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Before the

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23 and You: The Privacy and National Security Implications of the 23andMe Bankruptcy

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Chairman Grassley, Ranking Member Durbin, and other distinguished members of the Judiciary Committee, my name is I. Glenn Cohen, and I am a Deputy Dean and the James A. Attwood and Leslie Williams Professor of Law, Harvard Law School, and the Faculty Director, Petrie-Flom Center for Health Law Policy, Biotechnology & Bioethics. My research focuses on legal and ethical issues in medicine and the biosciences, including extensive work on genetics and privacy. Thank you for the opportunity to testify before you today about the need to protect genetic data, our existing privacy laws, and the 23andMe bankruptcy.

I want to focus on four main points: (1) Why genetic data is sensitive data and why protecting its privacy is paramount; (2) How the 23andMe bankruptcy highlights the need for legislative action; (3) Why existing federal law protections have significant gaps in protecting genetic privacy; and finally (4) to provide an analysis of some models for possible legislative action.

I. Why Genetic Data is Sensitive Data and Why Protecting Its Privacy is Paramount

Genetic information has some distinct aspects that jointly distinguish it from many other kinds of personal data in ways that are important for privacy. First, it is immutable in that one cannot change one's genetics in the relevant sense. That means that if someone gains access to your genetic sequencing information, that information is forever associated with you, and there is nothing you can do to change that. Second, and relatedly, genetic information is inherently identifiable. While we share the vast majority of our DNA with other human beings, the small amount of genetic variability in my versus your genetic information is enough to directly identify me.[1] Third, access to one's genetic information reveals information not just about oneself but

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[1] Luca Bonomi, Yingxiang Huang & Lucila Ohno-Machado, *Privacy Challenges and Research Opportunities for Genomic Data Sharing*, 52 NAT. GENET. 646, 646 (2020).

one's "blood relatives" because of their shared genetic inheritance.[2] Thus, participation in genetic testing like the kind offered by 23andMe exposes not only the customer's genetic information but that of many people related to him or her who never consented. Fourth, many health conditions have significant genetic components such that knowing about someone's genes may tell one a lot about their health.

I am sometimes asked: "Imagine someone had robust access to my genetic information, in concrete terms, what should I worry about?" Here is a non-exhaustive list of answers:

Health Information: Our genetic information can be revealing about our health state and susceptibilities, such as our risk and prognosis for breast cancer, Alzheimer's disease, or many other health conditions.[3]

Identification: Even with an otherwise deidentified genetic sample, researchers have shown the possibility of reidentifying a person from their genetic information using publicly available databases and indeed some have suggested that "whole-genome data may be able to correctly predict physical features, such as eye, hair and skin color, and facial and vocal characteristics."[4]

Discrimination: While, as I will discuss below, current federal law largely protects against employment and health insurance discrimination on the basis of genetic information, it has important gaps in terms of protecting individuals from discrimination by other entities such as in life, disability, and long-term care insurance.

Forensic Uses: A central database, known as the Combined DNA Index System ("CODIS"), allows all U.S. states, the District of Columbia, and several federal agencies to collect, store, and share genetic information for law enforcement uses. Theis includes DNA collected not only from those convicted of felonies, but in many instances, those convicted of misdemeanors, and even those who are arrested but not convicted of any crime.[5] These databases can be used not just to match genetic material collected at a crime scene to an individual but also to identify relatives of that individual who are in the database and impose surveillance on that relative and their family members and/or confront the relative for information. The issues are even more pronounced with the databases of companies like 23andMe that collect much more robust genetic information and can reveal a second, third, or more distant cousin and define the relationship of a person to the genetic sample collected at a crime scene.[6] As a result, many of us can, in a real sense end up in a "DNA dragnet," merely because of genetic relatedness to someone present at a crime scene.

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[2] *Id.*; Natalie Ram, *Investigative Genetic Genealogy and the Problem of Familial Forensic Identification*, *in* CONSUMER GENETIC TECHNOLOGIES: ETHICAL AND LEGAL CONSIDERATIONS 215 (I. Glenn Cohen, Nita Farahany, Henry T. Greely & Carmel Shachar, eds.) (Cambridge Univ. Press 2021).
[3] Bonomi et al, *supra* note 1, at 646.
[4] Bonomi et al., *supra* note 1, at 646.
[5] Natalie Ram, *Genetic Privacy After* Carpenter, 105 VA. L. REV. 1357, 1382-84 (2019).
[6] *Id*. at 1377-1378.

Misattributed Paternity and Upending Families: In the U.S., it is not standard to conduct a paternity test for children when they are born. A not insignificant portion of the U.S. public would be surprised to find out that their father is not, genetically speaking, who they thought he was. Whether it is a result of adoption, infidelity, embryo mix-ups as part of In Vitro Fertilization, or in some of the darkest cases, sexual assault, knowing someone's genetic information may reveal that their understanding of their family is, genetically speaking, fictitious.[7]

National Security: While others testifying have more expertise in the national security risks, it is notable that in 2019 the Pentagon warned members of the military against using direct-to-consumer genetic tests. A memo from Joseph D. Kernan, the Under Secretary of Defense for Intelligence, and James N. Stewart, the Assistant Secretary of Defense for Manpower and Reserve Affairs, Performing the Duties of the Under Secretary of Defense for Personnel and Readiness, cautioned that "[e]xposing sensitive genetic information to outside parties poses personal and operational risks to service members," that "[t]hese DTC (Direct to Consumer) genetic tests are largely unregulated and could expose personal and genetic information, and potentially create unintended security consequences and increased risk to the joint force and mission," and that "there is increased concern in the scientific community that outside parties are exploiting the use of genetic data for questionable purposes, including mass surveillance and the ability to track individuals without their authorization or awareness."[8]

These are just some of the prominent current known risks. As our knowledge about the human genome increases, many portions of the genetic code that were once thought of as "junk" (in the sense of non-revealing) regions will be recognized as predictive. Moreover, especially when combined with artificial intelligence, we are likely to see more use of genetic information in the future to try to learn about or predict future health conditions of individuals. Genome-wide association studies ("GWASs") use data from biobanks to try to identify correlations between genes and phenotypes (the observed characteristics of an organism) and enable the creation of polygenic risk scores that allow one to sum the effect sizes of all the variants from an individual's genome by using an index derived from population-level studies, that is to aggregate the contributions of multiple genomic loci (with varying effect sizes) to the disease/trait of interest.[9] These scores, some of which have been created using 23andMe data, have been developed not just to predict diseases like breast cancer, but also to try to predict risk tolerance, educational attainment, and other behavioral traits.[10] The value of many of these predictive

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[7] Kif Augustine Adams, *Generational Failures of Law and Ethics: Rape, Mormon Orthodoxy, and the Revelatory Power of Ancestry DNA*, *in* CONSUMER GENETIC TECHNOLOGIES: ETHICAL AND LEGAL CONSIDERATIONS 273 (I. Glenn Cohen, Nita Farahany, Henry T. Greely & Carmel Shachar, eds.) (Cambridge Univ. Press 2021).

[8] Luis Martinez, *Pentagon Warns Military Not to Use Consumer DNA Kits*, ABC News, Dec 24, 2019, https://abcnews.go.com/Politics/pentagon-warns-military-consumer-dna-test-kits/story?id=67904544

[9] Jin K. Park & I. Glenn Cohen, *The Regulation of Polygenic Risk Scores*, 38 HARV. J. L. & TECH 377, 380-81 (2024).

[10] Shawneequa Caller & Anya E.R. Prince, *The Legal Uncertainties of Sociogenomic Polygenic Scores*, 38 HARV. J. L. & TECH 554, 557-560 (2024).

scores is at the moment quite uncertain, but whatever their quality, one can easily imagine a future where our genetic information is used to try to predict much more about us and our role in society in a way that many might find worrying.

II. How the 23andMe Bankruptcy Highlights the Need for Legislative Action

Since 2006, through its direct-to-consumer genetic tests, 23andMe has amassed a vast database that includes the genetic and personal information of more than 15 million consumers.[11] It is in the midst of selling itself on a fast track in a recently-filed federal bankruptcy case with Regeneron Pharmaceuticals, Inc and TTAM research Institute as leading bidders. While the genetic data controlled by 23andMe is extremely sensitive, its data set -- which would be subject to sale as part of the bankruptcy -- also contains many other forms of personal data including biometric information to verify customers' identity, sample information (including saliva samples and laboratory values), self-reported information related to health, family history, behavior, and registration information (such as name, address, and credit card information), as well as user content (including messages sent via 23andMe's services).[12] The company experienced a significant cybersecurity breach in 2023 that exposed the data of its customers, showing the difficulty in keeping this data secure against cyberattacks.[13]

As I discuss below, while there are some federal and state laws that protect the data of 23andMe's current consumers in bankruptcy, the main privacy protection for its customers is actually a promise that the company has made in its privacy statement. That statement provides customers certain rights, such as the right to opt out of the storage of their saliva samples and the right to request the deletion of their account. It also indicates that 23andMe does not share personal information (i.e., individual-level information, such as information on diseases or genotypes, or deidentified information) voluntarily with insurance companies, employers, or public databases or with law enforcement agencies without a valid subpoena, search warrant, or court order, although the company does share personal information with its service providers and contractors for some purposes.[14]

However, on a closer read, the privacy statement provides less protection than it initially appears and thus highlights the problem with leaving decisions about the privacy protection of genetic material to individual company policies and consumer consent.

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[11] Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *Bankruptcy, Genetic Information, and Privacy—Selling Personal Information*, 392 NEW ENG. J. MED. 937 (2025), https://www.nejm.org/doi/abs/10.1056/NEJMp2415835; *An Open Letter to 23andMe Customers*, 23ANDME, https://blog.23andme.com/articles/open-letter (last visited June 7, 2025).

[12] Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *23andMe's Bankruptcy Raises Concerns about Privacy in the Era of Big Data*, 389 BMJ r1017 (2025), https://www.bmj.com/content/389/bmj.r1071; *Privacy Statement*, 23ANDME, https://www.23andme.com/legal/privacy/full-version/ (last visited June 7, 2025).

[13] Gerke et al, *supra* note 11, at 938; *Privacy Statement*, 23ANDME, *supra* note 12.

[14] Gerke et al, *supra* note 11, at 938; *Privacy Statement*, 23ANDME, *supra* note 12.

First, it bears emphasizing that the assumption that individuals carefully read and fully understand the privacy policy or terms of service blinks reality. As one set of authors wrote regarding terms of service more generally, "only 1 in 1000 visit terms of service; that number drops to 1 in 10 000 if getting there requires 2 clicks. The median reading time is 29 seconds."[15]

Second, 23andMe reserves the right to unilaterally alter these terms. It indicates: "We may make changes to this Privacy Statement from time to time. We'll let you know about those changes here or by reaching out to you via email or some other contact method, such as through in-app notification, or on another website page or feature."[16] Such changes could be radical and vitiate the promises customers relied on, for example, more readily sharing information with law enforcement or insurers than under the company's current policy. Moreover, 23andMe explicitly reserves the right to transfer customers' personal information in the event of a sale of the company or bankruptcy, and the company explicitly notes that the customer's personal information may be "accessed, sold or transferred as part of that transaction."[17]

The company has announced that as part of the bankruptcy process it "required anyone bidding for 23andMe to agree to comply with our privacy policies and all applicable privacy laws."[18] That is all well and good, but even if that becomes a condition of the sale nothing prohibits Regeneron, TTAM, or another buyer of the data from altering that privacy policy after a change in ownership of the data, just as there was nothing to stop 23andMe from doing so.[19] It is also unclear to me under the company's existing privacy policy how the stored customer saliva samples will be handled as part of the bankruptcy, and this may raise an additional problem for customers' privacy.

Trust is all about a relationship. Customers who chose 23andMe entered into a particular kind of relationship with a particular kind of company: they shared their genetic and other personal information, recognizing there was some privacy risk, to obtain potential ancestry and health-related insights. Some 23andMe consumers also opted in to research use, to help enable research and the development of potential new drugs or other therapeutics. Upon bankruptcy or sale of assets, consumers may end up in a relationship with a very different kind of company with goals they may not support and policies that have changed while they were not looking.

To some extent, bankruptcy offers an extra layer of privacy protection for the transfer of genetic information as compared to other methods of sale or acquisition. Under federal bankruptcy law in some instances a consumer privacy ombudsperson may be appointed to investigate the sale

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[15] Anya E.R. Prince & Kayte Spector-Bagdady, *Protecting Privacy When Genetic Databases Are Commercialized*, 333 JAMA 665 (2025) (citing Yannis Bakos, Florencia Marotta-Wurgler, and David R. Trossen, *Does Anyone Read the Fine Print? Consumer Attention to Standard-Form Contracts*, 43 J.L. STUDIES 1 (2014)).

[16] *Other Things to Know About Privacy*, 23ANDME, https://www.23andme.com/legal/privacy/#other-things-to-know (last visited June 7, 2025).

[17] Gerke et al, *supra* note 11, at 938; *Privacy Statement*, 23ANDME, *supra* note 12.

[18] *An Open Letter to 23andMe Customers*, *supra* note 11.

[19] Gerke et al, *supra* note 11, at 938.

and determine compliance with the bankrupt company's privacy statement and applicable non-bankruptcy law.[20] In this case, a well-regarded privacy law expert has been appointed to this role. That may not be the case for all forms of sale of genetic data, which underscores the need for more protection. Privacy statements and customer acquiescence have a role to play, but private ordering solutions can only go so far to deal with the concerns. More structural solutions through the legislative process are also needed.

III. Existing Federal Law Protections Have Significant Gaps in Protecting Genetic Privacy

There are a few important pieces of federal law that one might think would protect genetic privacy. Unfortunately, they either do not apply in this kind of case or only partially solve the problems identified.

First, given the amount of health-related information 23andMe collects and analyses, one might think the protections of our main federal health privacy law, the Health Insurance Portability and Accountability Act (HIPAA), would be important.[21] Unfortunately, as a direct-to-consumer genetic testing company, 23andMe is not considered a covered entity or a business associate of such an entity under the statute and therefore is not covered under HIPAA's requirements. In lay terms, individuals interact with the company as consumers, not as patients, and thus it escapes this regulatory regime.

Second, the Genetic Information Nondiscrimination Act (GINA),[22] would seem to be very helpful in assuaging fears related to genetic privacy. The Act prohibits discrimination based on an individual's genetic information by covered employers and health insurers. Congress passed GINA nearly unanimously, and it was signed into law by President George W. Bush in 2008. The statute's goal was to address fears about genetic discrimination, allowing Americans to feel comfortable participating in research and to benefit from genetic medicine.

The statute has provided valuable protection, but that protection is incomplete. GINA does not protect against genetic discrimination for life, disability, and long-term care insurance, nor does it apply to some small businesses, military employees, and some other groups subject to exceptions.[23] Many of our peer countries have gone further either through legislation or compacts with the insurance industry: For example, France strictly limits the use of genetic testing to medical or scientific reasons, while countries such as Australia, Switzerland, and the

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[20] Gerke et al, *supra* note 11, at 938.

[21] 42 U.S.C. § 1320d et seq.; 45 C.F.R. Parts 160 and 164.

[22] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

[23] Jean-Christophe Bélisle-Pipon, Effy Vayena, Robert C. Green & I. Glenn Cohen, *Genetic Testing, Insurance Discrimination and Medical Research: What the United States Can Learn from Peer Countries*, 25 NAT. MED. 1198, 1199 (2019).

United Kingdom do not allow the consideration of genetic information in life and disability insurance under a certain financial limit.[24]

Importantly, GINA also excludes protection from discrimination on the basis of conditions that have already *manifested* in the individual.[25] While in some cases the Americans with Disabilities Act (ADA), as amended, will protect such individuals, there may be cases that fall within the gap between GINA and the ADA.

Finally, it is worth emphasizing that freedom from discrimination is just one of the concerns that explain why genetic privacy is so important. Thus, even where GINA succeeds, it may leave many of the concerns unaddressed.

IV. Analysis of Models for Possible Legislative Action

As I hope I have made clear, while the sale of genetic information as part of a bankruptcy proceeding is what has led us to this hearing today, it just shines a light on a much larger set of issues with genetic privacy in the U.S.

It is also important to recognize that direct-to-consumer genetic testing companies like 23andMe have provided a service that many customers have valued. Moreover, as the federal government's commitment to the NIH All of Us program demonstrates, large genetic databases are crucial to building the next generation of therapeutics and improving our understanding of disease. 23andMe should be appropriately recognized for its own contributions to such research.

The question is: Are there good legislative actions that could reduce some of the genetic privacy risks without unduly hampering research and innovation? It is useful to think about intervening at different scales of the problem.

Comprehensive Privacy Legislation at the Federal Level: At the most ambitious level, some jurisdictions have attempted more comprehensive data privacy regulation that have specific rules for genetic information. The EU General Data Protection Regulation (GDPR) applies to all personal data and provides heightened protection for genetic and health data, which in essence by default bans processing (including collection, use, or disclosure) of genetic data and data concerning health unless an exception applies, such as with a customer's explicit consent under specific conditions.[26] Some states have also tried to implement comprehensive privacy legislation. Whether this is a feasible approach for the U.S. is a much bigger conversation.

Genetic Privacy: One level down is to focus only on genetic privacy. Here, some of the foreign antidiscrimination laws mentioned above might suggest amendments to GINA that would extend protection to life, disability, and long-term care insurance, perhaps only for policies below a

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[24] *Id.*; Anya E.R. Prince, *Political Economy, Stakeholder Voices, and Saliency: Lessons from International Policies Regulating Insurer Use of Genetic Information*, 3 J. L. & BIOSCI. 461 (2018).

[25] Bradley A. Areheart & Jessica L. Roberts, *GINA, Big Data, and the Future of Employee Privacy*, 128 YALE L. J. 544 (2019).

[26] Gerke et al, *supra* note 12, at r1071.

certain limit. Indeed, we have a good model at the state level. In 2020, Florida became the first U.S. state to ban insurers from discriminating on the basis of genetic information in areas not covered by GINA - life, long-term care, and disability insurance.[27] While federalism has many virtues, when it comes to freedom from discrimination in insurance it is less clear why those purchasing policies in some states should have more protections than those in other states. It would be worthwhile to consider extending similar protection at the federal level.

A different approach is to consider extending some of the existing HIPAA law to direct-to-consumer genetic testing companies and biotechnology or pharmaceutical companies or others buying or collecting this kind of data, treating them, where appropriate, as covered entities and regulating them more like health care systems.

Another approach is provided by the Genetic Information Privacy Act, a model law developed by 23andMe and Ancestry that has been adopted in several U.S. states.[28] The model Act requires companies to, among other things:

> provide clear notices of their privacy practices that are written in plain language, and must obtain express consent from consumers for numerous practices, including the collection, sharing, and continued storage of their genomic data, as well as other activities, such as marketing. Consumers must be able to revoke their consent and have their biospecimens destroyed. Companies also are required to establish strong security protections to minimize risk of unintended disclosure.[29]

While the model Act contains some valuable protections, some have criticized it as being too permissive in terms of permitting sharing genetic information with law enforcement and that its reliance on a notice-and-consent model is unrealistic given that so few individuals meaningfully engage with privacy policies.[30] It also has a more limited scope, applying by its terms only to a company that "(a) offers consumer genetic testing products or services directly to consumers; or (b) collects, uses, or analyzes genetic data that a consumer provides to the entity."

Regulating Bankruptcy, Sale, and Transfer of Assets of Direct-to-Consumer Genetic Testing Companies: Finally, legislative action could focus on something akin to the facts of this particular case -- how to handle the transfer of assets in bankruptcy or other sale of a company like 23andMe.

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[27] A.C.F. Lewis, R.C. Green, A.E.R. Prince, *Long-awaited Progress in Addressing Genetic Discrimination in the United States*, 23 GENET. MED. 429 (2021).

[28] *See, e.g.*, Utah S.B. 227 Genetic Information Privacy Act (2021), https://le.utah.gov/~2021/bills/static/SB0227.html; Anya E. R. Prince, *The Genetic Information Privacy Act: Drawbacks and Limitations*, 330 JAMA 2049 (2023).

[29] *Id*.

[30] *Id*.

One such bill, the Genomic Data Protection Act, S. 5433, sponsored by Senators Cassidy and Peters, has been introduced in the Senate.[31] The bill would with limited exceptions regarding law enforcement and other laws), among other things: (1) Require direct-to-consumer companies to "provide an effective mechanism" to consumers to delete an account, genetic data, or request destruction of biological samples; (2) Upon purchase or other acquisition of such a company require that adequate notice be provided to consumers and reminders of their rights to deletion/destruction of data/biospecimens and confirmation of the appropriate action. The Bill also specifies that a "violation of this section or a regulation promulgated thereunder shall be treated as a violation of a rule defining an unfair or deceptive act or practice under section 18(a)(1)(B) of the Federal Trade Commission Act."

Another recent Bill introduced by members of this committee, Chairman Grassley, and Senators Cornyn and Klobuchar, the Don't Sell My DNA Act,[32] would laudably clarify the definition of "personally identifiable information" in the Bankruptcy Code to include genetic information as covered in GINA. It would also importantly require that "no use, sale, or lease shall be approved if the personally identifiable information consists, in whole or in part, of genetic information unless all affected persons, including non-parties, have affirmatively consented in writing to such use, sale, or lease after the commencement of the case," and that notice be given to all affected persons. Finally, it would require the trustee or debtor in possession of the covered genetic information to permanently delete any data not subject to the sale or lease.

I think both bills would make helpful steps to improve genetic privacy, but I particularly endorse the model of strong affirmative consent in the Don't Sell My DNA Act and the deletion of data that is not subject to the sale or lease. It may be worthwhile to expand that Act's coverage to directly address the saliva samples or other biospecimens held by companies like 23andMe. There are, of course, limits to relying on action by consumers themselves to protect genetic privacy, but I think the approach of this bill would go a long way to ameliorating the situation. At the same time, this may be a good opportunity to consider supplementing this approach with other substantive protections and to consider issues of genetic privacy that go beyond the bankruptcy context.

V. Conclusion

The 23andMe bankruptcy has drawn significant attention to the current state of genetic privacy in the U.S., and just how many millions of Americans are exposed. While in this instance the issue has emerged in the context of a company going bankrupt, there are many other ways in which genetic privacy is at risk. Americans deserve more protection for their genetic privacy, and there are some good models for possible legislation in this space for this Committee to consider. Chairman Grassley, Ranking Member Durbin, Members of the Committee, I am appreciative of

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[31] S.5433. https://www.congress.gov/bill/118th-congress/senate-bill/5433/text/is

[32] https://www.grassley.senate.gov/imo/media/doc/dont_sell_my_dna_act.pdf

your focus on this important issue, and I thank you for the opportunity to testify before you today. I look forward to answering your questions.