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# consent and legal agreement

**THIS SERVICE IS FOR RESEARCH AND EDUCATIONAL USE ONLY.**

## What am I agreeing to?

**By participating in this study, you are agreeing to allow us to use your genetic data, survey responses and any other non-identifying data for research on genetic markers associated with traits, disease and other physical conditions. We will remove the Registration Information (information you provided about yourself when registering for and/or purchasing our Services, such as name, email, address, user ID and password, and payment information) that can identify you prior to using the data for research, in order to help protect your privacy as much as possible.**

This document describes 23andMe, an ongoing research study conducted by 23andMe. The 23andMe study aims to understand whether genetics influences how likely people are to get different diseases, how well treatments work for people, and how likely people are to have certain traits or conditions. 23andMe seeks your voluntary participation in this study. 23andMe plans to ask each of its customers to participate and expects to enroll at least 5,000 participants from among its customers. Additionally, participants may be recruited through external collaborators to participate in specific projects of interest.

The research consists of using your genetic data and/or survey responses and other non-identifying personal information to discover genetic and non-genetic markers related to traits, diseases, and other physical conditions. In order for this research to receive approval by an external ethical review board, people must give informed consent before joining. This document explains:

- the nature of the research
- what you are being asked to do
- any risks and benefits of participation
- and who to contact if you have questions

## How will my data be used in research?

**Your data will be used to discover links between genetic and non-genetic markers and a variety of traits, diseases, and other physical conditions.** Your genetic data and responses to surveys on these topics can help to find these links. Discoveries made as a result of this research could be used to understand the basic causes of disease, develop drugs or other treatments and/or preventive measures, or predict a person's risk of disease. The topics to be studied span a wide range of physical traits and conditions, from common to rare. The topics include simple traits such as hair color or freckles, serious diseases such as Parkinson's disease or diabetes, and less serious conditions such as migraine headache or response to over-the-counter drugs.

This study will not cover potentially sensitive topics such as sexual orientation, illicit drug use or other illegal behavior, or HIV/AIDS status. If 23andMe conducts future studies on these topics, 23andMe will seek specific ethical approval for the projects and you will be asked to provide separate informed consent for use of your information in research on those topics.

If you participate, 23andMe will use your genetic data, information you enter into surveys, forms, or features labeled with the 23andMe research logo, and your age and ethnicity. Together, these data are referred to in this document and the 23andMe website as "**Genetic & Self-Reported Information**". The Genetic & Self-Reported Information does not include identifying information you provided when you purchased the Personal Genome Service(TM) or created an account (such as name, address, e-mail address, or credit card information).

## How do I participate?

**Participation consists of allowing 23andMe investigators to access your Genetic & Self-Reported Information.** You may participate further by taking surveys while signed in to your account. Surveys generally take 5-20 minutes to complete, though some may take longer. If you do not feel comfortable answering questions in a particular survey, you may exit the survey without finishing it. You may take surveys at any pace you choose. Even if you have given consent to participate, you are not required to take surveys or use features; you may choose to take all, some, or none of the surveys. You may also participate by entering data about yourself into other 23andMe features on the 23andMe website.

This research project is open-ended, because new surveys and features may be added to 23andMe on a continuing basis. If new surveys or features are added, you may receive an email update. When signing in to your account, you may see announcements that new surveys or features are available. Sometimes we may focus on certain characteristics for research studies. If your Genetic & Self Reported information matches the research area of interest, we may invite you to participate in these studies.

**Your participation in this research project is completely voluntary.** Choosing not to participate will not affect access to your genetic data or use of the Personal Genome Service(TM). Giving consent to participate means that you agree to let 23andMe investigators access your Genetic & Self-Reported Information, **including any Self-Reported Information you submitted prior to giving consent.**

If you are concerned about the use of previously submitted Self-Reported Information in research, you should carefully consider whether you want to give consent for your data to be used in research.

### What will you do with my data?

Your Genetic & Self-Reported Information will be stripped of personally identifying Registration Information and made available to a separate research environment. **23andMe investigators will then compare all participants' Genetic & Self-Reported Information to identify associations between specific genetic and non-genetic markers and traits, behaviors, or conditions.**

23andMe may collaborate with external parties. Under this informed consent, external parties will only have access to pooled data stripped of identifying information. 23andMe will never release your individual-level data to any third party without asking for and receiving your explicit authorization to do so.

### Are there any risks to participating?

There are some potential risks to participating in the 23andMe research study, as described below. Several of these risks are also presented in the [Terms of Service](#) when you signed up for a 23andMe account.

- Some survey questions may make you or your family members uncomfortable if you have to ask them for help in responding.
- Your genetic data, survey responses, and/or personally identifying information may be stolen in the event of a security breach. If your data are associated with your identity they may be made public or released to insurance companies, which could have a negative effect on your ability to obtain insurance coverage. 23andMe has strong security procedures in place to minimize the possibility of a breach. Although 23andMe cannot provide a 100% guarantee that your data will be safe, 23andMe policies and procedures minimize the chance that a breach could take place.
- If 23andMe investigators publish results of this research study, your Genetic & Self-Reported Information may be made public, but only after being pooled so that identification of your individual-level data is extremely difficult. However, it is possible that a third party that has obtained partial genetic data from you could compare the partial data to the published results and determine your survey responses.
- As with any online service, if you disclose your account password to others, they may be able to access your account and your Genetic & Self-Reported Information.
- There may also be additional risks to participation that are currently unforeseeable.

None of the surveys or other procedures used by the investigators in this research study are invasive or experimental. The procedures involved do not involve more than the minimal risks described above, and no compensation or treatment is available if injury occurs as a result of participation.

### Are there any benefits to participating?

One of 23andMe's missions is to make meaningful scientific contributions by enabling its customers to participate directly in genetic research. If 23andMe publishes study results in peer-reviewed journals, there may be an indirect benefit to you as scientific knowledge increases and/or new drugs or tests are developed. However, you will not receive any direct compensation or other benefits from 23andMe or researchers for participating in research.

If 23andMe develops intellectual property and/or commercializes products or services, directly or indirectly, based on the results of this study, you will not receive any compensation.

### Do I have any alternatives?

**Your alternative is not to participate in the 23andMe research study.** If you do not give consent to participate at this time, you will be offered other opportunities to give consent, for example, if you take a 23andMe survey on the website.

Even if you do give consent to participate in this study, you may still choose not to take 23andMe surveys or use other 23andMe features.

If you choose not to give consent at this time, or if you choose not to take surveys, your use of the Personal Genome Service(TM) and access to your genetic data will not be affected.

### How will you protect my data?

**23andMe uses a range of physical, technical, and administrative procedures to protect the privacy of your personal information, your genetic data, and your survey responses.** These measures are in place for 23andMe participants and all users of the Personal Genome Service(TM), and are described in more detail in the 23andMe [Privacy Statement](#).

### Could my participation end without my consent?

The 23andMe study may be terminated without your consent. In the following cases, 23andMe will maintain your Genetic & Self-Reported Information according to the terms of our [Privacy Statement](#).

1. **Transfer of ownership.** If 23andMe undergoes a business transition such as an acquisition or merger, the 23andMe research study may be terminated. 23andMe will require an acquiring company or merger agreement to uphold the material terms of our [Privacy Statement](#).
2. **Termination of service.** 23andMe may terminate your access to the Personal Genome Service(TM) for any of the five reasons described in the Terms of Service: if a) you have breached the Terms of Service, b) 23andMe is required to do so by law, c) the partner with whom 23andMe offered the Personal Genome Service(TM) to you has terminated its relationship with 23andMe or ceased to offer the service to you, d) 23andMe is no longer providing the Personal Genome Service(TM) to customers in the country in which you are resident or from which you use the service, or e) the Personal Genome Service(TM) is, in 23andMe's opinion, no longer commercially viable. If your access to the Personal Genome Service(TM) is terminated for any of the above reasons, your participation in the 23andMe research study may also be terminated.

### How do I withdraw from this study?

**At any time, you may choose to withdraw all or some of your Genetic & Self-Reported Information from 23andMe research by sending a request to the Human Protections Administrator at [hpa@23andme.com](mailto:hpa@23andme.com).** (23andMe will notify you if additional ways to withdraw consent become available.) You will still be allowed full use of the Personal Genome Service(TM), but 23andMe will prevent the requested information from being used in all research occurring after 30 days from receipt of your request. Any research on your data that has been performed or published prior to this date will not be reversed, undone, or withdrawn. Your Genetic & Self-Reported Information may still be used for internal purposes as described in the [Terms of Service](#).

Withdrawal from 23andMe will not affect access to your Genetic Information or the use of the Personal Genome Service(TM).

You may also discontinue participation by closing your Personal Genome Service(TM) account, as described in the [Terms of Service](#). Requests for account closure must be made in writing to Customer Service at [help@23andme.com](mailto:help@23andme.com).

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