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النظام القانوني للجينوم البشري في القانون الدولي

د. اشويطر معمر عبدالمؤمن [1]* الساكته مفتاح صالح بلحاج [2]
[1] قسم القانون الدولي، كلية القانون، جامعة بني وليد، بني وليد ، ليبيا.
[2] باحثة في مجال القانون، مدينة بني وليد، ليبيا.
eshwiterali@bwu.edu.ly

The Legal Regime of the Human Genome in International Law

Eshwiter Muammar Abdel Moumen[1]* Alsaakitah Miftah Saleh Belhaj [2]
[1] Department of International Law, Faculty of Law, University of Bani Waleed, Bani Walid, Libya.
[2] Legal Researcher, Bani Walid, Libya.

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الملخص:
خلال السنوات الماضية ظهرت إعلانات دولية وإقليمية خاصة بأخلاقيات التعامل مع تعديل الجينوم البشري؛ أدخلت فيها العديد من المبادئ العامة الموجودة داخل هذه الإعلانات في دساتير بعض الدول وتشريعاتها الوطنية وذلك أما من خلال تبني هذه الإعلانات كما هي؛ أو من خلال تضمين بعض المبادئ في دستور الدولة أو بإنشاء قانون خاص بها.
فنجد أن المبادئ الدستورية والدولية المتعلقة بالجينوم البشري لا تقتصر على أخلاقيات التعامل مع الجينوم البشري فقط ولكن تتناول مبادئ دستورية ودولية أعم وأشمل؛ مثل الحق في الحياة، وسلامة الجسم وحرمة المساس به، والحق في الصحة، وكرامة الإنسان، والحق في الاستفادة من التقدم العلمي وعدالة استخدامه دون تمييز بين البشر، والحق في التنوع والاختلاف، والحق في الخصوصية وحماية خصوصية البيانات الشخصية، وحرمة الحياة الخاصة.
وتوجد بعض الدساتير المقارنة التي تناولت الجينوم البشري والإعلان عنها، والموقف من تجريم تعزيز القدرات البشرية الوراثية وموقف القضاء الوطني والدولي من تعديل الجينوم البشري.

الكلمات الدالة: النظام القانوني ، الجينوم البشري ، القانون الدولي ، حرمة الحياة ، حماية خصوصية البيانات.

Abstract:
Over the past few years, international and regional declarations have emerged regarding the ethics of human genome modification. Many of the general principles contained in these declarations have been incorporated into the constitutions and national legislation of some countries, either by adopting these declarations as they are, by including certain principles in the country's constitution, or by creating a special law. We find that the constitutional and international principles related to the human genome are not limited to the ethics of dealing with the human genome alone, but rather address broader and more comprehensive constitutional and international principles, such as the right to life, bodily integrity and inviolability, the right to health, human dignity, the right to benefit from scientific progress and its fair use without discrimination among people, the right to diversity and difference, the right to privacy and

protection of personal data, and the sanctity of private life. There are some comparative constitutions that address the human genome and their declarations, the position on criminalizing the enhancement of human genetic capabilities, and the position of national and international courts on human genome modification.

Keywor: Legal system, human genome, international law, sanctity of life, data privacy protection.

Introduction:

In recent decades, the international community has witnessed unprecedented advancements in the field of genetic sciences. This was clearly demonstrated by the Human Genome Project, which marked a significant scientific breakthrough that facilitated the precise mapping of the human genetic structure. This discovery triggered a knowledge revolution that has impacted various fields, including medicine, law, and ethics. Genetic information is now utilized across numerous domains, some of which may directly affect the fundamental rights of individuals, most notably the right to human dignity and genetic privacy.

In light of this advanced scientific reality, there is an urgent need for a legal framework that strikes a balance between the demands of scientific research and technological development on the one hand, and the need to uphold legal principles on the other. The use of genetic data has raised complex legal challenges concerning the legitimacy of its collection, the boundaries of its processing, and the mechanisms for safeguarding it against exploitation or discrimination, particularly given the lack of legislative coherence between national and international legal systems. In this context, international efforts, spearheaded by specialized organizations such as UNESCO, the WHO, and HUGO, have culminated in international declarations and conventions aimed at establishing general principles governing the treatment of the human genome as an inviolable aspect of human identity.

Based on the above, this research seeks to examine the legal framework for protecting the human genome within the context of international law, analyse the effectiveness of mechanisms designed to protect genetic rights, and review relevant national legislative models. Ultimately, this will lead to an assessment of the existing balance between scientific freedom and the legal protection of human genetic identity.

Significance of the Research:

From a scientific perspective, the importance of this research stems from the fact that the human genome is a critical and sensitive issue of global concern, affecting both international and national levels. This is particularly relevant given its profound significance in light of the developments brought about by artificial intelligence and its ongoing advancements.

From a practical standpoint, the application of international legal principles is an absolute necessity, as dictated by the nature of international law and the global interests reflected in international agreements concerning developments related to artificial intelligence.

Research objectives:

The research aims to explore the legal system of the human genome, while clarifying the most important international and national laws and legislation addressing this topic. It also aims to shed light on the international protection of the human genome by identifying the most important international agreements, both foreign and Arab.

Research Problem:

The research problem can be identified through the critical developments brought about by artificial intelligence, which require intervention from international law to address them, particularly with regard to international agreements and resolutions. This intervention is necessary to define the legal regime for the human genome and the protection granted to it under these agreements. The research problem can be defined by a key question that can be posed as follows: What is the role of specialized international and national resolutions in protecting the human genome?

Research Hypothesis:

The research hypothesis on the legal regime of the human genome under international agreements may anticipate solutions on how to regulate and protect the human genome within the framework of international and national laws. This hypothesis relates to assumptions regarding the effectiveness of current laws or the need for new laws to ensure the protection of the human genome from abuse and illegal uses. The research hypothesis may include several aspects, such as:

First: The Efficiency of Existing Laws: The hypothesis suggests that current laws are sufficient to protect the human genome from unlawful use.

Second: The Need for New Laws: The hypothesis suggests that there is an urgent need for new and updated international laws that more effectively address the legal challenges arising from advances in genome technology.

Third: International Cooperation: The hypothesis may relate to the idea that increased international cooperation is necessary to ensure the protection of the human genome, given the nature of the issue and the challenges facing this field.

Research Methodology:

The research focused on a descriptive and analytical approach, which aims to describe and collect facts and data, while attempting to adequately interpret and analyse these facts. This includes the phenomenon of the legal system for the human genome, its international protection, and the extent to which the provisions of international and national resolutions in this area are consistent.

The research also relied on a historical approach to cite the most important international agreements and resolutions issued by national legislation on this topic.

Research Plan:

In light of the above, we will divide the research into two sections: The first section addresses the legal regime of the human genome, while the second section addresses the international protection of the human genome under international and national laws.

Section One: The Legal Regime of the Human Genome

The human genome represents one of the most prominent topics at the intersection of law and the life sciences, especially in light of technological advances that have enabled the use of artificial intelligence to analysis genetic data.

This progress has raised a delicate legal issue related to the protection of genetic privacy and the regulation of the use of this data in a manner that does not violate human dignity or the principles of justice and equality.

In this context, this section examines the legal aspects related to the scientific and technical aspects of the human genome. To discuss this further, we will divide this section into two sections, as follows:

First Section: The Nature of the Human Genome and the Importance and Role of Artificial Intelligence in It.

The human genome is one of the most relevant contemporary scientific concepts in the fields of medicine, genetics, and law, due to the precise genetic information it contains, representing the complete genetic map of a human being and constituting a fundamental reference for understanding, diagnosing, and treating genetic diseases. The importance of this concept has increased with the development of artificial intelligence technologies, which are now widely employed in analysing genetic data, accelerating medical research, and even directing health and pharmaceutical policies based on the results of these analyses.

Recognizing the interconnectedness of these concepts, this section will introduce the concept of the human genome and the objectives of its projects, while addressing the growing role of artificial intelligence in the genetic field. This section is divided into two main branches:

Section One: The Concept of Artificial Intelligence, Its Importance, and its Role in the Field of Genetic Medicine.

Artificial intelligence (AI) is one of the most prominent concepts of the digital age. Its definitions have varied according to the orientations of researchers [1], but most agree that it is a branch of computer science that aims to design systems capable of simulating human intelligence. American scientist John McCarthy defined AI as "the science of engineering and manufacturing intelligent machines" [2], a definition he formulated in 1956 that later became one of the most important areas of technological advancement.

The role of AI in the medical field lies in its ability to analyses accurate conclusions regarding diagnosis and treatment. Its applications contribute to saving time and reducing costs, enabling doctors to develop personalized treatment strategies for each patient [3], based on linking and analysing complex genetic data and identifying relationships between genetic mutations and various diseases, through artificial intelligence and information technology research at the Arab British Academy for Modern Education.

Perhaps one of the most notable achievements of artificial intelligence is its ability to overcome human limitations in dealing with the vast amount of medical and genetic data, making it possible to develop more accurate and effective medical strategies, which constitutes a true revolution in the field of healthcare. Especially in light of human genome projects that rely heavily on in-depth analysis of genetic information.

Section Two: The Human Genome Project, Its Importance, and the Role of Artificial Intelligence in It.

The Human Genome Project is one of the most significant scientific achievements, aimed at decoding the genetic code of humans, thereby contributing to the unprecedented advancement of medical and genetic research. Artificial intelligence has enhanced the effectiveness of this project by processing and analysis vast amounts of genetic data with remarkable accuracy and speed, which raises legal and ethical issues that warrant further examination. Accordingly, this section will be structured as follows:

[1] - The term artificial intelligence is a compound, while intelligence is: quick wit, while artificial is: a name attributed to artificiality, meaning that which is made and not natural.

[2] - John McCarthy, What is Artificial Intelligence?, Stanford University, 12/11/2007.

[3] - Al-Qassim, Fahd, Introduction to Artificial Intelligence, p. 4

First: The concept of human genome projects:

The Human Genome Project is an international scientific project, one of the largest biological projects, which aims to analysis the human heritage in a detailed, partial manner, identifying the sequences of 3 billion pairs of the human genetic material. [1]

The project primarily aims to analysis the nitrogenous chemical bases that make up the DNA molecule. The Genome Project began in the United States, and soon many countries around the world began to show interest in establishing their own human genome projects. The term 'genome' is a relatively new one in genetics, combining two English words: the first, 'gen,' which refers to 'gene' in Arabic, and the second part, 'ome,' which consists of the last three letters of the word 'chromosome,' meaning 'chromosome' in Arabic.[2]

The human genome refers to the set of genetic material that a human being carries, and it consists of approximately 3.2 billion base pairs of DNA distributed over 23 pairs of chromosomes that contain all the genetic instructions necessary for human growth, development, and biological functions [3]. The genome is considered the genetic code that distinguishes each individual from others, despite the existence of great similarity in the genetic structure among all humans.

In this context, human genome projects were launched as global scientific initiatives aimed at decoding the human genome, identifying all the genes it contains, and understanding their functions and their impact on genetic and other diseases. The most well-known of these projects is the Human Genome Project, which was officially launched in 1990 under the leadership of the National Institutes of Health in the United States, in collaboration with international and research organizations. It was completed in 2003 and marked a significant milestone in medical genetics [4]. However, this scientific progress has raised serious legal and ethical challenges concerning the respect for genetic privacy, the limits of using artificial intelligence in analysing this data, and the risks of genetic discrimination or the commercial exploitation of individuals' genetic information. This calls for stringent legal regulation that balances scientific advancement with the need to uphold human dignity .[5]

Second: The Goals and Cautions of Human Genome Projects:

Since their inception, the Human Genome Project has sought to achieve a number of scientific and humanitarian goals that contribute to the development of medicine and the biological sciences and enhance understanding of human genetics. These goals are manifested in several key areas, most notably:

• In the field of healthcare and diagnostic medicine:

Genome projects focus on establishing the concept of diagnostic medicine, which enables medical treatments to be directed based on an individual's genetic characteristics. This enables the prediction of disease before it appears and the provision of advanced preventive and therapeutic care. [6]

[1] - - Al-Abidi - Iyad Muhammad Ali, Advanced Genetic Engineering, Foundations and Applications - Beirut - Dar Al-Masirah, 2001, p. 13.

[2] - Rizk, Hani Khalil - The Human Genome and Its Ethics - Genes of the Human Species and Genes of the Human Individual - Dar Al Fikr - Damascus - 2007, p. 3.

[3] - Muhammad Al-Tahir Mansouri, Genetic Data Protection Law, a Comparative Study, 1st ed., Dar Al-Fikr Al-Jami'i, Alexandria, 2020, p. 34.

[4] - Human Genome Project, NIHfact Sheet, National Human Genome Research Institute, 2020.

[5] - UNESCO and the Universal Declaration on the Human Genome and Human Rights, 1997, Articles 4-6.

[6] - Muhammad al-Tahir al-Mansouri, Genetic Data Protection Law, previous reference, p. 51

• In terms of supporting scientific research:

These projects have enhanced our understanding of human genes and their functions, contributing to significant progress in the diagnosis of genetic diseases and the discovery of drugs based on the patient's genetic makeup . [1]

• From the perspective of genetic justice:

The projects aim to achieve a fair distribution of the benefits of genetic research among individuals and communities and to direct genomic findings toward the benefit of the healthiest groups . [2]

However, these goals, despite their scientific and humanitarian legitimacy, are not without legal and ethical caveats that require legislative intervention. The most prominent of these caveats are:

1- Infringement of Genetic Privacy: The collection and analysis of genetic information is one of the most serious threats to the right to privacy, especially in light of inadequately protected data systems. [3]

2- The Risk of Genetic Discrimination: Some genetic-related applications threaten the potential exploitation of this information in many areas, which violates basic human rights principles and raises profound questions about the ethical use of genetic information. [4]

3- Lack of Appropriate Legal Governance: Many countries still lack specialized legislation that accurately regulates the use of the human genome, particularly with regard to the collection, processing, storage, and sharing of genetic data between research and commercial institutions. This necessitates the establishment of a national and international legal framework that balances scientific development with individual rights. [5]

Third: The jurisprudential view of the human genome and the role of artificial intelligence:

In light of rapid scientific developments, particularly in the field of human genomics and artificial intelligence, it has become necessary to examine the jurisprudential framework for the use of these tools and technologies, given their direct impact on the human being and their sexual rights. This topic is divided into two main issues:

1- The human ruling on the legitimacy of human genome research and related projects:

The majority of contemporary jurists and scholars agree that genetic research and human genome projects are fundamentally permissible, as long as they aim to achieve a legitimate interest, such as treatment, prevention, and early detection of genetic diseases. This falls within the scope of preserving life, which is one of the five major objectives of Islamic law [6], as indicated by the Almighty's statement: "And whoever saves a life, it is as if he had saved mankind entirely." This is also indicated by the hadith of the Prophet (peace and blessings be upon him): "Seek medical treatment, servants of Allah, for Allah has not created a disease without also creating a cure for it." (Narrated by Ahmad). Organizing these projects according to ethical and legal controls and not exceeding the limits of human dignity gives them the description of legal permissibility. It may even be desirable to carry them out if they are related to treating incurable diseases or protecting society from genetic epidemics. [7]

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[1] -Fatima Zahra Ben Yahiya, Genetic Data and the Right to Privacy – A Contemporary Legal Study, Algerian Journal of Legal Sciences, Issue 2, 2021, p. 224

[2] -Human Genome Organization (HUGO), Statement on Benefit Sharing, 2000.

[3] - Dr. Rabie Mohamed Abdel-Ati, Genetics and the Human Genome: A Legal and Ethical Perspective, Dar Al-Nahda Al-Arabiya, Cairo, 2019, p. 73.

[4] - unesco ،universal declaration on the human gerome and human right, 1997 ،article

[5] - International Bioethics Committee, Report on the Responsible Use of Artificial Intelligence in Human Genetics, UNESCO, 2021.

[6] -Surah Al-Ma'idah, verse 32.

[7] - International Islamic Fiqh Academy, Resolution No. 210 (11/23) on Genetic Engineering, Session 23, 2018.

2- The Ruling on the Use of Artificial Intelligence within the Framework of the Human Genome Project:

The use of artificial intelligence to analyze genetic data and guide medical decisions is permissible under Islamic law if it meets the conditions of safety and benefit, and is used within organized scientific frameworks that do not conflict with the objectives of Islamic law, nor lead to harm to humans or the disclosure of their privacy without their permission . [1]

Sharia scholars have determined that modern methods are governed by the objectives. If they are used for a legitimate purpose, they are permissible, but if they are used for something other than that, they become prohibited. This is supported by the principle that "the means have the rulings of the objectives," a fundamental principle that has established the rules and emerging methods, such as artificial intelligence, in the medical field [2]. However, the use of this technology must be regulated by Islamic law, the most prominent of which are [3]:

1. The prior consent of the person concerned with the genetic data is required.
2. No discrimination or genetic bias based on the results of the analysis.
3. Not relying solely on evidence without the intervention of the responsible physician, in order to achieve the principle of preserving life and adhering to the diagnosis (00).

These controls are in line with the objectives of Islamic law in protecting the soul, mind, and offspring, and avoiding expected harm.

Section Two: The Legal Regime of the Human Genome in International Legislation:

With the growing role of genetic sciences and the increasing applications related to the human genome, it has become imperative for the international community to address the ethical and legal challenges posed by these developments. The legal regime of the human genome has evolved gradually, moving from non-binding guidelines to efforts aimed at establishing more specific rules, without yet reaching the level of explicit legal obligation. Despite these limitations, international organizations have made attempts to establish various mechanisms to implement these principles, striving for a coherent international regulation of this sensitive field. To elaborate further, this section will be divided into two parts:

Section One: The International Legal Development of the Human Genome:

International interest in the legal aspects of the human genome was not a new phenomenon; rather, it emerged in the late twentieth century. With the emergence of preliminary results from the Human Genome Project and the accompanying concerns regarding the potential misuse of genetic data, UNESCO took the initiative to issue the Universal Declaration on the Human Genome.

and Human Rights in 1997, which is the first international text to codify ethical and legal principles related to the uses of the genome. This declaration stipulated in its first article that "the human genome represents the human basis for the unity of all members of the human family," considering it the common heritage of humanity .[4]

It is noteworthy that this declaration adopted an approach based on respect for human dignity and non-discrimination. Article 11 of the declaration, adopted in 2003, prohibited all forms of discrimination based on human genetic characteristics. It focused on regulations related to the collection and use of genetic

[1] -Dr. Hussein Hassan Al-Banna, Artificial Intelligence in Medicine from a Sharia Perspective, Dar Al-Nahda, Cairo, 2021, p. 95

[2] -The same reference, pp. 95-96.

[3] -- Al-Qarafi, Al-Furuq, Vol. 2, p. 34; see also: Al-Shatibi, Al-Muwafaqat, Vol. 2, p. 348.

[4] - UNESCO, Universal Declaration on the Human Genome and Human Rights, 1997, Article 1

data, emphasizing the need for free and informed consent and the importance of respecting confidentiality and privacy in this context. [1]

The accumulation of these reference documents has led to the formation of the nucleus of a non-binding international legal system based on shared humanitarian and ethical principles, which were quickly reflected in some national legislations, particularly in Europe, reflecting the influence of non-binding international law on national policies in this vital area. [2]

Section Two: Mechanisms for Implementing International Legal Principles Related to the Human Genome:

The non-binding nature of most international documents related to the human genome raises real questions about their effectiveness in addressing potential violations, especially in light of the absence of binding international agreements or oversight institutions with international judicial jurisdiction in this area.

In light of this vacuum, a set of non-judicial and non-mandatory mechanisms has been adopted. These mechanisms play a complementary role in implementing established legal principles, including:

The UNESCO International Commission on Human Genome Rights (IBC), which is tasked with interpreting and developing international principles and providing recommendations and proposals to states regarding their implementation. [3]

Institutional Ethical Review: Many international research bodies require that genetic projects undergo prior review by specialized committees to ensure their compliance with international principles . [4]

Technical and Scientific Cooperation Programs: Supervised by the World Health Organization, these programs aim to support developing countries in developing their national legislation that takes into account ethical standards in the use of genomes (00).

Genetic Data Exchange Platforms: Such as European Union projects that link funding to compliance with genetic governance standards, making adherence to ethics a condition for international participation . [5]

However, these mechanisms, despite their importance, remain limited in their impact unless they are supported by binding international agreements and independent oversight bodies capable of enforcing and ensuring compliance with the rules, especially with the growing role of private sector actors in the field of biotechnology.

Section Two:

International Protection of the Human Genome in International and National Laws

Legal protection of the human genome is an ethical issue related to the future of human existence after the discovery of the human genetic map, particularly the negative applications of genetic engineering, which violate fundamental human rights, particularly the right to human dignity, and pose real challenges to the existence and diversity of present and future generations. Therefore, the existence of legal rules at the national and international levels is an absolute necessity to prohibit these threats and establish civil and international liability for those who violate them. International and national legislation in this area seeks to ensure the protection of individual rights in light of ongoing scientific developments by preventing

[1] - Ibid., Article 11.

[2] - UNESCO, International Declaration on Human Genetic Data, 2003, Article 4.

[3] - UNESCO, Reports of the International Bioethics Committee (IBC).

[4] - World Health Organization, Ethical Review Standards for Health Research Involving Human Participants, 2011, p. 39

[5] - World Health Organization, Genomics and Global Health, 2002, p. 111

exploitation or discrimination based on genetic information. Based on the above, we will clarify this section and divide it into two sections:

First Requirement: The Human Genome and Its Protection in International Agreements:

The human genome is the fundamental foundation of an individual's biological identity, as it contains all the genetic information that determines the characteristics of regulating the use of the genome, ensuring its protection from any exploitation or interference that violates fundamental human rights. In response to these challenges, the international community has worked to establish binding legal rules and guidelines aimed at protecting the human genome through prominent international agreements and declarations, the most important of which are the Universal Declaration on the Human Genome and Human Rights issued by the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the Convention on the Protection of Human Rights issued by the Council of Europe. These legal texts affirm that the genome is the common heritage of humanity and oblige state parties to ensure respect for human dignity, protect genetic privacy, and eliminate any form of discrimination based on genetics.

At the global level, international law is invoked when there is a risk of attacking human identity, meaning the human species, through the modification of genetic heritage. When it comes to regulating gene therapy and the cloning of living organisms, or patenting them, isolated efforts by a single state will be ineffective. Therefore, international law is essential for regulating scientific research, particularly in its role of harmonizing national laws, as is the case with environmental or human rights issues. Bioethics is one of the new fields calling for a general law of nations; a law of international origin [1]. To discuss further the importance of the human genome in international agreements and international human rights treaties that aim to address and protect human rights and fundamental rights, we will examine it according to the following:

Section One: The Human Genome in the Context of Human Rights:

International human rights organizations are directly or indirectly involved in recognizing the protection of human rights in the field of biotechnology, as well as in protecting the corresponding rights of future generations. The declarations issued by the United Nations, dating from 1997 to the present, are closely concerned with the protection of the human genome and are certainly the most important and interesting from the standpoint of affirming the principles shared by Member States and generally accepted as the "common basic paradigm" regarding the vitality and use of human tissue, genetic resources, assisted reproduction, and scientific research on this subject. In addition to the organization's human rights conventions, UNESCO has taken the initiative to address this issue through a series of declarations, the most important of which is the International Declaration on Human Genetic Data, which was adopted unanimously and by acclamation at the 32nd UNESCO General Conference on November 16, 2003.

The specific issues addressed by this Declaration focus on the collection, processing, storage, and use of human genetic and proteomic data and biological samples[2] in accordance with international human rights law [3]. It also takes into account several principles outlined in the Universal Declaration of Human Rights.

[1] - Maljane Dubois Sandrin, Bioethics and International Law: French Annual of International Law, Vol. 46, 2000, p. 82.

[2] - Human genetic data refers to information about an individual's genetic characteristics obtained through the analysis of nucleic acids. Human protein data refers to information related to an individual's proteins, including changes, modifications, and interactions. Biological samples are samples of biological materials, such as blood or skin cells, that contain nucleic acids and contain characteristics of an individual's genetic makeup.

[3] -- Leonardo Sabugal Moshiar, “International Law in the Face of the Human Genome and Bioethics,” Criteriogor Tebdeko, Vol. 10, No. 2, 2010, pp. 155-156.

The most prominent topics covered relate to the collection, processing, and use of genetic data for diagnosis and healthcare, including screening and predictive testing, as well as for human medicine, civil or international proceedings, or other legal actions, and any other purposes consistent with the Universal Declaration on the Human Genome and Human Rights, along with international human rights law. UNESCO adopted this Declaration to prevent human rights violations by those who possess genetic data, which are considered indelible fingerprints of the individual. The text reaffirms the principles outlined in the Universal Declaration of Human Rights and the Human Genome, emphasizing equality, non-discrimination, and respect for human dignity, fundamental rights, and freedoms. In particular, it affirms on the importance of ensuring freedom of research and, on the other hand, the confidentiality of research and the safety of persons whose protection must be considered paramount in the collection, processing, preservation and use of human genetic data. [1]

Section Two: The Human Genome in the Light of International Agreements:

The international community's efforts to reach a global agreement regulating the ethics of biomedicine and bioethics continue. Despite this, there is the European Convention on Biomedicine and Human Rights (Oviedo Convention) [2]. Although it is regional, as it was issued by the Council of Europe, its scope is global. It was signed in Oviedo (Principality of Asturias, Spain) on April 4, 1997, and entered into force on December 1, 1999. It is considered the basic text against the applications of human genetic engineering in the member states. It is the declaration that has achieved the greatest degree of international coordination regarding the human genome, as it seeks to guarantee the dignity, rights, and freedoms of people in the fields of biology and medicine. Thanks to this Convention, the Council of Europe is considered a pioneer in international law regarding biomedicine and human rights as it is the first binding international legal instrument that sets standards applicable to clinical care, research and interventions in the human genome. It has a regional international scope, yet its message is global because under not very strict conditions any country outside the Council of Europe can accede to the Convention. [3]

In general, it emphasizes the necessity of using scientific progress in the field of biology to achieve the interests of present and future generations through three axes: the first relates to the individual; as the agreement aims to abort every threat to the use of scientific progress that is not beneficial, by prohibiting trade in any part of the human body and limiting the use of genetic experiments. The second relates to society, considering that the individual is part of society. The third is the species (the human race). The agreement emphasizes the protection of the human species, as the damage resulting from genetic engineering does not only affect the individual and society, but it affects the human race. Therefore, the agreement emphasizes the protection of present and future generations of humanity as a whole, which is a matter that by its nature requires international cooperation . [4]

The Convention as a whole aim to protect human dignity and fundamental rights in the field of biology and medicine. It stipulates that the Parties to this Convention shall protect human beings in their dignity and identity, and shall ensure to all, without discrimination, respect for their integrity and other

[1] - Anna Falcone, op.cit, p.291.

[2] - Officially known as the Convention for the Protection of Human Rights and Dignity with regard to the Applications of Biology and Medicine, this Convention aims to establish a legal and ethical framework for regulating medical and biological applications to protect human dignity and fundamental rights. The most important principles of this Convention are: 1- The priority of the human being over science.

[3] - It has been signed by 35 of the 47 countries that make up the Council of Europe and ratified by 29 countries.

[4] - Free and continuous consent 3- Prohibition of discrimination 4- Prohibition of human cloning.

fundamental rights and freedoms with regard to framework applications aimed at filling the legal vacuum created by biomedicine and human medicine due to the lack of consistency in national laws or regulations and the inadequacy of international texts focused specifically on the scientific world. The Convention also achieves a reasonable balance between the protection of inalienable human rights. The Council of Europe set the lofty ambitions of this Convention on 9 December 1998, stating that this Convention undoubtedly constitutes the global reference aimed at protecting human beings and their embryonic heritage through the international consecration of human dignity and identity.

Section Two: The Human Genome and Its Protection in National Laws:

The rapid development of genomics has created legal challenges that have forced countries to adopt legislative regulations to protect genetic data and regulate its use. This is consistent with the general principles of law requiring respect for human dignity, preserving genetic privacy, and eliminating any discrimination or exploitation that may arise from the analysis of genetic information.

Countries' approaches to regulating the human genome have varied, with some adopting specialized legislation and others simply including scattered provisions within existing laws. This section reviews the most prominent national legislative models in this field and analyses their consistency with ethical guidelines and relevant international standards. In order to address this topic in detail, it will be divided into two main sections:

Section One: Protection of the Human Genome in Foreign Legislation:

Based on their commitment to protecting the fundamental rights of individuals, most notably the right to genetic privacy and the right to non-discrimination, several foreign countries have enacted national legislation regulating the uses of the human genome and genetic data, in line with the ethical and legal challenges posed by the genetic revolution. France and Spain stand out in this context, as they were among the first countries to adopt advanced legal frameworks in this field. Through these frameworks, they sought to strike a delicate balance between the requirements of scientific research and the protection of human dignity.

This section examines the most important legal features of the French and Spanish legislative experiences, as follows:

First: Regulation of the Protection of the Human Genome in French Legislation:

Legislative regulation of the protection of the human genome came within the framework of a comprehensive approach that takes into account ethical and medical considerations and is based on the Bioethics Act of July 29, 1994, a significant turning point in legislation and criminalizes any practices that would infringe upon individuals' genetic rights.

Some of the key laws enacted are:

- The first, Law No. 94-653, relates to respect for the human body and stipulates the principle that the human body or any of its components are not subject to ownership or commercial disposal. It prohibits the donation of organs or products except under strict conditions and with informed consent.
- The second, Law No. 94-653, on the protection of personal genetic data, regulates its processing and prohibits any infringement of genetic privacy without explicit authorization.

These principles were further enshrined in subsequent amendments. Especially in the law issued in 2021 AD, where the penalties related to improving the race and reproductive cloning were strengthened [1]so they were included in the category of moral crimes and it was decided that anyone who engages in these practices shall be punished with imprisonment for a period of up to 30 years and fines of up to 750

[1] - Adnan Abbas Musa Al-Naqeeb and the International Community's Moral Responsibility for Human Cloning, Political Science Journal, College of Political Science, University of Baghdad, Issue 43, 2011, p. 97

thousand euros, especially in cases of conducting examinations or procedures aimed at giving birth to a child genetically identical to another sick child [1]; French legislation also includes precise provisions to protect genetic privacy. It prohibits subjecting any person to genetic testing for purposes other than medical research or therapeutic diagnosis, and imposes penalties of one year's imprisonment and a fine of up to 15,000 euros. The penalty is doubled if the data is used to determine a person's genetic heritage without their consent. It also strictly prohibits conducting tests to determine a person's lineage or genetic characteristics except under specific legal conditions and under strict judicial oversight. French laws affirm that the human genome is integral to human dignity and may only be modified for purely therapeutic purposes. They explicitly prohibit any intervention aimed at modifying genetic characteristics for the purpose of improving the population or for cosmetic purposes. The Penal Code also stipulates that respect for human dignity prohibits any assault on the human body. The laws also criminalize any genetic discrimination based on the results of genetic tests, whether in employment, insurance, or otherwise. The transfer or storage of genetic data to third parties is also prohibited without legitimate reason. [2]

Second: Regulating the Protection of the Human Genome in Spanish Legislation:

Spanish legislators have attached exceptional importance to the issue of protecting the human genome, recognizing the extremely sensitive ethical and legal issues posed by genetic research, particularly in light of the biological revolution.

This interest has taken on a comprehensive legal character through the adoption of a legislative framework concerned with regulating the use of genetic information, ensuring the protection of genetic privacy, and prohibiting discrimination based on genetic characteristics. Spanish Law No. 14 of 2007 on Biomedical Research [3]is a cornerstone in this field. It includes a set of legal principles that provide legal protection for the human genome, whether at the level of individuals, embryos, or even society as a whole, by regulating genetic research and restricting the use of genetic data within the bounds of medical ethics and human rights principles. Article 1 of the aforementioned law stipulates that all activity related to the use of genetic information must be conducted within a framework of respect for human dignity and fundamental freedoms, most importantly the right to non-genetic discrimination. [4]

Article 2 stipulates that any research or clinical procedure involving the analysis of genetic material must be subject to the explicit and informed consent of the person concerned, and that they must be provided with all information regarding the nature of the procedure, its risks, objectives, and future [5]consequences.

The law emphasizes that consent must be free, prior, and specific to all genetic interventions. It cannot be replaced by any form of implicit consent or institutional guardianship except in cases of extreme necessity, such as in cases of mental incapacity or when dealing with embryos.

The Spanish legislator has devoted significant space to the issue of genetic confidentiality, considering that genetic data is among the most sensitive and dangerous pieces of information, given its potential to predict future health or determine an individual's family and biological characteristics. In this context,

[1] - Article 16 Alinea 4d4 chapter deuxieme du titre du liver premier du code civil fracais.

[2] - - Article 226 (25/26/27/28) of the new French Penal Code.

[3] -Biomedical research is any scientific or experimental activity undertaken by physicians, scientists, or research centers with the aim of understanding biological and genetic phenomena. When Spanish law refers to "biomedical research," it refers to all activities that affect genetic material, hereditary characteristics, or human organs and cells, and which require precise rules to protect individual rights.

[4] - Article 1 of Spanish Law No. 14 of July 3, 2007, on biomedical research, states: "Any intervention in genetic material must be carried out with respect for human dignity and cannot lead to discrimination or stigmatization due to genetic characteristics."

[5] - See Article 2 of the same law, which requires informed, prior consent for any genetic analysis or testing.

Articles 4 and 5 stipulate the obligation to protect such data and prohibit its use, disclosure, or storage without explicit consent, with disciplinary and criminal penalties imposed on anyone who violates this obligation. [1]

The legal framework is not limited to legal relations, but rather extends to the ethical aspects of genetic research. Article 6 stipulates that all genetic tests must adhere to medical ethical principles and must not aim to eugenics or genetic modifications for non-therapeutic purposes. [2]

On the institutional side, the Spanish legislature requires all research centers and medical institutions involved in genomic technologies to establish scientific research ethics committees to evaluate research and ensure its compliance with the law and bioethical principles. These committees operate under state supervision, establishing preventive legal oversight against any misuse of genetic material.

Finally, Spain has supported this legal framework with complementary legislation, such as:

- Organic Law No. 3 of 2018 on the Protection of Personal Data and the Guarantee of Digital Rights.
- Law No. 30 of 1978 on the Transfer of Human Organs and Tissues.

Accordingly, it can be said that the Spanish legal framework is characterized by comprehensiveness and coherence, as it combines the protection of the individual and the interests of research with legal controls and ethical considerations. This makes it a model for protecting the human genome at the national level.

Section Two: Human Genome Protection in Arab Legislation:

Despite the recent interest in the human genome in the Arab legislative environment, some countries have taken significant steps toward regulating the use of genetic information and regulating genetic research to ensure the protection of individuals' dignity and privacy and to protect them from genetic discrimination.

The Arab Republic of Egypt and the Lebanese Republic are among the most prominent Arab countries that have attempted to formulate legal frameworks for dealing with genetic material, whether through independent legislation or by including separate provisions in health, medical research, and data protection laws. To address Arab legislation related to human genome protection in greater detail, this section will be divided into two sections, as follows:

First: The Legal Regulation for the Protection of the Human Genome in the Arab Republic of Egypt:

Despite the recent developments in Egyptian legislation in the field of genetic information protection, Egyptian legislators have paid increasing attention to genetic data in light of the scientific and medical progress witnessed worldwide. This is due to its essential role in shaping an individual's genetic identity and the risks it poses to privacy and discrimination if misused.

In this context, the Data Protection Law was enacted to regulate the use and processing of genetic data, considering it a category of "sensitive personal data" requiring strict protection. This law is consistent with the constitutional principles stipulated in Article (99) of the Constitution of the Arab Republic of Egypt [3], which stipulates that "any assault on personal freedom or the sanctity of private life is a crime that is not subject to statute of limitations." This confirms that the protection of the human genome is based on well-established constitutional guarantees.

Article [4] of the law defines genetic data as "personal data relating to the genetic characteristics of a natural person, which reveals their unique information," reflecting the legislator's awareness of the privacy of this

[1] - See Article 5 of the law, which affirms the obligation of health and scientific institutions to protect the confidentiality of genetic information under penalty of legal liability.

[2] - Article 6 of the law prohibits the use of genetic modification techniques for the purpose of selecting traits, improving offspring, or determining sex, and imposes strict bioethical obligations on research entities.

[3] -Article (99) of the Egyptian Legislation of 2024.

[4] - Article (1) of the Egyptian Personal Data Protection Law No. 151 of 2020.

data. Article (22) emphasizes the need to obtain prior authorization from the Personal Data Protection Center before undertaking any activity related to the collection, storage, or analysis of genetic data. This ensures institutional oversight and ensures that the use of this information does not deviate from ethical and legal frameworks.

On the other hand, Article (35) stipulates strict criminal penalties, including imprisonment and a fine, for anyone who violates the confidentiality of genetic data or processes it without a license or the explicit consent of its owner.

Despite these legislative guarantees, a number of researchers[1] have pointed to legislative shortcomings that require addressing, most notably the absence of specific legislation regulating genetic testing and genetic experiments independently, similar to some European countries.

On the other hand, the absence of a detailed executive regulation for the Personal Data Law is one of the most significant scientific challenges, leading to divergent interpretations of the legal standards to be followed in this sensitive field. Accordingly, this analysis recommends the adoption of specific legislation regulating the human genome in Egypt. This legislation should address in detail everything related to the collection, storage, and use of genetic data, establish strict rules for genetic research, and provide a balance between the requirements of scientific research and the fundamental rights of individuals.

Second: Legal regulation for the protection of the human genome in the Lebanese Republic:

Lebanese legislators, like many other comparative legislations, have begun taking gradual steps toward establishing legal protection for human genetic material, recognizing its extreme sensitivity and its close connection to fundamental human rights, particularly the right to privacy and protection from genetic discrimination.

Although there is no comprehensive law dedicated to protecting the human genome in Lebanon, there is a diverse legal framework that provides a degree of protection for this data through legislation related to the protection of privacy and health and genetic data.

Law No. 81 of 2018 on Electronic Transactions and Personal Data is the most prominent legislative framework in this field [2]. It includes a set of obligations for data processors against any breach or misuse. It also prohibits the transfer of sensitive data outside Lebanon except under special controls that ensure the legal transfer of data to them [3]. In addition to this law, Law No. 625 of 2004 Regulating Genetic Tests stands out. This law is one of the pioneering legislative initiatives in the Arab world, providing specific regulation for medical genetic testing, taking into account internationally recognized ethical and medical principles. This law also explicitly prohibits the use of genetic testing for non-medical purposes without legal authorization, including insurance, employment, or discriminatory purposes. This reflects the Lebanese legislator's commitment to preventing the use of genetic material to harm individuals' rights or violate their genetic dignity. However, despite these positive steps, Lebanese legislation still faces a number of problems, most notably the absence of an independent national body concerned with the protection of personal data in general and genetic data in particular, which weakens oversight and compliance mechanisms. Moreover, despite its importance, Law No. 81 of 2018 [4] has not yet been accompanied by detailed implementing regulations defining the standards and procedures for processing

[1] - Tariq Jumaa Al-Sayed Rashed, "Legal Protection of the Right to Privacy of Genetic Data," National Criminal Journal, National Center for Social and Criminological Research, Volume 63, Issue 1, 2020.

[2] -Electronic Transactions and Personal Data Law No. 81 of 2018, Chapter Five, published in the Lebanese Official Gazette.

[3] -Issued by the Lebanese Parliament, based on the recommendation of the National Advisory Committee on Ethics

[4] -- Taken from a SMEX article assessing the shortcomings of Law 81 in terms of implementation and the lack of regulatory regulations.

sensitive data, including genomic data. This creates a gap between the text and scientific application. Therefore, enhancing the protection of the human genome in Lebanon requires updating the current legal framework by issuing specific, independent legislation regulating genetic data, establishing effective oversight mechanisms, and establishing an independent national body to oversee the implementation of these provisions. This balance must be achieved between respect for human dignity and the requirements of scientific and medical research.

Conclusion

After completing the research topic, we reached a set of results and recommendations that we hope will be implemented:

First: Results:

1- The Human Genome Project is one of the greatest international scientific projects in biology, aiming to analyses human heritage in part, in addition to a range of important goals that will achieve a historic revolution in the healthcare sector.

2- Studies and applications have proven the importance of artificial intelligence in many scientific, medical, and economic fields. This technology has entered the field of medical services with great force, contributing to many achievements in this field.

3- Egypt and Lebanon are among the leading countries that have recognized the importance of the Human Genome Project, providing support for research and studies and achieving significant strides and impressive accomplishments in this field. Artificial intelligence also plays a significant role, as evidenced by the scientific and medical results.

4- Many countries still lack comprehensive national legislation regulating the medical and research uses of the human genome.

Second: Recommendations:

1. Through this study, the researcher recommends that the Libyan legislature expedite and expand its efforts to draft a Libyan law regulating the work of genomic research centres at the state level, and to enact laws specifically to codify and frame the issue according to Sharia and legal outcomes, as Egyptian and Lebanese legislatures have done.

2. The researcher recommends that Islamic jurisprudence assemblies, researchers, and Sharia and legal scholars monitor all developments in the field of human genome projects and genetic engineering.

3. The researcher recommends defining legal controls for this field and its practitioners, whether individuals, medical centers, or research centers, at the national and international levels.

4. We also recommend the need to activate the role of international human rights courts in confronting the grave violations to which the human genome may be subjected.

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