DOI: https:// DOI 10.34118/jskp.v5i01.4259

Article history (leave this part):
Submission date: 01-11-2024
Acceptance date: 23-05-2025
Available online: 30- 06- 2025

Keywords:
Privacy, Data, Genetic Privacy, Processing, Confidentiality

Funding:
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Competing interest:
The author(s) have declared that no competing interests exist.

Cite as (leave this part):
Dilmi, C., & Sakri , Z. (2024). Artificial intelligence's Impact on Higher Education Quality. Journal of Science and Knowledge Horizons, 4(01), 606-623.

Journal of Science and Knowledge Horizons
ISSN 2800-1273-EISSN 2830-8379

Protecting Genetic Privacy

1 Aicha Fadhel *,Faculty of Law and Political Science, University of Sfax(Tunisia) Misaichamsdk12@gmail.com

https://orcid.org/0009-0009-4527-4316

Abstract:

The article aims to demonstrate the risks posed by biomedical advances in genetic engineering and the consequences of violations of human dignity and the right to genetic privacy if the processing of individuals' genetic data is useful in some areas of treatment and scientific research, but it involves more negative, compromising the intangibility of the human body and the specificity of its mountain and genetic information that distinguishes it from others. Therefore, the right to confidentiality of individuals' genetic data prevented others from violating it as sensitive data and to process it only with their prior consent.

** FADHEL AICHA*

DOI: https:// DOI 10.34118/jskp.v5i01.4259

Résumé :

Cet article vise à démontrer les risques posés par les avancées biomédicales en ingénierie génétique, ainsi que les conséquences des atteintes à la dignité humaine et au droit à la vie privée génétique. En effet, bien que le traitement des données génétiques des individus puisse s'avérer utile dans certains domaines médicaux et de recherche scientifique, il comporte également de nombreux aspects négatifs, compromettant l'intégrité du corps humain ainsi que la spécificité de son patrimoine et de ses informations génétiques qui le distinguent des autres. Ainsi, le droit à la confidentialité des données génétiques des individus empêche autrui d'y porter atteinte en tant que données sensibles, et impose qu'elles ne soient traitées qu'avec leur consentement préalable.

Mots-clés : *vie privée, données, vie privée génétique, traitement, confidentialité.*

---

* ***FADHEL AICHA***

Introduction

Defining the concept of the right to privacy poses considerable challenges due to its inherently relative nature, which varies across time, place, cultural customs, traditions, and ethical values, as well as with the evolving dynamics of life and its environmental factors. If defining general privacy is already complex, defining the right to genetic privacy becomes even more problematic, particularly in the absence of clear legislative texts that outline and regulate its meaning and scope. Based on the broader understanding of privacy as a human right, genetic privacy can be defined as: “The right of an individual to determine what genetic information others may access about them, and to decide what genetic information they wish to know about themselves.”

The advent of new biotechnologies has opened unprecedented frontiers. The advancements in decoding the human genome have disrupted our understanding of genetic material, demanding that legal and legislative systems approach these developments with openness and objectivity to ensure effective and coherent protection of the human genetic heritage. This heritage has become a significant point of scientific and societal value. While genetic engineering has led to substantial benefits in medicine, food security, environmental protection, and criminal investigation such as treating hereditary diseases, producing medicines, and enhancing food products it has also sparked intense legal and ethical debate.

This debate centers on the conflict between scientific innovation and commercialization on one side, and fundamental legal principles—especially those related to individual rights and freedoms—on the other. Genetic research often involves accessing deeply personal information that touches on a person's life, family history, and psychological and emotional attributes—not merely biological ones. (Shams El-Din, 2002, p. 1099)

Thus, this article addresses a central research problem: To what extent is the legal protection of genetic data effective? In other words, has current legislation established a genuine and sufficient framework to ensure the privacy and integrity of genetic information in the face of rapid technological advances?

Therefore, this study was divided into two parts, the first of which we address the "concept of privacy of genetic data", while the second was devoted to "the scope of protection of the privacy of genetic data".

First: The concept of privacy of genetic data

The privacy of genetic data has been characterized by its objective and personal nature, which would make all information obtained from genetic examination subject to the protection of the right to genetic privacy, which requires that the handling of this information be surrounded by confidentiality. Genetic data is not personal data like any other data, it is sensitive and may lead to discrimination between individuals, and therefore it must have a special and highly protective legal status if the collection of personal data in general and sensitive data becomes of great importance to achieve security and stability in society and protect it from any terrorist or criminal attempts via the Internet.

The scientific and technological development in the field of genetics has led to a real revolution in the field of biological medical sciences, as it has resulted in many scientific discoveries that have followed one after the other, starting with the development of the first model of the structure of DNA A.N.D in 1953 by the workers "Watson" and "Crick", passing through the discovery of the genetic fingerprint by the scientist "Jeffrey" in 1985, and the wheel of scientific discoveries has not stopped in the field of Genetics to this extent, but it went beyond to establish a huge project in 1990 (Taheri & Al-Nahwi, 2021, pp. 2102 - 2131)called the "Human Genome Project" which aims to identify the complete structure of the DNA fingerprint A.N.D, and store the information resulting from the project in a global database to analyze it and uncover the secrets contained in human genes, if the great scientific and technological development in the field of precise medical sciences constitutes a serious threat to the rights and privacy of individuals, which prompted jurists to try to define the idea of "private life" and the concepts associated with it to ensure the maximum necessary protection, and to address the legal and ethical issues that genetic engineering applications have raised. The right to genetic privacy is characterized by its objective and personal nature in itself, as all information that a person wishes to conceal and is obtained from genetic examination is the subject of protection of the right to genetic privacy, and therefore we find that criminalization of tampering with this information is characterized by the breadth of its forms and the multiplicity of its means.

The right to privacy requires that a person has the right to know the information that others hold about him, even if this other person is the state authorities themselves. The implementation of the right to privacy requires that a person be granted the “right to view the information that others hold about him, as it is the right of a person to know the confidential information that is private to him and that may lead to influencing him. However, some countries allow the collection of genetic fingerprint data regarding certain types of crimes, namely sexual crimes, as is the case in the French law issued on June 17, 1998. Therefore, this information must be surrounded by a fence of secrecy given the serious consequences that may sometimes result from it).

Genetic privacy is nothing more than a distinct application of the right to privacy in general, and this was the approach that the French legislature adopted when it stipulated crimes affecting genetic privacy in a separate chapter attached to the chapter containing criminal texts specific to attacks on private life. The right to genetic privacy can thus be defined as the right of a person to decide for himself what genetic information others can know, and his right to decide what information he wants to know about himself. This right has a personal element based on the individual's will to decide whether others can access his information and an objective element based on the information subject to the right being "genetic," which is an objective matter in which the individual's will has nothing to do. Some believe that genetic information is nothing more than a type of medical information held by public or private bodies and covered by legal protection, the violation of which is a crime. In the view of the proponents of this opinion, the general texts that protect medical information include genetic information in general in protection, just like any other medical information. Therefore, protecting information is at the same time identical to protecting the right to genetic privacy, because they focus on one subject, which is information. Genetic privacy protection may harm others, despite the existence of certain considerations that require its protection from tampering in the event of an attack on it, especially since when this information is disclosed, this may contribute to reaching the truth and enlightening those dealing with the person about it.

Protecting this privacy leads to misleading others who are in good faith, as they may deal with this person and then surprise him that he suffers from a disease of genetic origin. Examples of this are when an insurance company concludes an insurance policy for a large amount, and the insurance applicant hides genetic information that is important for the insured to accept the insurance, or a pilot conceals information indicating the possibility of his exposure to future health problems for fear of the impact of this information on his future career.

The granting of privacy leads to the inaccuracy or incompleteness of the information collected about the person, which in turn leads to errors in making decisions related to this person and misjudgment and misunderstanding. Exaggerating genetic secrecy may also lead to perpetrators of crimes of assault on honor and crimes of assault on children escaping and not being exposed, which leads to the possibility of them mixing with members of society and re-committing their crimes. On the other hand, the results of genetic tests may be misinterpreted by some who may not be good at understanding genes or interpreting test results. The presence of a gene that causes a certain disease does not necessarily mean that the person will be susceptible to this disease.

This scientific fact may not be known to employers or insurance companies, and they may not make their decision based on the assumption that this disease is present. However, this license may be misused. Many non-medical uses of genetic information may be harmful to the individual and unjustifiably infringe upon his rights. Another example in the workplace is that the employer uses this information to dismiss workers who are not ideal under the pretext that they do not meet the health requirements for work. The same applies to the insurer who may use genetic information to deprive the person of health or life insurance protection.

The genetic material that forms the basis of the genetic examination can be obtained very easily and without much effort, and often without the person's knowledge, as genetic material can be obtained from various sources such as blood, saliva, semen, nails, urine, skin tissue from cigarette butts, hair, etc.

Given the tendency of many countries to store genetic information, the right to Genetic privacy is one of the risks of using biotechnology in the field of information technology. What has made it easier to violate this privacy is that medical records have become more centralized and are stored on computers, which many people and organizations can access. It has also become possible for state authorities to know the genetic secrets of any person by simply analyzing a drop of his blood. Studies have shown that the results of a genetic fingerprint test can be read, saved, and stored by various means, including computers until they need to be returned to.

In addition, saving them electronically makes comparing them with other results a matter that is easily justified. The extension of the scope of the right to privacy in this case and its extension to others raises many problems in determining who has the right to disclose genetic information, since the genes that are the source of this information are not owned by the person himself, but rather are owned by others who may reveal information that these genes may not want to be disclosed.

Second: The legal scope of protecting the privacy of genetic

data International agreements and declarations are the cornerstone of protecting human rights at the international level, as they are an effective method for unifying international efforts and a basic means for countries to empty the resulting rules and principles into their domestic legislation, if international conferences contributed significantly to crystallizing the rules related to protecting the right to genetic privacy in the face of genetic engineering applications, and the most important of these conferences are (Principles and Rules of the World Medical Association) Declaration of Helsinki 1964) The principles and rules of the World Medical Association are considered among the most important international documents that established the legitimacy of medical experiments on the human body, given the ethical principles and rules it issued at its eighteenth meeting in "Helsinki" in 1964, and confirmed at its 66th and twentieth meeting in "Tokyo" in 1975, the Fourteenth International Conference on Criminal Law 1989 Among what was addressed at the Fourteenth International Conference on Criminal Law held in Austria in October 1989 was the issue of "criminal law and modern medical technologies The twenty-fourth Council for International Organizations of Medical Sciences Conference was held in Japan in "Tokyo" and also in the city of "Inoyama" in 1990 This conference addressed the subject of genetics, ethics, and human values (mapping the human genome, genetic investigation, and gene therapy).

This conference resulted in a document with eight basic articles, all of which focused on establishing a set of ethical rules in the field of scientific research and experiments that make the human genome their subject. About genetic privacy, the fourth article of the document emanating from the conference stated that the data resulting from genetic tests should remain immune from publication unless approved by Its owner is responsible for this, and must maintain its confidentiality. Genetic information carried by genes is a great legacy for its owner, and at the same time it constitutes a deadly weapon for him if it is obtained and used for illegal purposes, or disclosed in a way that threatens the life and future of the individual, whether in the field of insurance and what it includes in terms of discrimination between individuals, given that the results of genetic tests enable the knowledge of the future health status of the individual, and thus if he is classified as a case with high insurance risk, this will lead to the rejection of his request to obtain insurance, which is contrary to what was recommended by the Committee on Ethical, Legal and Social Aspects of the Human Genome Project, which prevented insurance companies from making comparisons on discriminatory grounds, due to the results of genetic tests (Zaghbib, 2009, p. 66), on the one hand, on the other hand, discrimination can also be related to job opportunities and the extent of the safety of the genetic factor, as the employer obtaining the results of genetic tests, which is often illegal, may lead to the person being deprived of work after confirming the presence of genes carrying a disease, which leads to his inability to work or diminishing his ability to perform his work.

Sensing the seriousness of actions that may affect the human genome, the Algerian legislator resorted to issuing a new law bearing the number 16.03 related to the use of genetic fingerprints in judicial procedures and the identification of persons (No.16.03, 2016). Other types of crimes were not addressed by the aforementioned law 16.03 that may occur using genetic samples or the results of related tests.

Among these acts is the examination of biological samples without obtaining the explicit and sound consent of their owner, as Article 16 of Law 16.03 was limited to imposing penalties on those who refuse to undergo biological analyses that enable obtaining their genetic fingerprint in legitimate cases that require it only. It cannot be said that it is possible to apply the texts of the Health Protection and Promotion Law as they represent the general rules in this case, because the text of Article 44 of the Health Protection and Promotion Law only addressed the consent provided by the patient, as it stated: "Any medical procedure that poses a serious risk to the patient is subject to the patient's free and informed consent or the consent of persons authorized by him or by the law..." Hence, the text was limited to The above article on the patient's status is not always achieved in the subject of genetic testing (Razaki, 2018, pp. 736-751), as the latter may be a healthy person who does not suffer from any disease, and therefore there is no room for applying the general rules here, which constitutes a legislative deficiency in the field of protecting the right to genetic privacy that must be remedied, on the one hand, on the other hand, the process of destroying or falsifying the biological sample may also fall within the scope of illegal acts related to the biological sample, which the Algerian legislator did not address either, and all that is required is that it shows the possibility of destroying biological samples by the competent judicial authority or by the competent security services if keeping them is no longer necessary, and destruction occurs in all cases when a final judgment is issued in the case, and therefore the law has shown us the cases in which destruction is legitimate

Conclusion

In conclusion, genetic privacy is an integral part of the concept of human privacy, as human genes contain sensitive personal information that is directly related to the physical and moral entity of the human being, and therefore it is not permissible to tamper with them except within the limits determined by the law. To provide the necessary protection for the right to genetic privacy, legal efforts must be based on two foundations:

the first (the material foundation) is represented by the necessity of protecting the human body and its components connected to it from the processes of collecting biological samples and examining them genetically without obtaining prior consent,

And the second (the moral foundation) is represented by protecting the genetic information and data revealed by the processes of examining and analyzing human genes).

Therefore, through this article, we have tried to clarify the importance of genetic information and its close connection to a person's private life, and its role in revealing his identity, lineage, ethnicity, and affiliation, as well as his current and future health record. These openings have a positive role in protecting people from diseases that may kill them in the future or serving criminal justice by facilitating the identification of the perpetrator's connection to the crime and the extent of his participation in it. However, at the same time, it has a negative role, considering that it may be used in an illegal manner that harms the person, due to what the analysis of the genetic fingerprint reveals of secrets and privacy of the individual.

Accordingly, genes or genetic information can be considered a book that contains the history of a person, his past, present, and even his future, which requires its protection, as the violation of it is not limited to physical violation only and harming the human body of the victim, but rather extends to the extent of Violation of his privacy and disclosure of his secrets, and he may even be subject to discrimination and unfair treatment in the field of insurance, work and banks, which is a matter that the Algerian legislator addressed and provided criminal protection for.

Nevertheless, the effectiveness of protecting genetic data remains contingent upon several legal, technical, and ethical factors.

On the legal front, there is significant variation in legislation across countries—while some jurisdictions (such as EU member states) offer robust protections under frameworks like the GDPR, others lack explicit legal safeguards.

Technically, despite the use of advanced encryption and decentralized storage, genetic databases remain attractive targets for cyber-attacks due to the high value of this data.

Ethically, challenges persist around informed consent, and there is increasing concern over the potential for genetic discrimination.

These issues collectively limit the overall effectiveness of genetic data protection, and call for continuous legislative, technological, and societal efforts to ensure that human dignity and privacy are upheld in the face of rapid scientific advancement.

References

Abdel-Muttalib, T., & Suleiman, A.-N. (2021, June). Legal frameworks established to protect the right to genetic privacy in international conventions and in Algerian and French legislation. Al-Ustad Al-Baheth Journal for Legal and Political Studies - Volume 06 - Issue 01.

Hamouda, A. H. (n.d.). Genetic Engineering and Biosafety, an article published on the following. www.Arsco.Org.

No.16/03, L. (2016, June 22). of June 19, 2016 relating to the use of genetic fingerprints in judicial proceedings and the identification of persons , No. 37. Official Gazette.

Razaki, N. (2018, June). Criminal Protection of the Right to Genetic Privacy. Journal of Legal and Political Sciences, Volume 09, Issue 02.

Shams El-Din, T. (2002, May 5-7). Genetic Paradises and Criminal Protection of the Right to Privacy, a paper presented to on, Volume III. The Genetic Engineering between Sharia and Law Conference, held in the United Arab Emirates.

Zainab, Z. (2009). Genetic Engineering and Criminal Protection of the Human Genome, Master's Thesis. Constantine: Faculty of Law and Political Science, University of the Brothers Mentouri