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Nondiscrimination Policy and Privacy Protection in Case of Genetic Passport for Soldiers

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ABSTRACT

It is difficult now to imagine the field of life, where genetic technologies have not been used. In Russia, there are already genetic passports of athletes, which made it possible to identify so-called "sports genes" that can predict individuals' inclination to a particular sport. In the United States of America, the Department of Defense (DOD) collects and uses the genetic information of all U.S. service members, including active duty and reserve military personnel. This article aims to explore the connection between genetic discrimination and protection of privacy. Whether the accessibility of such genetic data at the disposal of third parties will not lead to violations of their privacy that could further result in genetic discrimination? Basic human rights instruments in domestic and international law that regulates the right to non-discrimination and right to privacy will be reviewed beneath.

KEYWORDS

Genetic discrimination, genetic passport, human rights, privacy, data protection

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INTRODUCTION

In the pursuit of knowledge in the light of all opportunities that big data and technology is providing nowadays, the appetite for access to the data of individuals is growing. Recently, scientists of the Russian Academy of Science and Military Medical Academy (MMA) have started a big scientific fundamental project – creation in Russia of a genetic passport of military personnel that would help to understand at the genetic level who is more predisposed, for example, to serve in the navy, or who may be readier to become a paratrooper or a tanker (Doffman, 2019). The essence of the project is to find such genetic predispositions in military personnel, which will allow them to correctly orient in military specialties (Reddy, 2008). In other words, it is about understanding at the genetic level about certain predispositions for the service that is navy or armed forces. The project involves not only assessment of the physiological state, but also a prediction of human behavior in stressful, critical situations, which are closely related to the military profession. Stress resistance, the ability to perform physical and mental operations under this stress, and so on can all be contained in a soldier's genetic passport (The Moscow Times, 2021). However, a sensitive concern arises: whether collection of genetic information of individuals will not lead to abuse and violation of their fundamental human rights, including right to data protection and the right not to be discriminated against? Before looking at the law regulating these rights, the next part will consider what is the relationship between genetic privacy and non-discrimination.

METHODS

In this article the comparative-legal method of analysis has been used to address the problems of genetic discrimination in different states. The method of analysis of international standards for the protection of the human genetic information has made it possible to disclose the provisions of documents aimed at protecting privacy and preventing discrimination on the basis of genetic data.

Genetic privacy and Nondiscrimination

The relationship between privacy and discrimination is complicated. In terms of the right to privacy, firstly it is important to look at how the privacy has been defined by academics and legal scholars. The definition of privacy presents a complex multilateral phenomenon. Privacy protects the right of the individual to control information that is intrinsically linked to his/her identity. As a result, genetic privacy has been portrayed as a 'traditional route for the protection of genetic information' of individuals (Clayton et al., 2019). The protection of genetic information is important, and the question is how effective should data privacy to be in order to prevent discrimination?

In this article, the definition of genetic discrimination by Pfeffer will be used. According to Pfeffer genetic discrimination is differential treatment of an individual based on his genetic characteristics. For example, ‘genetic data is being used to deny a person equal treatment or equal opportunities’ to access a social good, such as insurance and employment thereby creating a new pool of disadvantageous individuals (Geller et al., 1996). However, it is not just the genetic data determining how we live and who we work for. According to Lemmens and Hoffman "on closer look many types of genetic data are actually shared with other types of health or personal information such as cholesterol test, HIV status, fingerprints scan" which means that a final decision will be made by the employers. Thus, the predictive power of a given test depends upon its analytic and clinical validity that depends upon the proficiency and quality of the professionals performing the analysis. What if the professionals lack sufficient understanding of genetic testing to use these technologies accurately? Creation of a genetic

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passport of soldiers also requires conduct of biochemical analyses of the genetic data and its interpretation by geneticists, programmers, bioinformatics, and doctors. In fact, information about a person's hereditary predisposition to various diseases can cause deviation in hiring an employee or serve as a reason for dismissal from the workplace, as well as affect promotion. So, the risk is that it can lead to genetic discrimination.

After looking at the relationship between the genetic privacy and discrimination, main human rights documents in international law that regulate the principle of genetic non-discrimination and the right to privacy will be considered.

Legal Analysis on Genetic Privacy and Non - Discrimination

There exists a variety of national and international approaches which aim to eliminate genetic discrimination and violation of genetic privacy. Some countries have adopted legal instruments (convention, laws, regulations, etc.) having a more general approach to the protection of the right of genetic privacy and non-discrimination whereas others enacted genetic specific laws that looked to the genetic information as “deserving of special protections as it is inherently unique” (de Paor, 2014). However, there are also counties not following the call of international community and not enacting the laws at the national level that prohibit the right of genetic privacy and non-discrimination.

For example, currently the law in Russia does not disclose the content of the category of genetic information. Nevertheless, the Federal Russian Law on state genome registration in p. 3 art. 1 provides a provision that genome information presents a personal information that includes encoded information about certain fragments of the deoxyribonucleic acid of an individual or an unidentified corpse that does not characterize their physiological characteristics. At the same time p. 1 art. 11 of the the Russian Federal Law on Personal Data (No. 152-FZ), without providing the content of what is a genome information defines biometric personal data that is information that characterizes the physiological and biological characteristics of a person, on the basis of which it is possible to establish his identity. However, the current legislation cannot cover the features of genome information and provide effective protection from misuse and use, including from the committing actions aimed at establishing restrictions on the presence of hereditary diseases and other features during hiring a person, concluding insurance contracts, credit contracts, etc. For this reason, implementation of a genetic passport of a soldier seems to be risky in context of human rights.

In order to identify general trends and regulations used for the collecting, use and storage of genetic information, it would be useful to cite examples from the practice of states where genetic material collection technologies and military DNA tests are most commonly used (De Castro et al., 2016). This part will analyze the experience with the positive impact of the collecting genetic information, as well as cases when genetic material contributed to the effectiveness of the construction of individual training plans, disqualification from the call of candidates to military service in the presence of genetic predisposition to serious diseases, and deprivation of the social benefits from the state (Baruch & Hudson, 2008).

In the USA, starting from 1917, APA Committee on Psychological Examination of Recruits, led by Robert Yerkes from Harvard University, developed and implemented a test to distinguish between high and low intelligence recruits. Although the U.S. Army had little use for findings indicating that a majority of its recruits were intellectually unfit for service, Yerkes's team used the testing data to advance their theories of hereditary intelligence and corresponding political agendas, such as the enactment of immigration and sterilization laws to prevent the "feebleminded" from reproducing. There are certainly a number of advantages to repository of genetic information on all American service members, because the technologies used offer broad prospects for search of missing persons and victims of enforced disappearance and identifying cases of sexual violence of military personnel. At the same time, however, the application of these technologies in practice can jeopardize the interests of society, human rights and freedoms. Conducting a comparative analysis of the search for the remains of military personnel, it is possible to note the gradual formation of DNA repositories as a tool for identifying the remains and identification of military personnel. From the paragraphs 152-156 of the Ordinance, it follows that the relatives of the applicants should be considered shot by the Soviet authorities, despite the fact that the remains of most of them were not found or were not identified. In addition, the termination of the investigation in 2004 turned the victims of the Katyn shooting simply into "persons missing." Grand Chamber judgment Janowiec and Others v. Russia (application nos. 55508/07 and 29520/09). Genetic information and DNA played a significant role in the search, exhumation, identification and reburial of the remains of soldiers killed during armed conflicts, as well as during the crashes, plane crashes (Brannon et al., 2003).

Huge military cemeteries with the remains of unidentified soldiers, monuments, memorials and memorials to unknown soldiers formed the memory of participants in armed conflicts died during the war. The consequences of the First World War, the huge number of soldiers killed and the lack of systematic data on missing persons served as a catalyst for the honor of human remains, the transfer of their loved ones, and the identification of the remains of died soldiers. Until the end of the 20th century, identification procedures were unreliable, and were based mainly on the comparison of information, namely, on the data contained in the log of the combat unit, in the military ticket of the soldier, on the information on the location of the grave, on the objects found next to the body. Ineffective identification methods using identification marks, data cards, medallions, bracelets and metal suspensions of the military stayed in the past. It became possible to use the technology and methods of DNA analysis to identify the remains of those killed as a result of armed conflicts and other situations of armed violence.

In practice, the discovery of remains and the search for military personnel began to bring positive changes in the search for the dead soldiers, for example, in 1972 in the battle of northern Saigon, military pilot Michael J. Blessy was reported missing. After an ongoing search, his family obtained permission from the U.S. Department of Defense to carry out DNA identification of the remains of a soldier buried under the stele of the memorial complex (were laid to rest in the Tomb of the Unknown at Arlington National Cemetery). It was established that those remains belonged to Lieutenant Blessy. The degree to which human remains are fragmented or degraded determines the value of DNA analysis in the identification process. Intact, large body parts lend themselves to identification by less costly methods, such as X-ray, dental examination, and fingerprints. However, DNA analysis is the only viable method for identifying severely fragmented or degraded remains. Even when whole bodies are recovered, DNA analysis still may be the best approach when materials that are necessary for other modalities—for example, dental records or verified body identification by friends or relatives—are unavailable.

The practice of collecting genetic data from the military officers has already existed in the USA since the last century. In this article, the USA legal practice on genetic discrimination will be considered. In the USA, the Department of Defense (DOD) collects and uses the genetic information of service members in several ways. All U.S. service members, including active duty and reserve military personnel, must provide a DNA sample that may be used to identify their remains should they die in battle. According to the document, the provision of biological samples of military personnel became a mandatory measure and has been collected in DNA Repository since December 2002, the Repository, now known as the “Armed Forces

Repository of Specimen Samples for the Identification of Remains," contained the DNA of approximately 3.2 million service members (Peterson, 1996).

Initially, the purpose of DNA Repository lied in the use of a reliable method of identification of human remains through molecular genetic analysis. In the event that there are relatives of the deceased and biomaterial suitable for research, this method allowed comparing the genetic characteristics of the alleged relatives and establishing the identity of a dead soldier. The identification of human remains resulted from armed conflict includes complex scientific, technical and legal aspects. However, a small entry in the huge 2003 National Defense Authorization Act, "signed by President Bush on December 2, 2002, overrides Pentagon policy that the DNA samples be used almost solely to identity troops killed in combat," and allows access to the Repository for law enforcement purposes (Alvarez-Cubero et al., 2012).

At that time, debates did arise on the legality of the purpose of collecting information about the DNA of the military personnel, because it was contrary to the 4th Amendment of the U.S. Constitution. Mayfield v. Dalton case showed that under constitutional law, only on the basis of a warrant arrested persons can be searched, fingerprinted and DNA samples seized. The plaintiffs-appellants in this case, John C. Mayfield and Joseph Vlacovsky, filed this action when they were on active duty in the Marine Corps. They challenged the constitutionality of a Department of Defense program to collect and store blood and tissue samples from all members of the armed forces for future DNA analysis (the "repository"). Mayfield and Vlacovsky argued that the compulsory taking of specimens without proper safeguards to maintain the privacy of the donor was a violation of the Fourth Amendment prohibition against unreasonable searches and seizures. Mayfield v. Dalton, 901 F. Supp. 300, 303 (D. Hawaii 1995). In addition, they feared that information obtained from the repository samples, regarding the donors' propensities for hereditary diseases and genetic disorders, might be used to discriminate against applicants for jobs, insurance or benefit programs. In this context, a number of questions have been raised about the constitutionality of the 2003 National Defense Authorization Act regarding the violation of the guarantees of respect for the right to privacy, dignity and security of individuals against unwarranted interference. The expansion of the discretion rights of law enforcement agencies has led to a number of lawsuits concerning the legality and illegality of the use of DNA Repository. As one editorial writer stated, "America's service members and convicted felons now have something in common - they're the only U.S. citizens whose DNA data can be used without consent or probable cause in police investigations."

The order to a soldier, sailor, airman, or marine to contribute a DNA sample is a lawful order which, if disobeyed, subjects the service member to prosecution under the Uniform Code of Military Justice (UCMJ). If convicted at court-martial for the offense of violating a lawful general order, the service member carries the lifelong stigma of a federal felony conviction, and faces a maximum punishment of a dishonorable discharge, confinement for two years, as well as reduction to the lowest enlisted grade.

The practice of military training also influenced the justification for the collection of genetic tests, as soldiers are often killed during or at the end of exercises in a particular occupation (Scoville et al., 2004). 'There were 276 recruit deaths from 1977 through 2001 and age-specific recruit mortality rates were less than half of same-age U.S. civilian mortality rates. Only 28% (77 of 276) of recruit deaths were classified as traumatic (suicide, unintentional injury, and homicide), in comparison to three quarters in both the overall active-duty military population and the U.S. civilian population (ages 15–34 years). The age-adjusted traumatic death rates were highest in the Army (four times higher than the Navy and Air Force, and 80% higher than the Marine Corps). The majority (60%) of traumatic deaths was due to suicide, followed by unintentional injuries (35%), and homicide (5%). The overall age-adjusted traumatic mortality rate was more than triple for men compared with women in all military services.

The DOD also included a recruit screening system (Screening for sickle-cell trait (SCT) on military accession) to reduce the risk of injury and avoid sudden deaths for unknown reasons. Scans on the SCT and the policy of injury prevention and health protection also sparked controversial opinions (De Castro et al., 2016b). At the same time, the military's concerns were heightened about data privacy, as opposed to military necessity and health policy for the armed forces (Green et al., 2015).

Currently, protection from genetic discrimination in the US guarantees Genetic Information Discrimination Act (GINA), passed in 2008 in USA that prevents employers and insurance companies from requesting DNA tests results or family medical data from individuals. ‘GINA is a necessary and laudable policy response to the ongoing revolution in genetics and human health’.

Thus, the law prohibits genetic discrimination in health insurance and at work; however, it does not affect other areas of life. GINA, an act that limits discrimination on the basis of genetic information during hiring a person and issuing health insurance. GINA defines genetic information as the results of genetic testing of an individual, the results of genetic testing of family members and the manifestation of diseases or other disorders in the family members of the person. The GINA also prohibits employers from obtaining genetic information from such individuals or a member of their family, except in statutory cases, such as the voluntary provision of information by a person as part of a health programme. Despite such advanced anti-discrimination legislation, discrimination still takes place in the United States (Kaplan, 2019). The GINA act implies a total ban on compulsory genetic testing during employment process and health insurance based on genetic information. However, there are some important exceptions to the rules, in particular that the law does not provide protection for the U.S. military, members of the Department of Veterans Affairs, the Indian Health Service and public service employees (Baruch & Hudson, 2008b). Another US case that received media attention is that of Pamela Fink, who claimed she was dismissed from her job once she had disclosed that she underwent a double mastectomy after testing positive to the BRCA2 gene mutation associated with an increased predisposition to develop breast cancer. She alleged that she received negative reviews from her employer a day before her second surgery and was later dismissed. As a result, she filed the ‘first publicly identified case of its kind’ alleging breach of GINA against her former employer in 2010. Fink’s case is still unresolved and has yet to go to trial.

In comparison to, in China there is a different version of the use of the human genome as in recent time there has been increase in cases of intervention in the natural process, by changing the human genome. Previously, China's legislation was aimed at protecting the public interests and national security. However, in the wake of the genetic data change scandal, new rules – Regulation on Human Genetic Resources were introduced with a temporary ban on any experiments related to editing of the human genome. This has led to tighter regulation of the issues related to storage, processing, transmission, genetic research systematization and the ban on the trade of human genome-related data. Thereby, these rules have only become an addition to the protection of privacy, but in general are still not aimed at protecting the privacy of customers and consumers of genetic laboratory services. For example, in the United States, gene editing is prohibited, except for laboratory research.

International Standards of Protecting Genome Information

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Different international and European Union human rights norms support the proposition that genetic discrimination need special protection, not least from article 6 of the Universal Declaration on the Human Genome and Human Rights 1997, from 11 of the European Convention on Human Rights and Biomedicine of the European Council 1997. . .and from article 21 European Union's Charter of Fundamental Rights. For example, article 6 provides:

> No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity'.

Also, under p. 1 art. 16 of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes (CETS No 203):

> Everyone has the right to respect for his or her private life, in particular to protection of his or her personal data derived from a genetic test. Everyone undergoing a genetic test is entitled to know any information collected about his or her health derived from this test.

Thus, the Convention on Human Rights during the conduct of research on biomedicine considers genome information in context of personal data of an individual. States that sighed the Declaration have a moral obligation to promote the implementation of its proclaimed principles, as well as the right to be informed (Article 5 UDHGHR) about the results of genetic testing and privacy (Article 7 UDHGHR). As well as to have rules for those individuals who cannot consent to genetic research.

The right to know one's genetic origin has also been recognized by the European Court of Human Rights (ECtHR) as part of the right to privacy protected by Article 8 of the European Convention on Human Rights (ECHR). The Court has described this right as the 'right to identity and personal development, and the right to establish and develop relationships with other human beings and the outside world. The preservation of mental stability is in that context an indispensable precondition to effective enjoyment of the right to respect for private life.'

At the regional level, the UN's Economic and Social Council also issued a Resolution in 2004 called Genetic Privacy and Non-discrimination, where it called on states to take measures against 'the misuse of genetic information leading to discrimination' (UN Economic and Social Council 2004: section 5.) For instance, in Resolution 2001/39 on Genetic Privacy and Non-Discrimination, the Economic and Social Commission (ECOSOC) urged states to ensure that no one shall be subjected to discrimination based on genetic characteristics and to take measures to prevent the use of genetic information and testing leading to discrimination or exclusion against individuals, particularly in social, medical, or employment-related areas, whether in the public or the private sector. A later resolution, of 21 July 2004, on the same topic, contains similar injunctions (Motoc, 2009). In 2000, the European Union also went further by adopting its Charter of Fundamental Rights (Charter of Fundamental Rights of the European Union 2000), in which 'genetic features' were included as a ground against illicit discrimination, providing the possibility for contravening national laws to be invalidated (Otlowski et al., 2012). The key points of the Charter are the priority of the person, his interests and well-being over the interests of science and society, as well as the obligatory consent to participate in clinical trials and scientific experiments.

Even though the United States and European countries such as France, Sweden, Finland and Denmark have international measures and domestic initiatives, they are still facing with the issues of genetic discrimination and protection of privacy. In recent years, the ECHR has accumulated a sufficient number of cases related to the collection, storage and use of human genetic material. It is therefore very useful to study individual decisions, both in order to shape positions on specific cases and to analyse the experience of dealing with such a category of disputes in order to improve the content of national legislation and the activities of national judicial bodies. 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 deision of ECHR in case S. and Marper v. the United Kingdom applicants for whom criminal cases were discontinued demanded the destruction of their DNA samples and fingerprints, but the police and then the British court refused them.

As a result, the European Court of Justice found that the universal and unrestricted power of the powers to store fingerprints, tissue samples and DNA data of persons suspected but not found guilty of crimes, as in the case of the applicants in the case, breaks the fair balance between opposing personal and public interests and the UK has violated its limits of discretion in this regard. Accordingly, the continue to keep that data constitutes a disproportionate interference with the applicants' right to privacy and cannot be considered necessary in a democratic society. In this dispute, the ECHR considers the DNA of innocent persons as an invasion of privacy and a violation of its integrity. During the study of national English law it’s been found that the genetic information of suspected criminals can be stored in the database for an unlimited amount of time.

Thus, genetic testing contains information about individual DNA, which its owner would like to use independently, without the participation of third parties, or even to keep secretly. However, due to the increasing popularity of genetic research and the human genome, there were more serious problems associated with the theft of particularly sensitive data on genetic information. Thus, this led to an investigation by U.S. intelligence agencies involving the U.S. National Institutes of Health in nearly 200 cases of illegal data transfers of U.S. medical centers to other countries. The DOD advised to members of the military to avoid DNA tests because of the risk of disclosing their data, a risk caused by the risk of losing the privacy of medical information. The U.S. Department of Defense's concern stems from the unintentional discovery of markers that could affect the serviceman's ability and future career.

In Kazakhstan, it is worthy to mention that in the light of recent changes in the legal framework, the law on dactyloscopic and genomic registration was adopted in 2016, coming partially into force in 2021. According to the law, the main provisions were adopted for persons who subject to fingerprint registration that include children between the ages of twelve and sixteen during the application for a passport of a citizen of the Republic of Kazakhstan on a voluntary basis, foreigners and stateless persons, permanent residents of the Republic of Kazakhstan, convicted of grave or particularly grave crimes, unidentified persons, unidentified corpses, biological relatives of missing citizens.

The purpose of the law is to ensure security and public order, as well as to identify unidentified corpses and search for criminals in a quick manner. Having analyzed this law, we assume that it will not adequately provide a mechanism for the prompt collection and generalization of fingerprint information. There is a clear gap associated with ensuring proper interaction between the authorities in this area. This is because several authorized bodies including the government, the internal affairs bodies, bodies of foreign affairs, national security agencies, transport in the field of fingerprint registration are regulating fingerprinting and genomic registration of the person. As a result, there is a high probability of violation of the right to privacy and the use of information for discriminatory purposes. Since under the law the right to regulating fingerprinting and genomic registration of the person has been entrusted to various bodies; however, the procedure of supervision and control is entrusted only to the prosecutor's office. Thereby, the safety and enforcement of measures to ensure adequate protection against unauthorized access remains open. In this regard, Russian law contains provisions that provide protection of the rights and freedoms of a person and a citizen, through judicial control, in the case of actions of officials of state bodies and institutions conducting state genomic registration.

In addition, there is no appropriate guarantee that this information will not be subject to improper access by interested third parties. Most forensic scientists insist on the introduction of a measure for universal fingerprinting, citing positive statistics of the disclosure of particularly serious crimes, and often referring to such strong arguments as disclosure rape of underage children. Other proponents of the ban on mandatory fingerprinting have expressed concerns about the leakage of information from single databases and a danger of using it for criminal purposes, for total control, or falsification of fingerprint information. These fears and risks can serve as evidence of the ineffectiveness of measures associated with the single collection of fingerprint information, biobanks, and banks of genetic information. Because they can intervene with the basic fundamental human rights and principles specified in the law on fingerprinting. This is because a priori procedure of mandatory surrender of genomic information violates the principle of voluntariness and international standards as well as privacy and security requirements for the processing of personal information.

CONCLUSION

Recently, there has been a gradual filling of gaps in the legislation allowing the collection and storage of genetic information, in the processing and use of data obtained, except the use of data for illegal purposes that violate human rights and freedoms and privacy. This means that to some extent, there are benefits of using genetic information, however, when considering personal, confidential details obtained through genes, we should not forget that all this information may affect the interests of both the individual and his/her family. The sensitive private nature of the genetic information could easily be violated by third parties and lead to discrimination. That is why it is important to have effective law on regulation of data privacy in order to prevent discrimination. Anti-discrimination measures and measures protecting genetic privacy at the legislative level, both within states on national and international levels shall be adopted, and Russia\Kazakhstan shall not be exception.

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