



РИА НАУКА ▼

Gene thieves: why do British scientists study the opinions of Russians about DNA

10:20 05/08/2017

29 16 125

83

21

10



© Fotolia / Dan Race

MOSCOW, August 5 (Itar-Tass) - RIA Novosti. British and Russian scientists have launched a [large-scale project](#) to study the opinions of Russians about whether to protect genetic information and how it should be done. Anna Middleton, the project manager, talks about his first results in other countries and explains why people do not pay proper attention to this problem.

"Most people do not realize that their genome is part of their identity information, like a bank account number or medical record, and our first research shows that people do not understand that some of their personal data is already on the network. So we are very interested in how people in different countries refer to genomic data and consider whether they are different from medical information," - says Middleton.



[Genetics have learned how to integrate protection from gene modifications into cell DNA](#)

The problem of scale

The first methods for decoding DNA appeared in the mid-1970s, when British biologists Frederick Sanger and Walter Gilbert managed to decipher the DNA of one of the simplest viruses that infect bacteria. Full decoding of human DNA required about another two decades of experiments.

Initially, DNA sequencing technologies were an expensive pleasure, available only to large laboratories and large teams of scientists. According to current estimates, the first complete decoding of the human genome cost the US taxpayers 2.7 billion dollars.

Today, as Middleton notes, the situation has become completely different. Dozens of commercial companies are ready to decipher your DNA or for a relatively modest amount, or even for free, if the client agrees to use his genome for commercial or non-commercial research.

In many countries, large genomic banks have appeared in large universities, research centers and private companies, whose data stocks are used to study rare diseases, search for cancer predisposing markers, bad habits and syndromes, and a number of other health problems.



[Scientists: 83% of Russians turned out to be relatives](#)

The amount of information in genomic banks doubles about every seven months. In the near future, genomic studies will generate several zettabytes (billion terabytes) of data annually, which is equivalent to the amount of traffic that today passes through the global network for the year. There was a danger that some of this data could fall into the hands of intruders and unscrupulous researchers.

"This problem came to the fore only now because the volumes of data that we need to do research have changed. Rather recently we realized that such studies can be carried out only if we have a very large set of data, including the genomes of representatives of different peoples, sick and healthy, people of different ages, and when we started creating similar data banks and exchanging data, the problem of ensuring their safety appeared on its own," explains the sociologist.

Advertising, beating the genome

One of the main problems is that scientists do not yet know what consequences genomic data can bring to the hands of hackers or other intruders. They can be either minor or very serious.

For example, as Middleton tells us, if a woman who has undergone genetic testing is predisposed to developing breast cancer, then commercial structures can use it for a variety of purposes. For example, pharmaceutical organizations can constantly offer her various antineoplastic drugs or drugs to prevent the development of the disease,

insurance companies may refuse to provide their services, and employers - to fire or not to work.



© Photo: Cambridge University

Anna Middleton, a sociologist from Cambridge, studying the opinions of Russians

In turn, online trolls can use this information to harass one or another person in the global network. Nevertheless, all such information is of a probabilistic nature - breast cancer or Alzheimer's disease does not necessarily develop in carriers of unfavorable variants of genes, and therefore the material and psychological damage from such theft is extremely difficult to assess.

"The first results of observations show that most people are more concerned about the possibility that hackers will crack their credit card or bank account than by the fact that their personal genomic or simply medical data can be stolen." The reason for this is simple - the harm that your Money is stolen, it is quite understandable and clear, while the damage from the leakage of genomic data is not so obvious so far, "- explains Anna Middleton.

According to her, some people still understand the difference between "simple" public data and data on the structure of their genome and realize that these data connect them with relatives and contain information about their past and future. On the other hand, scientists do not exclude that interviewees could draw such information directly during the research and had no idea about this before participating in the Middleton project and its colleagues.



[Scientist: when people get sick, they immediately forget about the "harm" of genes](#)

Some people, as Middleton notes, understand that their genome is valuable information that can help companies make money, and they would like to participate in such studies not as "simple" volunteers or patients, but as full partners.

"Many people who took part in our project are afraid that their DNA donated for the benefit of science can be used by private companies to create medicines that they themselves can not use because of their ultra-high prices." Accordingly, they would like to receive an opportunity Use them in exchange for their genome, "- says the sociologist.

Ethics issues

"One of the most important questions in this respect is who actually owns the genomic data." If one looks at this situation from the position of British law, then after the person passes the DNA sample to the scientist, the latter becomes its owner. Has no control over his DNA and genome after it is decoded or studied by a geneticist. "On the other hand, on the moral and ethical side, a person should have the right to know and control how and where these data are used," continues Middleton.

According to the sociologist, this problem can be solved only if the rules for the use and exchange of genetic information will be standardized at the global level.

To realize this task, like-minded scientists from different countries of the world created four years ago the non-profit organization GA4GH (Global Alliance for Genomics and Health) - an international structure designed to develop standards and rules of the game in the world of genomic research and medicine. To date, the genomic alliance has been joined by more than four hundred commercial and government organizations and about a thousand individual scientists from 70 countries.



[The US authorities have banned a private firm decryption of the human genome](#)

One of the problems that this organization is trying to solve now is the issue of access and exchange of genomic data, which were originally intended for studying only certain diseases and genes. Some scientists believe that such an approach hampers scientific progress, while others consider it more optimal from the point of view of protecting the rights and identity of DNA donors.

Another problem, as noted by Middleton, is a certain risk: the largest companies and organizations engaged in genomic research can use their resources and influence in order to make these standards "convenient" for themselves, not caring about the safety of their customers or the ethical use of Data.

Participants in GA4GH, according to her, are trying to play today ahead of the mark and are developing standards taking into account similar scenarios, analogues of which already appeared in the history of Internet development, when Microsoft and Google tried to impose their own web standards, using the actual monopoly in the browser market.

"Theft of DNA - at least in the UK - is a crime, we already have laws that explicitly prohibit insurance companies from using genomic research data to determine the cost of insurance." Similar laws exist in other countries, and now the possibility of their Tightening, "continues Middleton.



[Scientists from the United States successfully "repaired" DNA for the first time in a human embryo](#)

The question arises: how to determine whether a particular DNA sample is legal or illegal? As Middleton explains, if a person did not know that his genome was sequenced by some company or organization or that already deciphered DNA was used without his knowledge, then he has the right to sue in those countries in which the relevant laws are enacted.

British scientists in Russia

Why do British researchers carry out similar studies in Russia, enlisting the support of the Russian Society of Medical Genetics, as well as geneticists from FGBOU DPO RMANPO and FGBICU "Medical Genetics Research Center" in Moscow?

As Middleton notes, a comparison of the results of similar surveys conducted by Cambridge scientists in other countries shows that people from different cultures and countries can very differently treat the problem of protecting genomic data.



Scientist: in the "mythologization" of GMOs, the media and politicians are to blame

"While I can not predict anything about how the results of the Russian part of our project will differ from the results of other surveys, that's why it's interesting for us." All our studies were conducted earlier in English-speaking countries, and we would be interested to hear opinions People who represent other cultures and speak a different language, and understand what their opinions are like, why and how they differ, and we also plan to conduct similar studies in China and a number of other Asian countries, "concludes the sociologist.

16	125
----	-----

ADD A COMMENT

RIA SCIENCE

[#Cambridge university](#) [#United Kingdom](#) [#Russia](#)

Inexpensive and convenient - Egypt 2017! ✕

[Ostrovok.ru](#)

Yandex.Direct

Trend of 2017! Invisible FlyBra ✕

[Flybra.vipstore.pro](#)

Купить

Test: Why do not you like money? ✕

[Yurkovskaya.com](#)

COMMENTS

21 user left 29 comments

POPULAR COMMENTS ALL COMMENTS**Yury Evdokimov**

Их озабоченность понятна. Уже стало очевидным ущербность европейских гаплогрупп, выходцев из Африки - с огромными проблемами умственного и физического развития. И они опять требуют скрыть информацию, кто есть кто. Опять околорасистские темы, как поняли когда то, что арийские языки - производные языка одного рода, потомки которого арии и русы, и возникло понятие Индо-европейские языки)) Сейчас уже понятно, что, кроме гаплогруппы R1a НИКТО НИЧЕГО НИКОГДА не изобрел, поэтому они лезут в Россию, где этого рода - большинство мужчин. НАШЕ МНЕНИЕ ДОЛЖНО БЫТЬ ПРОСТЫМ - МЫ ДОЛЖНЫ ВИДЕТЬ, КТО ЕСТЬ КТО.

11:38 05.08.2017 38



Ответить

**Billi Dzgonse**

Насчет этого не згаю, а вот когда геномы они изучали на территории РФ, то вполне могли использовать эту информацию для разработки избирательного биологического оружия.

12:33 05.08.2017 11



Ответить

КОММЕНТИРОВАТЬ

ПОПУЛЯРНОЕ



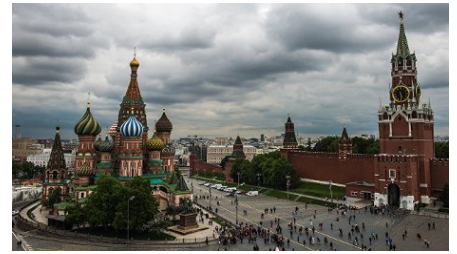
08:13 07.08.2017

Битва, которую Россия проигрывает: победителям не стоит радоваться



04:19 07.08.2017

Жительницы Алжира в знак протеста вышли на пляж в бикини



08:29 07.08.2017

Москве некому сдаваться, даже если она захочет



09:14 07.08.2017

Украинское село доедает город: о новом занятии для мертвого "Антонова"



22:14 06.08.2017

В Польше рассказали, на каких условиях будут покупать газ у США



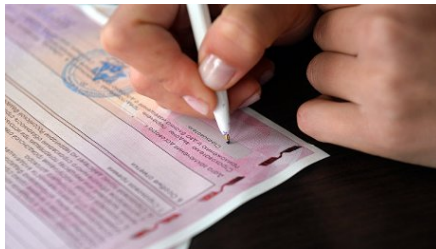
09:42 07.08.2017

Путин поздравил Софию Ротару с юбилеем



21:21 06.08.2017

Минэнерго Украины предупредило о возможных проблемах с транзитом газа



09:31 07.08.2017

Минфин разработал поправки к закону об ОСАГО для защиты водителей



Угадай по фото: Россия или за граница?

Реклама



What scientists discovered at the bottom of the Arctic Ocean (photo)



Vladimir Putin decided the fate of Lenin's body



The Ministry of Defense of Russia formed the "division of the 21st century"



A new turn in the history of the hero-hero criticized in Ukraine



McCain threatened Putin with repayment



What the Americans found on the Moon: unique footage hit the web

NEWS

AUTHORS

SPECIAL PROJECTS

THE INTERNATIONAL

PRESS CENTER

FOR CLIENTS

the main thing

Policy

Society

Culture

Справки

Анонсы

Фото

Инфографика

[Economy](#)[R-Sport](#)[Опросы](#)[Видео](#)[In the world](#)[On air](#)[Тесты](#)[Карикатуры](#)[Incidents](#)[Science and Technology](#)[Culture](#)[Религия и
мировоззрение](#)

ADVERTISING

[Enable site notifications](#)

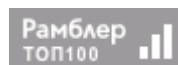
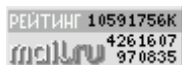
Version 5.1.11 beta. To contact the editorial team or report any errors you've seen, use the [feedback form](#) .

[Rules for the use of materials of the MIA "Russia Today"](#)

© 2017 MIA "Russia Today"

The network edition of RIA Novosti is registered with the Federal Service for Supervision of Communications, Information Technologies and Mass Communications (Roskomnadzor) on April 8, 2014. Certificate of registration AI No. FS77-57640

This resource can contain materials 18+



[The Rambler Partner](#)