

# Consumer Genetics and the Capitalization of Hope

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## **Abstract**

Users of direct-to-consumer genetic tests (DTCGT), commonly known as consumer DNA tests, often begin their journey with great hope. They have expectations of the amazing discoveries they will make from a genealogy and health perspective. Most, however, fail to grasp the benefits and risks, and many come to fear the privacy issues of exchanging their biocapital for promises of future-oriented knowledge. This article traces the transition from hope to fear and offers some suggestions for improving consumer safety.

## **Keywords**

biocapitalism, bioethics, biotechnology, biovalue, BRCA gene, direct-to-consumer genetics, DNA tests, human genome project, personalized medicine, Precision Medicine Initiative, regime of hope, regimes of truth

## **Introduction**

In the twilight of the last millennium, an audacious scientific project was started by an international team of researchers. Their objective, like the countless scientists who came before them, was to advance humanity. But unlike all of the preceding projects, this effort would map out what it meant to be human.

The project, known as the human genome project (HGP), had the seemingly impossible goal of describing every gene within the Homo sapiens genome and mapping all 3 billion base pairs. If completed, the applications were said to be limitless. From social science research to medicine, the innovation gatekeepers of the world said that our lives would change for the better.

But who has benefited from the HGP? Surely all of humanity, right? But at what point, and will it be equitable? These are questions I wrestle with, though I didn't always.

In this text I will trace my path from blind acceptance of the purported benefits to the more somber reality that I uncovered as part of my research. In doing so, I hope to shine a light on some of the ethical concerns I encountered, so that others can learn from my work, as I learned from theirs.

## **The Allure of Promissory Capitalism**

As an undergraduate studying biotechnology shortly after the completion of the HGP, sociotechnical expectations were high. From my vantage point, it seemed like the broader science community felt that bioscience knowledge had been commodified, and all that was left to do was unlock the latent economic value in our cells. Week after week, the media, in its performative role, feverishly covered the next soon-to-be world-changing innovation. I, too, was swept up in this regime of hope, and resolute on participating in the financialization of the bioeconomy.

But here we are, 17 years on from the completion of the HGP, and few innovations which have had a widespread impact on humanity have been developed and deployed at scale. That is not to say there has not been progress. We can certainly point to a number of useful diagnostics and therapeutics operating in limited use. We also recently witnessed the transformative potential of genomics with the rapid sequencing of the SARS-CoV-2 genome. But for most consumers, the most widely adopted technology application of

genomics is still for-profit consumer DNA tests, which is a far cry from loftier visions such as the Precision Medicine Initiative.

Now, this is not to say that direct-to-consumer genetics (DTCG) lacks any use. It does have the potential to unlock immense value for society, and in time, it will contribute to the goal of personalized medicine. But the question, like with so many other disruptive innovations, is who stands to gain, and at what cost?

I did not ask myself these questions years ago when I took multiple consumer DNA tests. At that time, I naively believed that all of us could gain from DTCG tests. But I came to realize that the results often lacked tangible value. There was nothing that I could easily put into practice. The results either lacked actionable recommendations or those recommendations varied across similar tests in a way that created confusion.

Ultimately, this led me not to act on my results and question the usefulness of DTCG testing. But it also led me to ask how we could make these tests better, which became a motivation for me to study DTCG testing for my graduate applied anthropology thesis.

## **Regimes of Hope vs. Regimes of Truth**

As I was still thoroughly under the spell of the promissory stance, my thesis research started with the goal of improving the user experience of DTCG tests from a product management perspective. I had assumed that with the right design, this product challenge could be overcome, and the aspirational values of a better life espoused by many of these DTCG companies could be achieved.

But as my research progressed, I realized that the problems went far beyond presenting the results in a more useful or intuitive way. The real issues had less

to do with the presentation and more to do with the costs of numerous underlying ethical issues regarding utility, informed consent, privacy, and biocapital, as several STS scholars have pointed out.

The cost, if not immediately apparent, does not come from the test price. That cost is arguably absurdly low for consumers because of the desire to “scale” the Monthly Active Users as quickly as possible in typical Silicon Valley fashion. The real cost is that consumers are drawn into a promissory and ethically questionable market transaction where they give up their invaluable biocapital in exchange for future-oriented knowledge (Hogarth, 2017).

Why future knowledge you may be asking? The answer is quite simple. The tests lack utility for most users at this time, and therefore most users get little to no biovalue— increase vitality as Waldby previously defined it—from this exchange. There are many reasons for this, not least being that the technology is evolving, our sample populations are still relatively small, and the vast majority of phenotypes are the result of complex multigenic interactions that we do not understand well enough at this point.

But despite these issues and the lack of value, DTCG companies have not stopped offering tests that claim to provide a lifetime of insights for achieving a better life. One only needs to Google DTCG tests to find a plethora of questionable tests for exercise, diet, beauty, complex medical conditions, and, most recently, COVID-19 risk.

The lack of utility has also not stopped consumers from adopting these tests. By February 2019, the MIT Technology Review estimated that 26 million

people had taken a DTCG test. Though industry growth has slowed since then, we know from public statements by two of the leading companies in this market—Ancestry and 23andMe—that the total is at least up to 30 million.

So, where does that leave consumers? Unfortunately, many are unknowingly left waiting for the future, hopefully, more accurate results. In the case of genealogy tests, the concerns are no-less real, yet the ever-changing results may be a fun diversion from the underlying bioethical dilemmas. But what about the cases in which a medical diagnosis changes? What of the harm that may cause, whether through inaction or action?

In a TEDx Talk I gave in March, I spoke of a family in which seven women were led to believe they had an elevated risk of breast and ovarian cancer based on a Myriad Genetics test. Many of those women decided to have their ovaries and fallopian tubes removed, and two of them of child-bearing age also had double mastectomies. They later learned that their particular genetic variant of the BRCA gene was reclassified as having “unknown significance,” and the surgeries may have been in vain.

For proponents of the DTCG testing model, the malleability of utility and focus on the assumed future value is accepted as part of the competitive landscape in which product innovation and capital (economic and bio) accumulation trump infallible truth. But for these women and others like them, their material reality and social identities have been needlessly reconstituted for the worse within the marketplace of biocapitalism, all because they believed in the regime of hope (Brown, 2005).

So given these facts, I ask, was this a fair exchange? Did these women get a fair amount of value for exchanging their priceless biocapital?

I argue, no.

## **Consumer Safety & Next Steps**

The reason for arguing that these women and other consumers stand to be on the losing side of consumer genetic exchanges is not solely grounded in the current lack of utility or biovalue. That is crucial, but history has taught us that incremental innovation does prevail with time. As our technology, data sets, and understanding of genomics advance, the biovalue will likely fall into place.

But what may not fall into place is the policies and procedures that private companies implement to protect consumers' safety. It is not enough for the regimes of hope to deliver on their promise of future utility if consumers are harmed in other ways for exchanging their genetic data.

During the course of my qualitative research, I found that the majority of consumers lacked the genetic literacy to assess the benefits and risks of DTCG appropriately (Artz, 2018). Participants seemed to struggle with evaluating the validity of the marketing claims and the privacy risks associated with data.

I would often hear similar statements, best encapsulated by these two quotes:

“Yeah, I mean I was like, you know, I think it’s all about genetics, so it’s not something I personally understand, but these are companies that do genetic testing, like they seem pretty sure. You know, like scientific facts.” (35-year-old male interviewed in 2018)

“I don’t think it’s significant because I don’t know. It’s just life. It’s not my address or my social security number. I don’t feel like I could have a monetary loss on this one so I can affect my health. I mean I don’t understand how my DNA being in the hands of somebody is going to hurt me.” (48-year-old male interviewed in 2018)

Further complicating the matter, in a follow-up survey of 353 participants, I found that 52% did not read the Privacy Policy and Terms of Service when buying the test. For some of us in the science community, we appreciate the ethical concerns this represents as it relates to informed consent. But for many in the industry, using click-wrap contracts is just part of “removing friction” from the onboarding process.

So given the fact that these tests are built on questionable utility, and the majority of consumers lack a sufficient degree of genetic literacy to assess the potential benefits and risks, there is a need for greater public and policy engagement by social scientists interested in genetics. The ethical concerns that currently exist with the DTCG need to be discussed louder, more strongly, and more widely.

## References

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## Author Bio

Matt Artz is a business and design anthropologist, consultant, entrepreneur, author, speaker, and creator. He is the Head of Product for Artmatcher and Cloudshadow and the Founder of Anthro to UX and Azimuth Labs. He holds an MS in Applied Anthropology (2018), an MBA in Finance and Management Information Systems (2008), a BS in Biotechnology (2008), and a BBA in Computer Information Systems (2006).