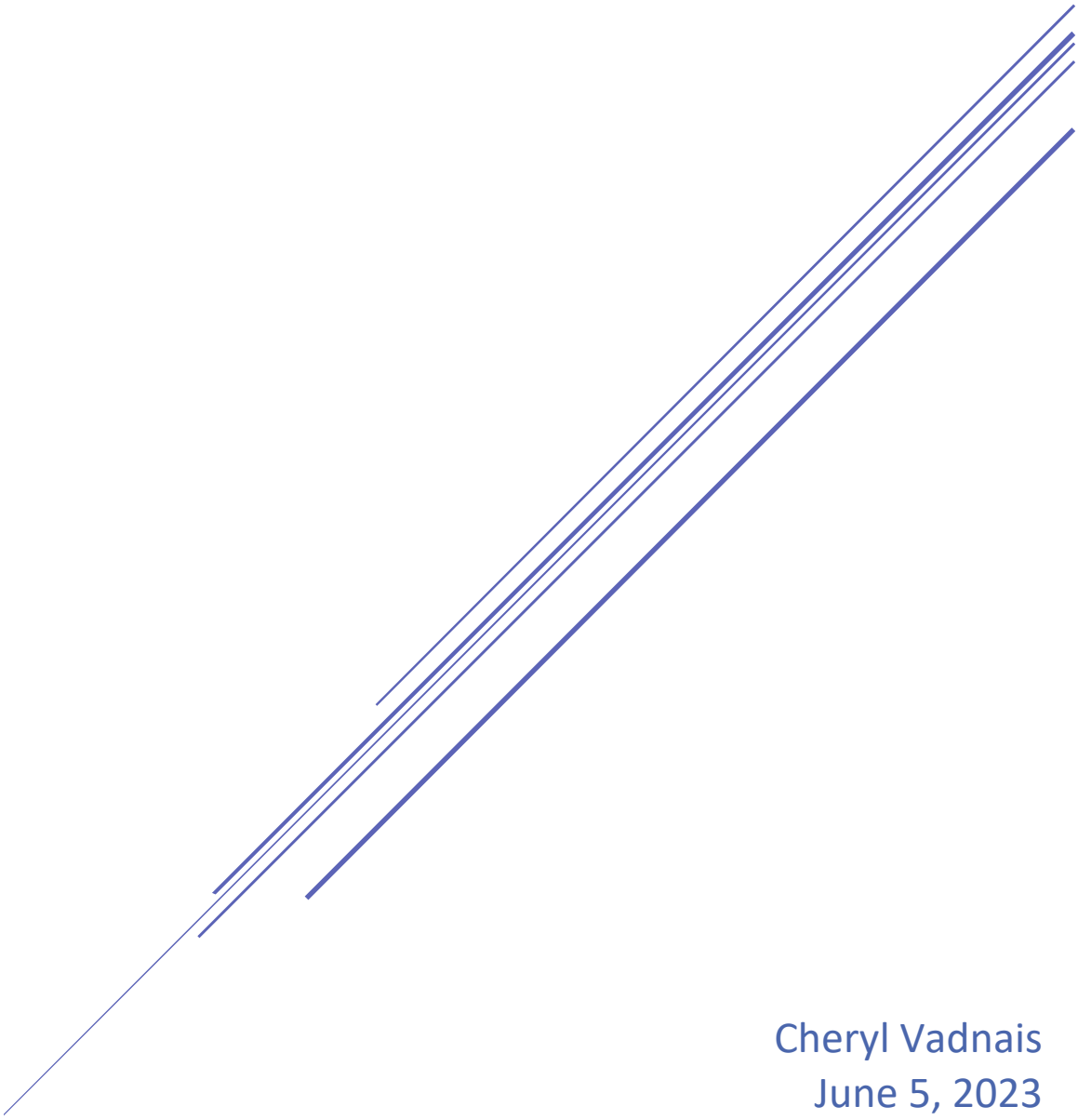
# ETHICAL USE OF CONSUMER HEALTH AND GENETIC DATA



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## INTRODUCTION

Many products capture consumer health and genetic data such as smart watches, cell phones, consumer marketed genetic testing and even internet search history. What are the ethical issues around medical, genetic, and health data obtained through consumer products? Is it ethical for this data to be used by insurance companies, marketers, employers, researchers, and even law enforcement agencies? "All technology requires us to consider both what we can do what as well what we should do". (Lee, 2017)

## SOURCES AND COMMON USES OF CONSUMER HEALTH DATA

### SOURCES:

One common source of health data comes from smart watches, such as Apple watch and google watches and fitness trackers like Fitbit. These trackers and smart watches can monitor heart rates, steps taken, sleep data and even measure body temperature. Apple's newest Apple watches can even take an electrocardiogram (ECG), which can detect abnormal heart rhythms. Another common source of health data includes apps for tracking health data, weight loss apps and even apps for tracking menstrual cycles. Data is also collected from internet browser history, online purchases, and online quizzes. Some companies, such as Ancestry and 23 and Me offer consumer genetic testing and maintain databases of customers genetic information.

### USES:

A common use for consumer health data is marketing. Beeler reports that many privacy policies and user agreements include the right for the company to sell the information to marketers. (2015) Online search history is used to target advertising and online businesses , such as Amazon, use customers purchase history to suggest products purchased by other customers with similar profile and purchase histories. This is commonly done with a "other people who

purchased your item also purchased" followed by suggested purchases. Public health agencies around the world used digital epidemiology in fighting the COVID-19 pandemic. Digital epidemiology is defined as "the use of data generated outside the public health system for disease surveillance". (Mello & Wang, 2020) Personal health and genetic data are also used for research purposes. Law enforcement has subpoenaed genetic information from consumer databases in order to solve crimes.

## THE REGULATORY ENVIRONMENT

Many consumers may be under the impression that all their medical and health data is protected under the federal Health Insurance Portability and Accountability Act (HIPAA), which restricts access to patients' medical records. However, Beeler reports that "Things that happen outside of a doctor's office—your apps, your fitness trackers, your gym memberships—none of that stuff is protected by HIPAA". (2015) This means that consumers currently need to read fine print on every user and privacy agreement to see if their health and genetic information is being shared with or sold to, third parties. Often the agreements are vague about secondary use of their data and do not explain who the data is being sold to for what purpose.

The regulations surrounding data privacy have lagged behind the technology, especially in the United States. Businesses in the United States have been largely left to decide for themselves what constitutes ethical use of consumer health and genetic data. For the most part, businesses are not self-regulating: "As we've seen over the past 10 or 20 years, that the industry does not police itself virtually at all." (Beeler, 2015) Apple is the exception as they have included health data privacy restrictions in their developer agreements: data from apple health and apple watch sensors cannot be shared without user permission and cannot be used for "targeted behavioral advertising" (Beeler, 2015)

The European Union has enacted General Data Protection Regulations (GDPR) which requires “businesses to obtain permissions from consumers in order to collect their data” and respond with in 72 hours to data usage inquires with substantial fines for violations. (Ferrell et al., 2022, p. 315) The state of California has also passed similar legislation, the California Consumer Privacy Act which applies to any company that does business with California Residents. (Ferrell et al., 2022, p. 315) The United States has not yet enacted national privacy regulations, however businesses can still face legal consequences for violating their own user and privacy agreements.

## LEGAL CONSEQUENCES: FLO HEALTH

Flo Health developed the Flow Period and Ovulation Tracker, which included due date and pregnancy calendars. Flo Health marketed their app to women and promised the individuals personal health information, such as menstrual cycles, pregnancy or symptoms wouldn’t share with third parties. (Fair, 2021) Flo Health then included software development kits (SDKs) from many third parties, including marketing and analytics firms as well as large social media companies such as Facebook and Google. (Fair, 2021) Without the consumer knowledge or consent, Flo Health used the SDK’s to transmit the private information about the user’s pregnancy and menstrual statuses to those third parties. (Fair, 2021)

When the story broke in 2019, the Wall Street Journal was able to “intercept unencrypted identifying health information transmitted by the Flo App to Facebook”. The Federal Trade Commission Complaint resulted in a settlement that includes requiring that “Flo Health must get that person’s express affirmative consent” to disclose health information to any third parties and undergo a compliance review. (Fair, 2021) This case shows that even without national consumer data privacy laws, companies can be held liable for misleading customers about how their data is used.

# ETHICAL ISSUES INVOLVING CONSUMER HEALTH AND GENETIC DATA

## INFORMED CONSENT AND DIGITAL PRIVACY

When rights to sell consumer health data are buried in privacy policies and user agreements, the ethical issue is that the consumers are not giving informed consent for the use of their data. This data is often collected through cookies, data stored on a computer that is transmitted to the website, where it is often aggregated and sold to other third parties. Beeler reports that an FTC study found that "that information gathered by 12 mobile health and fitness were transmitted to 76 different third parties. Even consumers who gave consent to use of their data, may not truly realize the scope of the future use. That information included exercise routines, diet, and symptom searches, and according to the FTC could be re-identified back to individual customers". (2015) . In fact, the Medical Futurist lists medical and genetic privacy as the top pressing bioethical issue in 2019. With the advances in AI over the last couple of years, the ability for companies to re-identify individual consumer's based on their medical and genetic data is even more of an ethical issue.

## SELLING GENETIC INFORMATION: 23 AND ME

23andMe is a company that provides direct to consumer genetic testing using saliva samples. In 2018, the company announced it was partnering with pharmaceutical company GlaxoSmithKline in which 23andMe would share customer's genetic information for drug development research (Brodwin, 2018) Research from consumer's genetic information provided by 23andMe has provided valuable data for research into many diseases and mental conditions including: Alzheimer's, Parkinson's, ADHD, and depression.(Segert and Nathan, 2018) The Medical Futurist raised ethical concerns about the $300 million deal between the two companies and noted that 23andMe has previously sold genotype information:

> *23andMe made around $130 million from selling access to about a million genotypes, before the GSK deal, implying an average price of around $130. That means if you purchased 23andMe's genetic test for $100-150, your genetic information could have been bought for another $130 on average price. The question is whether we are okay with that…(2019)*

Even if consumers give consent for their DNA to be used for research, there are ethical concerns for the companies who are profiting from both selling the genetic test and the results. Additionally, even when consumers do agree to share their genetic information with a company like 23andMe, once you opt-in, you can't fully opt-out as "the company will not wipe your genetic information from any active or completed research projects", only stop the DNA data from being used for new projects. (Brodwin, 2018)

## USE OF CONSUMER DATA IN REASEARCH: ANCESTRY AND GOOGLE CALICO

Ancestry provides genetic testing to allow customers to trace their genealogy learn more about their family history and ethnicity. Erin Brodwin with Business Insider reported in 2018 that Ancestry "had been partnering with Google's stealthy life extension spinoff Calico to study aging and longevity". Ancestry had quietly shared the health and genetic information from their 5 million customer databases with Google's Calico. (Brodwin, 2018) Brodwin reports that genetic testing companies "frequently share customer DNA data with other institutions" including private drug makers, research groups and public universities. (Brodwin, 2018) Medical Futurist raises the ethical question: should companies such as Ancestry and 23andMe even be legally allowed to sell and profit off of customers medical and genetic data? (Medical Futurist, 2019).

## ETHICAL ARGUMENTS FOR THE USE OF CONSUMER HEALTH & GENETIC DATA

### ECONOMIC VALUE ORIENTATION

Many businesses use the moral philosophy of economic value orientation to justify their use of consumer generated health and genetic data. Ferrell, et al. define economic value orientation as "if an act produces more economic value for its effort, then it should be accepted as ethical". (2022, p. 162) By this moral philosophy, use of consumer health and genetic data is ethical, because it allows the companies to make a profit and generate economic value. The profit can come from increased sales due to targeted advertising, charging higher life insurance premiums to those in high-risk groups, and the profits from new pharmaceuticals developed with the help of consumer health and genetic data.

### UTILITARIANISM: LAW ENFORCEMENT & PUBLIC HEALTH

A compelling ethical argument for the use of Consumer health and genetic data is that it can be used for the public good. This argument would be made by those who believe in the moral philosophy of utilitarianism which "defines right or acceptable actions as those that maximize total utility of the greatest good for the greatest number of people. (Ferrell et al., 2022, p. 163). This ethical discussion took place globally during the recent COVID-19 pandemic. Mello and Wang argue that when it comes to digital epidemiology and contract tracing, "sometimes it is unethical not to use the available data" and that trade-offs of individual privacy vs. public health are "not only ethically justifiable, but ethically obligatory". (2020) This is also the ethical justification for the use of consumer genetic databases by law enforcement. This use of consumer genetic data came to light in 2018 when the "Golden State Killer", responsible for numerous murders and rapes, was captured due to matching DNA from GEDmatch, a public database of family-tree and genetic information. (Hensman Saey). While

some sites, such as ancestry and 23andme, require the law enforcement to get a warrant, others strongly believe that law enforcement should have access to the information for the public good. In fact, GEDmatch even changed its terms of service "to explicitly embrace the use of their serve by law enforcement". (Hesman Saey, 2018)

## ETHICAL ARGUMENTS AGAINST THE USE OF CONSUMER HEALTH & GENETIC DATA

A major argument against the use of consumer health and genetic data is the belief that the consumer has the right to control their own data. This falls under the moral philosophy of deontology, which focuses on the "rights of individuals and the intentions associated with a particular behavior and not the outcome". (Ferrell et al., 2022, pp. 166-167) The Privacy Office at the University of Washington warns that "The proliferation of publicly available information online, combined with increasingly powerful computer hardware, has made it possible to re-identify "anonymized" data". (2019)

Additionally, with genetic data, even if consumers opt-in, there are privacy concerns for relatives, whose genetic data is also being shared. Even data from third cousins can identify individuals and there are no mechanisms to protect the genetic data of relatives. (Segert and Nathan, 2018). Hesman Seay notes that law enforcement use of consumer genetic data may violate Americans' civils rights to "privacy and security against unreasonable search and seizure" (2019) There is also the chance of implicating innocent close relatives in a crime because of the similarities in DNA.

Andrew Brightman, PHD argues against the use of consumer health data obtained from wearables such as smart watches due to ethical issues involving the privacy of subjects, informed consent and the general inaccuracy and security of the data generated by consumer devices. (2020) Privacy of consumers and security of that data are large concerns as who

develop wearable products and apps to truly provide informed consent through vague user agreements and privacy statements.

Another argument against the use of consumer health and genetic data is the lack of oversight on how companies secure the data especially as cyberattacks are becoming more common and there is little oversight for how companies are handling cybersecurity of medical and genetic information. Medical Futurist details a global ransomware attack that infected 300,000 computers in over 150 countries including the National Health Service in the United Kingdom. (2019)

Ethical concerns are also being raised about the use of AI algorithms using personally identifiable information for disease forecasting that assigns risk scores to individuals because of the potential consequences. (Mello and Wang, 2020) Some of the consequences for individuals range from predictive marketing about sensitive health topics, public disclosure of health information or being denied or charged more for insurance products. While the Affordable Health Care Act prevents insurance pricing to be based on individual health conditions and history, insurance policies provided by employers do allow for basing policy pricing on health status and claims history. (Beeler, 2015)

## CONCLUSION

Ethical management and use of consumer data is part of corporate social responsibility. Corporate social responsibility is defined by Ferrell et al as "an organization's obligation to maximize its positive impact on stakeholders and minimize its negative impact. (2022, p. 33). Part of that responsibility is ethics training for employees and accountability for the use of the consumer health data. "We must integrate ethics training for all personnel involved in digital health activities and hold them accountable for the ethical treatment of the data". (Lee, 2017)

Ethical use of consumer and health and genetic data means companies should only use the information on an opt-in basis and clearly communicate to consumers who will be using their data and for what purpose. It's important for consumers to be mindful of their digital privacy and read user and privacy agreements carefully, especially for free app. "If you're not paying for it, *you* are the product". (Beeler, 2015)

One solution is that genetic and health data could be owned and sold by the consumers and not by genetic testing companies or through health apps and consumer wearables. Some argue that by giving customers ownership of their data, it will "encourage companies to be more responsible" with that data as customers will choose to sell their data to companies doing valuable research and choose not to sell their data to companies who have a history of data breaches. (Segert and Nathan, 2018)

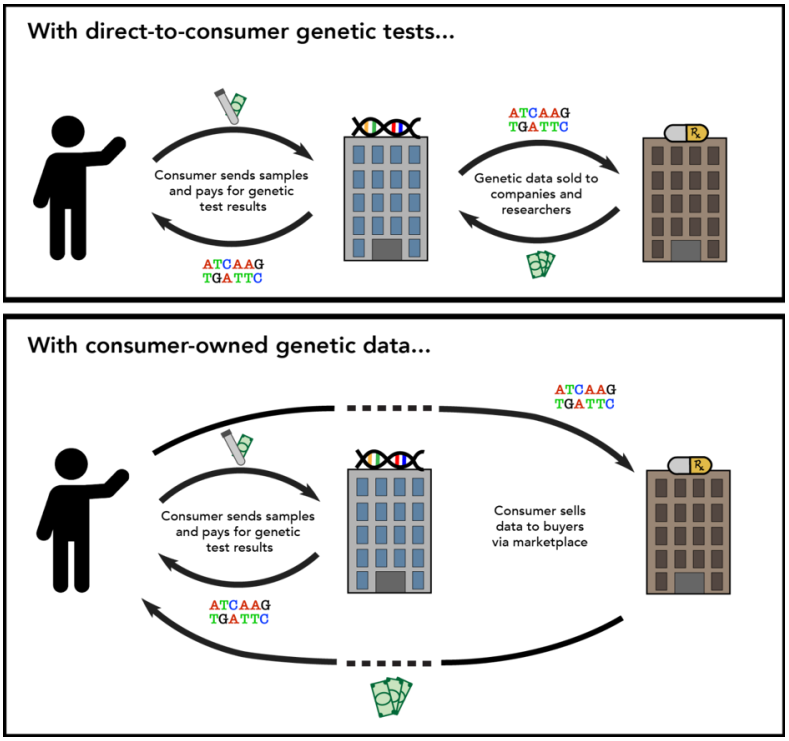


Figure 1 DTC genetic tests vs. consumer-owned genetic data. Segert & Nathan, 2018

While consumer health & data can be used for meaningful research purposes for the greater good, such as for research, public health, and safety. However, there needs to be oversight on how that data is used. Ideally, regulations will be passed in the United States that are similar to the European Union's General Data Protection Regulation and the Right to Be Forgotten legislation.

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