LEGAL ISSUES AND RISKS ASSOCIATED WITH IMPLEMENTATION OF ELECTRONIC REGISTER OF HUMAN GENOMIC INFORMATION IN UKRAINE

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SUMMARY
It is proposed to specify in the Law of Ukraine “On the State Registration of Human Genomic Information” some provisions regarding military personnel, policemen, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities, from which the selection of biological material, in the event of the implementation of martial law, will be carried out in a mandatory manner, namely: specify the possibilities of extraction and destruction of genomic information in connection with: dismissal from military service and subsequent removal from military registration; with death in order to minimize the risks of access to personal data of a person and his relatives. The Law should clearly define the structure of the Electronic Register of Human Genomic Information. Considering the fact that martial law has been implemented in Ukraine, it is necessary to introduce the following independent section “Genomic information of unidentified human corpses, their remains and parts of the human body, missing persons and close relatives of missing persons”. It has been proven that it is necessary to carefully write down the issue of information protection, namely: which body monitors compliance with information protection requirements; how to ensure the protection of the information of the Electronic Register of Human Genomic Information.

Key words: state registration of human genomic information, Electronic register of human genomic information, DNA, molecular genetic examination, identification of dead servicemen

Introduction
With the emergence in the 80s of the XX century of analysis of genomic information, forensic identification has taken a big step forward. For more effective use of the information contained in deoxyribonucleic acid (hereinafter referred to as DNA), databases have been created in a number of countries that allow identification of the DNA found at the scene of the incident with the information contained in the database.

The development of DNA databases is one of the most promising directions in the use of modern computer technologies during the investigation of crimes. The importance of maintaining these databases is explained by the fact that DNA can be obtained from any secretions or tissues of the human body. DNA can also be easily isolated from any material that has been in contact with human secretions.

Modern scientific discoveries in the field of genetics (genetic engineering, genetic correction of human characteristics, genetic identification) inevitably give rise to the beginning of new social relations, rights and opportunities, which give, in fact, the right to manage
human life on a qualitatively different level, which causes the need for their legal regulation, determination of the optimal ratio of state participation and individual autonomy in the organization of social life.

Implementation of Electronic Register of Human Genomic Information in Ukraine: Legal Issues and Risks

On July 9, 2022, the Verkhovna Rada of Ukraine adopted the Law of Ukraine “On State Registration of Human Genomic Information” (hereinafter referred to as the Law) [1], which is important for the field of expert forensic activity and the law enforcement system, which is especially relevant in the conditions of martial law for the identification of dead servicemen and civilian population. This Law is aimed at improving the work of law enforcement agencies in the investigation of crimes and establishing the persons who committed them, allowing to improve the work of searching for missing persons and identification of unidentified corpses of people.

The Law of Ukraine “On State Registration of Human Genomic Information” provides for the creation of an Electronic Register of Human Genomic Information.

According to Art. 1, Part 1, Clause 5 of this Law:

“1. In this Law, the following terms are used in the following sense:

5) The Electronic Register of Human Genomic Information (hereinafter referred to as the Electronic Register) is an information and communication system that ensures the collection, registration, accumulation, storage, renewal, search, use and distribution (transmission) of human genomic information” [1].

According to Art. 4, paragraphs 5, 6, 7 of the Law of Ukraine “On State Registration of Human Genomic Information”:

“5. The State Registration of Genomic Information consists in entering into the Electronic Register information about a person’s genetic characteristics and depersonalized personal data about a person defined by this Law.

The information contained in the Electronic Register is information with limited access and is not subject to publication.

6. The holder of the Electronic Register is the Ministry of Internal Affairs of Ukraine. The Electronic Register is a functional subsystem of the unified information system of the Ministry of Internal Affairs of Ukraine. The administrator of the Electronic Register is a legal entity authorized by the Ministry of Internal Affairs of Ukraine, who belongs to the sphere of its management or is subordinated to it.

7. The administrator of the Electronic Register is responsible for the technical, technological and software support of the automated system of creating and maintaining the Electronic Register, processing, saving, protecting and providing the information contained in the Electronic Register” [1].

In Ukraine, the Electronic Register of Human Genomic Information will be created based on the experience of other countries, so the genomic information that will be placed in the Register, in accordance with the provisions of the law, will be depersonalized. The peculiarity of the Ukrainian Electronic Register is that the Register will include not only genomic information from crime scenes and persons who have committed criminal offenses, but also missing persons and unidentified dead bodies. Given the martial law and current realities, the data of military personnel will also be entered into the Ukrainian Register of Genomic Information. That is why the research of the State Registration of Genomic Information of military personnel, policemen, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities is quite relevant.

The law [1] is essential in the conditions of the full-scale war, as it will allow, in the event of the implementation of martial law, to carry out the mandatory selection of biological material from military personnel, police officers, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities for further identification in case of necessity. This will provide an opportunity for family members to receive the bodies of dead defenders for burial following the results of molecular genetic examinations.

In accordance with Art. 8, Part 2 of the Law:

“2. In the event of the implementation of martial law, the selection of biological material for the purpose specified in clauses 2 and 3 of the first part of Article 4 of this Law is carried out in a mandatory manner from military personnel, police officers, members of the rank and file and senior staff of the civil defense service, as well as members of voluntary formations of territorial communities.

The categories of persons, the procedure and terms for the selection of biological material, as well as the place of storage of the selected biological material provided for in the second part of this article, are determined respectively by the Ministry of Defense of Ukraine, the Ministry of Internal Affairs of Ukraine, the Security Service of Ukraine, the State Security Office of Ukraine, the intelligence body, the State Service of Special Communication and Protection of Information of Ukraine, and regarding voluntary formations of territorial communities by the Cabinet of Ministers of Ukraine” [1].

Regarding the extraction and destruction of biological material selected for the State Registration of Genomic Information from military personnel, police officers, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities, the Law provides for only one case, which is specified in Art. 14, Part 3, Clause 2:

“2. Biological material selected for State Registration of Genomic Information:

2) in the persons specified in the first and second parts of Article 8 and in the first part of Article 9 of this Law - destroyed after the expiration of the storage period established by the manufacturer of means (systems) for the selection of biological samples” [1].

A person’s DNA information, unlike other individualizing features, is not fully covered by the concept of personal data, but goes beyond this definition. The DNA molecule, in addition to its individuality, is also associated with its other main property – heredity as...
a means of transmission. Modern methods of DNA research make it possible to obtain not only identifying genetic information about a specific individual, but also a number of significant information about the characteristics of their biological relatives, which can be inherited. Thus, the DNA molecule is not only a carrier of individual information about a specific person, but is also able to transmit hereditary information about relatives of this person. So, due to selection of biological material, which is carried out in a mandatory manner from military personnel, police officers, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities, access to the genetic information of the relatives of the specified persons is opened, i.e. access to information that goes beyond boundaries of the subject’s personal data.

According to Art. 1, Part 1, Paragraphs 4, 6, 7 of the Law:

“1. In this Law, the following terms are used in the following sense:

4) genomic information of a person (hereinafter referred to as genomic information) - information about the genetic characteristics of a person;

6) molecular genetic examination (research) – the study of human biological material, which is carried out with the aim of obtaining its genomic information;

7) processing of human genomic information – any action or set of actions, such as collection, registration, accumulation, storage, renewal, search, use and distribution (transmission) of depersonalized personal data about the person to whom the genomic information belongs, as well as destruction of genomic information” [1].

In accordance with Art. 1, Part 1, Paragraph 10 of the Law of Ukraine “On Personal Data Protection”: “In this Law, the following terms are used in the following sense:

personal data - information or a set of information about an individual who is identified or can be specifically identified” [2].

In any case, the processing of human genomic information includes work with information about individual DNA, which its owner would like to use independently, without the participation of third parties, or to keep secret at all.

Genomic information of a person – biometrical personal data extracted from certain fragments of DNA of a living physical person or a corpse, on the basis of which it is possible to identify a person, determine genetic predispositions, or reveal patterns of human development, obtained voluntarily, and in cases provided for by law, in a mandatory manner.

Due to its characteristics, genetic information can be classified as a person’s personal data only partially, since it contains information not only about this person, but also about all members of his/her family and relatives. At the same time, genetic information is closely related to the categories of “personal”, “family” secret, and the secret of “private life”.

In Art. 8 of the Convention on the Protection of Human Rights and Fundamental Freedoms states:

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

2. State authorities may not interfere with the exercise of this right, except when the interference is carried out in accordance with the law and is necessary in a democratic society in the interests of national and public security or the economic well-being of the country, to prevent riots or crimes, to protect health or morals or to protect the rights and freedoms of other persons” [3].

According to Art. 32 of the Constitution of Ukraine:

“No one can be subjected to interference in their personal and family life, except for the cases stipulated by the Constitution of Ukraine.

It is not allowed to collect, store, use and distribute confidential information about a person without his consent, except in cases specified by law, and only in the interests of national security, economic well-being and human rights” [4].

In accordance with Art. 11, Part 2 of the Law of Ukraine “On Information”:

“2. Collection, storage, use and distribution of confidential information about a person are not allowed without his/her consent, except for cases specified by law, and only in the interests of national security, economic well-being and protection of human rights. To confidential information about a natural person includes, in particular, data on his nationality, education, marital status, religious beliefs, state of health, as well as address, date and place of birth” [5].

Thus, genomic information is a type of restricted access, confidential information.

In this regard, the legal regime of genetic information obtained as a result of State Genomic Registration for forensic purposes is of particular interest. In particular, the well-known Resolution of the ECtHR dated 04.12.2008 in the case “S. and Marper v. the United Kingdom” (applications No. 30562/04 and 30566/04) covers the very important issue of preserving personal autonomy and balancing public and private interests: at some point reference to the public good nullifies the individual’s right to privacy life and personal autonomy, to the right not to share the most important information about oneself - information about one’s DNA. In this connection, the question arises about the limits of the state’s intervention in the private life and private choice of an individual.

The applicants, S. and Michael Marper, are two British nationals born in 1989 and 1963 respectively. They live in Sheffield (UK).

The case concerned the authorities’ retention of the applicants’ fingerprints, cell samples and DNA profiles after the acquittal and the decision to close the criminal proceedings against the applicants, respectively. The data was kept on the basis of a law that allows it to be kept for an unlimited period, so the police and then the UK court refused it.

As a result of the dispute, the European Court noted that cell samples contain a lot of confidential information about a person, including their health. In addition, DNA samples contain a unique genetic code that is of great
importance to both the individual concerned and his or her family members. Given the nature and amount of personal information contained in cell samples, their retention should be seen as in itself a violation of the right to respect for the privacy of the individuals concerned.

In paragraph 99 of the aforementioned Resolution, the European Court emphasized that “... it is extremely important to establish clear and detailed provisions that determine the scope and procedure for the application of the specified measures, as well as minimum requirements that relate, among other things, to the duration, storage, use of relevant information, access third parties to it, measures to preserve the integrity and confidentiality of information and the procedure for its destruction...” [6].

In paragraph 101 of the aforementioned Resolution, the European Court draws attention to the fact that “state intervention in the exercise of human rights is considered “necessary in a democratic society” to achieve a legitimate goal, if it corresponds to an “urgent social need” and, among other things, is proportionate to the legitimate purpose pursued and if the grounds referred to by the national authorities are “relevant and sufficient” [6].

The European Court emphasizes that “normal storage by authorities of information about a person, no matter how it was obtained, must be considered as directly related to interests related to his private life, regardless of whether this information was used later” [6].

The European Court came to the conclusion that “the nature of the powers of national authorities to store fingerprints and cell samples and DNA profiles of persons who have been suspected but not found guilty of crimes is undisputed and without any differences, as it is happened to the applicants in the said case, violates the fair balance between public and private interests and that in this connection the respondent State exceeded the limits of any permissible discretion. Accordingly, the storage of the materials in question constitutes a disproportionate interference of the state in the applicants’ exercise of the right to respect for their private life and cannot be considered necessary in a democratic society” [6].

Judicial practice unequivocally refers genetic and genomic information to personal information that defines a specific person and affects private life. Accordingly, the ability to collect, use and disseminate this information is limited, even if it is related to the adoption of “measures necessary in a democratic society”.

Improper disclosure of genetic information, the main part of which relates to a person’s susceptibility to diseases or other physical characteristics (race, ethnicity), contributes to discrimination of a person based on his genome. According to Art. 11 of the Convention on Human Rights and Biomedicine, any form of discrimination against a person based on his genetic heritage is prohibited [7].

Unauthorized disclosure of genetic information obtained through genetic testing can be linked to activities such as gene and genetic identity theft. Thus, R. Gonzalez notes that the practice of secretly collecting and testing a person’s genetic materials without their knowledge or consent is recognized as gene theft. Access to this kind of information creates an opportunity for an offender to disclose genetic information about a person in the most harmful and painful way for the person [8].

The possibility of so-called genetic identity theft, for example, when one person impersonates another with the help of such genetic materials as blood, hair, saliva, etc., is a cause for concern. [9, p. 1239], which requires, in our opinion, the creation of special methods of protecting a person’s right to genetic identity with the possibility of proving its illegal use by a third party.

The conducted analysis shows that genetic data require special legal and technical protection.

In the Law [1], it is necessary to establish additional possibilities for the extraction and destruction of genomic information of military personnel, police officers, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities. Since the preservation of such information after dismissal from service, deregistration, death of the listed persons violates the fair balance between conflicting public and private interests, it is disproportionate to the “legitimate purpose” pursued by this intervention. Such an intervention is not justified by an urgent public need and, accordingly, cannot be considered “necessary in a democratic society”.

Conclusions

Taking into account the positive experience of the functioning of the “state in a smartphone” and the use of electronic documents, Ukraine has every chance to become the owner of the most complete Electronic Registry of Human Genomic Information in Europe.

Today, Ukraine effectively administers data in state registers and promptly reacts to any attempts to illegally acquire information, however, it is worth noting that the issue of ensuring the preservation of information and preventing the leakage of data from state registers is currently quite relevant. Taking into account the development of information technologies and the experience of storing large amounts of information, we have positive forecasts for the existence and functioning of the Electronic Register of Human Genomic Information in Ukraine.

New technologies can significantly change both the life of each person and the development of human civilization in general. With this in mind, it is necessary to note the fact that the genetic information contained in a person’s DNA is growing in importance in various areas of their life and the need for legal science, taking into account this fact, to effectively protect the rights of a citizen in order to prevent harm from the improper use of his genetic information.

Based on the analysis of problems arising in connection with the use of genetic information about a person, it is possible to conclude on the need to improve legislation in this area.

Yes, the Law of Ukraine “On the State Registration of Human Genomic Information” should specify some provisions regarding military personnel, police officers, members of the rank and file of the civil defense service, as well as members of voluntary formations of territorial communities, from which the selection of biological material, in the event of the introduction of martial law, will be carried out in a mandatory manner, namely:
specify the possibilities of extraction and destruction of genomic information in connection with: dismissal from military service and subsequent removal from military registration; with death in order to minimize the risks of access to personal data of a person and his relatives.

In addition, the mechanisms for monitoring compliance with legality in the Electronic Register of Human Genomic Information should be clearly prescribed.

The Law must carefully spell out the issue of information protection, namely:

- which body monitors compliance with information protection requirements;
- how the protection of the information of the Electronic Register is ensured (observance of the requirements for the protection of information established in accordance with this Law and other acts of legislation; the use of computer equipment, software, means of communication and other means that meet the established requirements for the protection of information; implementation control over the state of work on information protection).

The Law should clearly define the structure of the Electronic Register of Human Genomic Information. It is advisable to accumulate information in separate sections. Considering the fact that martial law has been implemented in Ukraine, it is necessary to introduce the following independent section “Genomic information of unidentified human corpses, their remains and parts of the human body, missing persons and close relatives of missing persons”. Access to such information should only be allowed to identify unidentified human corpses.

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