

# How to Improve Consumer DNA Tests

By Matt Artz

Direct-to-consumer (DTC) genetic tests offer tantalizing yet speculative promises to connect us with our distant past and live a healthier life. Consequently, by February 2019, an estimated 26 million people had already taken a DNA test.

But as scholars have pointed out, there are a host of bio-ethical issues concerning validity and utility, genetic literacy, promissory business models, biocapital, and the reification of biological notions of race.

Concerns such as these have already manifested in unwarranted surgeries, an unavoidable loss of privacy for Americans of European descent, a data breach, the capturing of a serial killer, and a proliferation of racially questionable reveal videos.

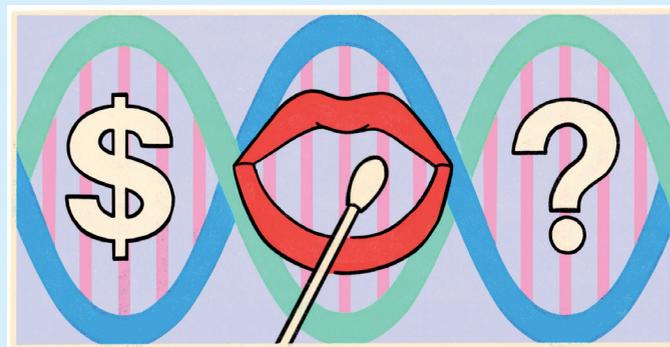
Here are just a few of the ways we might improve DTC tests.

**Transparency and informed consent.** For anthropologists working in user experience with DTC companies, one way to improve the tests is to better inform consumers about the potential benefits and risks before they purchase a test. This is critical because, given the lack of public genetic literacy, consumers are not fully aware of what they are opting into when they mail off their DNA for testing.

In fact, most consumers opt into the terms of service and privacy policies without reading or understanding the terms, and this is by design. User interface patterns, such as clickwrap contracts, incentivize sales and signups by removing friction from the process, and the use of legalese makes contracts incomprehensible to many.

We owe it to consumers to design online contracts in a jargon-free and inclusive manner so that all potential consumers, no matter their background, can use these products with greater confidence.

**Equitable business models.** For anthropologists working in business strategy, we need to address the structural issues in the business models that dominate technology and the DNA testing industry.



CHARLOTTE CORDEN

Like so many other tech products today, DNA testing companies' business models are based on the new currency: data. Consumers are enticed to exchange their biocapital, despite a lack of validity and utility in the tests, all premised on a promise of future knowledge. The speculative exchange value for consumers is not fair. The bigger problem though, is that our biodata is monetized, as exemplified in the \$300 million sale of 23andMe data to the pharmaceutical giant GlaxoSmithKline.

A business model based on the sale of private consumer information is not equitable. If a consumer's data is monetized, they deserve to understand what data was collected, how it was used, what were the results, and to earn a fair share of the profit.

**Advocacy and public policy.** Whether practicing or academic, all anthropologists can play a role in advocating for change at the policy level. The immediate place to start would be with the gaps in the Genetic Information Nondiscrimination Act (GINA).

GINA provides some protections to individuals from genetic discrimination in health insurance and employment. However, GINA does not apply to disability, life, or long-term care insurance, and businesses with fewer than 15 employees. It also doesn't protect us against discrimination in mortgage lending, housing, or education.

We can contact our representatives and advocate to expand GINA's protections at either the state or federal level. We should also consider supporting other proposals aimed at strengthening privacy and data protections, such as H.R.2155 - Genetic Information Privacy Act of 2019 and S.1842 - Protecting Personal Health Data Act.

Together, if we work at the product, business, and policy level, we can make a difference with consumer DNA tests, and similar biodata-centric tech products. 🌀

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