

Research Article

CRIMINAL LIABILITY FOR ANALYSING GENOMIC DATA WITHOUT OWNER'S CONSENT: A COMPARATIVE STUDY

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ABSTRACT

Background: In the rapidly evolving landscape of genomics and biotechnology, the United Arab Emirates (UAE) has launched the Emirates Genome Program to harness the potential of genomic technologies for advancing healthcare services. Central to this initiative is the informed and voluntary participation of citizens in genetic research aimed at contributing to national health objectives through genetic data utilisation. Notably, the enactment of UAE Decree-Law No. (49) of 2023 underscores the importance of safeguarding genomic privacy as a foundational element for data security and individual rights.

This study addresses the challenge of striking a delicate balance between individual genetic rights and the pressing scientific and medical needs of genomic research. It aims to analyse the right to genomic privacy and examine crimes associated with the unauthorised analysis of biological samples.

Methods: This research employed an analytical legal methodology and a comparative approach to explore the crime of disclosing genomic data. By analysing Decree-Law No. (49) of 2023 and other relevant Emirati legislation, we examined the legal framework governing genomic research and data protection in the UAE. Comparative legal analysis was then conducted between Emirati and French laws to identify similarities and differences in approaches to genomic data disclosure crimes. The study also considered international standards and ethical principles to provide a comprehensive, multidisciplinary understanding of the intersection of law, ethics, and science in genomic privacy.

Results and conclusions: This study's findings underscore the necessity of establishing a robust legal framework that safeguards individual rights and ensures the confidentiality of genetic data. Such measures are crucial for fostering public trust in genomic research and aligning the UAE's genomic endeavours with rigorous ethical and legal standards. Ultimately, Decree-Law No. (49) of 2023 exemplifies the state's commitment to promoting ethical and legal practices in genomic research, thereby facilitating sustainable advancements in medical science.

1 INTRODUCTION

The world is witnessing rapid advancements in biotechnology and genomics, with unprecedented progress leading to an increased use of genetic experiments for medical and non-medical purposes. As the pace of genetic sciences and technology accelerates, scientists continue to make genetic discoveries related to the human body's makeup and the causes and effects of potential diseases and disabilities in the future. Humans are increasingly relying on advanced scientific technologies to explore the secrets of genetics and determine human genetic makeup, allowing for the estimation of the likelihood of genetic diseases even before birth. We are beginning to see advanced steps towards genetic prediction, which aids in the early detection of individuals' genetic tendencies to develop serious diseases, alongside the development of now-possible early genetic testing. Genetic scientists are continuously exploring new possibilities in understanding human genetic material¹, aiming to intervene, modify, and reorganise it when necessary, including programming and altering its designs in complex and innovative ways.

Genomic data plays an important role in advancing medical advancement and scientific research. It is instrumental in understanding genetic diseases, developing targeted treatments, improving medical diagnosis, and potentially bringing about radical changes in the future human constitution in biological, psychological, and mental aspects, all under the guise of achieving medical and therapeutic human goals. Due to concerns surrounding these changes and their potential negative impact, as genomic data contains sensitive information related to individuals and carries unique details about their genes and genetic heritage, and recognising the complexity and breadth of this topic, as well as the urgent need to establish principles and standards to be adopted internationally, UNESCO issued the Universal Declaration on the Human Genome and Human Rights (1997),² and the International Declaration on Human Genetic Data (2003),³ thereby establishing the rules and provisions to ensure and guarantee the sanctity of genomic data.⁴

- 1 Mohamed Misbah Al-Naji, 'Constitutional Guarantees for the Protection of Genetic Privacy: A Comparative Analytical Study' (2023) 9(4) *Journal of Legal and Economic Studies* 749; Sandi Dheensa and others, 'Towards a national Genomics Medicine Service: The Challenges Facing Clinical-Research Hybrid Practices and the Case of the 100 000 Genomes Project' (2018) 44(6) *Journal of Medical Ethics* 398, doi:10.1136/medethics-2017-104588; Jodi Halpern and others, 'Societal and Ethical Impacts of Germline Genome Editing: How Can we Secure Human Rights?' (2019) 2(5) *The CRISPR Journal* 293, doi:10.1089/crispr.2019.0042.
- 2 Universal Declaration on the Human Genome and Human Rights (adopted 11 November 1997) <<https://www.ohchr.org/en/instruments-mechanisms/instruments/universal-declaration-human-genome-and-human-rights>> accessed 1 April 2024.
- 3 International Declaration on Human Genetic Data (adopted 16 October 2003) <<https://www.unesco.org/en/legal-affairs/international-declaration-human-genetic-data?hub=66535>> accessed 1 April 2024.
- 4 Shawn HE Harmon, 'The Significance of UNESCO's Universal Declaration on the Human Genome & Human Rights' (2005) 2(1) *SCRIPTed* 25, doi:10.2966/scrip.020105.20; Ana Nordberg and Luisa Antunes, *Genome Editing in Humans: A Survey of Law, Regulation and Governance Principles* (STOA 2022) <<https://lup.lub.lu.se/search/publication/3971ee6-b208-468c-82a3-1a4f781a10c7>> accessed 1 April 2024.

Driven by its commitment to enhancing healthcare, the United Arab Emirates launched the Emirates Genome Program,⁵ a national initiative aimed at utilising genetic information to identify and treat genetic diseases. This project seeks to leverage the capabilities of genome technology to improve the quality of healthcare services provided to citizens, supporting the achievement of national health objectives through the use of Emirates citizens' genetic data to improve the overall health status of Emirati citizens. Recognising the importance of privacy protection and ensuring the ethical and legal use of genomic data, the UAE legislature issued Decree-Law No. (49) of 2023 on regulating the use of the human genome.⁶

The significance of this research lies in demonstrating how Decree-Law No. (49) of 2023 on regulating the use of the human genome keeps pace with these developments by providing a legal framework that ensures the use of the human genome in a way that respects rights and privacy. The study focuses on the importance of genomic privacy as an integral part of human rights, exploring how the legal decree contributes to protecting this privacy through the necessity of participants' prior consent to undergo genetic testing, with participants' informed consent based on fundamental ethical principles that must be observed when conducting biomedical and behavioural research involving humans. These principles are based on the foundations of informed consent, which fundamentally rely on three key elements: providing information, achieving understanding, and voluntary participation.

The research problem lies in the challenge faced by the UAE legislature in achieving a balance between individuals' rights to genomic privacy and the scientific and medical necessity of conducting scientific experiments and developing medical research related to the human genome. This balance is essential to ensure the effective and safe use of genomic data, maximising the benefits of scientific research in the field of the human genome.

From here, the question arises whether the UAE legislature has successfully managed to balance individuals' rights to maintain their genomic privacy and the growing need to develop medical research and enhance public health. What are the possible legal mechanisms to ensure the non-violation of individuals' rights and obtain informed and voluntary consent before taking biological samples?

2 RESEARCH METHODOLOGY

In this study, we adopted an in-depth analytical approach focused on examining the legal texts related to Decree-Law No. (49) of 2023, which outlines the frameworks for regulating the use of the human genome in the United Arab Emirates. This methodology

5 'The Emirati Genome Programme' (UAE, 14 August 2023) <<https://u.ae/en/information-and-services/health-and-fitness/research-in-the-field-of-health/the-emirati-genome-programme>> accessed 1 April 2024.

6 Federal Law by Decree no (49) of 2023 'Regulating the Use of the Human Genome' [2023] Official Gazette 762 <<https://uaelegislation.gov.ae/en/legislations/2195>> accessed 1 April 2024.

allows us to scrutinise the legal and regulatory foundations accurately, considering international approaches through comparative legislation in specific areas to extract the best practices and lessons.

The study primarily aims to explore and analyse the fundamental concepts related to genomic privacy by delving into understanding the nature of the right to privacy and defining the concept of genomic data. Subsequently, it will investigate the criminal liability arising from analysing biological samples without the consent of their owner, with a particular focus on the context of UAE legislation and its comparison with other legal systems.

3 THE NATURE OF THE RIGHT TO GENOMIC PRIVACY

In addressing the intricate subject of genomic privacy, this paper will delve into two main topics. Initially, we will explore the concept of the right to privacy, elucidating its fundamental significance and how it underpins the broader discourse on individual autonomy over personal information. Following this, we will turn our attention to the concept of genomic data, delineating its unique characteristics and the specific privacy considerations it entails.

3.1. Concept of the Right to Privacy

Privacy is a fluid concept with no fixed boundaries, reflecting various aspects of human life. It varies from one society to another, influenced by prevailing customs and traditions and even by individual circumstances, distinguishing those who guard their privacy closely from those who live as an open book.⁷ Thus, defining privacy or finding a precise and logical formula for it is challenging, as it remains a delicate issue that stirs debate and disagreement in jurisprudence and comparative law.

Definitions of this right are diverse, articulating its essence and the way its boundaries are determined. Some provide a general descriptive definition, while others focus on identifying the key elements that comprise its content, leaving room for modifications that evolution might necessitate. For instance, a segment of French jurisprudence adopts a negative definition of private life (defining it as everything that does not constitute public life). Public life is described as the aspect of our lives that unfolds in the presence of or before the public, our public contribution to the life of the state or nation⁸. On the other hand, another school of thought within jurisprudence has opted for a positive definition of privacy,

7 Hossam Eldin Al-Ahwani, *The Right to Respect for Private Life* (Dar Al-Nahda Al-Arabiya 1978) 47; Mamdouh Khalil Baher, 'Protection of Private Life in Criminal Law: A Comparative Study' (PhD thesis, Cairo University 1983) 163.

8 Robert Badinter, 'Le droit au respect de lavie privée' (1968) 2136 JCP 1.

conceptualising it as "the sphere or the secretive zone of life, or rather, the area over which an individual has the authority to exclude others from..."⁹

The definitions of the right to privacy posited by jurisprudence reveal considerable variations in the perception of what this right entails. It is challenging to establish a criterion that fully distinguishes between private and public life, making it difficult to assert that there exists a comprehensive, all-encompassing definition of this right. This variability stems from the evolving concept of the right to privacy across different times and places. Social, economic, and cultural developments, along with prevailing customs and traditions, vary significantly from one society to another, influencing the understanding and application of privacy rights. This diversity reflects the dynamic nature of privacy as a concept that adapts to the changing contexts of human societies, underscoring the need for a flexible approach to defining and protecting privacy in the legal domain.

The UAE Constitution has incorporated individual privacy or private life within its provisions. Specifically, Article 26 states that personal freedom is guaranteed for all citizens. It addresses the sanctity of domicile in a separate article, Article 36, which prohibits entering homes except in cases specified by law and in the manner prescribed therein. Furthermore, Article 31 ensures the sanctity of a person's postal, telegraphic, and other forms of communication, making it illegal to examine, monitor, or detain such communications except in situations defined by law.¹⁰

The UAE legislature has adhered to this principle in the Law of Crimes and Punishments under Article 31, where this provision defines the principle of protecting the sanctity of private life by penalising any infringement on it. The forms of such infringement include eavesdropping or spying using any means, including audio recording or photography, and the public dissemination of private life secrets through any means of disclosure.¹¹

In the legislators' continuous effort to enhance digital security and protect privacy, the Federal Decree-Law No. 34 of 2021 on combating rumours and cybercrimes stands out. Article 6 of this law strengthens the legal protection of data and personal information by imposing penalties on anyone who obtains, possesses, modifies, damages, discloses, leaks, deletes, copies, or publishes electronic personal data without authorisation. The penalties are more severe if the data pertains to medical records, reflecting the utmost importance of protecting such information.¹²

9 Jean Carbonnier, *Droit Civil*, t 1: *Les Personnes, Personnalite, Incapacites, Personnes Morales* (Themis Droit Picé, PUF 1995) 254.

10 Constitution of the United Arab Emirates [1971] Official Gazette 1 <<https://uaelegislation.gov.ae/en/legislations/1000>> accessed 1 April 2024.

11 Federal Law by Decree no (31) of 2021 'Promulgating the Crimes and Penalties Law' [2021] Official Gazette 712 <<https://uaelegislation.gov.ae/en/legislations/1529>> accessed 1 April 2024.

12 Federal Law by Decree no (34) of 2021 'On Countering Rumors and Cybercrimes' [2021] Official Gazette 712 <<https://uaelegislation.gov.ae/en/legislations/1526>> accessed 1 April 2024.

Furthermore, Article 44 highlights crimes of invasion of privacy and disclosure of secrets through information systems, specifying penalties for those who use these technologies to eavesdrop, take pictures without permission, or publish information intending to harm others. Article 45 penalises the disclosure of confidential information obtained by virtue of one's work or profession, emphasising the necessity of maintaining the confidentiality and security of this information.¹³

In addition to the efforts made to protect private life, the UAE legislature has given special attention to the protection of genomic data, considering it an integral part of an individual's privacy. In this context, the Federal Decree-Law No. 49 of 2023 regarding the regulation of the use of the human genome was issued, establishing specific legal frameworks for the collection, use, and preservation of genomic data.¹⁴

From the foregoing, it is evident that the UAE legislature has sought to find a balance between encouraging scientific and technological research and protecting individuals' rights and privacy. This demonstrates a balanced approach that aims for scientific advancement without sacrificing the fundamental values of privacy and human rights. This approach highlights the United Arab Emirates' commitment to international human rights standards and reflects a proactive vision in addressing emerging issues in the field of privacy and genomic data.

3.2. Concept of Genomic Data

The term "genetic data" refers to data that can be extracted from biological samples, which determine the inherited or acquired genetic characteristics of an individual (including unique information about that individual's physiology or health).¹⁵ More importantly, genetic testing can reveal extensive information not limited to the physical aspects of an individual but also encompass deeper dimensions such as emotional traits and personality characteristics. Humans are increasingly relying on advanced scientific technologies to explore the secrets of genetics and analyse human genetic structures, opening the door to the possibility of predicting genetic risks for certain diseases before birth and early detection of individuals' genetic predispositions to serious diseases through advanced genetic testing.¹⁶

13 *ibid.*

14 Federal Law by Decree no (49) of 2023 (n 6).

15 Róisín Á Costello, 'Genetic Data and the right to Privacy: Towards a Relational Theory of Privacy?' (2022) 22(1) *Human Rights Law Review* ngab031, doi:10.1093/hrlr/ngab031.

16 James Brian Byrd and others, 'Responsible, Practical Genomic Data Sharing that Accelerates Research' (2020) 21(10) *Nature Reviews Genetics* 615, doi:10.1038/s41576-020-0257-5; Fruzsina Molnár-Gábor and others, 'Harmonization after the GDPR? Divergences in the rules for genetic and health data sharing in four member states and ways to overcome them by EU measures: Insights from Germany, Greece, Latvia and Sweden' (2022) 84 *Seminars in Cancer Biology* 271, doi:10.1016/j.semcancer.2021.12.001.

Genomics scientists are harnessing immense potential in the field of understanding the intricate details of human genetic material, aiming for intervention, modification, and reorganisation where necessary, in addition to the possibility of programming it according to specific requirements. These capabilities extend beyond medical and therapeutic goals, raising ethical challenges about the sanctity of life and interventions in the genetic foundations of humans in ways that could radically alter their biological composition and mental and psychological traits, all under the guise of achieving medical humanitarian objectives.¹⁷

Some view their genetic information as private or sensitive data, given that each person's genome is unique, differing from others, and serves as a life book revealing many aspects of one's future. Moreover, genetic data is not limited to the person undergoing genetic testing but also unveils information about their close or distant biological relatives. This means that accessing the genetic data of one individual could result in the disclosure of the genetic information of their entire family, necessitating the provision of strong legal protection for genetic privacy. This necessity has led some legislations to consider this.

3.2.1. The Universal Declaration on the Human Genome and Human Rights

The Universal Declaration on the Human Genome and Human Rights¹⁸ is the first international document to formally address the relationship between genetic engineering technologies and human rights, offering principles that summarise the global vision of the importance of finding a balance between scientific progress in medical sciences and ensuring the protection of human rights.¹⁹ Symbolically, as stipulated in Article 1 of the Declaration, the human genome is considered "the heritage of humanity." Article 2 emphasises the right of every individual to respect their dignity and rights regardless of their genetic characteristics. At the same time, Article 5 mandates the necessity of obtaining prior, free, and informed consent from the person before conducting any genetic examination on their biological sample, respecting their wish to know or not know the results of this examination and its implications.

Article 7 of the Declaration emphasises the necessity of protecting the confidentiality of genetic information pertaining to any identifiable person, whether this information is stored or processed for research purposes or otherwise. Article 9 states that no restrictions may be imposed on the principle of consent and the confidentiality of an individual's data except through the law for justified reasons and within the limits allowed by international law and international human rights law. Although the Declaration is not binding like international treaties, it holds significant importance due to the consensus among UNESCO

17 Abdulrazzaq Al-Dawai, 'The Revolution in Genetic Engineering and Human Rights: The Problematic of Human Cloning' (2003) 31(4) *World of Thought* 123; Dheensa and others (n 1).

18 Universal Declaration on the Human Genome and Human Rights (n 2).

19 Costello (n 15) 22; Lee A Bygrave, 'Privacy and Data Protection in an International Perspective' (2010) 56(8) *Scandinavian Studies in Law* 165.

member states on its formulation, enhancing its status as a detailed reference document addressing human rights in the context of genetic technologies.²⁰

It is worth mentioning here that, in adherence to the definition provided in Article 1 of the Universal Declaration of Human Rights, considering the human genome as "the heritage of humanity," and in light of the significant achievements witnessed in science and technology regarding the understanding and development of the human genome, a need arises for a comprehensive global responsibility. This responsibility should not only fall on the shoulders of states and governments alone but should also encompass the entire international community. Through a review of the provisions of the Declaration, it emphasises the following:²¹

1. The necessity of obtaining voluntary prior consent without unjustifiable inducements before conducting any research or testing in the field of human genetics or by the person's legal representative if they lack or have limited capacity.
2. Exceptions may be allowed if there are compelling reasons in accordance with local law and international human rights law.
3. The necessity of informing potential participants of their rights and providing them with the objectives, benefits, burdens, and expected outcomes of the research. This includes the right to withdraw from the research at any time, which should only be subject to limited exceptions.
4. The individual's right to decide whether or not to be informed of the research results and the consequences of genetic testing should be respected.
5. Disclosure of genomic data to a third party without the individual's consent is not permitted, and to protect the confidentiality of an individual's genetic characteristics, human genetic data and biological samples collected for research purposes should usually be anonymised.

3.2.2. The French Legislation

Under Chapter One of the French Personal Data Protection Act No. (493), issued on 20 June 2018, and its amendments, the French legislature adopted the definition provided in Article 4 of the General Data Protection Regulation (GDPR) of 2016.²² This definition identifies personal data as "any information relating to an identified or identifiable individual." The data subject is defined as the individual who can be identified, directly or indirectly, by

20 Tariq Jumah Al-Sayed, 'The Legal Protection of the Right to Genetic Data Privacy: A Comparative Analytical Study' (2020) 8(12) *Legal Journal* 3920, doi:10.21608/JLAW.2020.141898; Bygrave (n 19).

21 Universal Declaration on the Human Genome and Human Rights (n 2); CIOMS, *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (WHO 2002); Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) [2016] OJ L 119/1.

22 Loi n°2018-493 du 20 juin 2018 'Relative à la protection des données personnelles' <<https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000037085952>> accédé 1 avril 2024.

reference to specific identifiers such as name, identification number, location data, electronic identifier, or one or more factors specific to the physical, physiological, genetic, mental, economic, cultural, or social identity of that person, The French National Commission on Informatics and Liberty (CNIL) defines genetic data as "any information relating to an identified or identifiable natural person, either directly or indirectly." However, it specifies that genetic data is "not personal data like any other data".²³

In circumstances involving the handling of personal data, French law mandates obtaining clear and informed consent from the individuals concerned by the data processing operation. Additionally, individuals responsible for data processing or those with the right to access the data must adhere to professional confidentiality. Breaching this obligation exposes them to penalties stipulated in Article 226-13 of the French Penal Code.²⁴

3.2.3. The Emirati Legislation

The Federal Decree-Law No. (49) of 2023 on regulating the use of the human genome establishes a cornerstone in the country's legal system regarding genomic data.²⁵ The Emirati law recognises the importance of genomic data as a critical tool in developing healthcare and personalised medicine. This reflects the legislators' commitment to utilising this information to improve the health of citizens, enhance disease prevention, and provide customised treatments. This commitment is evidenced by the definition of key terms in Article 1 of the Decree-Law.

The genome is defined as all the genetic material in an organism, including the genes (alleles) that contain all the biological information needed for the construction and continuity of another organism similar to it and distinctive for its species. The human genetic stock consists of (46) tightly packed molecules of DNA called chromosomes, in addition to the mitochondrial genes. A gene is the fundamental unit for transmitting hereditary traits from parents to offspring, consisting of a DNA sequence occupying a specific position on a chromosome.

The legislators distinguished between genetic testing and genomic screening, indicating that genetic testing involves the analysis of one or several genes of individuals identified by their names, and it allows access to specific genetic regions in the DNA determined by the purpose of the test. Whereas, genomic screening involves the analysis of the complete

23 Ruth Horn and Jennifer Merchant, 'Managing Expectations, Rights, and Duties in Large-Scale Genomics Initiatives: A European Comparison' (2023) 31(2) *European Journal of Human Genetics* 142, doi:10.1038/s41431-022-01247-y; Marie Gaille and Ruth Horn, 'The Ethics of Genomic Medicine: Redefining Values and Norms in the UK and France' (2021) 29(5) *European Journal of Human Genetics* 780, doi:10.1038/s41431-020-00798-2.

24 Taher Abdel-Mutalib and Al-Nahwi Sulaiman, 'Legal Frameworks Established for the Protection of the Right to Genetic Privacy in International Charters and in Algerian and French Legislation' (2021) 6(1) *Professor Researcher Journal for Legal and Political Studies* 2121.

25 Federal Law by Decree no (49) of 2023 (n 6).

genetic material of individuals known by their names, allowing access to all genetic regions in the DNA.

The legislators also differentiated between genetic screening and genomic screening, stating that genetic screening is the process through which genetic analysis is performed on a wide scale that includes a group of individuals identified based on one or more common traits among them, not based on prior knowledge of their names, according to what is decided by the regulatory or implementing body for genetic screening. On the other hand, genomic screening is the process through which an analysis of all genes is performed on a wide scale that includes a group of individuals identified based on one or more common traits among them, not based on prior knowledge of their names, according to what is decided by the regulatory or implementing body for genomic screening.

Article 1 of the law defines genomic data as the information related to the complete genetic material of an individual obtained through genomic testing or screening and after analysing the biological sample. Genetic data is the information related to a part of an individual's genetic material, which may include their genetic fingerprint, obtained within the framework of genetic testing or screening or genetic fingerprint examination and after analysing the biological sample. The law specifies the establishments through which the collection, preservation, storage, and distribution of biological samples such as blood, tissues, cells, etc., and associated information for future use are conducted. Examples include blood banks, umbilical cord blood banks, stem cell banks, and others.

From the foregoing, it is evident that Article 1 of the Emirati Human Genome Law reflects a comprehensive and precise approach towards genetic and genomic data. This indicates an advanced appreciation of the importance of this information in the healthcare and scientific research sectors. This goes beyond merely defining basic concepts; it distinguishes between different types of tests and screenings to ensure a thorough understanding and appropriate application of these technologies. The distinction between genetic and genomic testing underscores the need to handle each type of information differently, with considerations for ethics and privacy.

By defining the nature of genetic and genomic data and how it is collected and used, the law establishes a foundation for protecting individuals' privacy and ensuring that their genetic data is handled responsibly. It emphasises the necessity of obtaining prior and explicit consent from individuals before collecting and using their genomic data for research or other purposes.²⁶ Consent is taken according to guidelines set by Article 6 of the law, stating: "Informed consent of the participant in the genetic or genomic testing or screening, or their legal representative if they lack or have limited capacity, is taken according to the following controls: 1. The individual or their legal representative must be provided with all the

26 Bruce Budowle and Antti Sajantila, 'Revisiting Informed Consent in Forensic Genomics in Light of Current Technologies and the Times' (2023) 137(2) *International Journal of Legal Medicine* 551, doi:10.1007/s00414-023-02947-w.

information related to the test or screening, ensuring they understand its purpose and potential implications. 2. The consent must be written and explicit according to the form approved by the health authority."

From the foregoing, it is evident that within the framework of the Emirati legislature's commitment to international standards, it has adopted the principles of the Universal Declaration on the Human Genome, thereby reaffirming its commitment to protecting human rights in the context of genomic research. By requiring prior voluntary consent, ensuring that participants are informed of their rights and the details of the research, and respecting their wishes regarding being informed of the research results, the Emirati law reinforces the principle of genomic data confidentiality. It implements specific rules concerning non-disclosing such data to any third party without the individual's consent. Thus, the Emirati law aligns with the provisions of the Universal Declaration, showing an advanced understanding of the challenges and opportunities related to genetic and genomic data. It balances the protection of privacy with the encouragement of scientific progress. This approach serves as a model that other countries could follow in developing their legislation related to genomic data, ensuring effective privacy protection while supporting innovation and scientific research.

4 THE CRIME OF OBTAINING GENOMIC DATA WITHOUT THE OWNER'S CONSENT

Most legislation has worked to protect individuals' will against the advances in biological science and the resultant genomic and genetic testing used for medical, scientific, or other purposes. To this end, these legislations,²⁷ including Emirati law, have stipulated the requirement to obtain prior consent from the person concerned with undergoing genomic or genetic testing and have penalised conducting such testing without the consent of the concerned individual.

In this regard, Article 4 Clause 1 of the Emirati Law Regulating the Use of the Human Genome stipulates that "no person shall be subjected to genomic or genetic testing without obtaining his consent or the consent of his legal representative if he is of limited or no capacity, or at his request...". Similarly, Article 5 Clause 2 of the same law states that "no person shall be subjected to genomic or genetic screening without obtaining his consent or the consent of his legal representative if he is of limited or no capacity...".²⁸

Furthermore, Article 30 of the mentioned law provides that "anyone who subjects a person to participate in any voluntary genomic or genetic test or screening without obtaining his consent or the consent of his legal representative if he is of limited or no capacity, according to the provisions of Clause 1 of Article 4 and Clause 2 of Article 5 of

²⁷ Nordberg and Antunes (n 4).

²⁸ Federal Law by Decree no (49) of 2023 (n 6).

this Decree-Law, shall be punished with a fine not less than ten thousand Dirhams and not exceeding one hundred thousand Dirhams".²⁹

In the same context, the examination of a person's genetic characteristics in French law is subject to the provisions of Article 16-10 of the Civil Code,³⁰ which states that the examination of a person's genetic characteristics is conducted for medical purposes or scientific research, and requires obtaining the person's written consent prior to conducting the examination.³¹ The French legislature has specified crimes that constitute an infringement on genetic privacy in the Penal Code,³² in Articles 226-25 to 226-30. Article 226-25 penalises the conduct of genetic testing without obtaining the consent of the concerned individual.³³

4.1. Elements of the Crime of Obtaining Genomic Data Without the Owner's Consent

Obtaining genomic data without the owner's consent involves several key elements that legally constitute the offence. Understanding these elements is crucial for defining the crime and enforcing the law. The main elements will be described below.

4.1.1. The Material Element of the Crime of Obtaining Genomic Data Without the Owner's Consent

The material element (or the *actus reus*) of this crime involves any action or series of actions that result in the unauthorised acquisition, access, or control over an individual's genomic data. This encompasses a wide range of activities, including but not limited to:

1. **Collection:** Actively gathering genomic data from various sources without consent, whether through direct extraction from biological samples or unauthorised access to medical records, databases, or other repositories where such data is stored.
2. **Copying or Replication:** Making copies of genomic data, regardless of the means or format, without the permission of the data owner.

29 *ibid.*

30 Code civil (version 21 février 2024) <https://www.legifrance.gouv.fr/codes/texte_lc/LEGITEXT000006070721/> accédé 1 avril 2024.

31 Philippe Pédrot, 'Le traitement des données médicales informatisées: un nouveau défi à la traçabilité' en *Traçabilité et responsabilité* (Economica 2003) 137; T Lemmens et L Austin, 'Les défis posés par la réglementation de L'utilisation de l'information génétique' (2021) 2(3) *Isuma* 28.

32 Code pénal (adoption 22 juillet 1992) <https://www.legifrance.gouv.fr/codes/texte_lc/LEGITEXT000006070719/> accédé 1 avril 2024.

33 International Bioethics Committee, 'Report of the International Bioethics Committee (IBC) on Updating Its Reflection on the Human Genome and Human Rights: Final Recommendations' (2015) 43 *Rev Derecho Genoma Hum* 195 <<https://pubmed.ncbi.nlm.nih.gov/27311162/>> accessed 1 April 2024; Tania Ascencio-Carbajal and others, 'Genetic/Genomic Testing: Defining the Parameters for Ethical, Legal and Social Implications (ELSI)' (2021) 22 *BMC Medical Ethics* 156, doi:10.1186/s12910-021-00720-5; Katie Nolan, 'Ethics Challenge Winner 2016/ 2017: Gene Editing' (2017) 10(1) *Royal College of Surgeons in Ireland, Journal contribution* 6.

3. **Transmission or Disclosure:** Sharing or disseminating genomic data to third parties without the explicit consent of the individual concerned. This could involve the physical transfer of data, electronic communication, or publication in any form.
4. **Use:** Employing the genomic data for any purpose, such as research, profiling, or commercial use, without obtaining prior consent from the data subject.
5. **Accessing:** Illegally accessing databases or systems where genomic data is stored, whether through hacking, deception, or exploitation of security vulnerabilities.

Article (30) of the Emirati Law Regulating the Use of the Human Genome references specific criminal acts by stipulating the crime of conducting genomic or genetic testing, as well as genomic or genetic screening of an individual without their consent or the consent of their legal representative, which results in accessing genetic regions in the DNA.³⁴

It is noted that genetic testing involves the analysis of a gene or several genes for one or more people. In comparison, genomic testing is the analysis of the complete genetic material of one or more people, regardless of their purpose. Accordingly, genetic testing represents the part, considering the subject of the analysis is one or more genes, while genomic testing represents the whole, considering the subject of the analysis. Genetic scanning is essentially the same as the aforementioned genetic testing, but it is typically carried out on a larger scale, potentially involving a broader scope of genes or individuals.

Based on the principle that what applies to the part applies to the whole, and vice versa, the UAE legislature could have simply criminalised the act of genetic testing without the consent of the sample donor, and this would apply to the other mentioned forms, including genetic screening and genomic screening. This is the approach adopted by the French legislature under Article 226-25 of the French Penal Code.³⁵ The French law penalises the examination of a person's genetic characteristics without obtaining their consent for medical or scientific purposes (paragraph 2 of Article 226-25). If genetic characteristics are examined for purposes other than medical or scientific research or anti-doping efforts, the act is punishable regardless of the consent of the individual, whether obtained or not, according to paragraph 1 of the same provision. Moreover, examining genetic characteristics for anti-doping purposes without informing the individual, regardless of their consent or refusal, is also punishable under paragraph 3 of the mentioned article.³⁶

Therefore, the mentioned criminal behaviour involves a dual act: firstly, obtaining a biological sample from the human body, such as blood, urine, or others, and secondly, examining the genes of the sample's owner by any means to access genetic information. This is done without the consent of the individual. Thus, taking the biological sample alone does not constitute a crime. However, if done without the consent of the individual, it constitutes an assault on bodily integrity.

34 Federal Law by Decree no (49) of 2023 (n 6).

35 Code penal (n 32).

36 Marie-Louise Briard, 'Encodrement juridique de La genetique en France' (2001) 34 *Médecine prédictive: mythe et réalité* 38.

The UAE legislature requires the validity of consent, termed in Article 6 of the Human Genome Regulation Law as "informed consent," for genetic testing or genomic examination. This consent entails two conditions:

1. Providing the individual or their legal representative with all information concerning the examination or survey, ensuring their understanding of its purpose and potential consequences.
2. The consent must be written, explicit, and obtained according to the approved model by the healthcare authority, preceding the examination.

Conversely, Article 16-10 of the French Civil Code stipulates the conditions for consent in cases of genetic testing for medical purposes or scientific research.³⁷ It mandates that consent precedes the examination, based on informing the individual of the nature and purpose of the test, whether for medical or scientific research purposes and must be in writing.

Based on the foregoing, if any of the mentioned conditions for the validity of consent are absent, its effect in authorising genetic testing or genomic examination is nullified, and the crime is committed.³⁸ Therefore, the consent of the party concerned is negated by taking a biological sample from their body without their knowledge, such as in cases of exploitation of diminished capacity, coercion, or consent that does not meet the conditions of validity. Consent for genetic testing must be obtained directly from the individual or their legal representative if they lack capacity.³⁹

4.1.2. The Moral Aspect or Criminal Intent

Committing the offence of obtaining genetic data without the owner's consent is an intentional crime that requires criminal intent. The criminal intent required for this crime is general intent, which entails knowledge of the elements and components of the crime, along with the direction of the will towards the criminal act and achieving the result. Therefore, the perpetrator must be aware of the nature of obtaining a biological sample from a person's body or its secretions and subjecting it to genetic testing by analysing one or more genes to access genetic information, whether whole or partial, without the consent of the sample owner as required by law. Then, the perpetrator's will is directed towards committing the criminal act and achieving the criminal result. Thus, if knowledge or the chosen will is absent, criminal intent is also absent.

37 Code civil (n 30).

38 Yann Padova and Charles Morel, 'Droit des Fichiers, droit des personnes' *Gazette du palais* (Paris, 10 janvier 2004) 2; Elsa Supiot, 'Empreintes génétiques et droit pénal: Quelques aspects éthiques et juridiques' (2015) 4(4) *Revue de science criminelle et de droit pénal comparé* 833, doi:10.3917/rsc.1504.0827.

39 Halpern and others (n 1) 297.

It is worth noting here that the concept of criminal intent in the context of crimes related to obtaining genetic data without consent reveals various challenges concerning privacy in the era of advanced technology. One of these challenges is proving the perpetrator's knowledge and deliberate intent to violate genetic privacy, which requires a meticulous analysis of available digital and technological evidence. Compared to other privacy crimes, criminal intent in genetic data crimes requires a higher level of awareness and scientific understanding, placing additional pressure on the judicial system to develop new investigations and evidence techniques. This underscores the urgent need to train judges and prosecutors to understand the complexities of genetic technology and its impact on personal rights. In addition, the importance of awareness and legal and ethical education for professionals in the medical and research fields is highlighted to shed light on the dangers of encroaching on genetic privacy and the necessity of respecting the rights of patients and research participants. These professionals must be familiar with the legal standards required for obtaining informed consent and how to apply them to ensure the protection of individual rights and enhance trust in the research and medical processes.

4.2. The Criminal Penalty Prescribed for the Crime

The criminal penalty prescribed for the offence varies depending on the jurisdiction and the severity of the crime. In the United Arab Emirates, for example, Article 30 of the Human Genome Regulation Law stipulates fines ranging from ten thousand to one hundred thousand dirhams for individuals who subject others to genetic testing or surveys without their consent or the consent of their legal representatives.⁴⁰ Additionally, in the French Penal Code, Article 226-25 penalises genetic testing without the individual's consent for medical or scientific purposes with imprisonment and fines.⁴¹ The severity of the penalty reflects the seriousness with which the legal system views violations of genetic privacy and underscores the importance of obtaining informed consent in genetic testing and research.

Therefore, the penalties stipulated in the Emirati Human Genome Law reflect the legislature's commitment to safeguarding genomic privacy while considering the ethical and legal dimensions of the individual. However, considering the rapid scientific and technological advancements and their potential for genomic privacy violations, there is a need to reconsider penalties to include custodial sentences that enhance the deterrent nature of the law. Such a step would demonstrate a greater commitment to protecting genomic data and a deeper appreciation of the seriousness of related crimes.

40 Federal Law by Decree no (49) of 2023 (n 6).

41 Code penal (n 32).

5 CONCLUSIONS

The study's conclusion discusses the complexities surrounding the right to privacy, evidenced by varying definitions across different jurisdictions. These definitions reflect unique challenges distinguishing between an individual's private and public aspects, underscoring the pluralistic conceptualisations influenced by social, cultural, and traditional contexts. Notably, the Universal Declaration on the Human Genome and Human Rights marks a significant step as the first international document that intertwines genetic technologies with human rights, advocating for a balance between scientific progress and human rights protection. In the UAE, the Federal Decree-Law No. (49) of 2023 illustrates the national legislature's commitment to safeguarding genomic data as a crucial aspect of individual privacy. This law not only aligns with international standards, as articulated in the Universal Declaration on the Human Genome, by mandating prior voluntary consent for genomic research and ensuring confidentiality but also demonstrates its unique approach by imposing fines—ranging from ten thousand to one hundred thousand dirhams—for unauthorised access to genetic information, diverging from practices that include imprisonment. This tailored approach reflects an evolving legal framework that promotes transparency, integrity, and respect in handling genomic data.

6 RECOMMENDATIONS

To address the complexities of genetic data management within the legal framework, it is imperative to refine specific articles of the Emirati Human Genome Law to enhance compliance and protection of individual genetic rights. A key amendment is proposed for Article (30), where introducing imprisonment as a punitive option and fines would significantly bolster the law's deterrent capabilities. Such a measure would grant courts the discretion to apply a more stringent penalty when necessary, thus fortifying the protective measures around individuals' genetic information.

Further modification is suggested for Article 25 to adapt to the evolving needs of genetic data handling. It is recommended that the law includes provisions for the controlled disclosure and exchange of genetic or genomic data, contingent upon the individual's consent. Particularly in cases of inherited genetic diseases that pose significant threats to the health or safety of relatives, provisions should allow for the informed exchange of data. Such exchanges would be strictly regulated to ensure that individuals are not only aware but also have the potential to access preventive or therapeutic interventions.

Moreover, the importance of comprehensive education and training cannot be understated. There is a pressing need to enhance the understanding of genetic technologies and their implications among judicial bodies and public prosecutors. This initiative should foster greater legal and ethical awareness among medical and research

professionals. By deepening their appreciation of the nuances of genetic privacy and the rights of patients and research participants, we can ensure a more informed, ethical approach to genomic research and healthcare.

By implementing these enhancements, the legal system can better safeguard genetic rights and adapt to the rapid advancements in genetic technology, ensuring that protections are robust and reflective of contemporary ethical standards.

REFERENCES

1. Abdel-Mutalib T and Sulaiman AN, 'Legal Frameworks Established for the Protection of the Right to Genetic Privacy in International Charters and in Algerian and French Legislation' (2021) 6(1) Professor Researcher Journal for Legal and Political Studies 2121.
2. Al-Ahwani HE, *The Right to Respect for Private Life* (Dar Al-Nahda Al-Arabiya 1978).
3. Al-Dawai A, 'The Revolution in Genetic Engineering and Human Rights: The Problematic of Human Cloning' (2003) 31(4) World of Thought 121.
4. Al-Naji MM, 'Constitutional Guarantees for the Protection of Genetic Privacy: A Comparative Analytical Study' (2023) 9(4) Journal of Legal and Economic Studies 749.
5. Al-Sayed TJ, 'The Legal Protection of the Right to Genetic Data Privacy: A Comparative Analytical Study' (2020) 8(12) Legal Journal 3907, doi:10.21608/JLAW.2020.141898
6. Ascencio-Carbajal T and others, 'Genetic/Genomic Testing: Defining the Parameters for Ethical, Legal and Social Implications (ELSI)' (2021) 22 BMC Medical Ethics 156, doi:10.1186/s12910-021-00720-5
7. Badinter R, 'Le droit au respect de l'avie privée' (1968) 2136 JCP 1.
8. Baher MK, 'Protection of Private Life in Criminal Law: A Comparative Study' (PhD thesis, Cairo University 1983).
9. Briard ML, 'Encodrement juridique de La genetique en France' (2001) 34 Médecine prédictive: mythe et réalité 38.
10. Budowle B and Sajantila A, 'Revisiting Informed Consent in Forensic Genomics in Light of Current Technologies and the Times' (2023) 137(2) International Journal of Legal Medicine 551, doi:10.1007/s00414-023-02947-w.
11. Bygrave LA, 'Privacy and Data Protection in an International Perspective' (2010) 56(8) Scandinavian Studies in Law 165.
12. Byrd JB and others, 'Responsible, Practical Genomic Data Sharing that Accelerates Research' (2020) 21(10) Nature Reviews Genetics 615, doi:10.1038/s41576-020-0257-5
13. Carbonnier J, *Droit Civil, t 1: Les Personnes, Personnalite, Incapacites, Personnes Morales* (Themis Droit Picé, PUF 1995).

14. Costello RÁ, 'Genetic Data and the right to Privacy: Towards a Relational Theory of Privacy?' (2022) 22(1) *Human Rights Law Review* ngab031, doi:10.1093/hrlr/ngab031
15. Dheensa S and others, 'Towards a national Genomics Medicine Service: The Challenges Facing Clinical-Research Hybrid Practices and the Case of the 100 000 Genomes Project' (2018) 44(6) *Journal of Medical Ethics* 397, doi:10.1136/medethics-2017-104588.
16. Gaille M and Horn R, 'The Ethics of Genomic Medicine: Redefining Values and Norms in the UK and France' (2021) 29(5) *European Journal of Human Genetics* 780, doi:10.1038/s41431-020-00798-2
17. Halpern J and others, 'Societal and Ethical Impacts of Germline Genome Editing: How Can we Secure Human Rights?' (2019) 2(5) *The CRISPR Journal* 293, doi:10.1089/crispr.2019.0042
18. Harmon SHE, 'The Significance of UNESCO's Universal Declaration on the Human Genome & Human Rights' (2005) 2(1) *SCRIPTed* 18, doi:10.2966/scrip.020105.20
19. Horn R and Merchant J, 'Managing Expectations, Rights, and Duties in Large-Scale Genomics Initiatives: A European Comparison' (2023) 31(2) *European Journal of Human Genetics* 142, doi:10.1038/s41431-022-01247-y
20. Lemmens T et Austin L, 'Les défis posés par la réglementation de L'utilisatian de l'information génétique' (2021) 2(3) *Isuma* 26.
21. Molnár-Gábor F and others, 'Harmonization after the GDPR? Divergences in the rules for genetic and health data sharing in four member states and ways to overcome them by EU measures: Insights from Germany, Greece, Latvia and Sweden' (2022) 84 *Seminars in Cancer Biology* 271, doi:10.1016/j.semcancer.2021.12.001
22. Nolan K, 'Ethics Challenge Winner 2016/ 2017: Gene Editing' (2017) 10(1) *Royal College of Surgeons in Ireland, Journal contribution* 6
23. Nordberg A and Antunes L, *Genome Editing in Humans: A Survey of Law, Regulation and Governance Principles* (STOA 2022).
24. Padova Y et Morel C, 'Droit des Fichiers, droit des personnes' *Gazette du palais* (Paris, 10 janvier 2004) 2.
25. Pédrot P, 'Le traitement des données médicales informatisées: un nouveau défi à la traçabilité' en *Traçabilité et responsabilité* (Economica 2003) 137.
26. Supiot E, 'Empreintes génétiques et droit penal: Quelques aspects éthiques et juridiques' (2015) 4(4) *Revue de science criminelle et de droit pénal comparé* 827, doi:10.3917/rsc.1504.0827.

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Without the Owner's Consent. – 4.1.1. *The Material Element of the Crime of Obtaining Genomic Data Without the Owner's Consent.* – 4.1.2. *The Moral Aspect or Criminal Intent.* – 4.2. *The Criminal Penalty Prescribed for the Crime.* – 5. *Conclusions.* – 6. *Recommendations.*

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АНОТАЦІЯ УКРАЇНСЬКОЮ МОВОЮ

Дослідницька стаття

КРИМІНАЛЬНА ВІДПОВІДАЛЬНІСТЬ ЗА АНАЛІЗ ГЕНОМНИХ ДАНИХ БЕЗ ЗГОДИ ВЛАСНИКА: ПОРІВНЯЛЬНЕ ДОСЛІДЖЕННЯ

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АНОТАЦІЯ

Вступ. В умовах швидкого розвитку геноміки та біотехнологій Об'єднані Арабські Емірати (ОАЕ) започаткували Програму генома Еміратів, щоб використовувати потенціал геномних технологій для вдосконалення послуг охорони здоров'я. Центральне місце в цій ініціативі посідає інформована та добровільна участь громадян у генетичних дослідженнях, спрямованих на внесок у досягнення цілей забезпечення національного здоров'я шляхом використання генетичних даних. Зокрема, уведення в дію Закону ОАЕ № (49) від 2023 р. підкреслює важливість захисту конфіденційності генома як основного елемента безпеки даних і прав особи.

У пропонованому дослідженні розглянуто проблему встановлення балансу між індивідуальними генетичними правами та нагальними науковими й медичними потребами геномних досліджень. Воно спрямоване на аналіз правового регулювання питань конфіденційності генома та дослідження злочинів, пов'язаних із несанкціонованим аналізом біологічних зразків.

Методи. У дослідженні використано аналітичний юридичний метод і порівняльний підхід для дослідження злочинів щодо розкриття геномних даних. Аналізуючи Закон № (49) від 2023 р. й інші закони, було охарактеризовано законодавство, що регулює геномні дослідження та захист даних в ОАЕ. З метою визначення схожості та відмінностей у підходах до злочинів, пов'язаних із розкриттям геномних даних, було проведено порівняльний правовий аналіз законів ОАЕ та Франції. У роботі також досліджувалися міжнародні стандарти й етичні принципи, щоб забезпечити комплексне міждисциплінарне розуміння перетину права й етики в геномній конфіденційності.

Результати та висновки. У висновках щодо цього дослідження підкреслено необхідність створення надійної законодавчої бази, яка б захищала права особи та гарантувала конфіденційність генетичних даних. Такі заходи мають вирішальне значення для зміцнення суспільної довіри до геномних досліджень й узгодження зусиль ОАЕ, спрямованих на популяризацію геномних досліджень, із суворими етичними та правовими стандартами. Зрештою, Закон № (49) від 2023 р. можна вважати прикладом зобов'язання держави надавати підтримку етичним і правовим практикам у геномних дослідженнях, сприяючи таким способом стійкому прогресу в медичній науці.

Ключові слова: кримінальний захист, геномне право на конфіденційність, інформована згода, право ОАЕ про геном людини, геномні дані, геномне тестування, геномний скринінг, етика геномних досліджень.