YOUR DNA DATA IS PART OF A GLOBAL SUPPLY CHAIN

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<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>THE DEMAND</td>
<td>4</td>
</tr>
<tr>
<td>THE SUPPLY CHAIN</td>
<td>6</td>
</tr>
<tr>
<td>THE 200+ BILLION DOLLAR MARKETPLACE</td>
<td>8</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>9</td>
</tr>
<tr>
<td>ABOUT THE AUTHOR &amp; HU-MANITY.CO</td>
<td>11</td>
</tr>
</tbody>
</table>
Your DNA Data Is Part of a Global Supply Chain

In business, and especially manufacturing, “supply chain” is the term used to describe the progression of raw materials or parts through various steps. At each step, the value of a piece of material or part is increased by virtue of some process being applied to it. At the end of the supply chain is the end user: the customer who will pay for the finished product that has been fashioned from its component raw materials.

For example, at the very beginning of the supply chain of an automobile, there’s an ingot of steel. It is raw material without much practical value in its present form. The ingot then enters the supply chain, and eventually, after being shaped and fitted together with other parts, it will emerge as part of a new car. The new car will be sent to the showroom floor where it will be bought by the end user — the customer. Because of the work that went into it, that ingot of steel will have increased in value, bringing a profit to the automaker.

What does this have to do with your DNA — or more precisely, the data that can be extracted from your DNA?
THE DEMAND

As recently as the turn of this century, this question would have been easy to answer: Nothing. Years ago, your DNA could not be part of a supply chain. While human DNA had been sequenced since the 1970s, it couldn't be done on a mass scale at a low cost. Your DNA, and its hidden data about you and your medical profile, was locked inside you, unavailable to those who could exploit it.

That has changed. In 2007, 23andMe became the first company to begin offering autosomal DNA testing for ancestry, which many other companies now offer. The following year, its saliva-based direct-to-consumer (DTC) genetic testing business was named “Invention of the Year” by Time magazine.¹

For consumers, this was a revelation. Now you could spit into a tube, send it off to the lab, and within six to eight weeks learn about your ancestry going back 500 years. You could find out how many “DNA relatives” you have living today, and even opt-into the company’s “DNA relatives’ tool” to find, connect, and message those who share DNA with you.²

This was a game changer for adopted children and their biological parents, giving them an amazing new tool to find each other.

The DNA test also provided information about your risk for genetically inherited diseases. The FDA has approved the company’s Genetic Health Risk reports that inform you of your genetic predisposition to various diseases including late-onset Alzheimer's disease, Parkinson's disease, celiac disease, and many more. This is information that some people want to know, while others don’t want to know.³

Consumers have responded with enthusiasm, and the market for DNA testing is rapidly expanding. As Antonio Regalado wrote for Technology Review, “2017 was the year consumer DNA testing blew up.” In that year, more people took genetic ancestry tests than in all previous years combined. According to industry estimates, the total number of genetic customers now exceeds twelve million, with most of those tested living in the United States, meaning that as many as one in twenty-five
American adults have had their DNA tested. The genealogy company Ancestry.com, based in Utah, has tested more than seven million people, including two million during just the last four months of 2017. 23andMe boasts over five million customers who have had their DNA analyzed for ancestral data, and there are many more testing services that have entered the marketplace, including MyHeritage™ and FamilyTreeDNA.  

What does this have to do with industrial supply chains today? Plenty.

Remember, in the twentieth century, human DNA data had no commercial value because it could not be extracted in sufficient quantity and at a low enough cost to make it worthwhile. People knew it was valuable, but they just couldn’t get to it. It was like gold in a mine that was too deep to reach.

Suddenly, almost overnight, human DNA data can be mined, sorted, packaged, and sold. It has commercial value because companies and other entities can buy it affordably. And, they want to buy it. Human DNA and digital health data have become very valuable parts of a robust, multi-billion-dollar marketplace. This issue came to public attention on July 25, 2018, when 23andMe announced it was entering a deal with pharmaceutical giant GlaxoSmithKline (GSK) in which GSK would invest $300 million into 23andMe in exchange for access to the genetic data of its five million customers.  

Do the math — that means to GSK, the data of each existing 23andMe customer was worth $60. Do you believe you deserve a portion of that data’s value?
THE SUPPLY CHAIN

This is how the DNA data supply chain works:

1) You have DNA inside you. It costs you nothing to produce and yet it can act as a natural resource. Think of your data like gold or oil deep underground on property you own.

2) Companies including Ancestry.com and 23andMe have the technology to mine your DNA for information on your genealogy and your risk for a variety of genetic diseases. They have detailed release forms you sign, which presumably delineate what can happen to your “anonymized” data. But unless you hire a lawyer to scrutinize the form, you’re probably not going to know what you’re signing. Adam Tanner, author of Our Bodies Our Data (2017), expands on this further by suggesting it’s not only consumers and patients that don’t know or understand the complex web of legalese and hidden data trading. He says it’s also many medical providers that are uninformed and remain naive.

Because this data is “anonymized”, medical patients have no say in whether their data is shared with data brokers. In most cases, as Mr. Tanner explained, even the medical professionals are generally not aware that data about their patients is being sold to data brokers. Although, this data is mostly “anonymized”, when cross-referenced against other information databases, it can be used to build a health record about you, which can then destroy the data’s anonymity.

3) Regardless of the risks to your identity, you choose to pay the testing service to analyze your anonymized DNA. They send results back to you. But they also retain a copy of your results. They know, for example, if you’re at risk for Parkinson’s disease. But most 23andMe and Ancestry customers don’t know their DNA also 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.” What do you think happens when an insurance company finds out about a major medical risk? Do they share it with your employer? Would they stop insuring you?

4) Thus, various industries — most notably the insurance and pharmaceutical, but many more — put great value on those insights that come from your genetic data. For example, as Matthew Herper wrote for Forbes magazine, a mutation in a gene called LRRK2 has been linked to some cases of Parkinson’s disease. A million Americans have the disease, and of these, perhaps one percent have the LRRK2 gene mutation — a sizable enough market to tap. GlaxoSmithKline is trying to develop a LRRK2 drug, but to find subjects for clinical trials requires testing one hundred Parkinson’s patients to find just one prospective test subject with the LRRK2 mutation. But Herper reported that 23andMe had 250 Parkinson’s patients with the LRRK2 mutation who were open to participation in a clinical trial. GlaxoSmithKline paid for access to these individuals.

5) The genetic data of anyone who has taken a direct-to-consumer genetic test — whether for ancestry, a medical condition, or even paternity — becomes part of the growing global supply chain of genetic data. This supply chain begins with the individual and goes through the broker — in this case, the testing service — where it becomes more valuable because it can now be sorted, correlated and potentially combined with other repurposed healthcare data to be sold as deeper and wider data sets. The broker then sells your healthcare data (often DNA, anonymized prescription info and electronic health record data) to end users such as an insurance companies or pharmaceutical companies.

Nowadays pharmacy chains are happy to make money selling anonymized copies of patient prescriptions – the companies just don’t like talking about it. (Tanner, 2017, p. 15)

Notice the data broker profits on both ends and they take advantage of the silent consent freely given by the public based on ignorance of
the backend transactions. These companies make money when the consumer pays for the genetic report to have the saliva analyzed. And they make money again when they sell your data to the end users.

**THE 200+ BILLION DOLLAR MARKETPLACE**

While human genetic data has legitimate scientific value to practitioners in areas of healthcare including medical research and drug development, the fact remains that too many people have no idea what happens to their data once it's been harvested. The fact is once you've spat your DNA into the vial and mailed it to 23andMe, you don't know what happens to your genetic data — or any of your personal and or medical data for the most part. Right now, global digital health data is being bought and sold without your consent, authorization, consideration, or compensation.

According to Statista,\(^\text{10}\) the global digital health data marketplace will be worth over $200 billion annually.

When companies profit from your personal digital health data, should you get a cut? The answer to that question should be an absolute resounding yes! This question is being asked more and more and many private and public groups are reevaluating the global health data supply chain and determining how to change the power dynamics shared among the players.

Until consumers and patients change their consent behavior, companies will continue to buy, sell and use your data because it serves their primary interests. Until we change our choices, we will have no control over where, when, how or by whom it is used. Furthermore, data brokers and data buyers will continue to purposefully obfuscate what is going on behind the scenes in the multiple transactions using your data. These transactions can slowly rebuild your “anonymous” identity that puts your personal, financial and professional lives at risk. All of this complicates your reach for legitimate participation in the accountability that should be required by the global supply chain. The reality is, to date this market essentially operated in the dark. But stay tuned, power changes are brewing.
REFERENCES


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