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Russia is making a contribution to the study of society's attitude to genetic information

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Anna Krasnova

After decoding the human genome around the world, genomic medicine began to develop actively. In this connection, the question arose about the safety of genetic information and its possible use, including for commercial purposes. While the mechanisms for regulating these processes are not formed.



Realizing the importance of the problem, the world scientific community was concerned about its decision. In 2016, the International Alliance for Genomics and

Healthcare (GA4GH) and the Cambridge Research Center Wellcome Genome

Campus (UK), a non-profit organization, initiated an international research project on public opinion on the processing and protection of human genetic information. Your DNA Your Say ("Your genes - you decide").

According to the initiator and head of the study, Dr. Anna Middleton of the Wellcome Genome Campus, "this is a very ambitious project whose purpose is to gather the opinions of people from all over the world. It is of immense importance, since there are a number of important ethical, legal and social issues concerning the transfer of genomic data. These issues require a clear public opinion for their solution. " And this is quite true, since the regulation of processes related to the acquisition, storage and use of genetic information must be based primarily on the opinions and preferences of people - in fact, the original sources and owners of this information.

The authors of the project want to hear the answers of patients and their families, scientists, medical workers of different specialties, people of different age and sex, living in different countries and belonging to different nationalities. The latter parameters are very important, as experience shows that people from different cultures and countries can very differently treat the problem of protecting genomic data. The project is designed for 2 years.

According to Vera Izhevskaya , the head of the Russian Society of Medical Genetics (who oversees the Russian part of the study), Deputy Director for Science of the FGBICU "Medical Genetic Science Center" , Russian scientists began to discuss the project and translate it into Russian in the fall of 2016. "Now we are informing the professional community and ordinary people about its launch," she clarified.

"Since it is important to know the opinion of a wide range of the public, anyone can participate in the survey, regardless of age (but not younger than 14 years), sex, profession, occupation, etc. Participation is completely anonymous. This is a non-commercial project for the benefit of all mankind, "- developed the topic of associate professor of the Department of Medical Genetics with the course of prenatal diagnostics of the State Public Health Service of the Russian Federation Ministry of Health Elena Baranova .

This project is also educational. To participate in it, you need to go [through the link](#) , watch educational films, from which you can find out that genomic data is also data that the DNA of each of us can be used, and for different purposes. After each film, you can answer a series of questions. Respondents are involved with the help of specialized media and social networks, as well as newsletters on various medical and scientific communities and educational institutions.

As Vera Izhevskaya explained to Medvednik.ru, the results will be primarily used by the International Alliance for Genomics and Healthcare to create regulatory documents on the use of genomic data. GA4GH unites more than 400 universities, medical organizations, research centers and research institutes around the world. Therefore, the regulatory documents developed by him will have to be taken into account by all the participants of the alliance. It is expected that the impact of this project on the further development of genomics and genetics will be enormous. In addition, it is still the only project in the world that assesses public opinion on the issue of the collective use of genomic information. The results of the research will be published in the scientific press and can be used to develop documents

regulating genetic testing, for example, professional guidelines. To the general public, they will be reported through various media.

"It was important for Russian scientists to join this project, since when there is a standard questionnaire, one can not only identify the preferences of people in Russia, but also compare them with the data of other countries, assess the influence of cultural, religious and other characteristics on the formation of opinions. This is an ambitious social project to collect and compare information around the world, but each country gets its results and publishes it in various forms in the scientific press for broad discussion," explained Elena Baranova to Medvestnik.ru.

According to Vera Izhevskaya, the study in Russian is planned to be completed by the end of 2017. The study in English should end in the fall. There is no specific date for the end of the global project. There is only a landmark - this is the end of 2018. "This is due to the fact that research in each individual language is a separate project. It takes time to translate, distribute it within the country or countries where they speak one of the languages. The duration of the project depends only on how many people will participate in the study in order to obtain a representative sample. Each country decides it for herself, a single standard for all - no " - she specified. At this time, the study is conducted in English (British, US, Canadian, Australian), German, French, Polish, Portuguese, Swedish,

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The senior lecturer of the chair of medical genetics with the course of prenatal diagnostics FGBOU DPO RMANPO of the Ministry of Health of Russia, cms



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