

# The Consumer-Driven Healthcare Revolution



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**The healthcare establishment, which has been slow to recognize that personal data have value for research, is beginning to embrace elements of the consumer revolution.**

My passion for owning my health data comes from a story of tragedy. My mother's little brother, David, overdosed on aspirin when he was 18 months old and unfortunately died. My grandparents and my mother went from hospital to hospital and were told David would be fine. David unfortunately continued to get worse, and they finally got a hospital to take him for the night. When they called in the morning about his condition, they were told he had died.

23andMe did not start because we wanted to just create a genetics company. It developed out of a passion and an insistence that individuals can take better care of themselves if they are in charge of their health or at a minimum true partners in the healthcare decision

process. We are just the beginning of the consumer-driven health tidal wave that is going to change and ultimately improve healthcare.

Nine years after our launch, over a million customers signed up and spat for 23andMe. These customers are learning about diseases they might pass down to their children, what disease risks they might have, what medications they might be sensitive to, and fun facts about themselves.

What motivates me every day to come in and work are the stories from our customers. I ran into a father of a child who found through 23andMe that his son had a rare condition for fructose intolerance, and the early diagnosis prevented liver and kidney damage. We did a

study of our customers who found they were high-risk for breast cancer and had the BRCA mutation—many of these women never knew they had a risk and went on to take measures to prevent developing breast cancer. I met hundreds of adoptees who found family members after years of searching. There are hundreds of stories that circle in my mind and remind me constantly that the information 23andMe provides changes lives and can be transformative to someone's life. Genetic information cannot solve all mysteries, but it can be an important clue in the health of many individuals.

The journey of 23andMe has not been without bumps. In 2013 we had to stop returning health information after an FDA warning letter. The path forward has required a long-term vision, a strong passion, and a very dedicated team. But in February 2015 we received our first FDA approval to market, and I feel confident about a direct to consumer path forward for additional genetic information. It has been a reminder to me and to other consumer health companies that the path for transformation in healthcare is not easy, but it is feasible.

The consumer healthcare movement is exciting and transformative. You, the individual, have never been the true consumer of healthcare—insurance companies, pharmacies, pharma companies, hospitals, physicians, etc. are all more of the end consumer than us, the individual. But that world is changing as we are actually paying for our care and making more decisions. Companies like Doctors on Demand enable you to chat with a physician anytime on your phone. Fitbit and other wearables companies enable us to track our steps and heart rate. Wearing my Fitbit last month

actually made me notice that my resting heart rate was high and I was getting out of breath despite exercising a lot—both signs that I was anemic. A blood test confirmed I was quite anemic. And we can't talk about blood without talking about Theranos and the potential for enabling easy, direct access to hundreds of essential blood tests. The consumer healthcare world opens up a tremendous amount of opportunity for individuals to be more in control of their health and get access to affordable care.

What 23andMe and many of these other companies have shown is that people want information about themselves. This isn't about vanity. On top of personal utility, this information can also have a real value for science. The healthcare establishment, which was slow to adopt this point of view, is beginning to embrace elements of the consumer revolution.

In January, President Obama announced his proposed Precision Medicine Initiative to fund the collection of genetic data from 1 million people to help jump-start research and discovery of treatment for disease. A cornerstone of this effort is to give people access to their genetic information while enlisting them in research. Both President Obama and the NIH, which is spearheading the Precision Medicine Initiative, recognize that engaging people in their health and enlisting them in a research effort is the key to transforming healthcare.

We are seeing this already. Over 80 percent of the 1 million 23andMe customers consent for research and actively take survey questions. This is more than just a big number. These customers are contributing to research in common diseases like cancer, heart disease, diabetes, and

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asthma as well as contributing to research into rare disease that are difficult if not impossible to conduct with meaningful sample sizes. By participating, the average customer has informed more than 270 studies. Combining genetic information with survey data has the potential to accelerate meaningful discoveries that could benefit everyone.

The perception about the consumer's role in healthcare and research is changing. It's clear that major institutions and governments around the world are recognizing that engagement is more than just participation—it's giving information back to people that has meaning. While this trend is impressive, change is slow.

My mother used to remind me regularly that no one cares as much about your health as you. I have a passion for owning my health data because I believe my health outcomes depend on it. If you want to do something today to be proactive for your health and help drive change, ask for your data. Take ownership of your medical records. Know your drug history. Own your genome and follow the genetics information revolution. Being in charge of your health is not just empowering, it could also be the most important factor in living a healthy, long life.