

Selling yourself? These companies want to pay for your genetic information



Perhaps you're one of the 12 million people who has spit into a tube in recent years to learn the secrets in your genetic code, like your ancestry, your health risks, or your carrier status for certain diseases. If you haven't participated in direct-to-consumer genetic testing, you may know someone who has.

It's for people who want more control over their genetic data — plus a share of the proceeds when and if that data is used.

Mountains of genomic data have been piling up [steeply](#) over the last several years, but according to some experts, not enough research and drug discovery is being done with the data collected, and customers rarely have a say in how their data is used. Now, a slew of ambitious startup companies are bringing together the best of blockchain technology and human genomics to help solve these problems.

But first, why is your genome so valuable?

Access to genetic information is an obvious boon to [scientific and medical progress](#). In the right hands, it has the potential to save lives and reduce suffering — by facilitating the development of better, safer, more targeted treatments and by shedding light on the [role of genetics](#) in countless diseases and medical conditions.

Research requiring access to direct-to-consumer (DTC) genomic data is already well underway. For example, 23andMe, the popular California-based DTC genetic testing company, has [published 107 research articles](#) so far, as of this May, using data from their five million-plus customers around the world. Their website states that, on average, of the 80 percent of their customers who have opted to share their genomic data for research purposes, each “individual contributes to 200 different research studies.”

Image credit: iStockphoto.com/Unknown And this July, a new collaboration was announced between 23andMe and GlaxoSmithKline, the London-based pharmaceutical company. GlaxoSmithKline will be using data from 23andMe customers to develop new medical treatments, while 23andMe will receive \$300 million from the four-year deal. Both companies are poised to profit significantly from their union.

Should 23andMe's customers share in the gains? Peter Pitts, president of the [Center for Medicine in the Public Interest](#), believes they should. “Are they going to offer rebates to people who opt in, so their customers aren't paying for the privilege of 23andMe working with a for-profit company in a for-profit research project?” Pitts told NBC. So far, 23andMe has not announced any plans to share profits with their customers.

But outside of such major partnerships, many researchers are frustrated by the missed opportunities to dig deeper into the correlations between genetics and disease. That's because people's de-identified genomic information is [“essentially lying fallow,”](#) siloed behind significant security blockades in the interest of preserving their anonymity. So how can both researchers *and* consumers come out ahead?

Putting consumers back in control

For people who want more control over their genetic data — plus a share of the proceeds when and if that data is used — a few companies have paired consumer genomics with blockchain technology to form a new field called “blockchain genomics.” Blockchain is a data storage technology that relies on a network of computers, or [peer-to-peer setup](#), making it incredibly difficult to hack. “It’s a closed loop of transactions that gets protected and encrypted, and it cannot be changed,” says Tanya Woods, a blockchain thought leader and founder of [Kind Village](#), a social impact technology platform.

The vision is to incentivize consumers to share their genomic data and empower researchers to make new breakthroughs.

“So if I agree to give you something and you agree to accept it, we make that exchange, and then that basic framework is captured in a block. ... Anything that can be exchanged can be ledgered on blockchain. Anything. It could be real estate, it could be the transfer of artwork, it could be the purchase of a song or any digital content, it could be recognition of a certification,” and so on.

The blockchain genomics companies’ vision is to incentivize consumers to share their genomic data and empower researchers to make new breakthroughs, all while keeping the data secure and the identities of consumers anonymous.

Consumers, or “partners” as these companies call them, will have a direct say regarding which individuals or organizations can “rent” their data, and will be able to negotiate the amount they receive in exchange. But instead of fiat currency (aka “regular money”) as payment, partners will either be remunerated in cryptocurrency unique to the specific company or they will be provided with individual shares of ownership in the database for contributing DNA data and other medical information.

[Luna DNA](#), one of the blockchain genomics companies, “will allow any credible researcher or non-profit to access the databases for a nominal fee,” says its president and co-founder, Dawn Barry. Luna DNA’s infrastructure was designed to embrace certain conceptions of privacy and privacy law “in which individuals are in total control of their data, including the ability to have their data be ‘forgotten’ at any time,” she said. This is nearly impossible to implement in pre-existing systems that were not designed with full control by the individual in mind.

One of the legal instruments to which Barry referred was the European Union’s [General Data Protection Regulation](#), which “states that the data collected on an individual is owned and should be controlled by that individual,” she explained. Another is the California Privacy Act that echoes similar principles. “There

is a global trend towards more control by the individual that has very deep implications to companies and sites that collect and aggregate data.”

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David Koepsell, CEO and co-founder of EncrypGen, told [Forbes](#) that “Most people are not aware that your DNA contains information about your life expectancy, your proclivity to depression or schizophrenia, your complete ethnic ancestry, your expected intelligence, maybe even your political inclinations” — information that could be misused by insurance companies and employers. And though DTC customers have been assured that their data will stay anonymous, some [data can be linked](#) back to consumers’ identities. Blockchain may be [the answer](#) to these concerns.

Both blockchain technology and the DTC genetic testing arena have a glaring diversity problem.

“The security that’s provided by blockchain is tremendous,” Woods says. “It’s a significant improvement ... and as we move toward more digitized economies around the world, these kinds of solutions that are providing security, validity, trust — they’re very important.”

In the case of blockchain genomics companies like EncrypGen, Luna DNA, Longgenesis, and Zenome, each partner who joins would bring a digital copy of their [genetic readout](#) from DTC testing companies (like 23andMe or AncestryDNA). The blockchain technology would then be used to record how and for

what purposes researchers interact with it. (To learn more about blockchain, check out [this helpful visual guide](#) by Reuters.)

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Obstacles in the path to success

The cryptocurrency approach as a method of payment could be an unattractive lure to consumers if only a limited number of people make transactions in a given currency’s network. And the decade-old technology underlying it — blockchain — is not yet widely supported, or even well-understood, by the public at large.

“People conflate blockchain with cryptocurrency and bitcoin and all of the concerns and uncertainty thereof,” Barry told us. “One can think of cryptocurrency as a single expression of the vast possibilities of the blockchain technology. Blockchain is straightforward in concept and arcane in its implementation.”

But blockchain, with its Gini coefficient of 0.98, is one of the most unequal “playing fields” around. The [Gini coefficient](#) is a measure of economic inequality, where 0 represents perfect equality and 1 represents perfect inequality. Around 90 percent of [bitcoin users](#), for example, are male, white or Asian, between the ages of 18 and 34, straight, and from middle and upper class families.

The DTC genetic testing arena, too, has a glaring diversity problem. Most DTC genetic test consumers, just like most genetic study participants, are of [European descent](#). In the case of genetic studies, this disparity is largely explained by the fact that most [research is done](#) in Europe and North America. In addition to being [over 85 percent white](#), individuals who purchase DTC genetic testing kits are highly educated (about half have more than a college degree), well off (43 percent have a household income of \$100,000 or more per year), and are politically liberal (almost 65 percent). Only 14.5 percent of DTC genetic test consumers are non-white, and a mere 5 percent are Hispanic.

Since risk of genetic diseases often [varies greatly between ethnic groups](#), results from DTC tests can be less accurate and less specific for those of non-European ancestry — simply due to a lack of diverse data. The bigger the genetic database, [wrote Sarah Zhang](#) for The Atlantic, the more insights 23andMe and other DTC companies “can glean from DNA. That, in turn, means the more [they] can tell customers about their ancestry and health...” Though efforts at [recruiting non-white participants](#) have been ongoing, and [some successes](#) have been made at improving ancestry tools for people of color, the benefits of genomic gathering in North America are still largely reaped by Caucasians.

So far, it’s not yet clear who or how many people will choose to partake in the offerings of blockchain genomics companies.

So one chief hurdle for the blockchain genomics companies is getting the technology into the hands of those who are under-represented in both blockchain and genetic testing research. Women, in particular, may be difficult to bring on board the blockchain genomics bandwagon — though not from lack of interest.

Although women make up a significant portion of DTC genetic testing customers (between 50 and 60 percent), [their presence is lacking](#) in blockchain and the biotech industry in general.

At the North American Bitcoin Conference in Miami earlier this year, [only three women](#) were on stage, compared to 84 men. And the after-party was held in a strip club.

“I was at that conference,” Woods told us. “I don’t know what happened at the strip club, I didn’t observe it. That’s not to say it didn’t happen ... but I enjoyed being at the conference and I enjoyed learning from people who are experimenting in the space and developing in it. Generally, would I have loved to see more women visible? Of course. In tech generally I want to see more women visible, but there’s a whole ecosystem shifting that has to happen to make that possible.”

Luna’s goal is to achieve equal access to a technology (blockchain genomics) that could potentially improve health and quality of life for all involved. But in the merging of two fields that have been [unequal since their inception](#), achieving equal access is one tall order indeed. So far, it’s not yet clear who or how many people will choose to participate. LunaDNA’s platform has not yet launched; EncrypGen released their beta version just last month.

[Sharon Terry](#), president and CEO of Genetic Alliance — a nonprofit organization that advocates for access to quality genetic services — recently shared a message that reflects the zeitgeist for all those entering the blockchain genomics space: “Be authentic. Tell the truth, even about motives and profits. Be transparent. Engage us. Don’t leave us out. Make this real collaboration. Be bold. Take risks. People are dying. It’s time to march forward and make a difference.”

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