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The attitude of young people in the city of Yakutsk to DNA-testing

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ABSTRACT

This pilot research was one of the first sociological studies with general questions on genetic testing with 300 participants, 75% of which were representatives of one people – the Sakha. A quantitative method was used: a sociological survey with quota sampling (Δ ± 5%), held in February – March 2018 in the City of Yakutsk (n = 350).

Analysis of the survey results have shown that the respondents have low levels of awareness about the DNA-testing method: 72.3% "do not know about the method". Only 18.7% of respondents knew that since 2000 the Medical-Genetic Centre of the Sakha Republic (Yakutia) conducts DNA diagnostics for hereditary diseases, with 81.0% replying that they didn't know that. The questionnaire has shown that 90.3% of participants would like to undergo DNA-testing to identify their susceptibility to genetic diseases. Our questionnaire has shown high levels of self-identity among the young Sakha and their desire to learn about their belonging to a specific ethnicity (49.3%) with the assistance of DNA-testing. Furthermore, based on the answers relating to motivations for undergoing DNA-testing, we can say that the respondents have confirmed the peculiarities of their national mindset, specifically, high value of children for a family: "concern for the health of my future children" was a great motivator for taking the test (50.3%).

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Introduction

The 21st century can be called the age of introducing genetic technologies not only into medical practice, but also into many facets of society, as well as personal life and human relations [1]. One of those genetic technologies is DNA-testing. There are various kinds of genetic testing: for research purposes, medical genetic testing, and commercial genetic testing.

Owing to the development of new technologies and significant scientific discoveries in the fields of human genome research and general molecular genetics, identification of the genetic nature of a number of diseases has allowed researchers to study them as a continuous chain of events, initiated by a specific biochemical and protein defect, leading to a specific clinical feature.

During their lives, individuals may undergo various forms of genetic testing, depending on their aims, for example, to find the cause of their current illness, or a hereditary illness, or to submit their DNA for scientific study [2,3]. Most often individuals go through genetic testing for medical reasons, for instance, to diagnose hereditary pathologies. At present, DNA diagnostics can identify a large number of diseases, but not all scientific advances in the field of genetic testing are implemented into medical practice. Historically, medical assistance and support to families burdened with inherited diseases has been provided by medical-genetic services. The community of medical geneticists are working to develop accepted principles of providing assistance to national and regional health departments, also paying a great deal of attention to educational programmes for the population [4].

At the same time, there is a big issue of commercialising genetic testing, when private companies advertise and directly offer to consumers a multitude of DNA tests outside the traditional system of healthcare [5,6]. The main disadvantages of DNA testing commercialisation are connected with the lack of medical monitoring,

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scientific accuracy, clinical justification, usefulness of genetic testing results, and their interpretation. Individuals are not informed or consulted before and after genetic testing, which is a violation of all international recommendations and guiding principles for genetic testing. Moreover, in some cases a presymptomatic testing of underage children is carried out, which violates not only the guiding principles, but also ethical requirements [7]. Later developments include the appearance of online websites, where the consumers can upload their unprocessed data from tests not connected to or connected to their health for a repeat interpretation by a third party [3,8].

At present, the field of personal genomic testing is growing, becoming more and more popular and accessible, including through online applications. Specialists are studying the necessity of applying specific rules for using personal genetic testing kits and bioethical issues of individual autonomy in the new reality [3]. Many recent papers are dedicated to studying public opinion on DNA testing, connected with pharmacogenetics, biobanks, forensic medical examinations [9–12].

The Sakha Republic (Yakutia) is in the North-East of the Asian part of Russia and is geographically remote from its central regions. It is the largest region of Russia by area (3,085.5 thousand sq. km) and is divided into 35 administrative districts. With 972 thousand people living in the republic, it has an extremely low population density, only 0.32 people per sq. km, as 40% of its territory is located beyond the Arctic Circle. The climate is harsh, sharply continental, with winter temperatures dropping to −60°C, and summer temperatures reaching +40°C. One of the biggest issues in the republic is the transportation accessibility for settlements, as some roads only exist in winter when the rivers and lakes freeze over. Central Yakutia is home to about 500 thousand people. Industrial production in the republic is primarily connected with the extraction of natural resources: diamonds, gold, coal, oil, rare metals. The rural areas of the republic are mostly settled by the indigenous people, dominating among whom are the Sakha, comprising 83.3% of the total rural population.

In the first half of the 17th century this land was colonised by the Russian State, which not only acquired vast territories, but also became a multi-ethnic Eurasian empire [13]. From this moment on the local population came into contact with the Russian Christian space. It marked a “long period of interaction of two cultural habitats” – paganism and Orthodox Christianity [14]. The indigenous people of the Sakha Republic (Yakutia) are the Sakha (‘Yakut’ in Russian), numbering 466 thousand people. Sakha language is part of the Turkic group of languages, but it has many words of Mongolic origin, which, according to specialists, greatly changed the phonetic structure of the Sakha language, and prove that there were contacts between the Sakha and the Mongols [15]. The mentality of the indigenous people of Yakutia formed in the constant struggles for survival in the harsh conditions of the North. 19th century ethnographers described the incredible endurance of these people towards unfavourable environmental conditions, hunger, cold [16,17].

The City of Yakutsk was founded as a fortress by a Russian Cossack Pyotr Beketov on the right bank of the River Lena in 1632. Since then, Yakutsk became a starting point for many expeditions to study and settle the northern lands of Russia. Today, Yakutsk is a modern, rapidly developing city, one of the cultural, scientific, and educational centres of the Russian Far East. The population of the city is 318,768 people, among which 49% are the Sakha, 38% are the Russians, and 13% are other ethnicities [18].

The development of molecular genetics in the Sakha Republic (Yakutia) began in 1992 during the Russian-American Scientific Program on the Biology of Vilyuisk Encephalomyelitis. Clinical-genealogic and molecular-genetic studies were done within the context of a scientific project on the Identification of Genes and Genetic Mechanisms that Cause Hereditary Neurological Diseases. In 1996 the results of the joint Sakha and American project were published, where the hereditary cerebellar ataxia, widespread in the Sakha Republic, was identified as spinocerebellar ataxia type 1 (SCA1). In this research the Siberian site of disease was identified as the largest known in the world (38.0: 100,000) with a tendency for further growth [19].

The targeted program on the Development of Gene Diagnostics for the People of the Sakha Republic (Yakutia) for 2001–2005, adopted by the Decree of the Government of the Sakha Republic (Yakutia), provided for an expansion of activities to diagnose hereditary diseases [20]. The funds provided by the program were used to train specialists in molecular genetics and to establish a molecular-genetic laboratory in the Republic Hospital No 1 – National Centre of Medicine. Thus, beginning in the 2000s, methods of DNA testing and prenatal diagnosis for the most common monogenic hereditary diseases became available in the practical medicine of the Sakha Republic (Yakutia) as routine screenings. At present, around 30 monogenic hereditary diseases are available for molecular-genetic diagnostics and that number will probably increase in the future. Concurrently, bioethics research was conducted in the field of using DNA testing in the republic [21] that included ethical issues of prenatal diagnostics for late-onset disorders [22].

Due to certain population reasons, there was an accumulation of some types of hereditary diseases in the Sakha Republic, the issue of studying and preventing which is quite urgent [23]. In our opinion, genetic technologies, including DNA testing for hereditary diseases, are a major breakthrough in science and medicine of the republic, but are also a clear bioethical challenge for our society. Introduction of DNA-testing for hereditary monogenic nosologies that are widespread in the republic into the practical medicine requires the development of differentiated bioethical approaches, depending on the mode of inheritance, age of onset, severity of pheno-genotypical manifestations, and clinical polymorphism of each hereditary disease [21]. For instance, ethical issues connected with late onset diseases (spinocerebellar ataxia type 1) are markedly different from issues, arising from consulting families with hereditary diseases that manifest in early childhood.

Interest of authors in these research works are mostly connected with the long-term study of spinocerebellar ataxia type 1 in Yakutia. Spinocerebellar ataxia type 1 (SCA1) is characterised by its late onset. On average, the disease manifests at age 35, though the age of onset for specific individuals can vary significantly, depending on the number of *CAG*-repeats in the mutated *SCA1* gene. Clinical aspects of SCA1 are characterised by extensire polymorphism, cerebellar-pyramidal syndrome. The pathological process develops through 5 clinical stages, identified by the degree of intensity of movement and speech disorders. The severity of the disease in advanced stages is due to the development of bulbar paralysis [19].

In our opinion, individuals with this mutation cannot be called sick with SCA1 before the actual onset of the disease, as they are completely healthy in their physical and intellectual development. Among people with *SCA1* gene mutation there were, and still are, well-known sportsmen, politicians, public figures, researchers, etc. As such, by offering parents to terminate pregnancy with a foetus who has SCA1 mutation, we are essentially offering them to get rid of a fully functional member of society. The main reasons for offering termination of pregnancy to parents are the absence of a cure for this disease and the suffering of the individual in the future when the disease manifests fully. However, many laboratories are working on finding cures for neurodegenerative diseases and may be successful in time.

In our practice, there were several cases when pregnant women refused to terminate pregnancy with a foetus who had SCA1 mutation. Their difficult and informed choice was accepted in the same way as the choice of women who decided to terminate their pregnancies after receiving positive results of DNA-testing. We have also observed that about half of women who came to us for prenatal diagnostics of SCA1 did not return for DNA-testing of the foetus after receiving the first prenatal genetic consultation. This fact also underscores the moral and psychological difficulty of deciding the fate of the foetus. We follow the principle of the "right to not know" when testing for late onset diseases. The ethical issues of prenatal diagnosis for SCA1 are described in more detail [22].

Genetics are now firmly ingrained in the consciousness of people, however individuals may not fully realise the efficiency and usefulness of DNA testing, as well as its personal consequences for them. In this paper we present the results of a pilot study, conducted with the aim of examining the opinion of young Sakha respondents on genetic technologies not only as a medical service, but also as a new reality of modern times.

Methods

This analysis uses the raw data from a pilot study conducted by the authors on the topic of "The attitude of young people in the City of Yakutsk to DNA-testing as a new method in the practical medicine of the Sakha Republic (Yakutia)". A quantitative method was used: a sociological survey with quota sampling ($\Delta \pm 5\%$), held in February – March 2018 in the City of Yakutsk ($n = 350$). This study was conducted according to the guidelines laid down in the Declaration of Helsinki. The survey was voluntary and anonymous, informed consent was given by the participants in spoken form during the consultation on how to fill out the questionnaire. We did not compensate the respondents either financially or in any other way. Data was collected offline using paper questionnaires. The questionnaire was developed by the staff of the Laboratory of Molecular Genetics at Yakutsk Scientific Centre of Complex Medical Problems; the research was approved by the Local Committee on Biomedical Ethics at Yakutsk Scientific Centre of Complex Medical Problems (Minutes No 48 of 19.01.2018, Decision No 1). The questionnaire consists of two parts and has 24 questions, as well as additional questions on the social and demographic data of the respondents. The first part has 12 questions aimed at identifying the level of awareness of respondents about the method of DNA diagnostics. This paper presents the analysis of answers to questions in the first part of the questionnaire. 50 questionnaires were lost or rejected as incomplete. The data was processed and analysed using IBM SPSS Statistics 24.0 software.

The average age of respondents in our survey was 30 years. Analysis of answers showed the opinions of young Sakha citizens, working or students, who live in the City of Yakutsk. 56.7% of them are not married, 71.3% have higher or incomplete higher education, 60% studied in North-Eastern Federal University, other working young people were selected by age and ethnicity in various organisations of Yakutsk, 75% were of Sakha ethnicity, the other 25% included representatives of the indigenous small-numbered peoples of the republic: the Evens, the Evenki, the Yukaghirs. Exclusion criteria: Russians and migrants. (Table 1).

Examples of questions:

The questionnaire included alternative questions, such as:

Question: Would you like to take a DNA test for yourself?

Answer: Yes No Don't know

Non-alternative questions allowed the respondents to choose three possible answers from a total of six, that is why the total sum of answers can exceed 100%, for example:

Question: What made you agree for DNA testing (please choose no more than 3 of the most important reasons)?

Answers:1. Concern for my personal health

2. Concern for my children's health

3. Concern for the health of my future children

4. Doctor's recommendations

5. Advertising

6. Curiosity

Other _____

Data from questionnaires was processed using IBM SPSS Statistics 24.0 software.

Confidence coefficient is 95%.

Confidence interval is (±%) 5.66.

Table 1. Demographic Characteristics of Participants.

Characteristics	Total (n = 300)	%
Age:		
average	29.7	
median	23.0	
moda	22	
Gender:		
Male	146	48.7
Female	154	51.3
Marital status:		
Single	170:	56.7
Married	84	28.0
Education :		
Higher	214	71.3
Secondary	80	26.7
Nationality :		
Sakha	225	75.0
Other	75	25.0
Occupation:		
Student	180	60.0
Working	143	47.7

Results

Assessment of the general awareness level of respondents about DNA testing showed low levels of awareness among young people: "don't know about the method" (72.3%), "learned about the method for the first time from the questionnaire" (7.7%), "familiar with the method of DNA diagnostics and its possibilities" (20.0%). To the question about the "existence of medical-genetic consultation in Yakutsk" 17.7% of respondents answered positively, 34.3% "heard something about it" and 48% "just learned about it from the questionnaire". About the fact that the Medical-Genetic Centre of the Sakha Republic (Yakutia) is offering DNA diagnostics for hereditary diseases since 2000 know 18.7% of respondents, while 81.0% know nothing about it.

The opinions of respondents about the possibilities of DNA testing are reflected in Table 2.

Respondent answers to point 9 (other):

- Identifying relatives, paternity, finding kindred blood – 11 people
- Genes, mutations, genetic diseases – 4 people
- Forensic medicine, forensics – 4 people
- Identifying gender – 1 person

90.3% of respondents noted the "identification of genetic susceptibility to a number of diseases", 49.3% "degree of belonging to a certain ethnic group", 26.3% "predisposition to obesity and overeating", 24.3% "identification of psychological features, character, and behaviour of a person" (24.3%).

To the question about the benefits of DNA testing 73.3% of respondents replied "determining the risk of diseases", 65.3% "possibility of preventing diseases if

Table 2. Answers (in %) of respondents to question: What are your expectations from DNA-testing, what would you like to find out for yourself with the help of DNA-testing? (you can choose any number of options).

№	Expectations from DNA testing	total	male	female
1	genetic predisposition to diseases	90.3	33.0	39.4
2	drug tolerance and dosage	22.3	9.1	8.8
3	character and psychological characteristics	24.3	11.3	8.2
4	athletic ability	19.7	11.3	4.5
5	tendency to obesity	26.3	11.0	10.1
6	belonging to a particular ethnic group	49.3	17.7	21.8
7	predisposition to adultery	6.7	2.7	2.7
8	predisposition to extreme sports and travel	4.0	2.1	1.1
9	other	6.7	4.8	8.4
10	no answer	1.7	1.4	1.9

they are identified", 47.0% "identifying the causes of diseases".

The question about the possible negative consequences of DNA-testing showed that 58.0% of respondents are "afraid of stress and depression from getting a negative prognosis for personal health", 48.0% are concerned by "possible mistakes in DNA testing", and 29.0% are concerned by "the possibility of revealing confidential information and related negative consequences" (Table 3).

A direct question was asked to respondents: "Would you like to undergo DNA testing for yourself?" The results were as follows: "definitely yes" (26.0%), "more likely yes" (41.0%), "likely no" (14.0%), and "definitely no" (5.0%).

To the question of "What could make you agree to undergo DNA testing?" respondents answered: "concern for my personal health" (58.3%), "concern for the health of my future children" (50.3%), "concern for the health of my existing children" (30.0%), "curiosity" (42.7%).

Table 4 reflects the answers to question "Susceptibility to which group of diseases would you like to learn about using DNA-testing, if you decide to take it?". High proportion of responses was received by the following answers: "susceptibility to hereditary diseases" – 62.3%, "oncological diseases" – 59.7%, "cardiovascular diseases" 47.3%.

The reasons for young people to refuse DNA-testing could include "high cost of the service (above 3 thousand roubles)" – 61.7% of respondents, "having to pay for the service of DNA-testing – 44.0%, "lack of free time" – 34.0%, "don't want to know about susceptibility for diseases" – 17.7%, and "I'm afraid that someone will learn about my susceptibility" – 7.3%.

Table 5 shows the options for possible preventive measures that our respondents would take if, as a result of DNA-testing, they learn about susceptibility to a certain disease. They are prepared to follow the doctor's recommendations (59.7%), change their eating habits (53.3%), give up harmful habits (42.3%).

Answers to point 7 (other):

Everything will depend on the results – 1 person,

Everything will depend on the severity of susceptibility – 1 person,

I am ready to do anything to avoid problems – 1 person.

Table 3. Respondent answers (in %) to question: What do you think are the possible negative consequences of DNA-testing for a patient? (choose no more than three options).

№	Possible harm of DNA testing	total	male	female
1	depression as a result of getting poor health prognosis	58.0	28.1	39.4
2	incorrect DNA testing results	48.0	24.5	31.4
3	disclosure of genetic information to other people	29.0	20.9	13.3
4	discrimination based on genetic characteristics	12.7	9.2	5.7
5	violation of personal autonomy	7.7	5.6	3.4
6	there are no undesirable consequences	15.7	11.6	6.8
7	other	0.0	0.0	0.0

Table 4. Respondent answers (in %) to question: Susceptibility to which group of diseases would you like to learn about with the assistance of DNA-testing, if you decide to take it? (please choose no more than 3 most important options for you).

№	group of diseases	total	female	male
1	cancer	59.7	25.2	27.7
2	cardiovascular diseases	47.3	23.3	19.2
3	senile dementia (Alzheimer's disease)	23.3	8.7	11.8
4	hereditary diseases	62.3	26.2	29.1
5	alcoholism or drug addiction	4.0	2.3	1.4
6	mental disorders	15.3	6.8	6.9
7	I don't want to find out	12.3	7.4	3.8
8	didn't answer	1.7	1,4	1,9

Table 5. Respondent answers (in %) to question: Imagine that the result of DNA-testing has shown you to be susceptible to some kind of disease. Would you be willing to change your life in that case? (you can choose any number of options).

№	respondents ' readiness for preventive measures	total	male	female
1	give up bad habits: smoking and alcohol	42.3	23.5	18.6
2	change the nature of consumed food, stick to a diet	53.3	22.7	29.0
3	strictly follow the doctor's recommendations	59.7	25.6	32.3
4	completely change your lifestyle	26.7	13.5	13.5
5	I won't change anything in my life	6.7	5.4	1.5
6	I can't answer	14.0	9.0	5.1
7	Other (please explain)	1.0	2.1	–

Discussion

The medical-genetic service in the Sakha Republic (Yakutia) has existed for 35 years, but, unfortunately, it is still a relatively closed service with regard to actively raising the awareness of the population. It is possible that people learn about the existence of DNA-testing from the internet and mass media, however, they do not know about the existence of medical-genetic consultation in Yakutsk. Only a handful of respondents (3.7%) personally used the services of the medical-genetic consultation, with 6.3% saying that their friends and relatives used such services, and 90.0% saying that they never used it. Despite this, our young people seem to be aware that there is a high level of hereditary diseases in Yakutia, as the questionnaire showed that 90.3% of respondents would like to use DNA-testing for

explicitly identifying their susceptibility for genetic diseases (Table 2). As such, in conditions of high levels of some autosomal dominant and autosomal recessive diseases in Yakutia, it is necessary to more actively introduce pre-conceptional medical-genetic consultation for young couples who are planning to marry and have children.

Young people are equally interested in finding out with the help of DNA-testing susceptibility for obesity (26.3%), identifying psychological characteristics of an individual (24.3%), and finding out sensitivity to medicines and their doses (22.3%). Athletic capabilities, as expected, are more interesting for men (11.3%) than women (4.5%). It is possible that this set of questions showed the character traits of the Sakha people, as young people are less interested in affinity for extreme sports and travel (4%) than in susceptibility for extramarital affairs (6.7%) (Table 2).

The results of the survey allow us to estimate the possible negative effects of DNA-testing for an individual (Table 3). As expected, the highest proportion of answers related to fears of falling into a depression if a negative health prognosis was received (58%) and possible mistakes during DNA diagnosis (48%). Violation of the ethical principle of confidentiality is a concern for 29% of respondents, as well as the possibility of discrimination based on genetic characteristics – 12.7%. It turned out that women are more apprehensive about the psychological consequences of DNA-testing (depression), while men are more concerned with the social aspect of negative consequences (discrimination).

Table 4 shows the most common socially important diseases, which are actively researched in various populations of the world for gene polymorphism that causes risk of disease development in individuals. It seems that the inclination of respondents to believe in the possibility of avoiding severe diseases with the help of early diagnosis and preventive measures has garnered the highest share of answers (oncological and hereditary diseases, 59.7% and 62.3% respectively), unlike answers related to diseases connected with human mental health (Alzheimer disease and mental disorders, 23.3% and 15.3.% respectively). Expectations that modern medicine is capable of curing and preventing cardiovascular diseases are also high among populations in other locations [24,25]. 47.3% of our respondents confirmed the importance of preventive DNA diagnostics for cardiovascular diseases.

General views of the participants about DNA-testing reflect the widespread public perceptions about the possibilities offered by it to consumers. For example, a study done by Stewart, *et al*. in 2018 on behavioural changes and psychological reactions of customers to the results of genetic testing shows that 23% of respondents noted positive changes in their way of life, 12% underlined the improvements in their eating and physical exercise habits, while 19% quit smoking [26]. In our study, 26.7% of respondents are ready to change their way of life, 53.3% are ready to follow specific diets, and 59.7% are ready to follow doctor's recommendations (Table 5).

Data presented in Table 5 shows the increased awareness of respondents towards their own health and creation of a way of thinking aimed at self-preserving behaviour in everyday life. In modern times individuals have unprecedented access to any information, including information on health, as well as treatment and prevention methods. Such situation is bound to affect the shaping of perceptions of the value of health and desires to preserve visual attractiveness and youth for as long as possible. The data shows that men are more ready to give up bad habits than women, while the latter are more prepared to follow doctor's recommendations and dietary requirements. The issue of forming habits for a healthy way of life and developing its concepts is more and more actively discussed among the people of various regions, as well as researchers [27,28].

Expected advantages and risks of genetic testing may differ between various groups of people with different cultural, demographic, and family-historical backgrounds. For instance, a similar study was conducted among Canadian Jewish women that looked at factors that influenced their decision to undergo genetic testing for *BRCA1* and *BRCA2*. A questionnaire was developed that was distributed among 134 people, included in the research program of testing Ashkenazi women. The survey assessed demographic, social, and family-anamnestic parameters, as well as the influence of medical, family, social, psychological, and cultural-religious factors on the decision to undergo genetic testing. 76% of women answered the questionnaire, of which 41% did not have a familial history of breast or ovarian cancer. The most important factors that affected the decision to undergo testing were the desire to contribute to research (87%), potential benefits for other family members (78%), curiosity (70%), and potential assistance in case there is no disease bearer (60%). The principal risks connected with undergoing genetic testing included the fear of discrimination (28%), breach of confidentiality (24%), lack of accuracy and incorrect interpretation of results (30%), potential effect on matrimonial prospects of family members (17%), and orientation towards the Jewish community (14%). This

study revealed new information on the motivating factors among the Canadian Jewish Ashkenazi woman deciding to undergo testing for *BRCA1* and *BRCA2* mutations [29,30].

There is a point of view that the clinical usefulness of genetic testing is a subjective matter as it is decided by the individual consumers themselves. This includes the ideas of "personal usefulness", "information as it is", "entertainment value or curiosity" of the knowledge of one's own genes. People are motivated to undergo genetic testing not by medical, but by psychological reasons, such as "comforting", "family planning", or "preparing for future life" [31–34].

In our study the leading motivations for DNA testing included the following: "concern for my own health" (58.3%), "identifying risk of disease" (73.3%), and "possibility of disease prevention in case it is identified by testing" (65.3%). In addition, the factor of "curiosity" was also significant with 42.7% of respondents choosing that answer. The answers of young Sakha related to their motivations for undergoing DNA-testing have possibly confirmed the peculiarities of their national mindset, specifically, high concern for the well-being of children in a family: "concern for the health of my future children" (50.3%), "concern for the health of my existing children" (30.0%). A Sakha researcher M. Tyrylgyn (2000) in his monograph *The Source of Phenomenal Resilience of the Sakha People* noted that the capability to rear children in a family and to understand their highest importance in life was the main factor for the Sakha people's survival in extreme conditions of the North [35].

We are not wrong when we say that throughout the Sakha people's existence, including in the more recent scientific community, there has always been a great interest in solving the mystery of the Sakha origins and their connection to other ethnic groups. The history of the Sakha, reconstructed in the research of S. Fedorova (2004) via DNA analysis, is as follows: the ancestor population was small and, most probably, was dominated by the men of one tribe (N1c). One man at the top of the social hierarchy, who had many sons, could have been the progenitor. The lack of variety in paternal lines was probably compensated by the high variety of maternal lines. The spectrum of mitochondrial lines indicates that the women who contributed to the gene pool of the Sakha people were of various origins. Some of the maternal lines are more ancient, autochthonic, while others seem to have appeared in the North later and are probably connected with the migration of some of the Sakha ancestors from Lake Baikal region.

A small number of lines was introduced only recently, starting in the 17th century, with the arrival of the Russian speaking population. Moreover, the Sakha gene pool preserved a few lines of ancient paleo-Caucasoid people, which makes the question of formation of the Sakha people even more interesting.

According to S. Fedorova, autochthonic tribes of Yakutia who contributed to the Sakha gene pool were not direct ancestors of the Chukchi, Eskimos, Koryaks and Itelmes. There is a greater degree of probability that they were Tungus-speaking tribes, and less probability that they were proto-Yukaghir [36,37].

Some results of ethnogenetic research were widely published in mass media, that is why it is not surprising that many respondents (49.3%) would like to know their "degree of belonging to a certain ethnos" using DNA-testing.

Conclusion

The use of genetic testing by consumers for various reasons is becoming part of our modern reality. In the Sakha Republic, a remote region of the Russian Federation with a low density of population and high levels of hereditary pathologies, genomic research and DNA-testing are extremely topical.

Analysis of the survey results have shown that the respondents have low levels of awareness about the DNA-testing method: 72.3% "do not know about the method". Only 18.7% of respondents knew that since 2000 the Medical-Genetic Centre of the Sakha Republic (Yakutia) conducts DNA diagnostics for hereditary diseases, with 81.0% replying that they didn't know that. It appears that the medical-genetic service in the republic needs to work more on informing the public about the existing medical genetic services. The questionnaire has shown that 90.3% of participants would like to undergo DNA-testing to identify their susceptibility to genetic diseases. It is necessary to more actively introduce the pre-conception medical-genetic consultation in Yakutia for couples who are planning to marry and have children.

Expected advantages and risks of genetic testing may differ between various groups of people with different cultural, demographic, and family-historical backgrounds. Our questionnaire has shown high levels of self-identity among the young Sakha and their desire to learn about their belonging to a specific ethnicity (49.3%) with the assistance of DNA-testing. Furthermore, based on the answers relating to motivations for undergoing DNA-testing, we can say that the respondents have confirmed the peculiarities of their national mindset, specifically,

high value of children for a family: "concern for the health of my future children" was a great motivator for taking the test (50.3%). The result of the question for identifying susceptibility to extreme kinds of sport and travel was quite interesting, as the young people of Yakutsk showed little interest in this way of life (4%). As for the possible negative consequences of DNA-testing, our respondents are concerned about psychological issues resulting from a negative health prognosis, the breach of confidentiality of genetic data, risks of discrimination based on genetic traits.

This pilot research has shown high levels of activity and interest in answering the questionnaire among the young people of Yakutsk. This was one of the first sociological studies with general questions on genetic testing with 300 participants, 75% of which were representatives of one people – the Sakha.

In the Sakha Republic (Yakutia), we need to prepare for challenges posed by direct access of individuals to commercial genomic testing, explain to the public the importance of clinical justification and rational use of genetic information, attract interested parties to ethics discussions and development of legal norms on the use of genomic testing technologies.

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