



THE 23ANDME GUIDE

Exercising Rights Under the GDPR

Right to Erasure (Right to Be Forgotten)





Exercise Your Rights

The 23andMe Guide to Erasure (Right to be Forgotten)

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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.





In order to understand your personal data rights under the 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 personal data and Personal Information 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:
 - o Order information such as your name, shipping address, billing information; and
 - Account information such as your email address, date of birth, and sex.
- **Genetic Information**: information regarding your genotypes (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, your height and weight as entered in your profile and the answers to survey questions within your account, such as the average number of times you brush your teeth in a week or your most recent LDL Cholesterol level, are considered Self-Reported Information.
- **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 <u>Cookie Policy</u> 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(s) to you and, in some countries, 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 receive. These tools help to ensure we proivide timely, high quality 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, such as the links you clicked on, the duration of your visit, and the URLs you visited. This information can help us improve site navigability and assess our Marketing campaigns.

Qualified Research Collaborators

Customers in many EU countries have the option to share Genetic and Self-Reported Information with **23andMe Research** by providing additional, explicit 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. If you are eligible to participate and give your consent to 23andMe Research by completing a consent cocument, your De-identified Genetic and Self-Reported Information may be used for 23andMe Research. 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 <u>Individual Level Data Sharing Consent</u>, 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.

You can read more about the discoveries and publications made possible by 23andMe Research here.

Exercising Your Right to Erasure (Right to Be Forgotten)

Under the GDPR, you have the right to have your personal data erased by 23andMe when it:

- is no longer necessary in relation to the purposes for which it was collected or otherwise processed;
- was collected in relation to processing to which you gave consent, but have since withrdrawn such consent and there is no other legal ground for processing;
- was collected in relation to processing activities to which you object, and there are no overriding legitimate grounds for our processing; or
- the data have been unlawfully processed.





We have implemented a personal data erasure (also referred to as "deletion") process for information associated with your 23andMe account. While we will delete the majority of your personal data, the right to erasure is not absolute; it is subject to limitations by relevant data protection laws, our data retention requirements, and other legal obligations. Notably, the following limitations apply:

- Genetic Information and/or Self-Reported Information that you have previously provided and for which you have given consent to use in 23andMe Research cannot be removed from ongoing or completed studies that use that information, as stated in any applicable Consent Document.
- Genetic Information, date of birth, and sex will be retained by 23andMe and our third party genotyping laboratory as required for compliance with applicable legal obligations, including the U.S. Clinical Laboratory Improvement Amendments of 1988 (CLIA), California Business and Professional Code Section 1265, and College of American Pathologists (CAP) accreditation requirements.
- Limited information related to your account and data deletion request will also be retained by 23andMe, including but not limited to, your email address, account deletion request identifier, and record of legal agreements for a limited period of time as required by contractual obligations, and/or as necessary for the establishment, exercise or defense of legal claims, and for audit and compliance purposes.

How to exercise your right to erasure

If you no longer wish to participate in our Services, or no longer wish to have your personal data processed, you may delete your 23andMe account and personal data within the "23andMe Data" section of your Account Settings.

Deleting an account and associated data will permanently delete the data for **all profiles** within the account. If you do not wish to delete data for **all profiles** do not click the 'Permanently Delete Data' button. You can <u>transfer a profile</u> into another account or Contact Customer Care for assistance.

Once you submit your request, we will send an email to the email address linked to your 23andMe account detailing our account deletion policy and requesting that you confirm your request. Once you confirm your request to delete your 23andMe account and personal data, your account will no longer be accessible while we process your request. **Once confirmed, this process cannot be cancelled, undone, withdrawn, or reversed.** When your account is deleted, all associated personal data is deleted and any stored samples are discarded, subject to the limitations discussed above.

How to request assistance with personal data erasure

If you have problems effectuating your erasure request within your settings for any reason, please contact our Customer Care team by emailing privacy@23andMe.com. When submitting your request, you should:

- Submit your request from the email address associated with the account in question.
- Include "Data Subject Deletion Request" in the email subject line.
- Include the account name about which you're inquiring.





- Include specific circumstances surrounding your request, any errors you encountered, 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 with the erasure of your personal data, 23andMe we will perform an initial review to determine if there was an error that prevented your deletion request from being completed automatically and work with you to ensure your personal data is deleted in a timely manner.

How to request third party service provider erasure

If you wish to submit a request to delete data held by our third party service providers, please submit your request to 3PDSAR@23andme.com. Please note that 23andMe will only be able to act on such a request after you have confirmed your request to delete your 23andMe account and data. When submitting your request, you should:

- Confirm that your account and data deletion request has been successfully submitted, by following the instructions detailed above.
- Submit your request from the email address associated with the account in question.
- Include "3rd Party Data Subject Deletion Request" in the email subject line.
- Include the account name about which you're inquiring and your account deletion request identifier (which was provided in your deletion confirmation email).
- Identify the types of third party data you would like erased and any additional contextual information that may be helpful to us in fultilling your request.
- 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 the erasure of data stored by third parties, 23andMe will follow the process outlined below:

- 1. We will perform an initial review to determine whether your submission includes all of the information necessary to proceed with the request. If it doesn't, we'll work with you via email to gather the relevant information.
- 2. In order to delete personal data processed by our third party service providers, we need to verify your identity. If your request includes all of the necessary information, we will follow up with you to verify your identity. We will temporarily save personal data necessary to verify your identity and fulfill your request.
- 3. Once we have determined your request includes all necessary information and verified your identity, 23andMe will review your request and make a determination about whether or not your request is valid under the GDPR. If we determine that it is <u>not</u> valid 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 erase your personal data within their systems in a timely manner. We will also notify you within thirty (30) days and include a summary of any action that will be taken to complete the request.





Limitations on the right to erasure

The right to erasure does not apply if processing your personal data is necessary for one of the following reasons:

- to exercise the right of freedom of expression and information;
- to comply with a legal obligation;
- for the performance of a task carried out in the public interest or in the exercise of official authority;
- for archiving purposes in the public interest, scientific research historical research or statistical purposes where erasure is likely to render impossible or seriously impair the achievement of that processing; or
- for the establishment, exercise, or defense of legal claims.

The GDPR also specifies two circumstances where the right to erasure will not apply to special categories of data, including Genetic Information or Self-Reported Information:

- If the processing is necessary for public health purposes in the public interest (e.g., protecting against serious cross-border threats to health, or ensuring high standards of quality and safety of health care and of medicinal products or medical devices); or
- If the processing is necessary for the purposes of preventative or occupational medicine (e.g., where the processing is necessary for the working capacity of an employee; for medical diagnosis; for the provision of health or social care; or for the management of health or social care systems or services). This only applies where the data is being processed by or under the responsibility of a professional subject to a legal obligation of professional secrecy (e.g., a health professional).

If we believe any of these exceptions applies to your erasure request, we will notify you of such a determination within thirty (30) days of receiving your request.

Frequently asked questions on the right to erasure

Why can't I delete only personal data processed by third party service providers?

Service providers are third parties (other companies or individuals) that help us to provide, analyze, and improve our Services. Sharing information with these service providers is necessary for us to perform on our contract with you and provide our Services. For example, our cloud storage providers provide secure storage for information in 23andMe databases and ensure that our infrastructure can support the continued use of our Services by 23andMe customers. Requesting that our service providers delete your data would render us unable to provide our Services to you and perform our contract with you. For that reason, you may only request that our service providers delete your personal data once you have confirmed your request to delete your 23andMe account and data.

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 information 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 erasure of personal data, in particular because of the online nature of the Services. We may also ask for your consent to transfer your





personal data to our third party service providers for the purposes of identifying you and fulfilling your request.

You said my deletion request will be completed within 30 days, does that mean I change my mind within 30 days if I have already confirmed my request?

No. Once confirmed, your deletion request will be processed and cannot be cancelled, undone, withdrawn, or reversed. If for any reason you change your mind after confirming your request to permanently delete your account and associated data, you will need to purchase a new 23andMe kit, create a new 23andMe account, and provide a new sample for analysis in order to participate in our Service. We identify the permanent nature of this request numerous times and require your positive confirmation in order to proceed.

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.