome and dignity.²²

Nevertheless, international human rights law is not entirely coherent or uniform in this matter. While the Oviedo Convention explicitly precludes genetic interventions aiming at introducing any modifications in the genome of any descendants (art 13),²³ the UDHGHR is slightly more flexible, as it does not explicitly prohibit interventions upon germ-line cells.²⁴ The latter international instrument, in fact, "only" states that

²⁰ R-M Lozano, *La Protection Européenne des Droits de l'Homme dans le Domaine de la Biomédecine* (Paris: Documentation Française, 2001), at 211.

²¹ Proposition for a European Parliament resolution on the right to a genetic identity filed by M Valverde Lopez, 21 December 1993, B3- 1651/93, PE 179.062, at 2 cited in *Ibid*, 213.

²² Furthermore, the International Declaration on Human Genetic Data (IDHGD) follows the same trend, failing to contemplate any reference to a right to genetic integrity, defining instead a person's identity in a broad and extra-genetic way: "Each 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".

²³ Allowing only human genome modifications performed for preventive, diagnostic or therapeutic purposes (art 13).

²⁴ R-M Lozano, see note 20 above, at 217.

“practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted” (art 11).²⁵

In addition, it is important to understand that not every intervention on the human genome aimed at modifying the germline necessarily equates to an eugenic practice. Therefore, it is more appropriate to follow the drafting example of the Charter of Fundamental Rights of the European Union’s art 3, “Right to the integrity of the person”, which unlike the Oviedo Convention, does not enshrine any general prohibition of germline genetic modifications. Art 3, refers instead to the prohibition of eugenic practices (in particular those aiming at the selection of persons) specifically and to the reproductive cloning of human beings (art 3.2). Contrary to the initiatives in the 1980s and 1990s led by European institutions, the right to genetic integrity is no longer formulated in terms of a general right to a non-modified genetic heritage or as an equivalent of a right to genetic identity.

The association of the right to genetic integrity (and, subsequently, the right to a non-modified genetic heritage) with the right to genetic identity constitutes an old-fashioned, narrow and detrimental view of human genetic manipulation, which focuses solely upon the perils of the latter without considering the potential benefits that can be derived from human genetic interventions. The right to genetic identity, therefore, should both foresee the integrity but also the changeability of one’s genetic architecture:²⁶ the right to personal identity may perfectly encompass the right to individual genetic modification.

3.1.2 The Ambiguity of the Right to Genetic Integrity and the Different Understandings of the Human Genome Concept

Despite the conceptual autonomy granted to the right to genetic integrity, it might be noted that a fundamental ambiguity still runs through the concept of genetic heritage, and hence of genetic integrity, as embodied in the various legal instruments pertaining to human rights law. In some instances, genetic integrity appears to be equated with the genetic constitution of the human species as a whole. According to this view, the human genome equates to the pool of all the genes of the human species.²⁷ In others, the concept of genetic integrity seems to correspond merely to the genetic inheritance of particular individuals,²⁸ be they existing or future individuals. The human genome, in those terms, seems to equate to an individual’s own genome.

This ambivalence has further implications for the circumstances under which contradictions might arise between the individual right to identity (and the right to individual genetic modification that is taken to imply) and the right to genetic integrity (along with the right to a non-modified genetic heritage). Suppose an

²⁵ Individual states complete the identification of these manipulations.

²⁶ Or, less dramatically, the possibility of attaining new and different genetic integrities.

²⁷ Art 1 of the UDHGHR states that: “The 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”.

²⁸ Art 8 of the Universal Declaration on Bioethics and Human Rights states that: “Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected”. Art 11 of the Oviedo Convention states that: “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited”.

individual undergoes genetic modification by incorporating favourable alleles of genes obtained from other humans. This will affect the genetic inheritance and integrity of future individuals descended from the modified individual, but will make no difference to the constitution of the collective human genome. In other words, it will have no implications for the genetic integrity and identity of the human species. Does this genetic intervention constitute, for instance, a modification of the human genome according to the Oviedo Convention, or not? If the concept of genetic integrity is understood as the collective human genome of all human beings, then the genetic integrity of the human species will only be changed if an individual or individuals undergo genetic modification that involves the incorporation of genes deriving from non-human sources. This understanding considerably restricts the scope of the law regarding collective human genetic identity and integrity. In practical terms, while gene therapy employing non-human genes is hypothetically possible, at present it appears highly unlikely to occur in the foreseeable future.

The protection of the human genome through the right to genetic integrity should therefore be further clarified in human rights law.

3.1.3 Therapy versus Enhancement

Another flaw in the international legal regulation of the human genome is the difficulty to distinguish between what therapy is and what is not. Art 13 of the Oviedo Convention, which restricts interventions on the human genome to only those serving therapeutic purposes, poses exactly this problem. In light of the current and forthcoming technological advancements, the problem consists in distinguishing between therapy and enhancement. This is a definitional²⁹ quandary that lawyers and judges, sooner or later, must face when interpreting the current rules regulating the human genome. In this regard, and as Frankel observes, one must realise that “what [m]akes inheritable genetic modification attractive is not its ability to treat disease, but its capacity, someday, to enhance human traits beyond what mere good health requires”. It is thus of paramount importance for legal scholars to consider the possible uses to which inheritable genetic modification (IGM) will be put, as they will most probably not only include the alleviation or elimination of genetic diseases, but also the enhancement of human traits.³⁰ The problem then is defining what good health means in terms of the frontier line between therapy and enhancement.

Coming back to the letter of the law, the problem legal scholars must face and acknowledge is that the distinction between therapy and enhancement is, in certain contexts and relative terms, a subjective, if not impossible, one to make. In fact, a distinctive line between enhancement and therapy has never been very clear and its lack of definition has hidden conceptual problems in distinguishing both terms. Furthermore, the line distinguishing treatment from enhancement will become increasingly difficult to draw. There will be many border-line cases in which it will be difficult to determine whether a set of conditions qualifies as enhancement or

²⁹ Enhancement, in this regard, is a matter of definition ET Juengst, “What’s Taxonomy Got to Do with It? ‘Species Integrity’, Human Rights, and Science Policy”, in J Savulescu and N Bostrom (eds), *Human Enhancement* (Oxford: OUP, 2008) 43-58, at 43.

³⁰ MS Frankel, see note 3 above, at 32. The author, furthermore, argues “that enhancement applications more than medical uses will determine the scope, direction, pace, and acceptance of IGM in the United States” *Ibid*, 33.

therapy.³¹ In this sense, “the treatment-enhancement distinction will seem arbitrary in a certain range of cases because our distinction between normal and abnormal health will sometimes seem arbitrary”.³² Many enhancements can simultaneously be characterised as treatments: “Is Ritalin a concentration enhancer, or is it a treatment for attention deficit hyperactivity disorder?”³³

Furthermore, and as Harris observes, clinicians and doctors can always tinker with the line between the world of the healthy and the one of the unhealthy by diagnosing any kind of symptom as an illness, impairment or disorder and recommending a treatment that was previously seen as an enhancement. In addition, and with the expected growth and development of enhancement technologies, what was not seen as a disease might start to be perceived as one, as for example ageing. Still following Harris’ reasoning, there are cases in which enhancements will raise no ethical doubt, seeming not only justifiable, but even desirable. This is the case, for example, of immunisations, which enhance a person’s immune system rather than cure or control an illness.³⁴

To complicate things even more, the technology developed for therapeutic purposes will be the same as that used for enhancement. In this light, the availability of medical treatment technologies, even if not intentionally, will inexorably promote enhancement applications as well.³⁵

Pursuing these arguments even further, and in light of the growing definitional indistinctness between therapy and enhancement, which puts into question the meaning of the concepts of illness and health, the possibility of classifying gene modification among health services will be a matter of opinion.³⁶ In effect, the right to health could be invoked to justify the use of germline genetic engineering.³⁷

The right to modify one’s genome (as implied by the right to personal identity) is thus constrained by this inoperable distinction between therapy and enhancement. Therefore, instead of sustaining the artificial distinction between therapy and enhancement – and taking into account the inexorable enhancement applications that will soon be made if they are not already – it would be more appropriate to draft a regulatory framework according to a different model, drawing different lines and distinctions, filtering and judging what genetic modifications should be admitted and which ones should be prevented. One of the cornerstones of this model could be the interest and value of identity.

³¹ Moreover, the accuracy of this distinction is important for practical reasons, “as many people argue that third-party payers (e.g. insurance companies) are obligated to pay for treatments, for example, but not for enhancements, such as breast augmentation surgery or Rogaine for baldness”. C Elliott, “Enhancement Technology”, in DM Kaplan (ed), *Readings in the Philosophy of Technology* (Lanham, MD: Rowman & Littlefield Publishers, 2004) 373-379, at 373.

³² D Degrazia, *Human Identity and Bioethics* (Cambridge: CUP, 2005), at 217.

³³ C Elliott, see note 31 above, at 374.

³⁴ J Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton, NJ: Princeton University Press, 2007).

³⁵ MS Frankel, see note 3 above, at 33.

³⁶ SP Marks, “Tying Prometheus Down: The International Law of Human Genetic Manipulation” (2002) 3/1 *Chicago Journal of International Law* 115-136, at 129.

³⁷ *Ibid*, 129-130.

3.1.4 *Common Heritage of Mankind*

Another important factor, present in the regulation of the human genome, that may undermine the right to personal identity is the declaration of the human genome as Common Heritage of Humanity.

The HGHRD declared the status of the human genome as a “common” heritage to which we all have a claim. In this light, art 1 confirms that the “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”.³⁸

In this manner, and in order to protect the genomic integrity of humanity, each country – according to cultural, ethical, social, religious and economic values (among others) – protects the set of genes of each person, not only in its tangible dimension (DNA and RNA), but also in its intangible aspect (information).³⁹ In practical terms, the genome is acknowledged as a human resource whose effective utilisation will be subject to an International Committee of the United Nations. Briefly, the information embedded upon the human genome, assumed as constitutive component of the human person, is now a Common Heritage of Humanity which has been delivered to the guardianship of humanity through its representative body, the United Nations.⁴⁰

There seems to be a growing acknowledgement and confirmation that the human genome is the common heritage of humanity at the international level. Nevertheless, and adding to the problems analysed above, this designation also raises a number of difficulties. In effect, the Common Heritage Doctrines that have been applied to the Human Genome present intricate problems with the right to personal identity.

The Common Heritage Property Doctrine (CHPD), in alleged accordance with the HGHRD, considers that the human genome is the property of all humankind. The problem with this legal proprietary construction of the human genome as common heritage of mankind is the difficulty of promoting a supposedly collective administration of a genetic resource that inhabits and constitutes our own bodies. In this light, and as Ossorio provocatively asks:

What would it mean to manage the human genetic resource for the common good when that resource resides, at least in part, in the bodies of all people? What goods and values would be pursued through this management, and how would such management be conducted without interfering with procreative liberty and personal privacy?⁴¹

³⁸ The Inter-Parliamentary Union, “Resolution on Bioethics and Its Implications Worldwide for Human Rights Protection” (1995) also affirms the common genetic heritage of humankind. UNESCO had only attributed the designation of Common Heritage of Mankind to physical realities, such as the moon, the deep seabed, and monuments with cultural value.

³⁹ D Serrão, “Nota Sobre o Anteprojecto da Declaração da UNESCO Sobre o Genoma Humano”, (Lisboa: Conselho Nacional de Ética Para as Ciências da Vida, 1997).

⁴⁰ D Serrão, “A UNESCO e o Genoma Humano” (1996) 146/6 *Brotéria*.

⁴¹ P Ossorio, “The Human Genome as Common Heritage: Common Sense or Legal Nonsense?” (2007) 35/3 *Journal of Law, Medicine & Ethics* 425-439, at 429.

Above all, I would add, how would this collective management be conducted without interfering with one's right to personal identity? Unlike the moon and the deep seabed, the human genome is not three hundred thousand kilometres away from earth or lying deeply on the ocean floor. The human genome in contrast "resides, at least in part, in the bodies of autonomous persons, who possess interests, values, projects, and legal rights".⁴²

As for the Common Heritage Duties Doctrine, its preservationist underpinning emphasises an important, and polemic, value relating to the human genome, that is, the value of non-intervention, or the value of respect for natural genomes.⁴³ This view advocates that the naturally evolved human genome should be preserved and protected for future generations. This position, as we have seen, corresponds with the one followed by the Council of Europe.⁴⁴

The designation of the human genome as a Common Heritage of Humankind and its supporting arguments are additionally based upon the utilitarian principle of "the greatest good for the greatest number of people". In our case, this translates the idea that genetic materials – like all of the world's resources – should be utilised to provide the greater good and benefit to all of humanity, as to do less would mean failing to recognise the common interests and needs of all humanity.⁴⁵ These common heritage arguments defend a "cultural imperative for us to...use the extraordinary scientific power that has been created through the development of DNA Technology...for the benefit of all people".⁴⁶ At first glance, these arguments may even seem valid and justified, namely in the field of disease prevention and treatment, in which the favouring of the whole to the detriment of the part may appear defensible. But what if genetic research dealt with a different type of application, related not to disease prevention and treatment, but to genetic manipulation of the human genome of a given individual for non-therapeutic purposes (assuming that a clear distinction between therapeutic and non-therapeutic purposes can actually be made)? Should the individual interest in pursuing this genetic modification be also subject to the scrutiny of the collective humanity group, having to be filtered by the criteria of the greater good and benefit to all of humanity? Nonetheless, and if so, what good and interest would that possibly be?⁴⁷

It has been observed that the "idea that the interests of the many will always trump the interests of the few in this field is obviously untrue".⁴⁸ Even in the area of research for

⁴² *Ibid.*

⁴³ *Ibid.*, 431-432.

⁴⁴ Furthermore, and as we shall see in the following, this view also raises the problem of the status quo bias of the current legal framework, which privileges natural modifications upon the human genome to the detriment of artificial ones. It is also a view that sustains an obsolete view of an untouchable status of the human genome, disregarding the beneficial interventions (e.g. for disease prevention) that can already be conducted in its core structure.

⁴⁵ L Underkuffler, "Human Genetics Studies: The Case for Group Rights" (2007) 35/3 *Journal of Law, Medicine & Ethics* 383-395, at 391.

⁴⁶ *Ibid.*, 391, n 89.

⁴⁷ This issue brings us back to the dual meaning that can be attributed to the concept of the human genome (as the human genome of all humanity or the human genome of a given specific individual).

⁴⁸ L Underkuffler, see note 45 above, at 391.

diseases and cures, the purely utilitarian calculation has its obvious limits, as despite the essential human interests at stake, the potential benefits deriving from the research cannot force individuals to undergo genetic testing or to be submitted to medical research.⁴⁹

Following Underkuffler's claims, common heritage arguments are a way to (falsely) assume the superiority of numbers and they lend no justification for assuming the supremacy of the many over smaller groups. Applying the author's reasoning to the prospect of human genetic modification, the conception of the human genome as a common heritage of mankind (and, consequently, as a resource to be maintained intact) acts as an instrument to preclude, in a single stroke, the assertion of any (identity) interests by the opposing individual.⁵⁰

Another intricate problem raised by the legal construction of the human genome as common heritage of mankind⁵¹ concerns the problematic conception of the human species, that is, humanity itself, as the subject of this collective right.⁵²

3.1.4.1 The Static Assumption of the Human Genome and Legal Bias for the Status Quo

The confirmation of UNESCO's International Bioethics Committee (IBC) that "the human genome must be preserved as a common heritage of humanity"⁵³ raises further problems about the right to personal identity. John Harris particularly identifies two problematic and incompatible assumptions that are rarely detected. The first one is that we have reached the peak of our evolution, achieving a status that is impossible to surmount. The second one is that the natural course of evolution, left alone from any artificial intervention, will continue to improve things for humankind, or at least not make things worse.

Taking into account that the common heritage of humanity is a result of evolutionary change, Harris argues that it is only rational to uphold the precautionary principle in this area if one can be sure that the evolution of humankind free of any human genome manipulation will be better than the one subject to proposed genetic manipulations. Without any term of comparison, there is no reason or basis to decide between which course of human evolution (natural or artificial) one should be cautious about. Harris states that:

⁴⁹ *Ibid.*

⁵⁰ The common heritage arguments have been fiercely criticised mainly within the legal debate concerning indigenous genetic resources, being depicted as "declarations of ownership, control, and exclusivity of interest". *Ibid.*, 392. Many scholars, in this context, oppose the idea that indigenous genetic resources belong to everyone; this claim transforms those genetic resources into public goods subject of being converted into private property by those who would exploit them. L Whitt, "Cultural Imperialism and the Marketing of Native America" (1995) 19 *American Indian Culture and Research Journal* 1-31, at 14-15.

⁵¹ This idea and construction of the human genome as common heritage has been subject of much criticism. One of those critics claims that "if the human genome is an abstraction and not a natural object, people's worries about preserving its integrity for future generations become concerns about the future of an idea not a natural resource". E Juengst, quoted in P Ossorio, see note 41 above, at 432.

⁵² As we shall see in section 3.1.4.2

⁵³ J Harris, see note 34 above, at 34.

...it is unclear why a precautionary approach should apply only to proposed changes rather than to the status quo. In the absence of reliable predictive knowledge as to how dangerous leaving things alone may prove, we have no rational basis for a precautionary approach which prioritizes the status quo.⁵⁴

This argument cleverly plays with the meaning and functioning of the precautionary principle, deriving from its task of preventing future risky actions a task of preventing present risky ones. In other words, it shifts the precautionary principle from being a passive principle (letting things stay as they are) to an active one (changing things as they are), inducing action instead of preventing it. Whether or not the precautionary principle should be interpreted in this manner, the argument is important because it underlines UNESCO's unexplained bias towards a static configuration of the human genome. It calls our attention to the fact that the human genome will inexorably keep evolving and that a comparative analysis of the perils and the advantages of human evolution, either with or without genetic induced alterations, should be done. Furthermore, it calls our attention to the fact that there is a status quo bias in the legal framework, which favours natural and progressive changes to the detriment of technological induced ones. This status quo bias, in addition, is not supported by any explanation of what exactly the dangers emerging from genetic modifications supposedly are. Why is it better to avoid every kind of artificial genetic modification? Law, in this case, seems to stipulate prohibitions to one's right to personal identity without giving proper justifications.

3.1.4.2 *Humanity as a Subject of Law*

Another relevant legal problem that may affect the individual's right to exercise his or her personal identity is the conceptualisation of humanity as a subject of law. With the proclamation of the human genome as the Common Heritage of Mankind,⁵⁵ the concept of humanity – present and future – has now been considered a subject of rights, representing a completely new notion and concept in international law.⁵⁶ According to some authors, this Declaration has converted the human genome, in addition to the human person, into a subject of rights.⁵⁷

The legal difficulty one faces in constructing the notion of common heritage of mankind, along with the collective right to an untampered human genome, is the concept of subject of law, that is, the right holder. What group has this collective right? Is humanity itself a subject of law?

⁵⁴ *Ibid.*

⁵⁵ For an overview of the main legal questions surrounding the legal construction of the human genome as Common Heritage (CH), as well as a synthetic explanation of the CH Property Doctrine and the CH Duties Doctrine applies to the human genome, see *Ibid.*

⁵⁶ S Barbas, see note 10 above, at 17.

⁵⁷ D Serrão, see note 39 above, at 3. Stela Neves Barbas, in this context, speaks of a shift from the "right to the human genome", with the genome as the object of the right, to the "right of the human genome", with the genome as the subject of rights. The author, in fact, entitled the published version of her doctoral thesis as "The Right of the Human Genome". SN Barbas, see note 10 above.

This issue relates to the rather polemic question of group rights in the field of genetics and its tension with individual rights. In this regard, different collective entities have been referred as legitimate subjects of presumed collective rights in the genetic domain. Three distinct groups can be envisaged: families,⁵⁸ specific communities (such as indigenous populations), and humanity. Unlike the usual scope targeted by the majority of the specified literature, the group to whom the affordance of the collective right (in this case, the right to identity) is being discussed is not an indigenous community, a family ensemble or an ethnic group, but all of humanity. The problem here is that the group is not defined too narrowly but too broadly.

While the “individual versus group” question has already received some detailed attention from a number of legal scholars regarding the issue of family and indigenous rights, the question of the individual versus humanity in terms of right to identity has not yet been explored and it lies in a limbo of legal vagueness and uncertainty. One of the main problems regarding the individual-collective tension contributing to this vague state of affairs is precisely the issue of the subject to whom the collective right should be attributed, that is, the concept of humankind. Bearing in mind the alleged right to an untampered human genome, the recognition of a collective right to the integrity of the human genome belonging to the human species immediately raises the problem of defining humanity as a subject of law. In other words, the crux of the problem lies upon the definition of humanity as a group concept, entitled to a collective right. What is humanity in the context of law?⁵⁹

Among the varying formulae put forward by theorists for group recognition in particular contexts, neither the sharing of a common culture, nor the partaking in a continuous history or the connection to a specific territory seem to provide a sufficiently valid and concrete evidence for the identification of humanity as a (legal) group. Since not every single human being shares a common culture and is neither connected through a continuous history (which, anyways, constitute two sets of very subjective criteria), what common factors could be envisaged in order to assert the group recognition for humanity? Dismissing the geographical factor as an appropriate one for establishing humanity as a group (the fact that all human beings are connected to the territory of planet earth constitutes such a broad criteria that it loses its meaning), the only factor remaining seems to be our shared genes. Following this logic, all human beings form the group of humanity because we all share the same pool of genes. Nevertheless, the problem with this construction is that it follows a clear, incoherent and contradictory genetic reductionist perspective. In this light, the inconsistency is evident: while a human individual should not be reduced to her genetic architecture, why humanity should? In addition, taking into account the imbalance between the individual and the group interests mentioned before, the outcome is that the right to personal identity (the right to identity of the individual),

⁵⁸ This has been the case of the family as group right (there are already specific proposed rights), and of indigenous people. In the case of family, the problem is that the genetic information revealing that a person has an increased risk for a given disease impacts not only the identity of that individual but also of his or her whole family (as they share the same genes).

⁵⁹ For a detailed analysis of the introduction and the implications of the notion of human species in law, as well as the problems arising from its primacy to the detriment of the human individual, see P Descamps, *Le Sacre de l'Espèce Humaine: Le Droit au Risque de la Bioéthique* (Paris: Presses Universitaires de France, 2009). The author compellingly argues that the notion of human species is deprived of both juridical and biological consistence.

framed as a developmental and existential one, is curtailed by a right to collective identity (right to identity of the human species), framed as strictly genetic. Does it make sense to exclude the genetic reductionist view at the individual level while imposing it at the collective level?

3.1.5. *The (False) Idea of Species Integrity and the Taxonomical Subtleties of the “Human” Concept*

A final flaw in the legal regulation of the human genome with negative implications for the right to personal identity is the idea of species integrity. In fact, the idea of “species integrity”,⁶⁰ which is behind the value of non-intervention and preservation of the human genome, along with the conceptualisation of the human genome as common heritage of mankind, the designation of humanity as a subject of rights and, ultimately, the humanity’s collective right to identity, are all misleading legal constructions. In this regard, one should realise that species are not static collections of organisms and that their genetic complexions shift across time and space.⁶¹ Scientifically speaking, the idea of integrity of the human species is, as a matter of fact, a slippery and relativistic concept. It has been pointed out that:

Rather than single organisms, human individuals, like termites, are in fact super-organismic eco-systems, involving multiple species’ genomes in complex interaction. Moreover, since those genomic profiles will vary between individuals and wax and wane over time, this science suggests that a canonical set of “human genes” will never be available as a ground for human rights, or for determining when humans’ species integrity has been breached.⁶²

Along these lines, and according to Juengst, the problem of the human rights approach to the preservation of the human species consists in the erroneous confusion between the legal and the biological use of the term “human”. While human, in the biological sense, serves as a taxonomic term, the word’s use in human rights “serves as a synonym for ‘natural’, ‘inalienable’ or fundamental to distinguish that class of moral claims from other conferred, negotiated or legislated rights”.⁶³ In this manner, the preservation of the human species approach in human rights mistakes making the recognition of our moral status and the attribution of inalienable fundamental rights dependent upon a taxonomical and biological classification.⁶⁴ Human rights are not (and cannot be) solely dependent on the taxonomical configuration of their subjects (just think, for example, of human tissue cultures and human cadavers).⁶⁵ The

⁶⁰ It is important to note that the notion of the integrity of the human species is not limited to international human rights law. Domestic private law has also enshrined this notion, namely in the French Civil Code, which stipulates in its art 16-4: “nul ne peut porter atteinte à l’intégrité de l’espèce humaine”. Quoted in *Ibid*, 15.

⁶¹ E Juengst, see note 29 above.

⁶² *Ibid*, 53.

⁶³ *Ibid*, 51-52.

⁶⁴ *Ibid*.

⁶⁵ *Ibid*, 52. Rather provocatively, the author even asks if “[i]t is even necessary to be taxonomically human to enjoy human rights?” *Ibid*, 52.

attribution of these inalienable rights, in fact, goes beyond this nomenclature, focussing on other qualities and features.

Juengst observes that what is at stake in genetic modification is our tolerance of human genetic diversity.⁶⁶ Taking into account the continuous and unstoppable course of human evolution, the right to inherit an untampered genome can only be effectively upheld if a snapshot of the human gene pool is taken at a particular moment and is then reified as the sacred “genetic patrimony of humankind”.⁶⁷ Both discourses on the genetic threats to human rights in terms of “species-altering” technologies, as well as the one on the need to uphold our “species integrity,” fall into the same mistake. Both of these views implicitly reserve the set of fundamental and inalienable rights (called human rights) to only those creatures whose specific collection of assorted genes match the snapshot of the sacred pool of human genes.

Given the incessant and inevitable development of humanity’s genetic architecture, the defenders of the supposed preservation of the human species are, as paradoxically as it may seem, acting in a genetic deterministically way.

All of these remarks and arguments render the definition of what humanity is extremely complicated, and even more complexly, they question what the right to identity at the human species level is.⁶⁸ The underlying problem is the conceptualisation of a right to identity that is able to conciliate both the collective and the individual interests.

4. Right to Identity: Individual versus Collective Dimensions

The recognition of group rights constitutes a thorny and problematic issue in general international human rights law, namely because this recognition will inexorably create a conflict with individual rights.

The classification of the human genome as a common heritage of mankind and the prohibition on imposing any modifications upon it raises, in terms of right to identity, an intricate problem of group rights versus individual ones. While, on the one hand, the rationale behind the right to an untampered human genome privileges an allegedly collective right, pertaining to all humankind and aimed at preserving the identity and integrity of the human species; this rationale clearly interferes with the right of any particular human individual to change his or her identity by modifying his or her human genome.

The tension between the interests of the human individual and of the human species reflects the classic conflict between individual and group rights, as the extent to which rights are conferred upon groups or other collectivities, they are inexorably taken

⁶⁶ In this regard, “[a]ppeals to ‘species integrity’ are about as helpful in that context as appeals to ‘racial purity’ are in designing population genetic research”. *Ibid*, 49.

⁶⁷ *Ibid*, 50.

⁶⁸ I do not intend to criticise the legal concept of humanity as a subject of law in its theoretical idea and potential with these remarks. Rather, I believe that one of the law’s greatest achievements in recent times has been the capability of conceptualising the human species as a whole, rendering it (at least theoretically) as an acting subject of rights. I do criticise, however, the lack of a legal solid construction of this concept, the juridical vagueness of its status, and especially the absence of a more balanced view regarding its inexorable clash with the archetypical concept of subject of law, the individual human person.

from individuals.⁶⁹ The blanket is irremediably short and covers either the head leaving the feet out or envelops the feet while uncovering the head. The problem here is that the granting of collective rights may, in fact, enhance the autonomy of that particular group, but it will do so the expense of the individual autonomy of their members.⁷⁰ In other words, the preservation of an allegedly common identity of the humankind group is pursued at the expense of denying any kind of technological modification to every single individual human being, curtailing the latter's possibility of inducing any changes to their individual identities.

By these means, the protection of the genetic identity of the individual as the depositary of the genetic heritage of the species seems to protect everybody except the individual! This legal construction protects the interests of future individuals and of the human species over time, but not the interests of the "present" and actual individual. The individual human being seems to be imprisoned by the whole of humanity. Furthermore, the interests of those future individuals are far from being clearly understood.

In balancing individual and collective rights one concludes that the collective interest on the human genome, rooted upon the need of its preservation, lacks a clear and solid justification, especially when compared to the "more traditional" and articulated right to personal identity.⁷¹ In this manner, and while the advocates in favour of a humanity's collective right to preserve the human genome justify the latter in the name of the preservation of species integrity and the right to a human identity, they forget that those constructions (further to being biologically unsounded) undermine individual autonomy and identity, contributing to the depersonalisation of the individual. As Dolgin observes,

the view that genes are shared substance and information facilitates depersonalization. The genetic 'substance' taken to define each person is also collapsed into a network of information that defines the group exactly as it defines the person and that defines every person exactly as it defines each other person. A universe predicated on the notion of genetic group would view the preservation of autonomy, and the protection of the individual, with indifference.⁷²

This depersonalisation, moreover, breaches the *raison d'être* of the right to personal identity, i.e. the interest in the uniqueness of one's being.⁷³

⁶⁹ L Underkuffler, see note 45 above, at 389.

⁷⁰ *Ibid.*

⁷¹ The right to personal identity is rooted upon a person's "definite interest in the uniqueness of his being". J Neethling, J Potgieter, and P Visser, *Neethling's Law of Personality* (Durban: Butterworths, 1996), at 39. The right to personal identity embodies a right to be unique, different from all the others. Having said that, this article questions what the foundation of a collective right to human identity is that justifies the (unfounded) need to preserve the human genome? If it is also a right to uniqueness, it is uniqueness in relation to what?

⁷² J Dolgin, "Personhood, Discrimination, and the New Genetics" (2000-2001) 66/3 *Brooklyn Law Review* 755-822, at 801.

⁷³ J Neethling, J Potgieter, and P Visser, see note 70 above.

The question of identity within the individual-group conflict in the genetic control context is, nonetheless, a delicate one. In this regard, this paper does not advocate for a model permanently prioritising individual decision-making to the detriment of the collective one;⁷⁴ instead it draws attention to the current imbalance between the individual and the collective interests in the regulation of the human genome, within the framework of a right to identity. The idea that, on the one hand, the inherent value of individual autonomy and personal identity should prevent the exercise of genetic-control assertions by groups is overly simplistic. On the other hand, the idea that a collective (humanity) identity interest (translated into the need of preserving an untouched human genome) should prevail over any individual identity interest is not only equally simplistic, but also poorly constructed. As there is no *a priori* reason why individual or collective identity interests should prevail over each other, it is not understandable why the current international regulatory framework has favoured a vague (and defectively elaborated and justified) collective interest in a supposedly humankind identity. As Underkuffler explains, addressing the case of family and indigenous group members, “[o]utcomes must depend upon the nature of group and individual relations, and the strength of the competing interests involved”.⁷⁵

The undeniable fact is that the present emphasis given to the collective interest, reflected in the crystallisation of the human genome asserted by the current international legal framework, undermines the right to personal identity of the individual human being and, consequently, the respect for his or her right to self-determination.

5. The Human Rights Approach to Identity: The Inner Contradiction

The emphasis given to the collective dimension to the detriment of the individual one also contradicts the broad and encompassing definition of identity enshrined in human rights law, as well as the existential, narrative and developmental meaning of personal identity promoted through the recent ECtHR’s jurisprudential interpretation.

In this light, one can find a notorious contradiction between, on the one hand, the “personality-identity framework” adopted by the ECHR,⁷⁶ which privileges a developmental and existential idea of individual identity (encompassing not only genetics, but also education, environment, personal factors); and, on the other, the “geneticist-identity framework” constructed by the Oviedo Convention and confirmed the UNESCO Bioethics Committee, which favours the conception of a humanity’s identity solely based on their genetic components. The ECHR’s approach to the right

⁷⁴ It is, nonetheless, curious to note that an alleged model of the supremacy of individual decision-making in the context of genetic-control claims may not be shared by individual persons belonging to groups that do not reflect the Western (primarily American) idea of radical individualism. LS Underkuffler, see note 45 above, at 390. For many Native Americans and non-Westerners, “human beings are born into a closely linked and integrated network of family, kinship, social and political relations. One’s clan, kinship, and family identities are part of one’s personal identity and one’s rights and responsibilities exist only within the framework of such familial, social, and tribal networks. Non-western thinkers, therefore, naturally think of their rights as part of a group”. R Clinton, “The Rights of Indigenous Peoples as Collective Group Rights” (1990) 32/4 *Arizona Law Review* 739-747, at 742.

⁷⁵ L Underkuffler, see note 45 above, at 391.

⁷⁶ G Smith, “Human Rights and Bioethics: Formulating a Universal Right to Health, Health Care, or Health Protection?” (2005) 38 *Vanderbilt Journal of Transnational Law* 1295-1321, at 1308.

to identity as “the freedom to become who we want to be” is, as a result, denied by the excessively restrictive regulation of human genome interventions articulated by the Oviedo Convention. It seems that, on the one hand, human rights open a door, by forging a personality-identity framework in which a person’s identity may be subject to “technologically-induced” modifications. On the other hand, human rights close the door by putting restrictions on the acceptable modifications on the human genome, thereby setting boundaries to a person’s capability of changing her or his identity.

As a right to identity that encompasses genetic characteristics, the protection of genetic identity must be understood within the broader concept of the right to identity. Accordingly, “genetic information is a component of, and therefore does not equate to, identity”.⁷⁷ This reasoning applies not only to individual identity, but also to collective identities. In other words, genetic identity does not equate to either individual or to collective identities.

Humanity cannot be reduced to its particular genetic architecture. “Genetic essentialism” or “genetic reductionism” are not only expressed by the tendency towards reducing the human subject to a mere expression of their genetic components but also by the tendency towards reducing humanity to a given and certain expression of their genetic elements.

6. The Current Regulatory Framework: Prudence, Precocity and Pavlovian Reflexes

In focussing upon the regulation of the human genome set up by the current legal framework, a few ideas are worth underlining that explain the prevalence given to the ideas of collective human identity and the preservation of the human genome (to the detriment of the idea of personal identity and the modification of the human genome).

The first idea concerns the cautious character of the regulatory actions undertaken in this field. European regulation of human genome interventions is characterised by its prudence and precocity.⁷⁸ The European Parliament and the Council of Europe were swift in putting forward a number of rules regulating the prospect of genetic modification, enacting them before those technologies could even be applied to the human person. Those rules, nevertheless, solely reflected the fears and concerns about the dangers posed by genetic engineering technologies, overlooking the advantages and opportunities that genetic manipulation could also bring. In this matter, European institutions have anticipated only the perils but not the benefits of the technology they propose to regulate.

Furthermore, UNESCO’s prohibitive stand on human genome intervention falls into the recurrent mistake of granting protection to the human genetic material strictly and merely because of its genetic label. There is an automatic and rather thoughtless protection granted to everything related to human genetics just because it is genetic. This important aspect has been raised by Gatter, who rightfully points out that the current regulatory approach to human genetics protects all genetic information regardless of context or substance.

⁷⁷ H Boussard, see note 7 above.

⁷⁸ R-M Lozano, see note 20 above, at 216.

Many legal safeguards...focus only on the fact that the information is genetic instead of looking at the substantive content that the genetic information represents. This myopia detrimentally alters the social meaning of genetic information by promoting the idea that a person's DNA is the essence of a person. Laws should instead regard genetic information as representing an attribute among many other important attributes, such as personality, ambition, character.⁷⁹

Focussing on the field of genetic research (and not just on the possibility of manipulating the human genome), Gatter argues that the legislator's lack of subtlety in recognising the different contexts in which researchers uncover genetic information elevates genetic information to an "essential entity".⁸⁰ This approach distorts the meaning of identity by placing too much emphasis on the genetic character and label of the information, rather than devoting attention to the actual impact that this information (seen in its substantive character instead of its taxonomical one) exerts upon individual identity.⁸¹ A similar reasoning should also be followed in our examination of the prospect of modifying the human genome, as its current regulatory framework also reflects a dogmatic sacralisation of the human genome (and its corresponding genetic information), conceiving the latter as an essential and untouchable entity of both the human individual and the human species. The crystallisation of the human genome not only distorts the meaning of individual identity, but also limits its scope and progression, impeding the further development of personal identity (assuming that, in the future, these genetic interventions will both be feasible and safe).

There is thus a sort of Pavlovian reflex affecting the regulation of human genetics, in which the mere sound of the "genetics label bell"⁸² triggers an automatic and protective legal response, either in the form of severe genetic privacy laws or in the form of legal dispositions prohibiting interventions on the human genome. This Pavlovian regulatory outcome prevents any kind of consideration and reflection upon the real and practical effects of genetics in personal identity, taking for granted that the former always bears an inexorable, dominant, and ultimate impact upon the latter. As a result, and as observed elsewhere, the current regulatory scheme has caused a change in the social meaning of genetic information, promoting deleterious effects on our identity and our belief in autonomy.⁸³

⁷⁹ K Gatter, "Genetic Information and the Importance of Context: Implications for the Social Meaning of Genetic Information and Individual Identity" (2003) 47/2 *Saint Louis University Law Journal* 423-462, at 424-425.

⁸⁰ *Ibid*, 440.

⁸¹ *Ibid*. Based on this construction, and transposing it to the legal domain, Gatter argues that "[a]n individual's legal rights should be implicated depending on the substantive attributes of the information, rather than the single attribute of the information being genetic". *Ibid*, 450.

⁸² Curiously, the question whether Pavlov ever actually used a bell in his experiments is unresolved. For divergent views on this matter, see A Catania, "Query: Did Pavlov's Research Ring a Bell?" (7 June 1994) *PSYCOLOQUY Newsletter*; R Littman, "Bekhterev and Watson Rang Pavlov's Bell" (1994) 5/29 *Psychology*; R Thomas, (1994), "Pavlov's Rats 'Dripped Saliva at the Sound of a Bell'" (1994) 5/80 *Psychology*.

⁸³ K Gatter, see note 78 above, at 425. Furthermore, and as Dolgin observes, "[t]his change involves a fundamental shift in the locus of social value from the autonomous individual – long the central agent

Furthermore, this sacralisation of genetics obfuscates other important factors and elements of one's personal identity, providing a clear and worrying example of how genetic exceptionalism may lead to a reductionist view of identity.⁸⁴

In other words, the relationship between genes and identity should be articulated through the ideas of context and substance. Accordingly, the regulation of human genetics should pay attention to the context within which genetic information is being dealt with, as well as to the substantive content of that genetic information. This evaluative process, which arises in opposition to the current and thoughtless Pavlovian regulatory scheme, should have the concept of personal identity as its operating paradigm, investigating both the context and the substance of genetic material in accordance with their impact upon individual identity. This suggested *modus operandis* will hopefully bring a number of important advantages. It will, in the first place, reflect the actual weight of genetic make-up in shaping one's personal identity more accurately by downgrading it from its status of identity's ultimate determinant factor. By placing our genes as one more identity attribute among others and locating them in the varied list of indicia of identity, this operating scheme will avoid genetic reductionist drawbacks and keep the legal concept of identity open, flexible, and mutable.

7. Conclusion

The underlying problem analysed in this article lies upon the over-inflation of the idea of a collective, static and heritable genetic identity, which must be protected, preserved and transmitted to future generations. The genetic identity of the human being, according to this view, is considered as an inalienable patrimony, and its protection as a fundamental condition and requisite for the survival of our species.⁸⁵ This idea, moreover, is supported by the current international law of human rights, which shares the assumption that the genome is not only a fundamental asset of the individual person but also of all of humanity, and – as such - must be protected and preserved at all costs. It was, in fact, precisely because of those assumptions that UNESCO proclaimed the human genome as Common Heritage of Mankind. This conception encompasses not only the goals of protecting the dignity and the rights of every single human being, but also of preserving the integrity of the human species.

In addressing the current human rights legal framework in the field of genetics, the role of individual identity constituted the key to this paper's criticism of how current regulations over-protect the human genome. The preservation of the latter is based upon a clear disproportion between the individual and the collective interests regarding interventions in the human genome. This conservative stand unreasonably prioritises a vague and unproven interest of humanity in the "untouchability" of the human genome to the detriment of any given human individual interest in "changing" it. This position contradicts the human rights view of the right to identity as an existential and developmental one. Furthermore, and paradoxically, the advocates of

of thought and action in most domains of life in the post-Enlightenment West – to a larger whole, defined through the presumption of a shared genome". J Dolgin, see note 71 above, at 756.

⁸⁴ K Gatter, see note 78 above, at 425.

⁸⁵ S Barbas, see note 10 above, at 15.

an untampered human genome fall into the genetic deterministic views that they strive to prevent.

The important fact to remember is that there are numerous aspects and elements that impact and shape identity. In this account, genetics is one of those factors, and – moreover – a very powerful one, as it tends to be associated with science and, consequently (and perhaps erroneously) to infallible objectivity and rationality. Two aspects should be taken into consideration regarding this relationship with science. First, science tends to be over-rated, as it does also present its own limitations and insufficiencies. Second, the question of identity is not so much a matter of science, rationality, and objectivity (truth), but of meaning, impact and subjectivity.⁸⁶

The legal discourse surrounding the delicate theme of genetic engineering has been characterised by extreme and irremediably opposite positions, either falling in dogmatic claims for an untampered human genome,⁸⁷ or in rampant defences in favour of a freely and unlimited manipulable genome.⁸⁸ Middle-ground propositions, conciliatory views and pondered solutions, capable of taking into account both the concerns and the perils that these interventions surely raise but also the opportunities and the advantages that these technologies will certainly bring have been lacking. However, the prospect of altering the human genome should not be seen as either a flagrant trespass of human rights or as a radical new stage in civilisation where humans will design the path and exert full control over their own evolution. It should be seen instead as a plausible course of action available to man, which should not be bluntly denied nor blindly accepted, but discussed, analysed, and evaluated. The manipulation of the human genome should thus be seen as an important possibility worthy of reflection. This reflective exercise should always be framed and conducted in accordance within the international legal framework of human rights. This article proposes the value and the right to identity as the touchstones for guiding this process.

⁸⁶ A good example of the struggle between different factors (genetics, tradition, historical narratives) which shape a person's identity can be found in so-called genetic ancestry tracing C Elliott and P Brodwin, "Identity and Genetic Ancestry Tracing" (2002) 325/7378 *BMJ* 1469-1471.

⁸⁷ According to this standpoint, genetic manipulation is viewed as "inhuman treatment" and labelled as a new category of crimes against humanity, endangering the preservation of the human species.⁸⁷ As a result, George Annas and other human rights lawyers proposed a new United Nations "Convention on the Preservation of the Human Species". G Annas, L Andrews and R Isasi, "Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations" (2001) 29 *American Journal of Law & Medicine* 151-178. For recent criticism of these conservative positions and treaty proposal, see Juengst's argument that this view "is a reliance on a set of morally idolatrous assumptions about biological taxonomy that are ultimately more mistaken than the naturalist's essentialism". E Juengst, see note 29 above, at 45.

⁸⁸ In this sense, genetic modification has been supported and defended as a moral imperative. See J Harris, note 34 above.