

## **Q&A: Need a little extra money? You'll soon be able to sell and rent your DNA**

June 9 2018, by Gary Robbins, The San Diego Union-Tribune

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Feel like earning a little extra money and maybe improving your health at the same time?

Consumers will soon be able to sell or rent their DNA to scientists who are trying to fight diseases as different as dementia, lupus and leukemia.

Bio-brokers want to collect everything from someone's 23andMe and Ancestry.com gene [data](#) to fully sequenced genomes.

The data would be sold or rented to biomedical institutes, universities and pharmaceutical companies, generating money for consumers who share their genetic secrets.

The roundup is mostly led by LunaDNA of Solana Beach and Nebula Genomics of San Francisco, startups that are still figuring out how much a person would be paid for their contribution.

It's part of the booming bio-economy, where so-called "sequencing subsidies" are starting to emerge.

Scientists say they need enormous amounts of [genetic data](#) from across different ethnic, racial and age groups, and different genders, to develop diagnostics and drugs.

The need for new and better therapeutics is deep and broad.

Most people never develop a genetic disorder. But single genes are responsible for causing more than 6,000 human diseases, including cystic fibrosis and muscular dystrophy. There are also many diseases influenced by multiple genes, notably obesity and type 2 diabetes.

LunaDNA is asking people to share data they've gotten from such direct-to-consumer personal genomics companies as 23andMe and Ancestry.com, both which are highly popular.

A subsidiary of Ancestry.com reportedly sold about 1.5 million saliva test kits last year between Black Friday and Cyber Monday.

"That's like 2,000 gallons of saliva—enough to fill a modest above-

ground swimming pool with the genetic history of every person in the city of Philadelphia," said Wired.com.

Nebula Genomics wants people to contribute their entire genome, and is prepared to help consumers get sequenced at reduced costs. The consumer could then sell or rent the data on Nebula's data exchange. Consumers would be paid in some form of cryptocurrency that could be converted to dollars.

The bio-brokers sense that a grand opportunity is at hand.

The cost of sequencing a person's genome has fallen dramatically over the past 15 years and now stands at about \$1,000. The price could drop to \$100 within three years.

Scientists also are benefiting from the invention of Crispr, a quick, easy and accurate way to modify DNA for therapeutic purposes.

"Thanks to continuous technological advancement, we have now reached a tipping point where the genomics revolution will spread beyond academic laboratories and affect the lives of millions of people," said Dennis Grishin, co-founder of Nebula Genomics.

"If remaining challenges such as data privacy protection are addressed, the number of people who have their genomes sequenced is going to grow exponentially, possibly more than doubling every year.

"Genomics will become an integral part of personal healthcare. Pharma companies will be buying large genomic data sets and using them to develop new drugs."

The medical, financial, legal and ethical implications of such change will be daunting and, in some cases, hard to fathom. So the San Diego Union-

Tribune decided to answer what are likely to be some common questions.

The answers were produced with help from scientists at the University of California, San Diego, the Scripps Translational Science Institute in La Jolla, Nebula Genomics and LunaDNA.

Q: What specific kind of data are scientists seeking from consumers?

A: You, me, the next person—we all have the same genes.

But there's variation in those genes. Some "variants" are neutral; they determine things like our hair color and height. Some are beneficial; they help protect us from illness. And some variants can make us susceptible to disease. We call those mutations.

Scientists are largely interested in the mutations because they can cause diseases and disorders.

23andMe tests the DNA in your saliva for more than 500,000 variants—with an eye for trouble. Last year, the FDA gave the company permission to screen people for genes associated with 10 diseases and disorders, including Huntington's disease and late-onset Alzheimer's disease. More recently, the agency gave 23andMe permission to screen for three genes associated with cancer.

The company uses this data to estimate a person's risk for developing the various diseases.

This is not a diagnosis; it is risk analysis based on an incomplete and changing understanding of human genetics.

"Tests like Ancestry and 23andMe only look at small areas of the

genome, and aren't considered to be useful tests for medical care by most genetics experts," said Lisa Madlensky, director of the Family Cancer Genetics Program at UC San Diego.

"However, they can sometimes identify something medically important that needs to be confirmed in a medical genetics laboratory."

The data always has to be put into perspective. The FDA emphasized that point last year when it approved 23andMe's first screening tests, saying, "It is important that people understand that genetic risk is just one piece of the bigger puzzle. It does not mean they will or won't ultimately develop a disease."

Q: If I take one of these tests, do I own the data that's generated from my DNA?

A. Generally speaking, yes. But you have to read the fine print. You should make sure that you say no if you don't want a company like 23andMe selling your data to a pharmaceutical company or some other type of institution.

Nebula Genomics and LunaDNA are trying to build databases that would be of commercial and scientific interest to the bio-pharma industry. There's nothing wrong with that. You just need to be aware that they need your permission to sell your data.

Q: Is it likely that a consumer could make a significant amount of money from either of these two companies?

A: That remains to be seen. They're both startups, so they haven't finalized how they're going to do things. Dawn Barry, the president of LunaDNA, told the Union-Tribune:

"Individuals will be rewarded when proceeds are generated through the sale of access to the data.

"Think of it like a co-op where the value comes from the data set as a whole and dividends are paid out to the individuals that contribute their genomic and health information. The more data you share, the more shares in the database you own, the greater your percentage of the proceeds."

Q: Is Nebula Genomics looking for something different from consumers?

A: The test used by 23andMe offers a very limited look at a person's genes. Nebula wants to get a complete look. So they're asking consumers to undergo so-called whole genome sequencing. As the name implies, this technique maps out a person's entire genetic makeup. Such data is widely used by biomedical researchers. And this kind of sequencing is moving into clinical settings. For example, this test is used to sequence bacteria, which helps hospitals fight infection diseases.

Q: There are many types of genetic testing. How accurate are the results?

A: Mistakes can be made in every type of testing. And it can be difficult to determine overall accuracy, especially with direct-to-consumer DNA tests that involve ethnicity and genealogy.

Some consumers have reported getting different results when they've used the tests marketed by 23andMe and Ancestry.com.

To be fair, Ancestry.com says that it's only providing an estimate when it calculates what percentage of your DNA that comes from different parts of the world.

But the company touts its reach, noting that it maintains "the world's largest online family history resource, which includes millions of family trees and over 20 billion historical records."

Tufts University researcher Sheldon Krimsky studied this kind of testing and told a campus publication, "Companies selling these services—and there are close to 40 of them—don't share their data, and their methods are not validated by an independent group of scientists and there are not agreed-upon standards of accuracy ...

"So you have to look at the percentages you receive back with skepticism."

Consumers also have to be prepared for surprises.

"You may discover things about yourself that trouble you and that you may not have the ability to control or change (e.g., your father is not genetically your father, surprising facts related to your ancestry, or that someone with your genotype may have a higher than average chance of developing a specific condition or disease)," says 23andMe's Terms of Service statement.

"These outcomes could have social, legal, or economic implications."

Sometimes, the outcome is joyful.

"I found my birth family using 23andMe, specifically my mother who had been trying to find me," BreAnne Custodio told the Union-Tribune. "We now talk weekly."

The results can also be jarring.

"You should not assume that any information we may be able to provide

to you, whether now or as genetic research advances, will be welcome or positive," 23andMe says in its Terms of Service.

"You should also understand that as research advances, in order for you to assess the meaning of your DNA in the context of such advances, you may need to obtain further services from 23andMe, your physician, a genetic counselor, or other health care provider."

Q: Do most people understand the risk analysis they get from a company like 23andMe?

A: It's difficult to say.

DNA is a popular topic in books, movies, TV and on the web. Basic genetics is taught in school. Most people probably have a rudimentary understanding of DNA testing.

But drawing meaning from DNA is a complex, nuanced, fast-changing field. It can be hard for [consumers](#) to keep up.

The public also has to cope with conflicting claims. We saw an example of that in March after the FDA gave 23andMe permission to check to see if a person has any of three specific BRCA gene mutations that are associated with cancer.

The National Society of Genetic Counselors said the test could help reveal undetected mutations, but stressed that "the results may be confusing or misleading without appropriate education."

Such comments reminded Anne Wojcicki, chief executive officer of 23andMe, of how some physicians lobbied against the use of at-home pregnancy tests when they were introduced 40 years ago



"They thought women might not be able to handle such information on their own and claimed that the results might trigger them to make irrational decisions," Wojcicki told Stat News.

"Some went so far as to claim it would lead to suicides. Looking back, it seems unthinkable that we questioned women's ability to access this kind of information."

Q: Should I be worried about the privacy of my data?

A: Barry said, "An individual's data contains no personal identifiers and is combined with the broad population to create the scale and scope necessary to drive medical discoveries."

You hear similar things from other companies, and from the government.

Keep in mind that hackers have stolen data from everyone from the National Security Agency to local hospitals. Anyone can be hacked.

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Citation: Q&A: Need a little extra money? You'll soon be able to sell and rent your DNA (2018, June 9) retrieved 19 April 2024 from <https://medicalxpress.com/news/2018-06-qa-extra-money-youll-rent.html>

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