

Case

23andMe:

Genetic Testing for Consumers

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Introduction

In 2003, The Human Genome Project, an international team of scientists, completed their work of thirteen years and \$2.7 billion, making their genome sequencing services available to the medical world. Initially, this was only done by request from doctors, and with a starting price of \$350,000 in 2007, the price dropped significantly to \$10,000 in 2013.

23andMe is one of the first consumer based genetic testing companies, co-founded by Anne Wojcicki in Silicon Valley in 2006. In 2007, the company, together with two other companies, announced that they were going to start selling Single Nucleotide Polymorphism (SNP) chip genetic testing kits directly to consumers, which would lead to easy access at an affordable price. The SNP chip genetic testing kits sequences only parts of the genome, which is why it could be done cheaper and faster than the first methods, you simply spit and wait for the results. Their plan to sell directly to consumers was met with skepticism and concerns as this had previously only been available through doctors, and that the consumer would not know how to interpret this data. However, the sale started, at a low speed, only boosted by increased awareness due to Angelina Jolie testing and openly speaking about her results.

Despite the free publicity from Angelina Jolie and boost in sales, Wojcicki's original goal of reaching one million customers by the end of 2013 was not met, only reaching 450,000 consumers.

As a response to low numbers in customers, the company spent \$5 million on television, radio and direct mail advertisement in August 2013 to target a new set of customers.

During this whole process, FDA had been involved trying to regularize this new profound innovation. The process demanded many resources from both the genome companies and the FDA, leading to a mess of an outcome for 23andMe and Wojcicki to solve, where they received a letter addressing their lack of cooperation, and seizure of further sales of medical tests.



Is the sale of genetic tests to consumers a good idea?

Yes and no, but mostly yes. A normal citizen of the world has no training nor knowledge to interpret the data of a test like this and being served with results to interpret your own genes, what diseases you are in chance of getting through life and more. A lack of knowledge and understanding of the result might lead to drastic measure by the consumer, and without the consultancy of a trained professional can cause much more harm than benefits to the consumer. Therefore, a b2c market can only be defended with the use of a trained professional who knows how to interpret the results and consult the consumer with wise decisions. All the information the consumer gets can alter the consumers life drastically, and the behavior might change completely based on the result. Therefore, a professional might be able to guide in the right direction of choices.

The consumer might have a huge interest in the service that 23andMe provides. What if a mother had breast cancer and her daughter wants to know if she has a high risk of getting breast cancer herself? Already by knowing your mother has battled cancer can lead to precautions from her daughter, but what if she has minimal risk and shouldn't need to change her life based on her mother's disease? With the leaps this industry is seeing in this field, I should not say it is too early to be in this space, but the pros and cons should be carefully considered before being available to consumers, and disclaimers and advise should be a high priority to protect the consumer from harmful incidents. What if the results you get is a false positive and you decide to remove your breasts to avoid breast cancer? Or what if your test says you are in no risk to get breast cancer, but you really are?

The benefit of being able to see where you are from is a benefit we might not think of immediately. Knowing and seeing your results of where your genes are from can help fight other things, such as racism. Maybe also a person can get a match and be reunited with a lost family member who nobody even knows exists based on gene testing. These are all clearly benefits of the tests, and we are all humans capable of our own decisions. If you can't handle seeing the result, don't order the test kit.

If no government implement testing of all citizens in the future, which is another debate, the market size based on the survey conducted by 23andMe is huge. 73 % of respondents said they would like to use a genome test in the future, and with a large country such as the United States we are looking at hundreds of millions in US alone. I would argue that the survey could not be generalized to the rest of the world, although if we assume that the numbers are a little bit lower with maybe half the world's population willing to take the test, you there have your answer of how big the market size can be.

Would you invest into 23andMe?

Personally, I would invest into 23andMe at some stage of my life where I might be economically capable and ready to see the results. The sooner the better I would say as the result might highlight a risk of disease at an early stage of my life. Looking at who is behind the company, and every benefit the world can possibly gain by adding more data from consumers to their database only increase my decision.

I also see the benefit of investing into 23andMe by the massive database they already have compared to their competitors, making the decision not only to take genome testing in general, but to take the test through 23andMe. 23andMe have a massive database that can lead to interesting and very helpful innovations in the field of health, and by supporting them I can contribute to my data being used for research of these fields. Maybe I also learn that I should be extra careful with something in my life to avoid an early death? Only by taking the test I can know this.

I would not take the test without consulting my doctor or other health professionals about the results as the one pictured below, and I hope no one does so either.




 23andMe Research Discoveries were made possible by 23andMe members who took surveys.


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NAME	CONFIDENCE	STATUS 
TTR-Related Familial Amyloid Polyneuropathy	★★★★	
BRCA Cancer Mutations (Selected)	★★★★	

NAME	CONFIDENCE	STATUS 
Phenylketonuria	★★★★	Variant Absent
Familial Dysautonomia	★★★★	Variant Absent
Canavan Disease	★★★★	Variant Absent
Hemochromatosis (HFE-related)	★★★★	Variant Absent
Familial Hyperinsulinism (ABCC8-related)	★★★★	Variant Absent
Primary Hyperoxaluria Type 2 (PH2)	★★★★	Variant Absent
Sjögren Larsson Syndrome	★★★★	Variant Absent
Rhizomelic Chondrodysplasia Punctata Type 1 (RCDP1)	★★★★	Variant Absent
Torsion Dystonia	★★★★	Variant Absent
Autosomal Recessive Polycystic Kidney Disease	★★★★	Variant Absent
TTR-Related Cardiac Amyloidosis	★★★★	Variant Absent
Mucopolidosis IV	★★★★	Variant Absent
Limb-girdle Muscular Dystrophy	★★★★	Variant Absent
Leigh Syndrome, French Canadian Type (LSFC)	★★★★	Variant Absent
Alpha-1 Antitrypsin Deficiency	★★★★	Variant Absent
Congenital Disorder of Glycosylation Type 1a (PMM2 CDG)	★★★★	Variant Absent

What should Wojcicki do?

Wojcicki should work together with the FDA and comply to the regulations set by them to make sure that not only the consumers are being delivered a safe service, but also the company has a future and can continue to innovate in the field of health care services. FDA has been clear in their intent and meaning behind the letter, and it would be unwise of 23andMe and CEO Wojcicki to not comply to their demands.

Regulation is important in each country, but sometimes it delays innovations. For example, in Norway when Uber was introduced, the current taxi companies were fighting to have them removed from the competition of the consumers. After all, that would lead to a massive reduction of their income and livelihood. The measures that the Norwegian Government did, made Uber only able to use their service of registered Uber-black companies, and to this date you can only get a hold of Uber black in Norway, if at all. For health issues, of course regulation can halt the amount of innovations we see, but they are also necessary to protect the consumers from harmful new inventions. They have to be approved and confirmed before anything is being used by you and me.

For privacy of the consumer, blockchain could be a good option as it is very secure and practically impossible to hack for a hacker. Deloitte writes this on their website about blockchain and health data: "Blockchain technology has the potential to transform health care, placing the patient at the center of the health care ecosystem and increasing the security, privacy, and interoperability of health data. This technology could provide a new model for health information exchanges (HIE) by making electronic medical records more efficient, disintermediated, and secure."¹

Further, to help consumers with interpreting the result in a safe manner, Wojcicki should create a better dashboard with personal feedback that can be generated based on the data that is collected. If she manages to do so, this can help the consumer make safe decisions, and where bigger decisions are needed, the consumers can be advised to discuss the results with a trained professional, and their doctor if they have this sort of training.

¹ <https://www2.deloitte.com/us/en/pages/public-sector/articles/blockchain-opportunities-for-health-care.html>