To the Editor of the San Francisco Chronicle,

Have you ever clicked "Agree" on an online service without scrolling through the endless terms and conditions? You might dismiss it as a harmless shortcut affecting only yourself. But what if this seemingly small act could shape the future of your descendants?

In our data-driven age, where devices on our wrists collect everything from heartbeats to sleep patterns, the implications of sharing genetic data are profound. Companies like 23andMe use genetics to predict not just our health tendencies but intrinsic personal traits—race, height, weight. Yet, this potent data is often exchanged without genuine informed consent, raising significant privacy alarms.

This concern grows as we witness rampant data harvesting across platforms, from Facebook to Google, where personal details are commodities traded without user's explicit approval. Genetic data is uniquely sensitive, not merely an individual marker but a familial blueprint, affecting not just one person but potentially entire family lines. Despite this, surveys show that only a fraction of users truly understand the consent they grant; companies exploit this gap, profiting under the noble banners of medical advancement and ancestry exploration, often without clear user agreements.

I propose a rigorous consent framework for genetic testing, modeled after the robust protections of California’s Consumer Privacy Act, which requires businesses to explicitly state the purpose of data collection and obtain clear approval. Under this new framework, users would be fully informed about how their genetic information will be used. They would have the option to receive notifications whenever any institution requests access to their data, and companies managing genetic data would be mandated to issue monthly reports detailing their usage. This model would necessitate that genetic testing companies secure informed consent by clearly outlining the permissible uses of the data and identifying who has access to it.

The need for stricter oversight is critical, given the millions of Americans engaging with these services, often without comprehending the long-term consequences. A standardized consent policy would ensure that all individuals know precisely how their sensitive genetic information is used and shared.

As a graduate student specializing in genetics at the University of California, San Francisco, I advocate for stronger FDA regulation in this sector to prevent misuse of genetic data. It is imperative that individuals have clear, accessible information to make informed decisions about their genetic data.

Sincerely,

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