



## UPDATE

# Occupational genetic mapping: axiological prospecting, bioethics and Brazilian legislation

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## Abstract

This work aims to verify the status of Brazilian legislation on genetic mapping, focusing on the occupational sphere, in comparison to international legislation, to assess the country's normative reality regarding social trends related to the recognition of differences and prospective legal opening. This is a review of literature and documents regarding the dialogue between bioethics, occupational medicine and genetics, taking into account that they have human dignity as a common ground. It was concluded that there is a tendency to accept the genetic mapping of workers for research and prevention of illness. Given their common reference and in accordance with the culturalist perspective of the Civil Code, it is inferred that this possibility extends to the genetic identification of workers' skills for the exercise of their duties.

**Keywords:** Genetics. Workers. Legislation-Brazil.

## Resumo

### Mapeamento genético laboral: prospecção axiológica, bioética e legislação brasileira

Objetiva-se comparar o estado da legislação brasileira sobre mapeamento genético com o de legislações internacionais visando dimensionar a realidade normativa do país quanto às tendências sociais de reconhecimento das diferenças e a abertura jurídica prospectiva, com foco na área laboral. Trata-se de revisão de literatura e pesquisa documental sobre o diálogo entre bioética, medicina do trabalho e genética, que têm a dignidade humana como ponto em comum. Concluiu-se que se tende a admitir o mapeamento genético de trabalhadores para pesquisa e prevenção do adoecimento, inferindo-se, dado seu referencial comum e de acordo com a perspectiva culturalista do Código Civil, que essa possibilidade se estende à identificação genética de habilidades do trabalhador para o exercício de atividades.

**Palavras-chave:** Genética. Trabalhadores. Legislação-Brasil.

## Resumen

### Mapeo genético laboral: prospección axiológica, bioética y legislación brasileña

El objetivo de este trabajo es comparar el estado de la legislación brasileña sobre mapeo genético en relación con el de las legislaciones internacionales, buscando dimensionar la realidad normativa del país ante las tendencias sociales de reconocimiento de las diferencias y la apertura jurídica prospectiva, con foco en el área laboral. Se trata de una revisión de la literatura y de una investigación documental sobre el diálogo entre bioética, medicina del trabajo y genética, considerando que tienen a la dignidad humana como punto en común. Se concluyó que se tiende a admitir el mapeo genético de los trabajadores para la investigación y prevención de enfermedades, infiriéndose, dada su referencia común y de acuerdo con la perspectiva culturalista del Código Civil, que esta posibilidad se extiende a la identificación genética de habilidades del trabajador para para el ejercicio de actividades.

**Palabras clave:** Genética. Trabajadores. Legislación-Brasil.

Declaram não haver conflito de interesse.

Bioethics, occupational medicine and genetics aim, respectively, at preserving dignity, protecting workers with basis on principles and studying genes and how they transmit biological characteristics. Dialogue between these fields is possible thanks to their common referent: human dignity. This principle is also recognized by the 1948 *Universal Declaration of Human Rights*<sup>1</sup> and most of the Constitutions of Democratic States. Since its *locus* is the person, one must understand from it one's own dignity and principle. Therefore, it is important to understand the meaning of the elements that underlie this locus to understand its totalizing perspective.

The concept of person has varied historically, with controversies of a hegemonic nature. Therefore, modern society is presented with the challenge of revaluing and re-framing *the human being as a person, independent of any other adjective characteristics*<sup>2</sup>. In the bioethical perspective, it is treated as *the unity of body and spirit a whole that must be considered in all its dimensions (physical, psychic, spiritual, social and moral)*<sup>3</sup>. This refers not only to the subject of law, but to the concrete being, with aptitudes, needs, possibilities and, especially, singularity<sup>4</sup>.

The concept of dignity itself is *polysemic and carries with it different meanings of ethical values*<sup>5</sup>. Secularly, it can be related to the notion of quality of life, which presupposes minimum conditions for existence, without which death would be preferable<sup>6</sup>. As a personal attribute, the discussion about this concept is wide, involving ideas from the legal field and human relations, having repercussions on the full individual development<sup>7</sup>. In this sense, *the importance that society attributes to human dignity in personal relationships and with the macro-system of social and legal culture, facing its concrete and effective repercussion, is intertwined with the potentiality attributed to the qualification of those who, ultimately, constitute society*<sup>8</sup>.

As principles of value enunciation, guiding norms, originate from proven truths and practices of a knowledge system<sup>9</sup>, human dignity (or "personhood") is a primary concern of bioethics. For Xavier, *bioethics seeks to reaffirm the unique character of respect for human dignity as a requirement for its equal consideration as a person, free from any form of discrimination and oppression*<sup>2</sup>.

This understanding can be seen in the notion of culturalism<sup>10</sup> that covers the matrices of the new Brazilian Civil Code<sup>11</sup> in times of pluralization of legal subjectivity. It is a consequence of society's recognition that there are concrete differences between people,

which are only qualifiedly accepted<sup>12</sup> – this is not tolerance for difference, but normative acceptance, which *operates according to axiological choices*<sup>12</sup>.

In this acceptance, it is recognized that the difference may result from the various social roles played by the same individual<sup>10</sup>. This leads to a prospective philosophical-legal panorama, open to the normalization of inter-subjective and plural relations, especially those with principles ensured in the legal order, such as human dignity. Martins-Costa<sup>10</sup> defines this prospecting as an axiological look directed at the concrete, which singularizes behaviors or personalities in their particular existential circumstances.

Inserting in this context the proposed dialogue between bioethics, occupational medicine and genetics, it is considered that the individual is to be singular and unequal, with different possibilities, aptitudes, needs and ways of being. However, it needs to be understood that not every kind of life and not every kind of work respects the dignity of the person. Reality shows that, over time, labor relations have developed on the basis of the employer's power over the employee and, in many cases, the latter's submission to any working condition in view of daily needs. In both realities, dignity was not considered.

The interface between occupational medicine and genetics, made possible by bioethics, can provide the change signaled by the cultural openness present in the new Civil Code. Genetics can contribute to the transformation of business habits, allowing hires that meet the profile sought, admitting workers in tasks for which they are fit. With such openness in practice, it is inferred that genetics can even modify the modalities of hiring workers by companies, focusing more on the relationship between what they seek in the market and the aptitude of the professional.

The quality of work goes beyond the physical and mental safety of workers, and it is up to the State, companies and workers to respect their basic rights through the promotion of health, damage prevention, and assistance.

Society is moving towards the "axiological look that singularizes", an advanced paradigm for the labor market in relation to the current one, by recognizing and accepting qualified difference. This path, which passes through culture, requires laws that ensure new legal bases and ensure respect for the recognized principle. Thus, the aim of this study is to verify the state of the current legislation in Brazil and its purposes, compared to international legislation, to measure the normative reality of the

country regarding the use of genetic data, social recognition of difference and the prospective legal openness signaled the by Civil Code.

This is a bibliographic and documentary research, for which, initially, publications on bioethics were used, aiming to structure the basic theory about genetic mapping of workers. With the key concepts “genetic privacy”, “chromosome mapping” and “person-hood” of the *Descritores em Ciências da Saúde (DeCS)* (Health Sciences Descriptors)<sup>13</sup> were consulted, obtaining the following search synonyms respectively: genetic information, personal genetic; gene mapping, genome mapping; person-hood, human dignity. With them, we consulted the *Biblioteca Virtual em Saúde – BVS* (Virtual Health Library)<sup>14</sup> database and then PubMed<sup>15</sup>, searching for works published in the last 10 years.

As the articles found focused on key concepts in general or associated with diseases, but not related to the worker, other sources were consulted. In the documentary research, we consulted the portals of the Brazilian Federal Government<sup>16</sup>, the Chamber of Deputies<sup>17</sup> and the Federal Senate<sup>18</sup>, regarding Brazilian legislation, and the portals of the United States<sup>19</sup>, Germany<sup>20</sup> and France<sup>21</sup>, regarding international legislation.

### Brazilian laws on examination and genetic data

Innovations are not always absorbed on time by the dominant moral configuration and legislation. In the case of genetic knowledge, *Article 11 of the Universal Declaration on the Human Genome and Human Rights states that practices contrary to human dignity (...) shall not be permitted. States and competent international organizations are called upon to cooperate in identifying such practices and to take, at national or international level, the necessary measures to ensure compliance with the principles set forth in this declaration*<sup>22</sup>.

In Brazil, Law 11,105/2005, called the Biosafety Law, establishes *safety standards and (...) supervision of activities involving genetically modified organisms (...) and their derivatives, creates the Conselho Nacional de Biossegurança (CNBS)* (National Biosafety Council), *restructures the Comissão Técnica Nacional de Biossegurança (CTNBio)* (National Biosafety Technical Commission) [and] *provides for the Política Nacional de Biossegurança (PNB)* (National Biosafety Policy)<sup>23</sup>. It aims to legalize DNA testing and to institute multidisciplinary advice to monitor technical

and scientific development in the fields of biosafety, biotechnology, bioethics and related fields increase the protection capacity of human health<sup>23</sup>.

However, this law generally covers the protection of the health of humans, animals, plants and the environment, neither prioritizing the protection of a given group nor determining its scope. Genetic mapping, which can benefit companies and workers, is implied in the recognition of the biotechnological advance for the preservation of life and human health, considering that performing activities for which one has no aptitude negatively reflects on workers’ health. Its specifications do not cover the need for emerging directions. This law, however, encompasses the protection of the health of humans, animals, plants and the environment in general terms, without prioritizing any of these groups and without referring to the respective scope of normative safety. In its context, genetic mapping, which can benefit companies and workers, can be understood in the biotechnological advance to preserve life and human health. This, if it is considered that the performance of activities for which one is not apt is negatively reflected in the health of the worker. In short, the specifications of this law do not cover the need for emerging directions, as said.

Law 12,654/2012<sup>24</sup> provides for the genetic profile as a resource for criminal identification. In its article 1, this law amends article 5 of Law 12,037/2009, stating that *criminal identification may include the collection of biological material to obtain the genetic profile*<sup>24</sup>. Included in the same law article 5-A, §1 indicates that *genetic information in databases may not reveal somatic or behavioral traits of persons except the genetic determination of gender, according to constitutional and international norms on human rights, the human genome, and genetic data*<sup>24</sup> This law regulates the confidentiality of authorized genetic examinations, except for exceptions.

More recently, Law 13,709/2018 provided, in its Article 1, on the processing of personal data, including genetic data, in order to *protect the fundamental rights of liberty and privacy and the free development of the personality of the natural person*<sup>25</sup>. Article 2 provides, as fundamentals of data protection: *I – the respect for privacy; (...) IV – the inviolability of intimacy, (...); (...) VII – human rights, free development of personality, [and] dignity*<sup>25</sup>.

Article 5, item II, of Law 13.709/2018 also considers *sensitive personal data [as] personal data on racial or ethnic origin, religious belief, political opinion, union affiliation or religious, philosophical*

or political organization, data referring to health or sex life, genetic or biometric data<sup>25</sup>. According to article 7, the processing of personal data may only be carried out in the following hypotheses: I – upon the consent of the holder; (...) V – when necessary for the performance of the contract or preliminary contract-related procedures to which the holder is a party (...); (...) IX – when necessary to meet the legitimate interests of the controlling shareholder or third party, except where the fundamental rights and freedoms of the holder prevail<sup>25</sup>.

This law is clear as to the need to protect personal data to guarantee the fundamental rights and free development of the individual. This reflects item III of Article 1 of the Federal Constitution<sup>26</sup>, which elects human dignity as the absolute principle and foundation of the Democratic Rule of Law. With the “free development of the person”, it leads to legal openness to differences inferred from the Civil Code<sup>11</sup>.

Human dignity is still seen from the perspective of the right to liberty, for the human person [is] valued by itself for the sole fact of being “human” – that is, the person in his irreducible subjectivity and dignity, endowed with singular personality<sup>27</sup>. Thus, rules and principles are built within the legal framework to safeguard this existential, non-patrimonial dimension (...) fundamentally linked to the protection of the human person and personality and what is their specific attribute, the quality of being human<sup>27</sup>.

Law 13,709/2018 25 is in line with international law and was inspired by the also recent European Union General Data Protection Regulation (GDPR)<sup>28</sup>. It comes into force in February 2020, with the provision that will have an impact on society like few before have, creating a rule for the use of personal data<sup>28</sup>. However, while on the one hand this rule will generate requirements and control to ensure privacy, on the other hand it can enable the safe use of extensive genetic mapping in other areas. It remains to find ways to overcome the legal-cultural barrier of applying this mapping in the interests of both the worker and the employer.

New directions are emerging. Recently, the Ministry of Health issued Ordinance MS 18/2019, which aims to incorporate the complete sequencing of the exome for etiological investigation of intellectual disability of undetermined cause within the Sistema Único de Saúde – SUS (Unified Health System)<sup>29</sup>. Overall, even with these advances, Brazilian legislation is far from catching up with biotechnology and genetics. Chromosomal mapping, which has existed since 1913, helps to understand

biological processes and has relevant practical applications<sup>30</sup>, but is restricted to agriculture, livestock, health and criminal identification – beyond these areas, there is still no question about it.

Another proof that Brazilian legislation evolves slowly is the genetic data Law Proposals (LP) that are still in the legislative houses. Only the Chamber Law Proposals (CLP) 53/2018<sup>31</sup> was voted urgently, pressed for the need to control data leakage scandals. This CLP originated the aforementioned Law 13,709/2018<sup>25</sup>, but, as seen, in this law the genetic data appeared among the others, the specific gap remains.

### Genetic testing and discrimination bills

Several LPs on human genetic knowledge and its use have been proposed, four of them from 1997<sup>32</sup>, 1998<sup>33</sup>, 1999<sup>34</sup> and 2006<sup>35</sup>, specifically on discrimination and genetic testing. However, specific projects on genetic mapping were not identified in the research. Frame 1 characterizes the localized LP and its objectives.

The Oswaldo Cruz Foundation has published an opinion by lawyer Eliane Moreira<sup>36</sup> on LP 4,900/1999 and 4,610/1998, suggesting altering elements essential to effectiveness, deleting and altering items. This document concludes that it is necessary to broaden the discussion of the proposed issue, and it is mainly relevant to reaffirm the need for the Ministry of Health to participate in the legislative process and to present its contributions to the debate<sup>36</sup>.

In general, it is clear in these projects that the theme is treated superficially, without following the latest demands or technologies in use. Moreover, comparing the time elapsed since the proposition of these LPs with the agility conferred to CLP 53/2018<sup>31</sup>, it is inferred that the legislative houses lack the motivation to analyze them: wouldn't the topic be interesting enough or would it not pose risks to the population? Regarding the first aspect, neglecting processes that aim to regulate real situations does not seem to be of particular interest and does not match the evolution promoted by science for the good of society. Martins-Costa states:

*Law not only “is” the production of norms, it also “serves” the production of norms designed to resolve cases through decisions, to achieve socially relevant choices and actions, and thus a fundamental aporia lies – to know the which is fair here and now, for every concrete social problem an equally concrete and immediate answer must be given<sup>37</sup>.*

**Table 1.** Law Proposals in Brazil, concerning genetic data.

Proposals	Authors	Organ	Goal
LP 149/1997 <sup>32</sup>	Lúcio Alcântara (PSDB/CE)	Federal Senate	It defined the crimes resulting from genetic discrimination. It originated LP 4.610/1998 and was terminated in 2008.
LP 4,610/1998 <sup>33</sup>	Lúcio Alcântara (PSDB/CE)	Federal Senate	It defines the crimes of genetic discrimination (text of LP 149/1997) and establishes that conducting predictive tests for genetic diseases or identifying a person carrying a gene responsible for a disease or genetic susceptibility or predisposition to a disease is only allowed for medical or research purposes and after genetic counseling by a qualified professional.
LP 4,900/1999 <sup>34</sup>	Eduardo Jorge (PT/SP) e Fábio Feldman (PSDB/SP)	Chamber of Deputies	It provides for protection against discrimination against persons on the basis of genetic information and makes other provisions.
LP 7,373/2006 <sup>35</sup>	Juvêncio da Fonseca (PSDB/MS)	Federal Senate	It adds provisions to Law No. 9.656 of June 3, 1998, which provides for private health care plans and insurance to curb the requirement for genetic testing to detect disease.

As for the second, even considering the principle of proportionality, genetic discrimination exists, even if it is not propagated. Clayton and collaborators point out that *little attention is paid to understanding the factors – sociocultural, relational and media – that influence opinions and decisions*<sup>38</sup>. Genetics thus becomes a matter of great complexity, since the general public shows *concern mainly regarding its use by employers, insurers and the government*<sup>38</sup>.

In this case, the presumed risk to the population refers to the consequences of misuse, in addition to the lack of privacy, which affronts dignity. The lack of legal regulation constitutes the absence of a *duty that materializes in social experience, correlating with factual conjunctures and axiological demands*<sup>39</sup>, as Martins-Costa explains, mentioning Miguel Reale. This is because the must-be implicit in legal norms is not only a *logical statement*<sup>39</sup> but an adjustment between empirical sources (situations of reality without legal response) and prescriptive models, which are endowed with *essential prospective meaning*<sup>40</sup> whose process consists in their confirmation.

Indications of the use of genetics in the workplace have not yet been included in the legislative field, justifying this study, which has, on the one hand, possibilities arising from the continuous and profound advance of genetics and, on the other, legislation still far from corresponding to this progress. Regarding legislation, there are two points to consider: a broad one, the inferred culturalism of the Civil Code matrices<sup>11</sup>, a reflection of the gradual paradigm shift faced by society with advances in technology; and another, specific,

one, which addresses the requirements of Law 13,709/2018<sup>25</sup> in response to data leakage.

At national level, workers may be subjected by the employer to medical examinations during the process of admission, dismissal and periodically, in accordance with article 168 of the Consolidação das Leis do Trabalho (CLT) (Consolidated Labor Laws)<sup>41</sup>, and for occupational health control, according to Regulatory Standard 7 of the Ministry of Labor<sup>42</sup>. These examinations do not cover genetic analyzes that, although absent in the laws and proposals, are employed by some areas that seek to enjoy their benefits, such as training strategies. The extensive knowledge about the human genome and its influence on physiology have allowed us to locate, for example, *genes linked to greater aptitude for sports that involve power and speed, that is, that favor the development of muscle fibers*<sup>43</sup>.

Initiatives like this reflect the legislative vacuum as to what science has been developing, so this work represents progress concerning the legal system. However, it is not about progress from a social point of view, as workers tend to submit to working conditions that sometimes go beyond their ability. Nor is it in the theoretical-institutional view, since the Human Genome Project provides for two types of genetic intervention. The first one is straightforward, with genetic therapy and surgery, combining or turning off genes to improve health. The second one is indirect, with pharmacology, embryo selection, genetic testing and therapeutic intervention, respectively designed to produce drugs, implant embryos with specific characteristics,

provide information to guide reproductive decisions and mitigate diseases<sup>44</sup>.

The project is not intended to make predictive genetic examinations feasible, but its objective of mapping and sequencing the human genome represents what Vilaça and Palma<sup>44</sup>, based on Foucaultian thinking, call “life-taking”, the focus of biosciences. This is the condition for the emergence of preventive and popularizable techniques, aiming at normalization.

Still justifying this proposal, in parallel with the evolution of genetic engineering, there is the recognition of human dignity and the support of the person’s value as the sole holder of one’s personality, which is not limited to the technical concept of capacity. This path involves paradoxes and modifications, and the concept of dignity has been changing: as a legal principle, it will refer to one’s being and humanity. This means the symbolic gathering of all individuals in what they have in common – and if all human beings represent humanity, they all have the same degree of dignity<sup>45</sup>.

Thus, this study addresses the vulnerability to which the worker is exposed. According to Silva and collaborators, *in today’s globalized capitalist system, profits, market laws, and progress at all costs are the cornerstone, as it is necessary to “maximize profits and minimize costs”*<sup>46</sup>. Between profit maximization and the minimization of costs lies the worker, this relationship being responsible for the precariousness of work and the employee’s depreciation in this process, hurting their dignity and undermining their health. There is no parity in the employment relationship, which often allows disrespect for morals and principles that, even if not directly linked to the market, deserve and must be guaranteed.

To promote the health of the professional it is necessary to comply with criteria of safety, welfare and minimum fulfillment of needs. Today, people are getting closer, even in professional relationships, and the damage and benefits of these relationships are manifested even more clearly. Laws need to safeguard people’s privacy against the offenses of others – in which case dissatisfied workers may turn against others. Thus, genetic mapping and its criteria involve a broad and realistic look at what protection is.

Chromosomal mapping can then be used to direct workers to tasks consistent with their skills, representing the necessary direction in the face of rapid bio-techno-scientific advance. Schramm<sup>47</sup> states that this progress includes knowledge that seeks to alleviate suffering and improve living

conditions. These findings aim to overcome the limitations imposed by the natural condition of life, reprogramming human nature, and positively interfere with the quality of life.

Citizens, scientists, businesses, and class entities need legal guidance to use genetic knowledge consciously and ethically. The fact that the genome is studied around the world and that its findings are widely publicized makes it a duty for lawmakers to update and direct society.

### Brazilian law and genetic mapping of workers: an ethical evaluation

Advances in biotechnology and the use of genetic knowledge are part of contemporary reality. Research on genetic aspects is progressing surprisingly, and legal guidance is essential to indicate possibilities and curb abuses. The legality of actions positively influences the responsible and ethical application of knowledge, especially in the biotechnological development of everyday life.

In any area legal certainty is indispensable since, without an up-to-date legal framework, the vacuum becomes dangerous, as the absence of limits is interpreted as permissive. The contemporary look at laws and public enlightenment, especially regarding scientific knowledge, are vital to effective progress. According to Séguin, *human knowledge has changed (...), but prejudices remain, (...) scientific possibility is not synonymous with legal and ethical convenience. The sciences have evolved giving way to the relativity of scientific truths, (...) creating (...) confusion in the layman, who, attentive to scientific information (...), does not know what to believe, because he does not know the scientific jargon*<sup>48</sup>.

In Brazil, the legal gap on the subject for labor purposes can be filled provisionally and generally by the traditional legislation:

- Article 196 of the Brazilian Federal Constitution of 1988 states that *health is the right of all and the duty of the state, guaranteed by social and economic policies aimed at reducing the risk of disease and other diseases and universal and equitable access to actions and services for all. its promotion, protection and recovery*<sup>26</sup>. It further states in article 24, item XII, that it is for the federal and state governments to protect and defend health.
- Article 1,440 of the former Civil Code, Law 3,071/1916, revoked by Law 10,406/2002 11 but

still cited by jurisprudence, stated: *life and human faculties can also be estimated as insurable, and insured against the possible risks, such as involuntary death, disability to work, or the like*<sup>49</sup>.

- Article 157 of the CLT determines: *it is up to the companies: I – to comply with and enforce safety and occupational health standards; II – instruct employees, through work orders, on precautions to be taken to avoid occupational accidents or occupational illnesses*<sup>50</sup>. Its amendments until January 2019 cover aspects of worker health (overtime, intermittent work, and others) Not to mention the improvement of situations associated with axiological issues, such as the protection of worker dignity.
- Article 1 of Law 9,459/1997, which amends Article 1 of Law 7,716/1989, provides that (...) *crimes resulting from discrimination or prejudice of race, color, ethnicity, religion or national origin shall be punished*<sup>51</sup>.
- Item V of article 57 of Decree 7,724/2012 does not require the confidentiality of personal information if access to it is necessary to *protect the overriding general public interest*<sup>52</sup>.
- Article 1 of Law 9,029/1995 provides: *the adoption of any discriminatory and limiting practice for the purpose of accessing or maintaining the employment relationship, on grounds of sex, origin, race, color, marital status, family situation, is prohibited, disability, professional rehabilitation, age, among others, except, in this case, the hypotheses of protection to children and adolescents provided for in item XXXIII of art. 7 of the Federal Constitution*<sup>53</sup>.

Unfortunately, genetic knowledge and its usual applicability have not yet sensitized legislators, even after the prospective view of the new Civil Code<sup>11</sup> regarding the urgency of discussing the use of genetics. This stance is reflected in the legal gap that has lasted since 1997, briefly interrupted in 2018 with the issuance of Law 13,709<sup>25</sup>. It is worth noting that, as Jonas, quoted by Siqueira indicates, *modern technology has introduced actions of such different magnitude (...) that the frameworks of previous ethics can no longer control them*<sup>54</sup>.

### International law and bills against genetic discrimination

As seen, Brazilian society has not yet definitively positioned itself on gene mapping and,

in the legal context, the matter is not the subject of specific laws. Although the Constitution safeguards human rights, it is necessary that the Legislature take a specific position on the subject and reorganize agendas. For Zaneti Júnior, *if there is a judiciary, there must be a means of control over the rationality of its decisions in order to ensure uniformity and continuity of law for all future analogous cases*<sup>55</sup>.

Brazil tends to follow international recommendations, seeking the responsible and ethical use of this technology, taking into account the international agenda that privileges human dignity. This was the case with Law 13,709/2018<sup>25</sup>, inspired by the GDPR of the European Union. It is also clear from the content of Bills 4,900/1999<sup>34</sup> and 7,373/2006<sup>35</sup> the concern to avoid genetic discrimination since both follow international norms on the subject, such as articles 6 and 7 of the Universal Declaration on the Human Genome and Human Rights, of 1997<sup>22</sup>, and Article 11 of the Universal Declaration on Bioethics and Human Rights, of 2005<sup>56</sup>.

International law generally follows that established by the United Nations Educational, Scientific and Cultural Organization, an important governing body. Some laws, such as the American Genetic Information Nondiscrimination Act<sup>57</sup> of 2008, the German *Gesetz über genetische Untersuchungen bei Menschen*<sup>58</sup> (on genetic testing in humans), of 2009, and Law 2,004-800/2004<sup>59</sup>, (on bioethics), they focus mainly on the secrecy of genetic information and reject discrimination. In 2018, the European Union conceived the aforementioned GDPR<sup>60</sup>, introducing high quality standards for processing and storing personal data, emphasizing their accountability.

It is relevant to any legislation to curb discrimination. Similarly, human dignity is not just about data privacy, but also about raising awareness and ensuring its commitment to human rights, from education to jurisprudence, to international agreement and support.

To date, under Brazilian law, human genetics has been limited to a judicial tools: techniques for identifying criminals, forensic investigation, and paternity verification. Concerning other extensions of the subject, only Law 13,709/2018<sup>25</sup> has advanced, not specifically concerning genetic data, nor because of the need for positive prohibitions, but for factual impositions.

Genetics also embraces prominent areas, such as human health, involving both aspects of personal and professional life. The application of genetic

knowledge must comprehensively embrace the human being and, in this context, ethical issues are paramount. Since awareness and social acceptance affect morality, initiatives to avoid prejudice and the counterproductive effects of biotechnology are, from an ethical point of view, a reliable way to ensure the dignity of the individual. It is up to society to monitor and collect accountability, using assertive means that promote health and quality of life.

The international community has positioned itself for the dignity and autonomy of the human person. While promoting integration, it presents possibilities for access to knowledge and its applications. There are points of consensus between the international recommendations, the Brazilian LPs and the referred international legislations. Frame 2 points out gaps between Brazilian LPs and international legislation and directive instruments.

**Table 2.** Main points of the Brazilian law proposals on human genetic mapping

International direction	LP 4.900/1999 <sup>34</sup>	LP 7.373/2006 <sup>35</sup>
Non-discrimination / support to the person	x	
Secrecy/confidentiality	x	
Voluntary consent		
Prohibits the previous detection of diseases to join private health plans	x	x
Prohibits the previous detection of diseases to join health insurance	x	
Accepts mapping to prevent disease		
Accepts mapping aiming at medical treatment/research	x	
Prohibits detection for recruitment and selection of professionals in public and private services		
Accepts mapping as part of a labor welfare program		
Accepts mapping to check the effects of toxic substances at work, notifying the worker in writing		

The Brazilian LPs on the subject seek to support the parameters of non-discrimination and confidentiality of genetic data. Although they contemplate these minimally, they are careful not to hurt dignity and respect for individuality.

The technique is even used for labor purposes, as observed in foreign laws such as in the US<sup>57</sup> and Germany<sup>58</sup>. These standards address the issue more systemically, and there are advances in guidelines related to the world of work, which represents respect for the principle of beneficence from a bioethical perspective<sup>61</sup>.

### Bioethical view

This proposal is theoretically, socially and legally delimited by the bioethical perspective, based on the dual conception of dignity, the person and his humanity. Martins-Costa states that *the notion of a "dignity of humanity" (...), understood concretely and (...) historically, [should act] as a guide, criterion and limit to the dilemmas brought about by the Biotechnological Revolution<sup>62</sup> and the use of genetic data.*

Beneficence, in principles bioethics – known as foundations, by the philosophical-moral basis

with which it seeks to discuss bioethical issues – is imperative in the perspective treated in this work, as it expresses the moral obligation of the ethical agent to act *on behalf of others (...). Obligation to help others by promoting their legitimate and important interests<sup>63</sup>*. Ethics can only be considered authentic if actions go beyond the individual: *To be ethically defensible, it must be shown that acts based on personal interest are compatible with ethical principles of the broad base because the notion of ethics carries with it the idea of something larger than the individual. If I will defend my conduct on ethical grounds, I cannot show only the benefits it brings me. I must report to a larger audience<sup>64</sup>.*

In this sense, utilitarianism reflects normative ethics, pondering over the subject of the action and all those affected by it. The utilitarian root lies in the impartiality that leads to the objectivity of acting. Mill<sup>65</sup>, on the principle of utility, indicated greater happiness as the foundation of ethics, and the maximization of pleasure and the minimization of pain as the ethical purpose. *Everyone has the right to equal treatment unless some recognized social convenience requires otherwise<sup>66</sup>*. Utilitarian principles are increasingly present in society, especially as regards collective health and well-being to the detriment of the individual.



In short, the principle of beneficence and utilitarian ethics can serve as a basis for assessing the ethics of the genetic mapping of the worker. While the former considers the social risk situation and its consequences, utilitarianism aims for the good of all. Bioethics can reflect on individual and collective rights and duties in the use of this technology by occupational medicine and point out, as an ethical foundation, the protection of the dignity of workers, safeguarding their information, i.e., the purpose is to protect everyone and not punish, segregate or expose.

Therefore, the analysis of the benefits of this technique for labor aims at the individual interest of the worker, without interfering with the safety of the community. Thus, even obeying the protection criteria for the mapped worker, in order not to make them vulnerable in their socio-professional relationships, the use of genetic information for labor purposes is only ethically justified if the work to be developed ensures the safety of people.

### Final considerations

There is a universal consensus on the admission of genetic mapping of people for research, disease prevention or medical treatment, as the current forms of direct and indirect genetic intervention point out. Thus, considering that the framework that underlies these purposes is the same – the person and his or her particular dignity –, it is feasible to extend the mapping to the genetic identification of workers' aptitudes for professional practice, especially because of the current market demands.

The effects of these requirements can be exemplified by indicators from the Brazilian National Institute of Social Security: the number of bank employees on sick leave increased considerably between 2009 and 2017<sup>67</sup>. According to a report published by the National Federation of Caixa Econômica Federal Staff Associations, *the total of workers who had accidental or social security benefits was 13,297 in 2009. Eight years later, 17,310 had to leave work due to illness. (...) More than 50% of cases refer to mental disorders (61.5% increase) and repetitive strain injury-related illnesses (13% growth)*<sup>67</sup>.

In the relationship between employer and employee, which aims to maximize profits and minimize costs, in addition to disruptive working conditions, abusive conduct may harm the dignity,

personality and physical or mental integrity of the worker<sup>68</sup>. For Ashton-Prolla and Giugliani<sup>69</sup>, certain personal illnesses and particularities are more influenced by genetic factors, and others may depend on the environment or on the events and conditions under which work activities take place. Such an influence would take place in different ways.

In the broad sense, the proposal to admit genetic mapping is inserted in the perspective of the aforementioned culturalism of the current Civil Code and, in the narrow sense, in the prevention of diseases (physical, emotional and psychological) and, consequently, medical treatment. Legally, this admission can be understood in articles 1, 3 and 5 of the 1988 Constitution, as follows:

*Article 1. The Federative Republic of Brazil (...) is constituted as a Democratic State of Law and has as its foundations:*

*(...) III – the dignity of the human person.*

*(...)*

*Article 3 – The fundamental objectives of the Federative Republic of Brazil are:*

*(...)*

*IV – to promote the good of all, without prejudice of origin, race, gender, color, age and any other forms of discrimination.*

*(...)*

*Article 5 All are equal before the law, without distinction of any nature, guaranteeing*

*(...) the inviolability of the right to life, liberty, equality, security and property, as follows:*

*(...)*

*XIII – the exercise of any work, craft or profession is free, provided that the professional qualifications established by law*<sup>26</sup>.

Genetic knowledge related to the likelihood and prevention of disease is a real and important resource for the medical sciences, which, by using the biotechnological framework to manage health preventively, can eradicate/mitigate illness and thus maximize the quality of life. This is one of the senses of human dignity that, in the secular view, is associated with the minimum conditions for life to be lived<sup>6</sup>.

Thus, to regulate the adoption of genetic mappings, already used in particular interests that will be increasingly requested, it is necessary to structure a consistent legal order that meets modern demand and accompanies biotechnological development. International laws can serve as a reference for drafting Brazilian laws.

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Albany Leite Ossege designed the project, carried out the research and produced the manuscript. Marie Togashi guided the project and critically reviewed the manuscript.


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