



THE 23ANDME GUIDE

# Exercising Rights Under the GDPR

Right of Access. Right to Data Portability.

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# Exercise Your Rights

## The 23andMe Guide to Access and Data Portability

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# Introduction

23andMe is committed to protecting our customers' personal data and complying with the EU's General Data Protection Regulation (GDPR). At its core, the GDPR enables individuals in the EU to find out what personal data we hold about them, why we hold it, and who we disclose it to. We developed this guide, and other guides in the Exercise Your Rights series, as a tool to help you better understand our information practices and exercise your rights as they relate to 23andMe held personal data.

The GDPR applies to the processing of personal data of individuals who are in the European Union, and where the processing activities are related to the offering of goods or services to individuals in the Union.

For this reason, **this guide is applicable to and intended only for 23andMe customers based in an EU member state who purchased 23andMe Services marketed and sold in that member state**. You can view a full list of the EU member states in which we provide our Personal Genetic Service (PGS) [here](#).

## Important Information About This Guide

This guide is meant to help individuals located in the EU understand their personal data rights under the General Data Protection Regulation (GDPR) and provide an overview of some core components of our data handling practices. Please be sure to review our [Full Privacy Statement](#). This guide is suitable for informational purposes only, and is not intended to provide you with legal advice. In the event of any inconsistency between this guide and the 23andMe Privacy Statement and/or Terms of Service, the provision contained in the Privacy Statement and/or Terms of Service shall control.

If after reading this guide you require additional clarification or have questions, please contact us at [privacy@23andMe.com](mailto:privacy@23andMe.com).



# Overview Of Our Personal Information Practices

In order to understand your personal data rights under GDPR and how 23andMe supports them, it's important to understand what personal data we process, how we use your personal data, and what kinds of third party service providers we engage to provide, analyze, and improve our Services.

## What is personal data?

As defined in the GDPR, "personal data" is any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

Different jurisdictions may refer to personal data differently. In the U.S., the same or similar types of data are often called "Personal Information". As a result, our Privacy Statement and Terms of Service use the term Personal Information. For the purposes of this guide, the terms can be used interchangeably.

## What are the categories of personal data being processed by 23andMe and its third party service providers and collaborators?

23andMe collects and stores the following types of personal data:

- **Registration Information:** information you provide about yourself when registering for and/or purchasing our Services, for example:
  - Order information such as your name, shipping address, billing information; and
  - Account information such as your name, email address, date of birth, and sex.
- **Genetic Information:** information regarding your genotypes (e.g. the As, Ts, Cs, and Gs at particular locations in your genome), generated through the processing of your saliva by 23andMe or by its contractors, successors, or assignees; or otherwise processed by and/or contributed to 23andMe.
  - Our contracted, certified laboratory processes your saliva sample for the purposes of generating your Genetic Information.
- **Self-Reported Information:** information you provide directly to us, including your disease conditions, other health-related information, personal traits, ethnicity, family history, and other information that you enter into surveys, forms, or features while signed in to your 23andMe account.
  - For example, entering your height and weight in your profile and answering a survey question within your account about the average number of times you brush your teeth in a week, or your most recent LDL Cholesterol level, both provide Self-Reported Information to 23andMe.
- **User Content:** all information, data, text, software, music, audio, photographs, graphics, video, messages, or other materials, other than Genetic Information and Self-Reported



Information, generated by users of 23andMe Services and transmitted, whether publicly or privately, to or through 23andMe.

- Examples of User Content include any files, text, or other content posted to our Forums, sent to Customer Care, or sent to other customers through 23andMe tools like DNA Relatives.
- **Web Behavior Information:** information on how you use 23andMe website (e.g. browser type, domains, page views) collected through log files, cookies, web beacons, and similar technology.
  - Certain Web Behavior Information, including IP Address, device ID, browser and operating system information may be considered personal data.
  - If you choose to consent to allow Functionality and Advertising Cookies when using our website, we may generally collect information about your visit, including the duration of your visit, the links you clicked on, and the URLs you visited.
  - Please review our [Cookie Policy](#) for more information about cookies and how we use them on our website.

## What are the categories of recipients your personal data has been or will be shared with?

### Service providers

Service Providers are third parties (other companies or individuals) that help us to provide, analyze and improve our Services. While 23andMe directly conducts the majority of data processing activities required to provide our Services to you, we engage some third party service providers to assist in supporting our Services, including in the following areas:

- **Order fulfillment and shipping.** Our payment processor processes certain Registration Information related to your order, such as your billing address and credit card information, as necessary to enable you to purchase a 23andMe kit from the 23andMe.com online store. Our distribution centers ship your kit to you, and in some cases help return your kit safely to our third party laboratory for analysis.
- **Our certified genotyping lab.** To use our genetic testing services, you must purchase, or receive as a gift, a 23andMe Personal Genetic Service testing kit, and ship your saliva sample to our third party laboratory. Once delivered, receiving personnel at the laboratory remove and discard kit packaging, which in some cases may contain "sender information" (e.g., name, address), before testing personnel receive the samples for processing. Receiving personnel do not perform testing, and testing personnel handle saliva samples that are only identified by a unique barcode. When the laboratory has completed their analysis, they securely send the resulting Genetic Information to us identified by your unique barcode.
- **Customer Care support.** Our Customer Care team uses a number of tools to help organize and manage the requests we get to ensure they receive timely and helpful information and quality support, including email and phone support.
- **Cloud storage, IT, and Security.** Our cloud storage providers provide secure storage for information in 23andMe databases, ensure that our infrastructure can support continued use of our Services by 23andMe customers, and protect data in the event of a natural disaster or other disruption to the Service. Our IT and security providers assist with intrusion detection and prevention measures to stop any potential attacks against our networks.
- **Marketing and analytics.** When you visit our EU, UK, or International websites you will be presented with a cookie opt in. If you choose to consent to allow Functionality and



Advertising Cookies our third party service providers may collect information about your visit, the links you clicked on, and the URLs you visited. This information can help us improve site navigability and assess our Marketing campaigns.

### **Qualified Research Collaborators**

You have the choice to share your Genetic and Self-Reported Information with **23andMe Research** by providing your consent. "23andMe Research" refers to research aimed at publication in peer-reviewed journals and other research funded by the United States government (such as the U.S. National Institutes of Health - NIH) conducted by 23andMe. Your De-identified Genetic and Self-Reported Information may be used for 23andMe Research only if you have consented to this use by completing a Consent Document. If you have completed the [Main Research Consent Document](#):

- i. Your Genetic Information and/or Self-Reported Information may be used for research purposes, but it will be de-identified and will not be linked to your Registration Information.
- ii. 23andMe may use individual-level Genetic Information and Self-Reported Information internally at 23andMe for Research purposes.
- iii. 23andMe may share summary statistics, which do not identify any particular individual or contain individual-level information, with our qualified research collaborators.

If you have completed the [Individual Level Data Sharing Consent](#), or additional consent agreement, in addition to the uses above under the Main Consent Document, 23andMe may share De-identified Individual-level Genetic Information and Self-Reported Information with qualified third party research collaborators for 23andMe Research purposes. Qualified research collaborators range from academic institutions and non-profit organizations to pharmaceutical and diagnostic companies.

You can read more about our collaborations [here](#) and [here](#).



# Exercising Your Right of Access and Data Portability

Under the GDPR, you have the right to access the personal data undergoing processing by 23andMe and our service providers, who process personal data on our behalf.

You also have the right to data portability, which entitles you to receive a copy of the personal data concerning you, processed by 23andMe, in a structured, commonly used, and machine-readable format, where the following apply:

- the processing is based on consent or on a contract; or
- the processing is being carried out by automated means; and
- portability of this information does not adversely affect the rights and freedoms of others.

Where technically feasible, you also have the right to have your personal data transmitted from 23andMe to another controller.

## How to access and download your personal data

In addition to the existing reports, tools, and features within your account, we've added new functionality to your 23andMe account to support your access and portability rights. To sign in to your account, visit [23andme.com](https://23andme.com), click on "sign in", and enter your account email address and password. You can also sign in [here](#).

Once signed in, you will be able to access the 23andMe reports available to you, either Ancestry or Health + Ancestry. You may also access and download certain 23andMe Data within your [Account Settings](#) page. Scroll down to "23andMe Data" and click "View".

### Download 23andMe Data

23andMe processes your personal data as necessary to provide, analyze, and improve our Service. You can download the following 23andMe data within your account in commonly used, machine readable formats (.txt and .csv). Simply choose the data you would like to download:

The following downloads primarily contain **Genetic Information**:

- **Reports Summary** - Print or save an overview of your 23andMe reports, which includes brief descriptions of all report results. You can visit each report within your account for more details or to print or save each report individually.
- **Ancestry Composition Raw Data** - Download genomic coordinates (NCBI Build 37) for your Ancestry Composition results in .csv format.
- **DNA Relatives Data** - Download shared DNA segments and profile data for your DNA Relatives as a .csv file. The information about each relative is dependent on their personal privacy settings and sharing level. You must be opted-in to DNA Relatives in order to download this information.
- **Raw Data** - Submit a request to download your genetic data in its raw, uninterpreted format (your A's, T's, G's, and C's), as a plain text (.txt) file. When your raw data is ready, we'll send a message to the email address linked to your 23andMe account.

The following downloads primarily contain **Registration Information** and **Web Behavior Information**:

- **Account Event History** - Website and data processing events associated with your account.



- **Addresses** - Mailing addresses associated with your account.
- **Consent History** – Record of agreements to 23andMe legal documents, such as our Terms of Service and Consent Document.
- **Gift Cards** - Gift cards you've received from 23andMe.
- **Name Change History** - Changes made to your profile and/or Account name.
- **Order History** - 23andMe orders associated with your account.
- **Shared Reports** - Data about reports you've shared outside of 23andMe via email, link, Facebook, and/or Twitter.

The following downloads primarily contain **Self-Reported Information**:

- **Phenotype Data** - Data about yourself that you've provided through research participation and/or other forms and surveys, including your 23andMe profile.

You should only download your data from a personal computer and not a public computer.

## Assistance with your right of access and data portability

If you have trouble accessing or downloading your personal data for any reason, please contact our Customer Care team by emailing [privacy@23andMe.com](mailto:privacy@23andMe.com). When submitting your request for assistance, you should:

- Submit your request from the email address associated with the account in question.
- Include “Data Subject Access Request” in the email subject line.
- Include the account or profile name about which you’re inquiring.
- Include an overview of your request and any details or specific circumstances surrounding problems or issues regarding your attempt to download your information within your account, and any additional contextual information that may be helpful.
- Include information about any other open data subject rights requests you’ve submitted in conjunction with this request or would like to request.

Once we receive your request for assistance, we will perform an initial review to determine if there was an error that prevented your download from being completed automatically and will work with you to ensure you receive access to your personal data in a timely manner.

## How to access and download your third party personal data

If you wish to access personal data processed by our third party service providers, you can submit your request for a copy of data processed by third party service providers from within your [Account Settings](#). Scroll down to “Third Party Data” and click on “View”. You will then see the option to click on a blue “Submit Request” button, which will automatically notify us of your request.

Once we receive a request for third party personal data access, the following process will be followed by 23andMe:

1. We will follow up with the email address associated with your account to request additional information about the categories of data you are interested in accessing. We will also request the documentation and/or information we need to verify your identity.
2. Once we receive your reply and accompanying documentation, we will perform an initial review to determine whether your submission includes all of the necessary information to



verify your identity and handle your access request. If it doesn't, we'll work with you via email to gather the relevant information.

3. If we review your request and make a determination that it is not a valid request we will notify you, within thirty (30) days, via email of our determination, the rationale, and your rights to make a complaint to the relevant supervisory authority contesting our determination.
4. If your request is valid, we will take reasonable steps, including technical measures, to inform our third party service providers, which are processing your personal data on our behalf, to provide us with a copy of your personal data in a timely manner. We will also notify you within thirty (30) days and include a summary of any action that was or will be taken to complete the request, and instruct you on how to access and download the requested data.

## Exercising Your Right To Other Information

The right of access also entitles you to the certain information. Below we have detailed the information specified in the GDPR and where you can access or request that information:

- **Purposes of the processing.** Section 3 of our [Full Privacy Statement](#) details how we use your information, including to:
  - Provide you with Services and analyze and improve our Services
  - Process, analyze, and deliver your genetic testing results
  - Allow you to share personal information with others
  - Allow you to share personal information for research purposes
  - Recruit you for external research
  - Provide customer support
  - Conduct surveys, polls, and testimonials
  - Provide you with marketing communications.
- **The categories of personal data being processed.** The categories of personal data processed by 23andMe are detailed both in the introduction to this guide and in our [Privacy Statement](#), Section 2 “Information we collect”.
- **The categories of recipients** your data has been or will be shared with are detailed both in the introduction to this guide and in our [Privacy Statement](#), Section 4 “Information we share with Third Parties”;
- **The retention period for personal data**, where possible, or, the criteria used to determine that period. As stated in our [Privacy Statement](#), Section 9(e)(ix) “Retention of your Personal Information”, unless you make a request for us to delete your account or delete certain Personal Information (e.g., User Content, etc.), we will store your personal data as long as your account is open. If you request to delete your account, we will take the steps described under “Your Choices – Account Deletion” and delete all your Personal Information, unless a longer retention period is required or permitted by law.
- **The existence of your rights.** The rights available to individuals in the European Economic Area (EEA), United Kingdom, or Switzerland (“Designated Countries”) are detailed in our [Privacy Statement](#), Section 9(e) Privacy Rights. Additional information can be located in our guide, [Exercise Your Rights: The 23andMe Guide](#).
- **Right to Lodge a Complaint.** You have a right to lodge a complaint with a competent supervisory authority situated in a Member State of your habitual residence, place of work, or place of alleged infringement. You can find the relevant supervisory authority name and contact details [here](#).



- **The source of personal data not collected from you directly.** 23andMe stores and processes personal data such as identifiers generated by 23andMe for the purposes of providing our Service that uniquely identifies you, your sample, account profile, or other information within our systems. For example, a randomly generated, fourteen (14) digit barcode used to identify your sample, 00-1234-5678-9999.
- **Right to be informed of the appropriate safeguards** utilized in any transfer of information; 23andMe implements contractual terms with each service provider to protect the confidentiality and security of your information. Specifically, 23andMe requires service providers to implement and maintain accepted industry standard administrative, physical, and technical safeguards to protect personal data.
- **The existence of automated decision-making**, including profiling, and meaningful information about the logic involved, as well as the significance and the envisaged consequences of such processing.

If you have any questions about the information detailed above, please contact our Customer Care team by emailing [privacy@23andMe.com](mailto:privacy@23andMe.com). You should:

- Include "Data Subject Access Request" in the email subject line.
- Identify the information you are specifically requesting and/or an overview of your request and any additional contextual information that may be helpful.

## Limitations on your right of access and data portability

We may share De-identified, Aggregate Information, which is information that has been stripped of your name and contact information and combined with information of others so that you cannot reasonably be identified as an individual, with third parties. Aggregate Information is different from "Individual-level" information and is not personal data because it does not identify any particular individual or disclose any particular individual's data.

For example, Aggregate Information may include a statement that "30% of our female users share a particular genetic trait," without providing any data or testing results specific to any individual user. In contrast, Individual-level [Genetic Information](#) or [Self-Reported Information](#) consists of data about a single individual's genotypes, diseases or other traits/characteristics information and could reveal whether a specific user has a particular genetic trait, or consist of all of the Genetic Information about that user.

Aggregate information is not personal data, and therefore is not subject to Right of Access or Right to Portability under the GDPR.

## Frequently asked questions on access and data portability

### What are .txt and .csv files and are they structured, commonly used, machine readable formats?

23andMe provides your downloadable data as Plain Text files (.txt) and Comma Separated files (.csv) which are both structured, commonly used and supported by software applications, and forms that a computer can process.



### **Why does 23andMe need to verify my identity in order to request information from their third party service providers?**

23andMe has a legitimate interest in protecting the personal data of its customers and, as identified in Article 12(6) of the GDPR, may request additional information as necessary to confirm the identity of any data subject who requests access to personal data, in particular because of the online nature of the Services.

### **How can I transfer my data to another controller?**

We provide you with downloadable data in a structured, commonly used, machine readable formats. You may independently decide to disclose your personal data outside of our Services, including through third party services. You will need to contact these third parties to understand whether or not they accept 23andMe data and the processes for uploading your data to these sites or services.

There may be important privacy consequences to sharing data with third parties. These third parties may use your personal data differently than we do under this Privacy Statement. Please carefully evaluate the practices and privacy policies of these third parties prior to transferring your data and make such choices carefully.

## **Frequently Asked Questions About Exercising Your Rights**

### **Can 23andMe extend the time to respond to a request?**

We work very hard to respond to your requests as soon as practical, and within thirty (30) days. We can extend the time to complete your request by a further two (2) months if the request is complex or we have received numerous requests from you. We will let you know within thirty (30) days of receiving your request if we need additional time to respond to your request and explain why the extension is necessary.

### **Can 23andMe refuse to comply with a request?**

Yes, 23andMe can refuse to comply with a request if the request is manifestly unfounded or excessive. If we believe the request is unfounded or excessive, we will provide you with our justification when we respond to your request within thirty (30) days.

### **In which languages can you exercise your rights?**

At this time, 23andMe communicates all information in our normal course of business with you in English. As such, we are only able to receive, process, and respond to requests in English. If we receive a request in a language other than English, we will request that you resubmit your request in English. We may otherwise make efforts to assist you, though we may not be able to do so.