

## STUDY ON THE THEFT OF GENETIC INFORMATION AND POSSIBLE CONSEQUENCES

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*Aim.* To consider the legal and ethical aspects of DNA identification and theft of genetic information, to study the opinions of students of Toraigyrov University about the possible risks of theft of genetic information.

*Materials and methods.* A questionnaire was compiled for the study. This survey was conducted to study the awareness and opinions of students regarding the topic. Questions include determining the level of knowledge about DNA identification methods, assessing the fears and concerns of intruders about the theft or abuse of genetic information, understanding public opinion regarding genetic privacy protection measures and legislation. These questions helped determine not only the respondents' knowledge and understanding of genetic concepts, but also their attitude to the issues of privacy, ethics and regulation of the use of genetic information.

The survey on the topic «DNA identification and theft of genetic information» involved 103 respondents. Of these, 96% are students, and the remaining 4% are graduates of Toraigyrov university, that is, employees who currently work in various institutions of the city.

*Results and discussion.* The results show that, firstly, there is a high level of awareness about the possible risks of DNA theft, which indicates the urgency of this problem in society. Secondly, half of the respondents expressed concern about the possibility of abuse of their genetic information and supported the introduction of strict security measures to protect their privacy. The third result indicated that most respondents were willing to take precautions, such as protecting personal information and using safe methods to store DNA samples.

**Key words:** DNA identification; genetic information; information theft; society; potential threats

### INTRODUCTION

Theft of genetic information is the illegal acquisition or use of someone else's DNA material without the consent of the owner. This can include access to genetic information from genetic tests, medical records, and even DNA fragments. The purpose of DNA theft is to obtain information about hereditary diseases, personal identification or use data for fraud and discrimination [1].

Modern society is on the verge of a biotechnological revolution that will radically change our understanding of Health, Personal Identification and the protection of personal information [2]. DNA identification is one of the key technologies that has had a significant impact on many areas of life and is widely used in forensic science, medicine, genealogy and even in everyday life. However, with the development of these technologies, new threats are emerging, such as theft and abuse of genetic information.

DNA theft is a crime that has serious consequences for people's privacy and security. This can lead to a violation of the confidentiality of genetic information, improper use of personal information, and even false accusations of a crime.

The topic is important for society in protecting the rights of citizens to privacy and security [3, 4].

Discussion of DNA theft in society is important to raise awareness of possible threats to the confidentiality of Genetic Information [5, 6]. This will help people understand the importance of protecting genetic information and take appropriate precautions, such as choosing reliable genetic testing laboratories, setting strong passwords to access online accounts. Such discussions may also contribute to the development of legislation aimed at protecting the confidentiality of genetic information [7, 8, 9, 10].

Genetic information can reveal many aspects of a person, including genetic predispositions to various diseases and health conditions, hereditary characteristics such as eye color, hair color and skin type, and information about family relationships [11]. In addition, it can be used to determine ethnic origin and various physiological characteristics. All this makes genetic information very valuable, sensitive and requires special care.

Given the rapid advances in genomic analysis technologies and potential threats to data privacy, it may be appropriate to strengthen genetic information laws. This may include expanding the

rights of data subjects, stricter requirements for the protection and processing of genetic information, and the introduction of sanctions for violations. Such measures help maintain public confidence in the processing of genetic information and effectively protect the privacy of citizens [12].

Genetic information is unique and very individual. Publishing such data without a person's consent violates their right to privacy. This can lead to the use of personal information without a citizen's permission, which in turn poses a serious threat to personal security and Privacy [13].

There is no specific legislation in Kazakhstan to protect the genetic information of citizens. However, data protection and privacy laws such as the personal data and Protection Act (2013) may apply to genetic information in certain contexts. The law of the Republic of Kazakhstan on «Personal data and their protection» establishes the legal basis for the processing and protection of personal data of citizens. This law regulates the collection, storage, use of personal data, including genetic information, and provides for measures to ensure its confidentiality and security [14].

The aim of the study was to examine the risks of DNA identity and genetic information theft.

## MATERIALS AND METHODS

103 respondents took part in the survey on «DNA identification and theft of genetic information». Of these, 96% were students and the remaining 4% were graduates of Toraigyrov University, i.e. employees who are currently working in various institutions of the city. This survey was conducted to explore students' awareness and opinion on this topic. Objectives included determining the level of knowledge about DNA identification methods, assessing the fear and concern of malicious actors about the theft or misuse of genetic information, and understanding public opinion regarding genetic privacy protections and legislation. These questions helped determine not only respondents' knowledge and understanding of genetic concepts, but also their attitudes toward privacy, ethics, and regulation of the use of genetic information. The results were to determine respondents' awareness of the

dangers associated with the leakage of genetic information and the support and need for legislative action to protect privacy in this area.

Responses to the first two questions were designed to determine respondents' knowledge and understanding of basic genetic concepts and their attitudes toward issues related to privacy and protection of genetic information (Table 1).

The following survey questions reflect the level of public concern and awareness about the confidentiality of genetic information, and assess public opinion and needs for the protection of genetic information. The question on knowledge of DNA theft assesses how familiar people are with the potential threats associated with the theft of genetic information and these risks, and whether they understand the importance of this issue.

The question on the privacy threat of DNA theft reflects respondents' level of awareness of the potential risks associated with the theft of genetic information and determines the extent to which they understand the importance of this risk to their own privacy (Table 2).

The following three questions illustrate ways to know possible human consequences, identify the motives of attackers, and develop security measures to protect genetic information (Table 3).

It is important to evaluate the effectiveness of the legislation and identify technological means to protect DNA (Table 4).

The importance of questions about the ethics of genetic information collection and the problem of DNA theft in society:

- they raise public awareness of the ethical issues surrounding the collection and use of genetic information, which can influence public opinion and legislative decisions in this area;
- promotes discussion and awareness of the importance of protecting the confidentiality of genetic information, leading to the development and implementation of effective security measures;
- assist in identifying problems and risks associated with DNA theft, which are crucial for organizing preventive measures and reducing risks to society (Table 5).

Table 1 – Questions about the concepts of DNA and genetic information

№	Questions	Answers
1	How would you describe the concept of DNA?	The process of converting light into electrical energy in the elements of The Sun; Group of chemical compounds involved in the respiratory process; C. A genetic virus that affects the structure of the cell membrane; D. A molecule that carries genetic information that determines the structure and function of living organisms.
2	What is genetic information?	Instructions encoded in DNA that determine the development and function of living organisms; Special recipes for the preparation of genetically modified products; Group of secret codes for bank accounts; Fiction created to describe genetic research in the literature.

## RESULTS AND DISCUSSION

When asked about the concept of DNA and genetic information, 93% answered correctly and the remaining 7% answered incorrectly. From this we can conclude that most of the respondents know important terms about genetics.

Only 22% of the respondents were very concerned about the privacy of genetic information, 29% of the respondents were not particularly con-

cerned about it, 27% were not sure if they should be concerned, and the other 22% did not know or were not interested in it. 7% of respondents had knowledge about DNA theft, 23% had basic knowledge, 26% of respondents had limited knowledge and 44% did not care. 28% of the respondents think DNA theft is dangerous, 32% are not sure of the risk, 10% do not think it is dangerous and 30% are not interested in the topic.

Table 2 – Questions about awareness, fears and risks of genetic information theft

№	Questions	Answers
3	Are you worried about the confidentiality of your genetic information?	A) Yes, I am very concerned about the confidentiality of genetic information; B. No, I have no special concerns about this; C. I don't know if it's worth worrying about the confidentiality of genetic information; D. I have no knowledge or interest in genetic information.
4	How do you assess your awareness of the issue of DNA theft?	A. I have fully mastered the topic of DNA theft; B. I know the basics, but I have no deep knowledge of the issue of DNA theft; C. My knowledge of DNA theft is limited, but I've heard about this issue D. I am not very aware of the issue of DNA theft, nor was I interested in it; E. I don't know about the problem of DNA theft.
5	Do you think that DNA theft is a serious threat to the privacy of citizens?	A. Yes, I believe that DNA theft can seriously disrupt the privacy of citizens; B. Maybe, but I don't know how real or dangerous DNA theft is; C. No, I don't think DNA theft poses a serious threat to privacy; D. I cannot form an opinion on the importance of the risk of DNA theft because I have not received enough information; E. It is difficult to answer because we do not know the question of DNA theft.

Table 3 – Questions about motives for DNA theft and security measures

№	Questions	Answers
6	What are the consequences of a person whose DNA was stolen?	A. I believe that the main threat is the potential disclosure of personal data and the loss of privacy; B. Loss of Health Information and possible discrimination in employment; C. The possibility of using stolen DNA for fraud or other illegal purposes; D. The possibility of psychological and emotional consequences such as stress and anxiety in the event of genetic data leakage; E. Difficulties may arise in personal relationships, especially if the stolen data reveals information about Hereditary aspects.
7	What do you think the motives of the intruder could be in the theft of DNA?	A. Ethnic or racial reasons: seeking information to discriminate on the basis of ethnicity or race; B. Financial gain: selling stolen genetic information on the black market; C. Medical motives: uncoordinated use of DNA in medical research; D. Extortion: disclosure of genetic information in order to gain the benefit of extortion; E. Personal Identification: the use of stolen information for personal benefit.
13	What security measures do you take to prevent possible DNA theft?	A. I avoid sharing my genetic information with companies that do not have a clear Privacy Policy; B. If necessary, I will only perform genetic tests in verified and certified laboratories; C. I try not to share genetic information in public places and networks to prevent accidental leaks; D. I use strong passwords and two-factor authentication for registrations associated with genetic information; E. I participate in genetic information security education programs to learn more about the potential risks.

## Организация и экономика здравоохранения

Table 4 – Questions about laws and technology in protecting personal information

№	Questions	Answers
8	Do you think the current laws adequately protect citizens from DNA theft?	A. Yes, I am sure that the current laws adequately protect citizens from DNA theft; B. Yes, but some aspects of the legislation need to be tightened; C. I'm not sure, because I don't have detailed information about the laws in this area; D. No, I think the laws do not provide sufficient protection and it is necessary to make changes; E. It is difficult to say, I do not know the current laws regarding DNA theft.
9	Do you think government agencies should strengthen measures to prevent DNA theft?	A. Yes, I believe that strengthening measures is an important step to ensure the safety of citizens' genetic data; B. It is possible, but it is necessary that there be a balance between security and the protection of civil liberties and rights; C. I'm not sure because I don't know the full extent of the measures taken to prevent DNA theft; D. No, I think the current measures are sufficient and their strengthening can disrupt individual freedoms; E. It is difficult to say, because I do not have enough information about measures in this area.
12	How do you assess the role of technologies in preventing and detecting DNA theft?	A. Technologies play a key role in preventing DNA theft and ensuring the security of genetic data; B. Technological innovations can significantly improve DNA theft detection, but broader standardization needs to be done; C. Technologies can be useful in preventing DNA theft, but legal and ethical considerations are also important; D. Technological solutions provide certain protection, but at the same time, attention should be paid to education and awareness of the threat; E. I don't know about DNA theft prevention technologies.

Table 5 – Questions about the ethical reliance on and discussion of DNA theft in society

№	Questions	Answers
10	What are your views on the ethical aspects of DNA collection and use in society?	A. The collection and use of DNA must strictly comply with ethical standards, taking into account the privacy and consent of the person; B. It is important to balance scientific and medical goals with respect for privacy and rights; C. Ethical considerations are fundamental and the collection and use of genetic information must be carefully regulated; D. It is necessary to strengthen ethical standards and regulations to prevent the abuse and violation of privacy; E. Wider public dialogue and participation is needed in the development of ethical standards in this area.
11	Do you think the public should widely discuss DNA theft and its consequences?	A. Yes, public discussion of DNA theft is important to raise awareness and develop effective protection measures; B. It is possible, but it should also be borne in mind that the discussion does not cause panic and does not lead to unjustified unnecessary security measures; C. I do not know how widespread and relevant the problem of DNA theft is for society; D. No, I think this is a problem that should be solved by specialists and legislators, and not by ordinary people of society; E. It is difficult to say because I do not have enough information about the scale of the problem and public opinion.

## Организация и экономика здравоохранения

The following conclusion can be drawn from this: a small proportion of respondents are concerned about the security of their genetic information, even if the majority of them consider DNA theft dangerous. The rest of the respondents are not interested in this topic (Fig. 1).

The next group of questions has several answers. About the consequences that can occur when DNA is stolen: 42% chose the answer as dissemination of personal information as the main answer, 46% chose the question about the occurrence of discrimination in employment, 61% of respondents say that a person uses genetic information for fraud, 47% of respondents believe that a person suffers mental consequences, and 46% of respondents believe that there may be difficulties in personal relationships. In another question, the respondents' most preferred answer as the abusers' motive: 52% of respondents ethnic or racial discrimination, 52% of respondents selling stolen genetic information on the black market, using DNA in medical research without consent 50% of respondents, 41% of respondents disclose

genetic information to gain extortion benefits, and 41% of respondents to obtain stolen information for use 43% of respondents chose. On the issue of security measures: 52% of respondents do not share their genetic information on websites, 53% of respondents only conduct screenings at certified facilities, 41% of respondents do not share personal information in public places, 36% of respondents use two-factor identification and 14% of respondents participate in programs about possible risks. It can be concluded that most respondents have heard about DNA theft issues and know how to protect themselves from threats (Fig.2).

When asked about laws sufficiently protecting citizens from the consequences of DNA theft: 21% of respondents are fully confident in the law, 20% of respondents believe that some aspects of the law need to be tightened, 23% are not confident, 17% of respondents do not know about the laws, and the remaining 19% believe that the laws do not protect enough. Government agencies on the issue of strengthening measures to prevent DNA theft: 33% of respondents need reinforcement, 31% believe

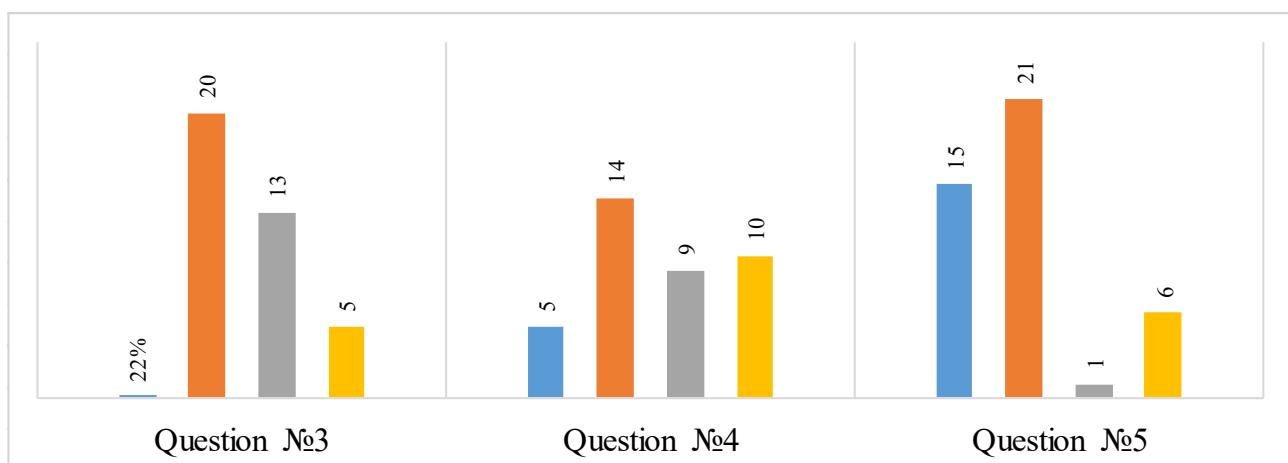


Figure 1 – Answers to questions about the challenges and risks of DNA theft

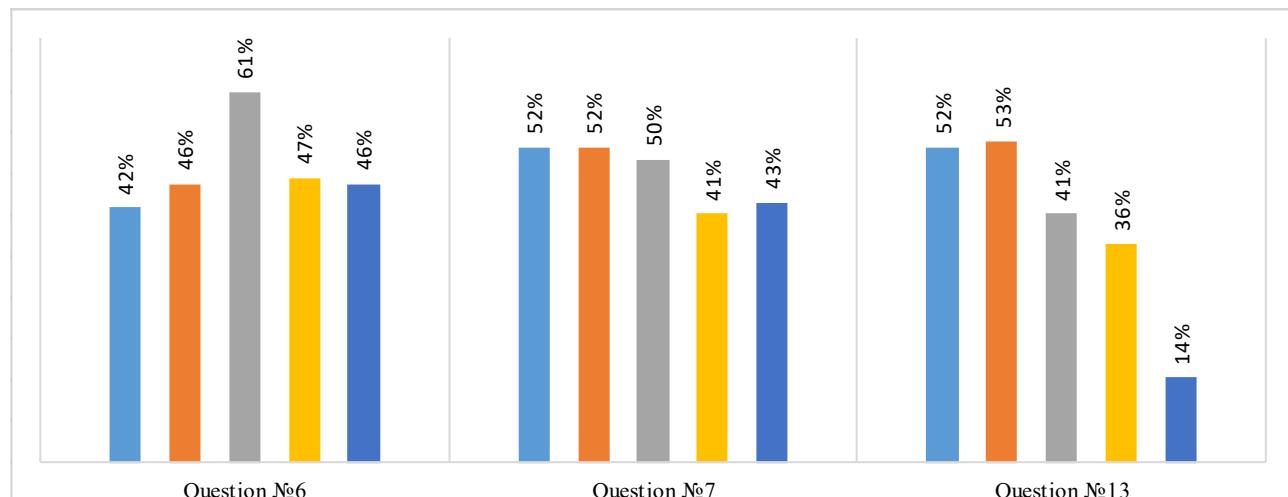


Figure 2 – Answers to questions about the perpetrators' motives in stealing DNA, the resulting consequences and defenses

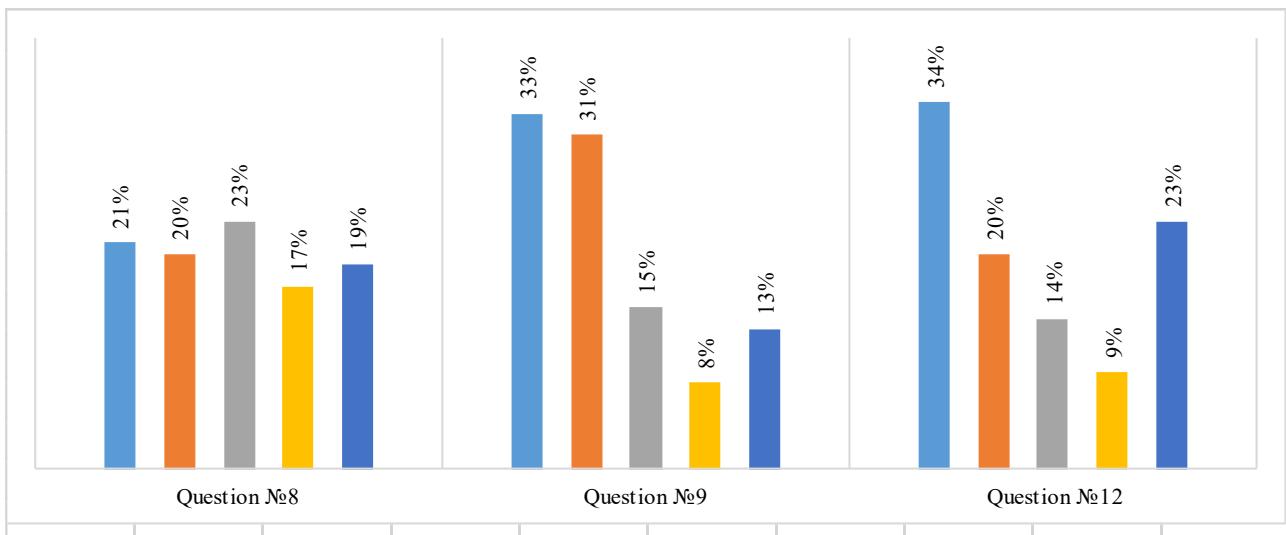


Figure 3 – Answers questions about strengthening laws to protect personal information, role of technology in protecting DNA from theft

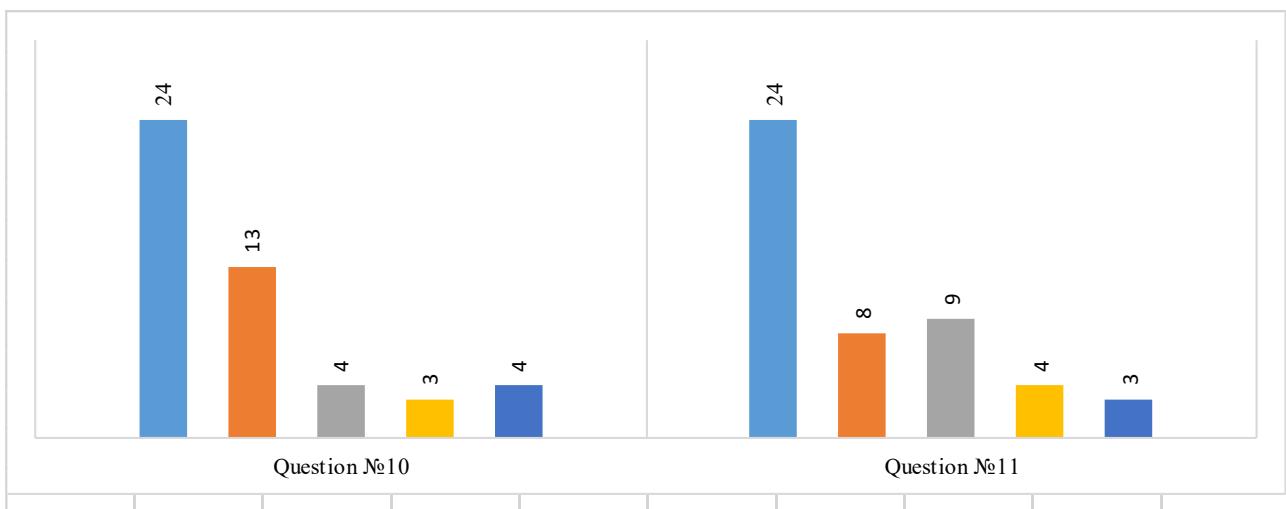


Figure 4 – Responses to questions about ethical leanings and discussion of DNA theft in society

there needs to be a balance between citizen rights and ethical considerations, 15% express distrust, and 8% believe strengthening laws violates personal freedom, 13% believe respondents can answer the question with little information.

On the role of technology in preventing DNA theft: 34% of respondents say that technology plays a key and important role, 20% believe that technology should be standardized, 14% of respondents believe that law and ethics should be considered, 9% believe that possible risks should be considered, 23% find it difficult to answer this question. From this we conclude that most of the respondents are not sure about the protection of their genetic information in the laws, so we propose to tighten the rules (Fig. 3).

On the reliance on ethical aspects of DNA collection and use: 43% of respondents believe that ethical standards should be strictly enforced, 25% insist on respect for privacy and citizens' rights,

12% of respondents believe that the collection of genetic information requires careful consideration, 8% of respondents need to strengthen the rules to avoid violations, 12% of respondents introduce an ethical standard believe that public involvement is necessary. About the discussion of DNA theft and its consequences in society: 46% of respondents believe that DNA theft should be widely discussed in society, 17% disagree completely because they think there may be unnecessary panic in society, 17% do not know how widespread and relevant the problem of DNA theft is to society, only 7% of respondents are general public and refuse to hold discussions about DNA theft because this issue needs special experts to share their opinions, and 13% of respondents find it difficult to answer because they have little information about DNA theft.

Most respondents believe that ethical issues are important when collecting information about

DNA and that the topic of DNA theft should be widely discussed in society (Fig. 4).

## CONCLUSION

In this study, a 13-question survey was designed to explore public opinion on issues related to DNA testing and the protection of genetic information. The survey included questionnaires to different courses of students, alumni and staff. This allowed for a comprehensive expression of their opinions and comments.

The survey shows that the majority of respondents are aware of DNA testing options and express serious concerns about the privacy of genetic information. Many respondents believe that genetic information should be strictly regulated and protected from unauthorized use.

One of the main conclusions of the study is the need for increased awareness of the rights and dangers of people with genetic information and the implementation of educational programs. It is important that society not only becomes a user of modern technologies, but also actively participates in the discussion and development of norms and rules governing their use.

In general, the protection of genetic information requires the coordination of the development of technical and legal standards. Maximizing the use of DNA identification results and reducing the risks associated with the theft of genetic information can be achieved through integrated ways, including technical, legal and educational measures.

In conclusion, this study contributes to explaining the complex problems associated with DNA identification and theft of genetic data and suggests directions for future research and practice in the field of genetic information protection.

### Contribution of the authors:

A. K. Sharipova – head of the research, writing and statistical processing.

A. K. Sharipova, N. Zh. Akimbekova – collection of materials, writing and editing.

N. Zh. Akimbekova – data processing and translation.

### Conflict of interest:

No conflict of interest is declared.

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### ПРОБЛЕМЫ КРАЖИ ГЕНЕТИЧЕСКОЙ ИНФОРМАЦИИ И ВОЗМОЖНЫХ ЕЕ ПОСЛЕДСТВИЙ

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**Цель.** Рассмотрение правовых и этических аспектов ДНК-идентификации и кражи генетической информации, изучение мнения студентов НАО «Торайгыров университет» о возможных рисках кражи генетической информации.

**Материалы и методы.** Был проведен опрос для изучения осведомленности и мнения студентов по проблемам кражи генетической информации и возможных ее последствий. Задачи включали в себя определение уровня знаний о методах идентификации ДНК, оценку беспокойства по поводу кражи или злоупотребления генетической информацией, а также понимание общественного мнения в отношении мер защиты генетической конфиденциальности и законодательства. Эти вопросы помогли определить не только знания и понимание респондентами генетических концепций, но и их отношение к вопросам неприкосновенности частной жизни, этики и регулирования использования генетической информации. В опросе на тему «Идентификация ДНК и кража генетической информации» приняли участие 103 респондента, из которых 96% студентов и 4% выпускников «Торайгыров университет», то есть сотрудники, которые в период проведения исследования работали в различных учреждениях города.

**Результаты и обсуждение.** Результаты показали, во-первых, высокий уровень осведомленности о потенциальных рисках кражи ДНК, что подчеркивает актуальность этой проблемы в обществе. Во-вторых, половина респондентов выразила обеспокоенность возможностью злоупотребления своей генетической информацией и поддержала введение строгих мер безопасности для защиты их конфиденциальности. В-третьих, большинство респондентов выразили готовность принять меры предосторожности, такие как защита личной информации и использование безопасных методов хранения образцов ДНК.

**Выводы.** Результаты подчеркивают необходимость разработки эффективной политики и законодательства для использования генетической информации и сбора образцов ДНК для защиты личной информации.

**Ключевые слова:** ДНК-идентификация; генетическая информация; кража информации; социум; потенциальные угрозы

# Организация и экономка здравоохранения

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## ГЕНЕТИКАЛЫҚ АҚПАРATTЫ ҮРЛАУ МӘСЕЛЕСІН ЖӘНЕ ОНЫҢ ҚЫТЫМАЛ САЛДАРЫН ЗЕРТТЕУ

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*Зерттеу мақсаты.* ДНҚ-идентификацияның және генетикалық ақпаратты үрлаудың құқықтық және этикалық аспектілерін қарастыру, Торайғыров университеті студенттерінің генетикалық ақпаратты үрлаудың ықтимал қауіптері туралы пікірлерін зерттеу.

*Материалдар және әдістер.* Зерттеу үшін саулама құрастырылды. Бұл саулама тақырыпқа қатысты студенттердің хабардарлығы мен пікірлерін зерттеу үшін жүргізілді. Міндеттерге ДНҚ сәйкестендіру әдістері туралы білім деңгейін анықтау, қасқунемдердің генетикалық ақпаратты үрлау немесе теріс пайдалану туралы қорқыныш пен алаңдаушылығын бағалау, генетикалық құпиялылықты қорғау шаралары мен заңнамаға қатысты қоғамдық пікірді түсіну кіреді. Бұл сұрақтар респонденттердің генетикалық концепциялар туралы білімі мен түсінігін ғана емес, сонымен қатар олардың жеке өмірге қол сұғылмаушылық, этика және генетикалық ақпаратты пайдалануды реттеу мәселелеріне қатынасын анықтауға көмектесті. «ДНҚ идентификациясы және генетикалық ақпаратты үрлау» тақырыбындағы сауламаға 103 респондент қатысты. Олардың ішінде 96 % студенттер, ал қалған 4% Торайғыров университетінің бітірушілері, яғни қазіргі кезде қаланың түрлі мекемелерінде жұмыс істейтін қызметкерлер.

*Нәтижелер және талқылау.* Нәтижелер, біріншіден, ДНҚ үрлігіның ықтимал қауіптері туралы хабардарлықтың жоғары деңгейі бар, бұл қоғамда бұл мәселенің өзектілігін көрсетеді. Екіншіден, респонденттердің жартысы өздерінің генетикалық ақпаратын теріс пайдалану мүмкіндігіне алаңдаушылық білдірді және олардың жеке өмірін қорғау үшін қатаң қауіпсіздік шараларын енгізуі қолдады. Үшінші нәтиже респонденттердің көпшілігі жеке ақпаратты қорғау және ДНҚ үлгілерін сақтаудың қауіпсіз әдістерін пайдалану сияқты сақтық шараларын қабылдауға дайын екендіктерін білдірді.

*Қорытынды.* Нәтижелер генетикалық ақпаратты пайдалану және ДНҚ үлгілерін жинаудың жеке ақпаратты қорғау үшін тиімді саясат пен заңнаманы әзірлеу қажеттілігін көрсетеді.

*Кілт сөздер:* ДНҚ-идентификациясы; генетикалық ақпарат; ақпаратты үрлау; қоғам; ықтимал қауіптер