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Profit in Your DNA: How Consumer Genetics Companies Monetize Health & Privacy

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ABSTRACT:

Direct to consumer genetic testing offers valuable health and ancestry insights while storing a large amount of sensitive data. This paper help to examine how companies like 23andMe and AncestryDNA monetize genetic information through data partnerships, subscriptions, research collaborations and advertising Case studies and literature can further reveal regulatory gaps in GINA, HIPAA, and GDPR, along with ethical concerns over consent, data ownership, and re-identification risks. The recommendations include plain language consent, stronger oversight, and transparency measures. While DTC testing supports research and consumer engagement, its commercialization raises questions about the privacy autonomy, and the commodication of genetic identity.

Introduction:

In the past couple of years, direct to consumer otherwise known as DTC genetic testing has surged in popularity. Major companies such as 23andMe, AncestryDNA, and MyHeritage give people the ability to see their ancestry, inherited traits, and potential health risks, all from an at home kit. While these services can serve as valuable tools they also collect vast amounts of genetic data. In fact, this data is being monetized in ways that can raise serious concerns about consumer privacy, consent, and the ethics of commodifying ethnic information. This paper seeks to explore how consumer genetics companies generate revenue beyond test kit sales, focusing on data partnerships, business models, regulatory frameworks, and the possible ethical implications of their practices.

Section 1: The Biology Behind Consumer DNA Testing

Direct to consumer testing(DTC) companies primarily analyze a customer's DNA by focusing on single nucleotide polymorphisms otherwise known as SNPs, which are specific points in the genome where genetic variation commonly occurs. These variations are associated with traits, place of origin, or the likelihood to get certain diseases. Most companies use these genotyping technologies rather than using full genome sequencing which allows for an affordable yet efficient means of providing personalized genetic reports.

Although, these tests can cause probabilistic results rather than definitive diagnoses. For instance, a person may be told that they have a higher than normal risk for Type 2 diabetes based on established genetic markers, but this risk is not 100% certain and may be influenced more by certain lifestyle factors. Furthermore, the depth and accuracy of the interpretations can vary a lot between companies making the consumer experience both inconsistent and sometimes misleading.

Section 2: Business Models and Revenue Streams

Many companies see DTC testing as a one time purchase, but the companies behind the tests have developed an increasingly complex and evolving business model. These kit sales, most of the time, serve as the entry point but the real value lies in the data that is collected.

1. Data Partnerships

A big example of this is the 300 million dollar partnership between 23andMe and GlaxoSmithKline(GSK), a known pharmaceutical giant. The deal was granted for GSK access to anonymized genetic data from millions of 23andMe customers, which could be used to identify drug targets, refine clinical trials, and accelerate the development of new treatments. For pharmaceutical companies these datasets from 23andMe are goldmines for R&D.

2. Subscription services

To maintain a consistent revenue stream companies like 23andMe offer premium subscriptions. These services can provide general health insights, trait analyses, and updates as new genetic discoveries are made. In addition, subscribers also receive features like ancestry timeline adjustments and wellness reports which drive up engagement on the platform.

3. **Research Collaborations**

Beyond big pharma, genetics companies collaborate with universities, biotech firms, and public health institutions. These collaborations are often framed as contributing to scientific progress, although they also drive up the commercial value of the companies' datasets.

4. **Advertising and Cross Promotion**

Some companies monetize by partnering with health related brands or recommending lifestyle changes based on genetics which lead to targeted advertising and cross marking opportunities.

Section 3: Literature Review and Academic Perspectives

Over the past couple of years there has been a lot of discourse especially in academia on consumer genetic testing, especially in the fields of bioethicists, law, and medical research. Some scholars have expressed their concerns over the blurred lines between consumer products and medical diagnosis. A 2020 study in Nature Genetics had noted that the predictive power of certain genetics tests for some conditions are often oversold, especially when more complex diseases are at play such as for cancer or mental health disorders where environment also plays a major role.

Many bioethicists have raised red flags about the potential for where individuals view their genes as defining their fate, and how these perspectives can lead to psychological stress. Furthermore, some studies published in The American Journal of Bioethics emphasize that many consumers do not fully understand the implications of consenting to data sharing especially when they are buried in privacy policies.

Section 4: Case Studies in Genetic Monetization

23andMe and GlaxoSmithKline(GSK)

In 2018, a partnership was announced between 23andMe and GSK and it was seen as a landmark example of how genetic data can be commercialized. GSK gained exclusive rights to access anonymized data from millions of customers to fuel its drug research pipeline. In return, 23andMe not only secured funding but also put a claim in the pharmaceutical value chain. Although, some people argue that customers may not have realized their genetic information would be used in this way despite signing consent forms.

AncestryDNA and Third-Party Use

While AncestryDNA has not entered into partnerships as 23andMe’s, it has faced some scrutiny over how it shared customer data with law enforcement agencies and other third party researchers. A 2019 report by MIT technology review highlighted that users often underestimate the potential for re-identication, even when their data is anonymized.

GEDmatch and Law Enforcement

A third party site known as GEDmatch enabled users to upload raw genetic data and became a tool in the Golden State Killer investigation Although not a DTC company itself, GEDmatch in cooperation with law enforcement can highlight how consumer genetics data can be used in other unexpected ways.

Section 5: Legal and Regulatory Frameworks

Regulations surrounding genetic data are not sufficient and leave a lot of gray area. In the United States, the Genetic Information Nondiscrimination Act (GINA) stops employers and insurers from discriminating due to genetic background.[1] However, GINA does not cover life insurance, disability insurance, or long-term care insurance, which leaves holes in the protection of people.[1] The Health Insurance Portability and Accountability Act (HIPAA) offers protection for people’s medical data but does not apply to DTC companies because they are not classified as healthcare providers.[1] Due to this, companies like 23andMe use this gray area to operate in.[1] Globally, there are differences in regulations. The European Union’s General Data Protection Regulation (GDPR) gives consumers the ability to access, delete, and control their own data, including genetic information.[2] This forced companies operating in the EU to adopt better practices, but enforcement of those practices is not consistent.[2]

Section 6: Ethical and Privacy Concerns

1. Informed Consent

Informed consent often crosses roads with the intricacies of privacy policies. A 2022 Consumer Reports investigation showed that most users do not read the terms and conditions, and those who do read them often struggle to understand them.[3] This raises the question: can consent be “informed” when you do not actually understand the information?[3]

2. Data Security

In 2023, 23andMe went through a data breach that affected 6.9 million users.[3] The breach revealed details and information, which outlined major insecurities in the data storage of 23andMe.[3] The incident called for stronger security protocols in the genetics industry.[3]

3. Data Ownership and Control

Who owns your DNA? Once you mail your sample to a company, there is no clear answer.[3] While users have limited ownership of their genetic information, companies reserve the right to use, store, and even sell the data.[3] This is usually done through "anonymized research." But multiple studies have shown it is possible to match anonymous research through cross-referencing genetic data with public information.[4]

Section 7: Future Outlook and Recommendations

As direct-to-consumer genetic testing becomes more integrated into health tech, the stakes surrounding privacy and ethics will only grow.[1] Artificial intelligence and machine learning tools will enhance the predictive power of genetic analysis, creating new opportunities and risks.[1]

There is a growing consensus among ethicists, scientists, and policymakers that more robust regulation is needed.[1] Recommendations include:

- Mandatory Plain-Language Consent Forms[1]
- Data Minimization and Expiration Policies[1]
- Stronger Federal Oversight in the U.S.[1]
- Universal Opt-Out Options for Research Use[1]

Additionally, consumer education should be prioritized so individuals understand the ramifications of sharing their genetic information.[1] Transparency reports, similar to those published by major tech companies, could be adopted by genetics firms to show how and with whom data is being shared.[1]

Conclusion

The rise of consumer genetic testing has changed personal health and ancestry tracing, offering individuals new insights into their DNA.[1] However, these findings come at a cost.[1] Companies like 23andMe have built their business not only on the DNA kits but on the collection and monetization of users' genetic data.[3] While the use of genetic information could help in medical discoveries, it also makes us question what is the limit of consumer protection.[3] Informed consent, data ownership, and security must be heavily enforced to keep these companies in check.[1] As genetic data becomes more prevalent, both consumers and companies must ensure that privacy and ethics are not lost in the pursuit of profit.[1]

Footnotes

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