

**A D D E N D U M**  
**to**  
**23 AND YOU: THE PRIVACY AND  
NATIONAL SECURITY IMPLICATIONS  
OF THE 23ANDME BANKRUPTCY**

**This Addendum is available at:**

*<https://www.govinfo.gov/content/pkg/CHRG-119shrg61889/pdf/CHRG-119shrg61889-add1.pdf>*

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June 9, 2025

Senator Chuck Grassley  
135 Hart Senate Office Building  
Washington, DC 20510

Dear Chairman Grassley, Ranking Member Durbin, and other distinguished members of the Judiciary Committee:

We are law professors with expertise in bioethics, privacy, and health law, and we write to express our concerns about gaps in genetic privacy law that have been highlighted by the possible sale of certain assets currently held by 23andMe (including 23andMe Holding Co. and affiliated debtors) as part of its bankruptcy proceeding. The views expressed here are our own and do not necessarily reflect the positions of our employing institutions.

### **23andMe's Business and Relevant Assets**

Similar to other companies in the market, 23andMe operated a direct-to-consumer DNA analysis service. Consumers would buy a kit from 23andMe (or an affiliated seller), fill a testing device with saliva, and ship the kit back to 23andMe.<sup>1</sup> Once in possession of the saliva sample, 23andMe (or its laboratory partner) would extract DNA from cells in the sample, genotype or sequence significant portions of that DNA, analyze the resulting data, and make the results of that analysis available to the consumer who registered the kit on 23andMe's website.<sup>2</sup> Residual saliva would either be retained by the lab or destroyed.<sup>3</sup> Data developed through 23andMe could include estimates of geographic ancestry, health risks to the consumer or potential future children, and other traits.<sup>4</sup> Consumers were invited to opt in to the DNA Relatives feature, which "allows you to find and connect with genetic relatives and see specific DNA segments you share with them."<sup>5</sup> In addition, consumers were invited to opt in to allow their genetic data to be used in research.<sup>6</sup> As part of this research effort, consumers were asked to complete survey questions online, which

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<sup>1</sup> *Where to Buy 23andMe DNA Test Kit?*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/115014501108-Where-to-Buy-23andMe-DNA-Test-Kit>.

<sup>2</sup> *How Does 23andMe Genotype My DNA?*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/202904610-How-Does-23andMe-Genotype-My-DNA>; *Difference Between DNA Genotyping & Sequencing*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/202904600-Difference-Between-DNA-Genotyping-Sequencing>.

<sup>3</sup> *Privacy*, 23ANDME, <https://www.23andme.com/privacy/>.

<sup>4</sup> *What You Can Learn*, 23ANDME, <https://customercare.23andme.com/hc/en-us/sections/200565460-What-You-Can-Learn>.

<sup>5</sup> *What Ancestry Information Can I Learn from 23andMe?*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/115013846688-What-Ancestry-Information-Can-I-Learn-from-23andMe>.

<sup>6</sup> *Becoming Part of Something Bigger*, 23ANDME, <https://www.23andme.com/research/>.

would be linked with their genetic data.<sup>7</sup> Finally, consumers had the option to allow 23andMe to store their samples, called biospecimens, into the future.<sup>8</sup>

23andMe's dataset for sale includes personal information from over 15 million consumers.<sup>9</sup> Importantly, this dataset includes genetic information as well as other personal details, such as samples, broad self-reported data related to health or other behavioral variables, and registration information, including consumers' addresses and credit card information.<sup>10</sup> A dataset of this magnitude requires heightened protection in terms of privacy and security, and 23andMe itself struggled to keep this data protected, suffering a data privacy breach in 2023.<sup>11</sup>

### **Federal and State Privacy Laws Offer Insufficient Protection for Most 23andMe Consumers**

23andMe promises consumers that “potential buyers must, among other requirements, agree to comply with 23andMe's consumer privacy policy and all applicable laws.”<sup>12</sup> However, if the applicable laws provide insufficient protection for consumers, then consumers can only rely on a buyer's promises in the privacy policy, which can be changed after the sale (see more below). The Health Insurance Portability and Accountability Act (HIPAA) is a key federal law in the U.S. that protects the use and disclosure of certain health information. However, HIPAA is limited in its scope and applies to “covered entities” (e.g., most healthcare providers) and their “business associates,” but it typically does *not* apply to direct-to-consumer genetic testing companies like 23andMe or biotechnology companies like Regeneron.<sup>13</sup> In contrast to other jurisdictions like the EU, the U.S. does *not* have a federal privacy law that comprehensively protects Americans' personal information and gives them numerous rights over their data, such as the right to erasure.<sup>14</sup>

Some protection exists for 23andMe consumers under U.S. state laws. A minority of states have enacted general data privacy laws in recent years, such as

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<sup>7</sup> *Becoming Part of Something Bigger*, 23ANDME, <https://www.23andme.com/research/>.

<sup>8</sup> *Privacy Statement*, 23ANDME, <https://www.23andme.com/legal/privacy/full-version/>.

<sup>9</sup> *An Open Letter to 23andMe Customers*, 23ANDME, <https://blog.23andme.com/articles/open-letter>.

<sup>10</sup> *Privacy Statement*, 23ANDME, <https://www.23andme.com/legal/privacy/full-version/>

<sup>11</sup> 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>.

<sup>12</sup> News Release, 23andMe, 23andMe Confirms All Potential Buyers Must Agree to Comply with Privacy Policy and Applicable Law (Mar. 26, 2025), <https://www.globenewswire.com/news-release/2025/03/26/3050213/0/en/23andMe-Confirms-All-Potential-Buyers-Must-Agree-to-Comply-With-Privacy-Policy-and-Applicable-Law.html>.

<sup>13</sup> Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *Bankruptcy, Genetic Information, and Privacy—Selling Personal Information*, 392 NEW ENG. J. MED. 937 (2025) ; Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *23andMe's Bankruptcy Raises Concerns About Privacy in the Era of Big Data*, 389 *BMJ* r1071 (2025), <https://www.bmj.com/content/389/bmj.r1071.full.pdf>

<sup>14</sup> Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *23andMe's Bankruptcy Raises Concerns About Privacy in the Era of Big Data*, 389 *BMJ* r1071 (2025), <https://www.bmj.com/content/389/bmj.r1071.full.pdf>.

California, Colorado, and Delaware.<sup>15</sup> A number of states have also adopted a model Genetic Information Privacy Act, which regulates how direct-to-consumer genetic testing companies handle sensitive data.<sup>16</sup> These laws generally apply only to direct-to-consumer genetic testing companies, defined as “an entity 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.”<sup>17</sup> If the buyer does not meet this definition, these privacy protections may no longer be applicable.

### **After a Sale, a Buyer Could Change the Terms of Service and Privacy Policy**

In the absence of comprehensive privacy protections, a company’s terms of service and privacy policy govern. Therefore, most Americans are dependent on what 23andMe and its future buyer promise.<sup>18</sup> 23andMe has stated that a buyer must comply with its consumer privacy policy,<sup>19</sup> but the privacy policy allows a buyer to change those terms following the sale. Generally, companies maintain the right to unilaterally change the terms.<sup>20</sup> In its terms of service, 23andMe “reserves the right at any time to modify or discontinue, temporarily or permanently, the Services (or any part thereof) with or without notice.”<sup>21</sup> Moreover, 23andMe’s terms of service state, “Notices to you may be made via either email or regular mail. 23andMe may also provide notices of changes to the Terms or other matters by displaying notices or links to notices to you generally on or through the Services.”<sup>22</sup> Additionally, 23andMe’s current privacy policy provides, “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

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<sup>15</sup> *State Privacy Law Chart*, IAPP, <https://iapp.org/resources/article/us-state-privacy-legislation-tracker/#state-privacy-law-chart>.

<sup>16</sup> Anya E.R. Prince, *The Genetic Information Privacy Act: Drawbacks and Limitations*, 330 JAMA 2049 (2023), <https://jamanetwork.com/journals/jama/fullarticle/2811606>;

<sup>17</sup> Utah 2021 SB227 Genetic Information Privacy Act

<sup>18</sup> Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *Bankruptcy, Genetic Information, and Privacy—Selling Personal Information*, 392 NEW ENG. J. MED. 937 (2025) ; Sara Gerke, Melissa B. Jacoby & I. Glenn Cohen, *23andMe’s Bankruptcy Raises Concerns About Privacy in the Era of Big Data*, 389 *BMJ* r1071 (2025). <https://www.bmj.com/content/389/bmj.r1071.full.pdf>

<sup>19</sup> News Release, 23andMe, 23andMe Confirms All Potential Buyers Must Agree to Comply with Privacy Policy and Applicable Law (Mar. 26, 2025), <https://www.globenewswire.com/news-release/2025/03/26/3050213/0/en/23andMe-Confirms-All-Potential-Buyers-Must-Agree-to-Comply-With-Privacy-Policy-and-Applicable-Law.html>.

<sup>20</sup> Jessica L. Roberts & Jim Hawkins, *When Health-Tech Companies Change Their Terms of Service*, Policy Forum, 367 SCIENCE 745 (2020); Leah R. Fowler, Jim Hawkins, & Jessica L. Roberts, *Uncertain Terms*, 97 NOTRE DAME L. REV. 1 (2021).

<sup>21</sup> *Other Things to Know: Modifications, Termination, and Survival*, 23ANDME, <https://www.23andme.com/legal/terms-of-service/#other-things-to-know>.

<sup>22</sup> *Other Things to Know: Modifications, Termination, and Survival*, 23ANDME, <https://www.23andme.com/legal/terms-of-service/#other-things-to-know>.

notification, or on another website page or feature.”<sup>23</sup> Consumers, however, rarely read terms of service or privacy policies in full or check back for updates.<sup>24</sup>

### **Genetic Data Is Private, Sensitive Data that Merits Protection**

Genetic data is sensitive, personal, and presumptively private<sup>25</sup>—and using a service like 23andMe should not forfeit that privacy.<sup>26</sup> The data developed by direct-to-consumer genetic testing companies, like 23andMe, can inform assessments about an individual’s identity, genetic relatedness, physical traits, and even potential health risks. While other data sources may be *about* people, genetic data, in a very real sense, *is* people. Given the unique nature of one’s genetic code, there are risks of reidentifying individuals from their data, even after their names and other identifying information are removed.<sup>27</sup> Moreover, the family-tree building power of consumer genetics data means that a database of 15 million people makes hundreds of millions, if not billions, of people indirectly identifiable.<sup>28</sup> Robust privacy protection for genetic data is therefore even more essential, since it is only the consumers, and not their genetic relatives, who give consent.

### **Genetic Data is Susceptible to Misuse and Discrimination**

The privacy of genetic information is all the more important given gaps in U.S. discrimination law. The federal Genetic Information Nondiscrimination Act (GINA) prohibits discrimination in health insurance and employment but does not regulate the use of genetic information by other entities. One area of concern is how life, long-term care, and disability insurers can underwrite based on genetic information, potentially leaving individuals uninsurable based on their genetic predispositions. State law creates a patchwork of regulation, but only Florida bars all three insurers from considering genetic information in underwriting.<sup>29</sup> Thus, if a buyer decides to change the privacy policy after the sale, sharing genetic data with life, long-term care, and disability insurers would not be protected under GINA and could be legally permissible in most states.

Additionally, law enforcement access to or use of genetic data stored by 23andMe would be a betrayal of consumers’ trust. Since the 2018 arrest of Joseph

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<sup>23</sup> *Other Things to Know About Privacy*, 23ANDME, <https://www.23andme.com/legal/privacy/#other-things-to-know>.

<sup>24</sup> See Natalie Ram, *Genetic Privacy After Carpenter*, 105 VA. L. REV. 1357, 1397 (2019).

<sup>25</sup> Natalie Ram, *Genetic Privacy After Carpenter*, 105 VA. L. REV. 1357, 1382-84 (2019); Natalie Ram, *DNA By The Entirety*, 115 COLUM. L. REV. 873, 891-98 (2015).

<sup>26</sup> Natalie Ram, *Genetic Privacy After Carpenter*, 105 VA. L. REV. 1357, 1381-95 (2019); Natalie Ram, *DNA By The Entirety*, 115 COLUM. L. REV. 873, 891-98 (2015).

<sup>27</sup> Kayte Spector-Bagdady, “*The Google of Healthcare*”: *Enabling the Privatization of Genetic Bio/Databanking*, 26 ANN. EPIDEMIOLOG. 515 (2016).

<sup>28</sup> Natalie Ram, *Investigative Genetic Genealogy and the Problem of Familial Forensic Identification*, at 219, in CONSUMER GENETIC TECHNOLOGIES: ETHICAL AND LEGAL CONSIDERATIONS (I. Glenn Cohen, Nita Farahany, Henry T. Greely & Carmel Shachar, eds.) (Cambridge Univ. Press 2021).

<sup>29</sup> Jarrod O. Anderson, Anna C. Lewis & Anya E. Prince, *The Problems with Patchwork: State Approaches to Regulating Insurer Use of Genetic Information*, 22 DEPAUL J. HEALTH CARE L. (2021).

James DeAngelo as the Golden State Killer, who was identified as a suspect following uploading of crime scene DNA to several other consumer genetics platforms, 23andMe has assured consumers that “we will closely scrutinize all law enforcement requests and we will only comply with court orders, subpoenas, or search warrants that we determine are legally valid—we are prepared to exhaust available legal remedies to protect customer privacy.”<sup>30</sup> 23andMe marketed itself, in part, based on its commitment to resist law enforcement access.<sup>31</sup> Yet, the scale of 23andMe’s genetic data makes it a tempting target for law enforcement. Law enforcement could seek access to or use of 23andMe consumers’ genetic data in a number of ways, including coordinating directly with the buyer of those assets or if the buyer permits consumers to upload genetic data developed elsewhere. Despite its own contrary guidance,<sup>32</sup> the FBI has uploaded casework DNA profiles to platforms that permit third-party uploads but do not authorize that pathway for law enforcement.<sup>33</sup>

### **Biospecimens Merit at Least as Much Protection as Genetic Data**

As discussed above, the genetic data held by 23andMe is derived from the spit sample that consumers originally provided to the company. This means that 23andMe is in possession of not only the consumer’s genomic and potentially survey data, but also potentially their saliva specimen. While 23andMe has an explicit consent for specimen storage,<sup>34</sup> it is unclear what share of consumers have requested 23andMe destroy their residual saliva specimen. 23andMe’s privacy policy, terms of service, or biobanking consent document<sup>35</sup> do not speak to the sale of those biospecimens, even as these policies were amended to account for bankruptcy-related sale of related data. Specifically, 23andMe’s terms of service provide, “If we are involved in a bankruptcy, merger, acquisition, reorganization, or sale of assets, your Personal Information may be accessed, sold or transferred as part of that transaction and this Privacy Statement will apply to your Personal Information as transferred to the new entity.”<sup>36</sup> Personal Information, in turn, is defined to include the information stemming from the biospecimen.<sup>37</sup> But these policies do not address the residual spit

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<sup>30</sup> *Transparency Report*, 23ANDME, <https://www.23andme.com/transparency-report/>

<sup>31</sup> Natalie Ram, *Genetic Privacy After Carpenter*, 105 VA. L. REV. 1357, 1406-11 (2019) (describing 23andMe’s emphasis on refusing law enforcement use following the Golden State Killer case).

<sup>32</sup> U.S. DEP’T OF JUSTICE, INTERIM POLICY: FORENSIC GENETIC GENEALOGICAL DNA ANALYSIS AND SEARCHING (approved Sept. 2, 2019), <https://www.justice.gov/olp/page/file/1204386/dl>.

<sup>33</sup> Mike Baker, *To Identify Suspect in Idaho Killings, F.B.I. Used Restricted Consumer DNA Data*, N.Y. TIMES (Feb. 25, 2025), <https://www.nytimes.com/2025/02/25/us/idaho-murders-bryan-kohberger-dna.html>.

<sup>34</sup> *Your Privacy Settings and Controls*, 23ANDME, <https://www.23andme.com/legal/privacy/#your-privacy-controls>.

<sup>35</sup> *Biobanking Consent Document*, 23ANDME, <https://www.23andme.com/about/biobanking/>

<sup>36</sup> *Data Sharing*, 23ANDME, <https://www.23andme.com/legal/privacy/#data-sharing>.

<sup>37</sup> *The Information 23andMe Collects*, 23ANDME, <https://www.23andme.com/legal/privacy/#information-we-collect> (defining, among “Personal Information we collect,” “Sample Information: information regarding any sample, such as a saliva sample, that you submit for processing to be analyzed to provide you with Genetic Information, laboratory values or other data provided through our Services”).

sample itself. Nonetheless, in addition to genomic information, these saliva samples contain a wide range of biomolecules associated with health information such as infectious diseases (e.g., COVID-19) and other systemic diseases (e.g., Crohn's).<sup>38</sup>

If 23andMe consumers consent to research, the Research Consent form states that, in addition to its typical Single Nucleotide Polymorphism (SNP) analysis (which assesses variations at a predetermined set of locations in the genome),<sup>39</sup> it might conduct whole genome sequencing (WGS) on the sample.<sup>40</sup> WGS not only generates much more genomic information than SNP analyses, but can also make the data more identifiable.<sup>41</sup> 23andMe also states it may analyze microbiome data which can “provide a snapshot of the trillions of microbes found in a human body, which may influence health and wellness.”<sup>42</sup>

23andMe consumers are asked if they would like to have their biospecimen destroyed after their genetic data is analyzed “subject to laboratory legal and regulatory requirements.”<sup>43</sup> Its Biobanking Consent adds that “samples are stripped of personal identifiers (i.e. name and contact information).”<sup>44</sup> But, despite the fact that people report wanting to be clearly notified of commercial use of their specimens<sup>45</sup> and are often confused by disclosures regarding specimen commercialization,<sup>46</sup> they must read four different documents (Privacy Statement,<sup>47</sup> Biobanking Consent Document,<sup>48</sup> Research Consent Document,<sup>49</sup> and the Terms of Service<sup>50</sup>) to understand what may be done with their specimen, which can be confusing.<sup>51</sup>

The disposition of biospecimens for research caught the public eye with the publication of the 2010 *The Immortal Life of Henrietta Lacks* about an important cancer cell line derived from an impoverished, Black patient’s sample without her

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<sup>38</sup>Janice M. Yoshizawa et al., *Salivary Biomarkers: Toward Future Clinical and Diagnostic Utilities*, 26 CLIN. MICROBIOL. REV. 781 (2013).

<sup>39</sup> *How 23andMe Reports Genotypes*, 23ANDME, <https://customercare.23andme.com/hc/en-us/articles/212883677-How-23andMe-Reports-Genotypes>

<sup>40</sup> *Research Consent Document*, 23ANDME, <https://www.23andme.com/about/consent/>

<sup>41</sup> Mara Thomas et al., *Assessing Privacy Vulnerabilities in Genetic Data Sets: Scoping Review*, 5 JMIR BIOINFORM. BIOTECHNOL. e54332 (2024).

<sup>42</sup> *Research Consent Document*, 23ANDME, <https://www.23andme.com/about/consent/>

<sup>43</sup> *Privacy Statement*, 23ANDME, <https://www.23andme.com/legal/privacy/full-version/>

<sup>44</sup> *Biobanking Consent Document*, 23ANDME, <https://www.23andme.com/about/biobanking/>

<sup>45</sup> Kayte Spector-Bagdady et al., *Reported Interest in Notification Regarding Use of Health Information and Biospecimens*, 328 JAMA 474 (2022)

<sup>46</sup> Kayte Spector-Bagdady et al., “*My Research Is Their Business, but I’m Not Their Business*”: Patient and Clinician Perspectives on Commercialization of Precision Oncology Data, 25 ONCOLOGIST 620 (2020).

<sup>47</sup> *Privacy Statement*, 23ANDME, <https://www.23andme.com/legal/privacy/full-version/>

<sup>48</sup> *Biobanking Consent Document*, 23ANDME, <https://www.23andme.com/about/biobanking/>

<sup>49</sup> *Research Consent Document*, 23ANDME, <https://www.23andme.com/about/consent/>

<sup>50</sup> *Terms of Service*, 23ANDME, <https://www.23andme.com/legal/terms-of-service/>

<sup>51</sup> Kayte Spector-Bagdady, “*The Google of Healthcare*”: Enabling the Privatization of Genetic Bio/Databanking, 26 ANN. EPIDEMIOLOG. 515 (2016).

explicit consent.<sup>52</sup> Backlash over unconsented research use of specimens reached such a furor<sup>53</sup> that the federal government briefly considered offering more protections for specimens than data in federally funded work because of a “distinct autonomy interest in research using biospecimens.”<sup>54</sup> In fact, many individuals express discomfort with commercial use of their specimens, even when they are de-identified.<sup>55</sup> They are particularly concerned when commercial interests share genomic information with additional parties for profit,<sup>56</sup> and have reported that they would like to be able to choose specifically *which* commercial companies to share with.<sup>57</sup> This has led major academic medical centers to change their specimen sharing policies to be more protective of patients.<sup>58</sup>

## Conclusion

In view of the foregoing concerns, we encourage Congress to act to robustly protect the genetic data and biospecimens of all Americans. We thank the committee for bringing attention to this important matter and welcome continued conversation in how to strengthen federal protections. Thank you for this opportunity to submit this written testimony. We appreciate your consideration of these comments.

Sincerely,

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<sup>52</sup> REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* (2010).

<sup>53</sup> Kayte Spector-Bagdady et al., *Biospecimens, Research Consent, and Distinguishing Cell Line Research*, 5 *JAMA ONCOL.* 406 (2019)

<sup>54</sup> Federal Policy for the Protection of Human Subjects, 80 *Fed. Reg.* 53,933, 53,942 (2015).

<sup>55</sup> Kayte Spector-Bagdady et al., *Reported Interest in Notification Regarding Use of Health Information and Biospecimens*, 328 *JAMA* 474 (2022); Kayte Bagdady et al., *Respecting Autonomy and Enabling Diversity: The Effect of Eligibility and Enrollment on Research Data Demographics*, 40 *HEALTH AFFS.* 1892 (2021).

<sup>56</sup> Kayte Spector-Bagdady et al., “*My Research Is Their Business, but I’m Not Their Business*”: *Patient and Clinician Perspectives on Commercialization of Precision Oncology Data*, 25 *ONCOLOGIST* 620 (2020).

<sup>57</sup> Kayte Spector-Bagdady et al., *Lessons for a Learning Health System: Effectively Communicating to Patients About Research with Their Health Information and Biospecimens*, 13 *LEARNING HEALTH SYS.* e10450 (2024).

<sup>58</sup> Kayte Bagdady et al., *Sharing Health Data and Biospecimens with Industry—A Principle-Driven, Practical Approach*, 382 *NEW ENG. J. MED.* 2072 (2020).

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June 10, 2025

Chairman Chuck Grassley  
Ranking Member Dirk Durbin  
United States Senate Committee on the Judiciary  
224 Dirksen Senate Office Building  
Washington, DC 20510.

**Re: CAIDP Statement for the Record: *23 and You: The Privacy and National Security Implications of the 23andMe Bankruptcy***

Dear Chairman Grassley, Ranking Member Durbin, and Members of the Committee,

The Center for AI and Digital Policy (CAIDP) welcomes the Committee’s hearing and submits this statement for the record concerning the critical privacy and national security issues arising from 23andMe’s bankruptcy and subsequent sale.<sup>1</sup> “Companies create assurances of protection, run into financial troubles, seek protection under bankruptcy law, and then sell their customers’ data to the highest bidder.”<sup>2</sup>

In May 2025, 23andMe announced it had sold all its assets, including the entire genetic database of approximately 15 million customers, to the pharmaceutical company Regeneron for \$256 million.<sup>3</sup> This sale transferred an enormous trove of uniquely personal, identifying DNA data to a third party without those individuals’ meaningful consent, raising alarms about privacy and potential misuse. An earlier data breach at 23andMe compromised the ancestry and health-related genetic information of millions of users.<sup>4</sup>

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<sup>1</sup> United States Senate Committee on the Judiciary, *23 and You: The Privacy and National Security Implications of the 23andMe Bankruptcy* (Jun. 11, 2025), <https://www.judiciary.senate.gov/committee-activity/hearings/23-and-you-the-privacy-and-national-security-implications-of-the-23andme-bankruptcy>

<sup>2</sup> Testimony of Marc Rotenberg before the Committee on Commerce, Science, and Transportation, United States Senate on S. 2201, *The Online Personal Privacy Act* (April 25, 2002).

<sup>3</sup> Reuters, *Regeneron to buy bankrupt 23andMe, vows ethical use of customer DNA data* (Jun. 2, 2025), <https://www.reuters.com/business/healthcare-pharmaceuticals/regeneron-buy-bankrupt-genetic-testing-firm-23andme-256-million-2025-05-19/>

<sup>4</sup> Reuters, *Regeneron to buy bankrupt 23andMe, vows ethical use of customer DNA data* (Jun. 2, 2025), <https://www.reuters.com/business/healthcare-pharmaceuticals/regeneron-buy-bankrupt-genetic-testing-firm-23andme-256-million-2025-05-19/>; See also, United States Supreme Court, *Brief for States of Montana, Virginia, and 20 Other States as Amici Curiae in Support of Respondent in Tiktok Inc.et.al vs. Merrick B. Garland, Attorney General*, pg. 13, “[I]n October 2023, hackers stole the ancestry data of almost seven million of 23andMe’s customers, apparently targeting users of Ashkenazi Jewish descent”.

Whether exposed to a cyber breach or a bankruptcy sale, personal data should not be left in the hands of predatory actors or the highest bidder. The 23andMe bankruptcy is one more reminder that Congress and the FTC need to address the data collection and monetization practices of businesses. CAIDP urges Congress and the Federal Trade Commission to safeguard Americans' sensitive personal data from misuse, particularly when personal data may be transferred from a bankrupt firm. We offer three overarching recommendations:

1. Require companies that declare bankruptcy to obtain meaningful, opt-in consent before the personal data acquired by the firm is transferred to another entity
2. Demand that the Federal Trade Commission (FTC), conclude its investigation of OpenAI, a complaint now pending before the Commission for over two years.
3. Enact federal privacy legislation that would establish baseline safeguards of data minimization, purpose limitation, and data deletion practices to protect Americans' privacy

### ***About CAIDP***

The Center for AI and Digital Policy (“CAIDP”) is an independent research and education organization, based in Washington, D.C.<sup>5</sup> CAIDP’s mission is to ensure that artificial intelligence (AI) serve the public interest based on fundamental rights, democratic institutions, and the rule of law. CAIDP routinely provides nonpartisan advice to Congressional committees on matters involving AI and privacy.<sup>6</sup>

### ***Privacy Protections and AI***

Since 2018, 23andMe has been selling user data to third-party companies<sup>7</sup> for further commercialization and business expansion into therapeutics and drug development,<sup>8</sup> personalized telehealth services, and market research services.<sup>9</sup>

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[https://www.supremecourt.gov/DocketPDF/24/24-656/336145/20241227161330787\\_130828\\_Brief%20of%20Amici.pdf](https://www.supremecourt.gov/DocketPDF/24/24-656/336145/20241227161330787_130828_Brief%20of%20Amici.pdf)

<sup>5</sup> CAIDP, <https://www.caidp.org/>

<sup>6</sup> CAIDP, *Statements*, <https://www.caidp.org/statements/>

<sup>7</sup> Forbes, *How DNA Companies Like Ancestry And 23andMe Are Using Your Genetic Data*, (Dec. 5, 2018), <https://www.forbes.com/sites/nicolemartin1/2018/12/05/how-dna-companies-like-ancestry-and-23andme-are-using-your-genetic-data/>

<sup>8</sup> 23andMe, *Partner*, [https://www.23andme.com/partner/?srsltid=AfmBOopB0PEjSMIFfu5d0xdBhX--5S8Zq6slFn2zpKPV5fJhYq\\_NY\\_J](https://www.23andme.com/partner/?srsltid=AfmBOopB0PEjSMIFfu5d0xdBhX--5S8Zq6slFn2zpKPV5fJhYq_NY_J); 23andMe, *23andMe Launches Discover23 to Help Accelerate Large-Scale Genetics Research For Biopharma Collaborators, Powered By Lifebit's Trusted Technology*, Press Release, (Jan. 8, 2025), <https://investors.23andme.com/news-releases/news-release-details/23andme-launches-discover23-help-accelerate-large-scale-genetics>

<sup>9</sup> Securities and Exchange Commission (SEC), *23andMe Holding Co. Form 10-K*, (Mar. 31, 2024), <https://www.sec.gov/ix?doc=/Archives/edgar/data/0001804591/000180459124000038/me-20240331.htm>

The Bipartisan House AI Task Force warned that AI’s hunger for information can exacerbate privacy harms, inferring sensitive attributes even from legally obtained data and embedding them permanently in models.<sup>10</sup> Indeed, many businesses (including AI developers) are still largely unrestricted in the types of sensitive information they can collect, how they use or share it, and how long they retain it, leaving individuals with few rights or remedies against encroachments.<sup>11</sup>

Genetic and biometric data magnify these risks: DNA is immutable and uniquely identifying, and once incorporated into an AI training set, it can never be “altered once compromised.”<sup>12</sup> The risks are not overstated; 23andMe states:

Our analyses may highlight new connections between human populations, identify genetic and non-genetic factors that predict disease risk or drug response, or reveal the biological pathways underlying disease. These insights may then be used to develop new features for customers to enhance their health, wellness, and medical care, (including care accessed through our Lemonaid telehealth platform), and to support genetically-informed drug target discovery and validation.<sup>13</sup>

AI’s unbounded data acquisition amplifies every privacy risk, but the risk of exposure of genetic information underscores the need for guardrails and enforcement. As TIME reported, 23andMe’s vast genetic repository represents a “gold mine” for AI firms seeking to improve their predictive algorithms, who are incentivized to use an “abnormally large and nuanced data set.”<sup>14</sup> Moreover, these firms have insufficient governance frameworks in place.<sup>15</sup> Without any action against the use of genetic data, AI can expose and weaponize our most intimate personal details, endangering civil liberties and national security.

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23andMe, Personalized Recommendations, <https://customercare.23andme.com/hc/en-us/articles/9295505340183-Personalized-Recommendations>; Lemonaid Health, <https://www.lemonaidhealth.com/>;

<sup>10</sup> 118th Congress, *Bipartisan House Task Force Report on Artificial Intelligence*, (Dec. 2024), pg 36, <https://www.speaker.gov/wp-content/uploads/2024/12/AI-Task-Force-Report-FINAL.pdf>

<sup>11</sup> 118th Congress, *Bipartisan House Task Force Report on Artificial Intelligence*, (Dec. 2024), pg 38, <https://www.speaker.gov/wp-content/uploads/2024/12/AI-Task-Force-Report-FINAL.pdf>

<sup>12</sup> Andrew Chow, TIME, *Why 23andMe’s Genetic Data Could Be a ‘Gold Mine’ for AI Companies* (Mar. 25, 2025), <https://time.com/7271463/23andme-data-ai-bankruptcy/>

<sup>13</sup> Securities and Exchange Commission (SEC), *23andMe Holding Co. Form 10-K*, (Mar. 31, 2024), <https://www.sec.gov/ix?doc=/Archives/edgar/data/0001804591/000180459124000038/me-20240331.htm>

<sup>14</sup> Andrew Chow, TIME, *Why 23andMe’s Genetic Data Could Be a ‘Gold Mine’ for AI Companies* (Mar. 25, 2025), <https://time.com/7271463/23andme-data-ai-bankruptcy/>

<sup>15</sup> Andrew Chow, TIME, *Why 23andMe’s Genetic Data Could Be a ‘Gold Mine’ for AI Companies* (Mar. 25, 2025), <https://time.com/7271463/23andme-data-ai-bankruptcy/>

The gravity of these threats has not fallen on deaf ears. In April 2025, Senator Bill Cassidy sounded the alarm that 23andMe’s bankruptcy sale could permit foreign adversaries to access Americans’ genetic profiles, posing national security risks.<sup>16</sup> As such, “[s]afeguarding sensitive consumer data is a top goal to protect . . . national security.”<sup>17</sup> Senator Mark Warner similarly called for legislative action to safeguard personal data:

23andMe's users provided their sensitive, personal genetic data to a privately-owned U.S. company, potentially without fully understanding the implications of this data falling into the hands of adversaries, including cybercriminals and foreign nation-states. Further, the genetic information held in 23andMe's databank has implications for relatives of 23andMe users who share common genetic markers, creating additional privacy concerns for such individuals who had no opportunity to consent to how 23andMe's data could be used in ways that affect them.<sup>18</sup>

Chair Grassley with Senators Cornyn and Klobuchar introduced the *Don’t Sell My DNA Act* to safeguard consumers’ sensitive genetic data during corporate bankruptcy proceedings.<sup>19</sup> The bill aims to close loopholes in the current bankruptcy code which does not afford protections for genetic information during bankruptcy sales and was spurred by 23andMe’s bankruptcy.<sup>20</sup>

### **CAIDP Recommendations**

CAIDP offers the following recommendations for the Committee considering the unique privacy and national security concerns posed by genetic data and AI.

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<sup>16</sup> United States Senate, Committee on Health, Education, Labor and Pensions, *Chair Cassidy Sounds Alarm on 23andMe Bankruptcy, Foreign Adversaries Potentially Accessing Americans’ Genetic Data* (Apr. 9, 2025), <https://www.help.senate.gov/rep/newsroom/press/chair-cassidy-sounds-alarm-on-23andme-bankruptcy-foreign-adversaries-potentially-accessing-americans-genetic-data>

<sup>17</sup> United States Senate, Committee on Health, Education, Labor and Pensions, *Chair Cassidy Sounds Alarm on 23andMe Bankruptcy, Foreign Adversaries Potentially Accessing Americans’ Genetic Data* (Apr. 9, 2025), <https://www.help.senate.gov/rep/newsroom/press/chair-cassidy-sounds-alarm-on-23andme-bankruptcy-foreign-adversaries-potentially-accessing-americans-genetic-data>

<sup>18</sup> Mark Warner, *Print Warner, Young Push DOJ, FTC to Use Every Available Resource to Protect Americans’ Data Amid 23andMe Bankruptcy Proceedings* (Apr. 29, 2025), <https://www.warner.senate.gov/public/index.cfm/pressreleases?id=4F6A7E59-CD51-46EB-9FEB-3ABBCE62DF77>

<sup>19</sup> U.S. Senate Committee on the Judiciary, Grassley, *Cornyn Introduce Bipartisan Bill to Safeguard Consumers’ Genetic Data After 23andMe Bankruptcy Sparks Privacy Concerns*, Majority Press Release, (May 27, 2025), <https://www.judiciary.senate.gov/press/rep/releases/grassley-cornyn-introduce-bipartisan-bill-to-safeguard-consumers-genetic-data-after-23andme-bankruptcy-sparks-privacy-concerns>

<sup>20</sup> *Id.*

## 1. Require companies that declare bankruptcy to obtain meaningful, opt-in consent before transfer of personal data

The transfer of personal data of Americans is now a national security matter. The Department of Justice (DOJ) has published a rule preventing access to U.S. Sensitive Personal Data by Countries of Concern.<sup>21</sup> The DOJ stated “Americans generate a vast digital footprint that, without protective measures, countries of concern can weaponize to threaten our national security. These countries of concern can purchase or access American’s bulk sensitive personal data or government-related data through various commercial transactions and relationships.”<sup>22</sup> The prohibited transactions under DOJ’s rule are “are data brokerage and covered data transactions involving access to bulk human biometric data or human biospecimens from which such data can be derived.”<sup>23</sup>

Remarkably, 23andMe’s Privacy Statement states,

If we are involved in a bankruptcy, merger, acquisition, reorganization, or sale of assets, your Personal Information may be accessed, sold or transferred as part of that transaction and this Privacy Statement will apply to your Personal Information as transferred to the new entity. We may also disclose Personal Information about you to our corporate affiliates to help operate our services and our affiliates’ services.<sup>24</sup>

This statement leaves the company with broad authority to transfer the personal data of those who signed up for a genetic testing service to almost anyone for any purpose following bankruptcy. It is well-established that blanket and unintelligible privacy practices are woefully inadequate and meaningless causing “consent fatigue” rather than informed consent.<sup>25</sup> Some customers who tried to delete their data after the bankruptcy announcement said they received

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<sup>21</sup> Department of Justice, *Rule Preventing Access to U.S. Sensitive Personal Data and Government-Related Data by Countries of Concern or Covered Persons*, (Jan. 8, 2025), 90 FR 1636, 2024-31486, <https://www.federalregister.gov/documents/2025/01/08/2024-31486/preventing-access-to-us-sensitive-personal-data-and-government-related-data-by-countries-of-concern>

<sup>22</sup> Department of Justice, *FACT SHEET: Justice Department Issues Final Rule to Address Urgent National Security Risks Posed by Access to U.S. Sensitive Personal and Government-Related Data from Countries of Concern and Covered Person*, <https://www.justice.gov/archives/opa/media/1382526/dl>

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

<sup>25</sup> CAIDP, *Comment to FTC on COPPA*, (Mar. 11, 2024), [https://downloads.regulations.gov/FTC-2024-0003-0262/attachment\\_1.pdf](https://downloads.regulations.gov/FTC-2024-0003-0262/attachment_1.pdf); Marc Rotenberg, *Artificial Intelligence and Democratic Values: The Role of Data Protection*, *European Data Protection Law Review*, Issue. 4, pg. 496, 2021, <https://doi.org/10.21552/edpl/2021/4/6>

error messages, and the login portal of the company’s website went down. Those trying to resolve the issue reported long customer service wait times.<sup>26</sup>

More than 25 states have recently filed suit to block the sale of the personal data to Regeneron in 23andMe’s bankruptcy proceedings.<sup>27</sup> The states include Arizona, Colorado, Connecticut, the District of Columbia, Florida, Illinois, Kansas, Kentucky, Louisiana, Maine, Michigan, Minnesota, Missouri, New Hampshire, New Mexico, New York, North Carolina, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, Virginia, Washington, West Virginia and Wisconsin. Oregon Attorney General Dan Rayfield said:

This isn’t just data – it’s your DNA. It’s personal, permanent, and deeply private. People did not submit their personal data to 23andMe thinking their genetic blueprint would later be sold off to the highest bidder. We’re standing up in court to make sure Oregonians – and millions of others – keep the right to control their own genetic information.<sup>28</sup>

The FTC has previously issued orders for data/model deletion for ill-gotten personal data against and should enforce such remedies vigorously to address the serious privacy and national security risks of current data practices.<sup>29</sup> The FTC has not only ordered the deletion of data but also “any information or work product, including any algorithms or equations, that originated, in whole or in part, from that data.”<sup>30</sup>

<sup>26</sup> Wall Street Journal, *23andMe Is Bankrupt. Here’s What You Need to Know About Your Genetic Data*, (Mar. 25, 2025), <https://www.wsj.com/tech/biotech/23-and-me-bankruptcy-genetic-data-what-happens-625794fc?>

<sup>27</sup> U.S. News, *Dozens of States Sue to Block the Sale of 23andMe Personal Genetic Data Without Customer Consent*, (Jun. 9, 2025), <https://www.usnews.com/news/us/articles/2025-06-09/dozens-of-states-sue-to-block-the-sale-of-23andme-personal-genetic-data-without-customer-consent>

<sup>28</sup> Oregon Department of Justice, *Oregon in Multi-State Legal Fight to Protect Genetic Information in 23andMe Bankruptcy Case* (June 9, 2025), <https://www.doj.state.or.us/media-home/news-media-releases/oregon-in-multi-state-legal-fight-to-protect-genetic-information-in-23andme-bankruptcy-case/>

<sup>29</sup> Cyberscoop, *The FTC’s biggest AI enforcement tool? Forcing companies to delete their algorithms*, (Jul. 5, 2023), <https://cyberscoop.com/ftc-algorithm-disgorgement-ai-regulation/>

<sup>30</sup> Federal Trade Commission, *FTC Order Prohibits Data Broker X-Mode Social and Outlogic from Selling Sensitive Location Data*, Press Release, (Jan. 9, 2024), <https://www.ftc.gov/news-events/news/press-releases/2024/01/ftc-order-prohibits-data-broker-x-mode-social-outlogic-selling-sensitive-location-data>; Federal Trade Commission, *Rite Aid Banned from Using AI Facial Recognition After FTC Says Retailer Deployed Technology without Reasonable Safeguards*, Press Release, (Dec. 19, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/12/rite-aid-banned-using-ai-facial-recognition-after-ftc-says-retailer-deployed-technology-without>; Federal Trade Commission, *FTC Issues Opinion and Order Against Cambridge Analytica For Deceiving Consumers About the Collection of Facebook Data, Compliance with EU-U.S. Privacy Shield*, (Dec. 6, 2019), <https://www.ftc.gov/news-events/news/press-releases/2019/12/ftc-issues-opinion-order-against-cambridge-analytica-deceiving-consumers-about-collection-facebook>

Indeed, this is exactly what the proposed *Do Not Sell My DNA Act* requires.<sup>31</sup> While the bill moves forward in the legislative process and can future-proof protections for American’s sensitive data, action by the FTC is required now. This Committee should require the Federal Trade Commission to enforce “sensitive personal data and model deletion” for the 23andMe’s bankruptcy, and require meaningful, opt-in consent before transfer of personal data

## **2. Urge the Federal Trade Commission (FTC) hold AI companies accountable for unbounded data collection**

The FTC has acted against genetic testing companies that “failed to protect the privacy and security of DNA data” and changed their privacy policies retroactively,<sup>32</sup> highlighting the Commission’s focus on protecting biometric and genetic information. The FTC’s Biometric Information Policy explains that businesses who failed “to assess foreseeable harms to consumers before collecting biometric information” could be in violation of Section 5 of the FTC Act.<sup>33</sup> The policy statement also “mandates going monitoring of technologies . . . in connection with biometric information,” and the Committee should urge the FTC to exercise its authority to address privacy harms caused by AI-based practices monetizing genetic data.<sup>34</sup>

Chair Ferguson was swift to highlight the privacy risks of the 23andMe bankruptcy and underscore the need to maintain privacy protections through the bankruptcy proceedings.<sup>35</sup> As Chairman Ferguson detailed:

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<sup>31</sup> U.S. Senate Committee on the Judiciary, Grassley, *Cornyn Introduce Bipartisan Bill to Safeguard Consumers’ Genetic Data After 23andMe Bankruptcy Sparks Privacy Concerns*, Majority Press Release, (May 27, 2025), <https://www.judiciary.senate.gov/press/rep/releases/grassley-cornyn-introduce-bipartisan-bill-to-safeguard-consumers-genetic-data-after-23andme-bankruptcy-sparks-privacy-concerns>

<sup>32</sup> *Federal Trade Commission, FTC Says Genetic Testing Company 1Health Failed to Protect Privacy and Security of DNA Data and Unfairly Changed its Privacy Policy* (Jun. 16, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/06/ftc-says-genetic-testing-company-1health-failed-protect-privacy-security-dna-data-unfairly-changed>

<sup>33</sup> *Federal Trade Commission, FTC Warns About Misuses of Biometric Information and Harm to Consumers* (May 18, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/05/ftc-warns-about-misuses-biometric-information-harm-consumers>

<sup>34</sup> *Federal Trade Commission, FTC Warns About Misuses of Biometric Information and Harm to Consumers* (May 18, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/05/ftc-warns-about-misuses-biometric-information-harm-consumers>

<sup>35</sup> *Federal Trade Commission, Federal Trade Commission Chairman Andrew N. Ferguson Issues Letter on 23andMe Bankruptcy Impact to Consumers*, Press Release, (Mar. 31, 2025), <https://www.ftc.gov/news-events/news/press-releases/2025/03/federal-trade-commission-chairman-andrew-n-ferguson-issues-letter-23andme-bankruptcy-impact>

23andMe collects and holds sensitive, immutable, identifiable personal information about millions of American consumers who have used the Company’s genetic testing and telehealth services. This includes genetic information, biological DNA samples, health information, ancestry and genealogy information, personal contact information, payment and billing information, and other information, such as messages that genetic relatives can send each other through the platform.

Chairman Ferguson appeared largely assured that the privacy representations made by 23andMe would be upheld by the successor firm. But it remains entirely unclear at this point whether those who signed up for 23andMe and transferred their sensitive personal data to that firm would have agreed to provide their data to the firm that paid 23andMe \$256 million for the vast trove of personal data.

State AGs have also been sounding the alarm for consumers. AGs from states including Alabama, Arizona, California, Kentucky, New Hampshire, North Carolina and Texas issued similar press releases that recommended customers ask the company to delete their genetic profile and destroy the saliva sample used to create it.<sup>36</sup> But consumers should not be left with the daunting task of asking companies in bankruptcy that are transferring their personal data to not engage in such conduct. The burden should be on the firm to obtain opt-in consent prior to the transfer, if adequate data protection safeguard in law has been established. In the absence of legal safeguards, the company in bankruptcy should simply delete the personal data it had obtained.

Also concerning is the rapid deployment of generative AI built on personal data. 23andMe has integrated machine learning and more recently generative AI -based tools. Yet the company’s privacy statements are silent as to how privacy protections and data deletion is addressed in generative AI tools built upon the customers’ sensitive and personal data.

CAIDP highlighted the risks to privacy and public safety of AI-based services, in an earlier complaint to the FTC regarding ChatGPT.<sup>37</sup> Shortly afterward, both the *New York Times* and the *Wall Street Journal* reported that the FTC had opened the investigation CAIDP requested.<sup>38</sup> But two years have now passed, and the FTC still has not concluded the investigation or established necessary guardrails for AI services.

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<sup>36</sup> Oklahoma Voice, *23andMe users’ genetic data is at risk, state AGs warn*, (May 21, 2025), <https://oklahomavoice.com/2025/05/12/23andme-users-genetic-data-is-at-risk-state-ags-warn/>

<sup>37</sup> CAIDP, *In the Matter of OpenAI* Original Complaint (2023), <https://www.caidp.org/cases/openai/>

<sup>38</sup> *The New York Times*, *F.T.C. Opens Investigation Into ChatGPT Maker Over Technology’s Potential Harms* (Jul. 13, 2023), <https://www.nytimes.com/2023/07/13/technology/chatgpt-investigation-ftc-openai.html>

This Committee took note of the public safety concerns of AI-companies business practices when Senators Blumenthal and Hawley convened the hearing on *Insiders Perspective* last year.<sup>39</sup> Prompted by the OpenAI whistleblower reports Chair Grassley has also introduced the Artificial Intelligence (AI) Whistleblower Protection Act because the opaque business, employment, and privacy practices of AI companies continue unabated and those trying to shed light are being victimized.<sup>40</sup> Rep. Obernolte, Chair of the House AI Taskforce said “Protecting whistleblowers who report AI security vulnerabilities isn’t just about workplace fairness—it’s a matter of national security.”<sup>41</sup>

Chair Grassley is right – “Transparency brings accountability.”<sup>42</sup> We urge members of this Committee to demand that the FTC to conclude its investigation into ChatGPT and issue an order. The FTC’s order will be integral to preventing a future privacy and national security disaster greater than the 23andMe bankruptcy.<sup>43</sup>

### 3. Enact federal privacy legislation that would establish baseline safeguards

We are encouraged to see the bipartisan concern from the Senate and House on the risks of unregulated data transfers, especially when businesses commoditize American’s most sensitive personal data like genetic information.<sup>44</sup> Congress should act swiftly to pass baseline federal

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<sup>39</sup> U.S. Senate Committee on the Judiciary, Subcommittee on Privacy, Technology, and the Law, *Oversight of AI: Insiders’ Perspectives* (Sept. 17, 2024), <https://www.judiciary.senate.gov/committee-activity/hearings/oversight-of-ai-insiders-perspectives>; S.Hrg. 118-37 — OVERSIGHT OF A.I.: RULES FOR ARTIFICIAL INTELLIGENCE (2025), <https://www.congress.gov/event/118th-congress/senate-event/LC71543/text>.

<sup>40</sup> U.S. Senate Committee on the Judiciary, *Grassley Introduces AI Whistleblower Protection Act*, Majority Press Release, (May 15, 2025), <https://www.judiciary.senate.gov/press/rep/releases/grassley-introduces-ai-whistleblower-protection-act>

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*

<sup>43</sup> See, CAIDP, *Statement to Senate Commerce Committee on the Nomination of Mark Meador as Commissioner of the FTC*, (Feb. 21, 2025), <https://www.linkedin.com/posts/center-for-ai-and-digital-policy-caidp-senate-commerce-ai-ftc-meadorfebruary-activity-7299138737165271040-DH03?>

<sup>44</sup> U.S. House of Representatives, Committee on Oversight and Government Reform, *Comer Launches Investigation into 23andMe Bankruptcy, Seeks Testimony to Protect Americans’ Personal DNA Data*, Press Release, (Apr. 15, 2025), [comer-launches-investigation-into-23andme-bankruptcy-seeks-testimony-to-protect-americans-personal-dna-data](https://www.house.gov/committees/oversight-and-government-reform/comer-launches-investigation-into-23andme-bankruptcy-seeks-testimony-to-protect-americans-personal-dna-data); U.S. Senate Health, Education, Labor, & Pensions Committee, *Chair Cassidy Sounds Alarm on 23andMe Bankruptcy, Foreign Adversaries Potentially Accessing Americans’ Genetic Data*, Press Release, (Apr. 9, 2025), [chair-cassidy-sounds-alarm-on-23andme-bankruptcy-foreign-adversaries-potentially-accessing-americans-genetic-data](https://www.senate.gov/committees/health-education-labor-and-pensions/committee-chair-cassidy-sounds-alarm-on-23andme-bankruptcy-foreign-adversaries-potentially-accessing-americans-genetic-data)

privacy legislation and would establish essential safeguards of data minimization, purpose limitation, and data deletion practices to protect Americans’ privacy.<sup>45</sup>

Baseline safeguards establishing data minimization requirements would set the right incentives to deter the temptation to commoditize personal data, particularly sensitive personal data like genetic data. Requiring the implementation purpose limitation practices and privacy enhancing techniques would help safeguard personal data transfers.<sup>46</sup>

More importantly, federal privacy legislation would help ensure all American’s benefit from privacy protections<sup>47</sup> and would prevent businesses from unfairly putting the onus on individuals to investigate and track how their data is being used across a myriad of increasingly AI-driven services and products.

CAIDP urges the Senate Judiciary Committee members who are also on the Senate Commerce Committee to advance federal privacy legislation, such as the Americans Privacy Rights Act,<sup>48</sup> and to extend more robust protections to biometric data aligned with the Federal Trade Commission’s Biometric Information Policy.<sup>49</sup> By safeguarding sensitive genetic information so it “cannot be weaponized against [Americans] or made public without their

<sup>45</sup> CAIDP, *Statement to House Oversight Committee on AI Regulation and the Future of US Leadership*, (May 20, 2025), <https://www.congress.gov/119/meeting/house/118288/documents/HHRG-119-IF17-20250521-SD003.pdf>; CAIDP, *Comment to House Energy and Commerce Committee Privacy Working Group*, (Apr. 11, 2025), [https://www.linkedin.com/posts/center-for-ai-and-digital-policy\\_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI?](https://www.linkedin.com/posts/center-for-ai-and-digital-policy_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI?)

<sup>46</sup> CAIDP, *Comment to House Energy and Commerce Committee Privacy Working Group*, (Apr. 11, 2025), [https://www.linkedin.com/posts/center-for-ai-and-digital-policy\\_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI?](https://www.linkedin.com/posts/center-for-ai-and-digital-policy_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI?); CAIDP, *Statement to OSTP on the Promotion of Privacy Enhancing Technologies (PETS)*, (Jul. 8, 2022), <https://s899a9742c3d83292.jimcontent.com/download/version/0/module/8402029763/name/CAIDP-PETS-OSTP-07082022.pdf>; CAIDP, *Statement to OSTP on a US AI Action Plan*, (Mar. 15, 2025), <https://files.nitrd.gov/90-fr-9088/CAIDP-AI-RFI-2025.pdf>

<sup>47</sup> See, 23andMe, *Privacy Statement*, (last updated Mar. 14, 2025), “For example, in the United States, residents of California and other states have specific privacy rights,” <https://www.23andme.com/legal/privacy/full-version/> [“23andMe Privacy Statement”]

<sup>48</sup> CAIDP, *Comment to House Energy and Commerce Committee Privacy Working Group*, (Apr. 11, 2025), [https://www.linkedin.com/posts/center-for-ai-and-digital-policy\\_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI](https://www.linkedin.com/posts/center-for-ai-and-digital-policy_caidp-hec-ai-privacy-and-security-april-activity-7317210152003067904-lksI); U.S. Senate Committee on Commerce, Science, & Transportation, *The American Privacy Rights Act of 2024 – Section by Section Summary*, (Apr. 2024), <https://www.commerce.senate.gov/services/files/E7D2864C-64C3-49D3-BC1E-6AB41DE863F5>

<sup>49</sup> Federal Trade Commission, *Policy Statement of the Federal Trade Commission on Biometric Information and Section 5 of the Federal Trade Commission Act*, [https://www.ftc.gov/system/files/ftc\\_gov/pdf/p225402biometricpolicystatement.pdf](https://www.ftc.gov/system/files/ftc_gov/pdf/p225402biometricpolicystatement.pdf)



knowledge and consent,”<sup>50</sup> Congress can directly address both privacy and national security concerns.<sup>51</sup>

We thank you for your consideration of our views. We ask that this statement be included in the hearing record. We would be pleased to provide you and your staff with additional information.

Sincerely,

Handwritten signature of Marc Rotenberg in blue ink.

Marc Rotenberg  
CAIDP Executive Director

Handwritten signature of Merve Hickok in blue ink.

Merve Hickok  
CAIDP President

Handwritten signature of Christabel Randolph in blue ink.

Christabel Randolph  
CAIDP Associate Director

Handwritten signature of Kevin Kim in blue ink.

Kevin Kim  
CAIDP Research Assistant

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<sup>50</sup> United States Senate, Senate Committee on the Judiciary, *Grassley, Cornyn Introduce Bipartisan Bill to Safeguard Consumers’ Genetic Data After 23andMe Bankruptcy Sparks Privacy Concerns* (May 27, 2025), <https://www.judiciary.senate.gov/press/rep/releases/grassley-cornyn-introduce-bipartisan-bill-to-safeguard-consumers-genetic-data-after-23andme-bankruptcy-sparks-privacy-concerns>; see also, U.S. Supreme Court, *Brief for States of Montana, Virginia, and 20 Other States as Amici Curiae in Support of Respondent in Tiktok, Inc. et al vs. Merrick B. Garland, Attorney General*, Pg. 13, “In October 2023, hackers stole the ancestry data of almost seven million of 23andMe’s customers, apparently targeting users of Ashkenazi Jewish descent.” [https://www.supremecourt.gov/DocketPDF/24/24-656/336145/20241227161330787\\_130828\\_Brief%20of%20Amici.pdf](https://www.supremecourt.gov/DocketPDF/24/24-656/336145/20241227161330787_130828_Brief%20of%20Amici.pdf)

<sup>51</sup> United States House of Representatives, Committee on Oversight and Government Reform, *Comer Launches Investigation into 23andMe Bankruptcy, Seeks Testimony to Protect Americans’ Personal DNA Data* (Apr. 15, 2025), <https://oversight.house.gov/release/comer-launches-investigation-into-23andme-bankruptcy-seeks-testimony-to-protect-americans-personal-dna-data/>