

## **DNA Privacy Policies**

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As biotechnology is advancing, more opportunities are becoming available to gain insights about personal information based on genetic discoveries. 23andMe and Ancestry are genetic testing companies that provide information based on individual's genome samples. To pursue the discovery of new information, sensitive personal information is required through personal accounts. With the surplus of information available in someone's account, there are policies in place that describe the handling procedures. The privacy policies on both sites describe how the information is protected with regards to processing of samples and sharing with other outside entities.

The policies are similar regarding genetic data protection and the connection to personally identifiable information (PII) for Ancestry and 23andMe. Both companies describe protecting genetic data through administrative, physical, and technical methods. Ancestry explains that they are partnered with security companies and encrypt personal information. This company describes themselves as global which they feel justifies their sharing of personal information to other countries such as Ireland, France, and the United Kingdom which may not follow the same privacy practices as the United States. I thought it was particularly interesting that Ancestry states that they are not a protected entity under the Health Insurance Portability and Accountability Act (HIPAA). In the privacy practice, I could not find an explanation about what this means regarding sensitive health information of individuals but the uncertainty of this raises a red flag for me. 23andMe prides themselves on having an internationally recognized security standards certification. Research analyses and published research from this company is claimed to not contain any personal identifiers. While these companies have data protection policies, neither can guarantee that PII will be protected from an unintended data breach which is a risk for anyone providing information. Ancestry did not elaborate on any separation between PII, and the data collected so it is assumed that the genetic data connected with the personal account, containing PII, is linked. 23andMe explained their separation to better protect PII. This includes researchers within 23andMe do not have access to identifying personal information. There are many opt-in and opt-out options regarding privacy that 23andMe offers. It is explained that if an individual shares information from 23andMe with an outside party such as a doctor, friends, or family, that 23andMe is not responsible for what happens to that information. Information sharing within these companies is vital to understand so that information is not irresponsibly shared.

These companies come to acquire large amounts of data from a diverse set of individuals. This information could be widely beneficial to the wrong sources such as law enforcement, health insurance companies, or companies targeting advertisements for users. Ancestry explains that information will be disclosed to third parties. Unique personal identifiers, internet usage samples, location, sensory data, inferences, and biological samples will be shared with service providers. De-identified DNA data, internet usage information, sensory data and inferences will be shared with research partners. The privacy practices did not give any further information to elaborate on what "inferences" are being shared with third parties which is a concern. 23andMe explains that information is shared with service providers for the processing, analysis, and

possible storage of samples. Personal information is shared to these sources. Both companies use Cookies on their websites to gain information about the user regarding interweb usage. Regarding sharing information with law enforcement, both companies state law officials must complete a legal process to access personal information. The legal process may include a court order, search warrant, or subpoena. Ancestry states that genetic information is not shared with health insurance companies. 23andMe state that information will not be voluntarily disclosed to public databases or insurance companies, including health insurance companies. Due to the vast amount of information is readily available to these companies, it raises questions about how this data is stored.

Once a personal account is made with one of these companies, they immediately have access to sensitive data, but the privacy practices explain the storage of this information and how it could be used in the future. Ancestry highlights that genetic discovery is an on-going, long-term process which is an optimistic reasoning to soften the blow that they essentially keep all information they have acquired in their database indefinitely. However, there is a way to delete the personal account. To have personal information deleted from this account, there are several administrative obstacles to conquer. 23andMe seem to have a more streamlined process for deleting a personal account. Regarding storage of the genetic sample, 23andMe allow to opt-in or opt-out of sample storing in a biobank while Ancestry does not elaborate on sample storing. 23andMe allows for an opt-in to future research which would be conducted without connection to PII. Ancestry describes that, similar to 23andMe, samples will be stored in a biobank for further research if the “Informed Consent to Research” is agreed upon. If not, the genetic sample will be destroyed. From analyzing the privacy practices, 23andMe seems to be more user friendly regarding the several optional choices regarding personal information.

Between Ancestry and 23andMe, I am on the fence about pursuing these companies. I would like the information about my genetics and the connection to possible health conditions in the future. However, I am not comfortable with the amount of personal information these companies have access to. No matter how protected my information is, there is always risk of a data breach or ownership change within the company that may change the privacy policies. If I did pursue one of these companies, I would delete my account and request my sample to be destroyed immediately after I receive my results. 23andMe seems to have a streamlined process for account deletion so I would pursue this company over Ancestry. Both companies seem to take several steps to ensure privacy and limit sharing of information. Some of the wording found in both privacy practices are alarming to me. For example, Ancestry states they will not “voluntarily” disclose information to law enforcement, but it raises questions as to how strict or persuasive outside entities must be to gain access to my personal information. 23andMe also uses the same wording when they state they will not “voluntarily” share information with insurance companies. While genetic informatics is advancing, the amount of intel this offers is alarming which makes privacy practices even more crucial to explore and understand fully.