

LunaDNA Consent

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(Effective 30 days from member notification on June 23, 2020)

LunaDNA Consent Agreement

Sharing Genomic, Health, or Medical Data to the LunaDNA Platform Means Consenting to Share Your De-Identified Aggregate Data for Ethical Research

This platform is part of a novel endeavor to give individuals a way to exert their right to control their own data, to speed up research on the things that matter to them, to share in the value created from that research, and to ultimately find avenues to better health. This agreement includes the elements of consent as required by major oversight bodies.

In this Agreement with LunaPBC, the public benefit corporation that owns and manages this platform, we refer to genomic data (that is, data about your genes, or DNA) and medical or health data (for example, medications, allergies, surveys, health records, information collected by integrated apps and devices) as **Shared Data**.

We refer to any personal information (for example, your name, contact information, payment information) as **Personal Data**. Personal Data does not include your Shared Data.

By sharing any Personal Data or Shared Data into this platform, you agree to and consent to the use of that data as set forth in this LunaDNA Agreement and in our Privacy Policy. The Privacy Policy contains further detail on many of the concepts in this LunaDNA Consent, and we urge you to read it in full.

Key Policies

1. All research studies in LunaDNA will have oversight consistent with human research protection regulations in various countries. This oversight assures, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of individuals participating in research.

2. Shared Data is de-identified and aggregated before being made available to researchers. To make meaningful discoveries that improve health and quality of life, researchers need millions of participants sharing genomic, medical and health data. To protect your privacy, we separate your Shared Data from your Personal Data.

We refer to the separation of your Personal Data from your Shared Data as **de-identifying** your Shared Data. Your Shared Data is then combined, or aggregated, with the entire pool of de-identified Shared Data of our community, to create a searchable database to power research and discovery.

LunaDNA and researchers (including our manager, LunaPBC) may perform population-level searches based on a pre-defined and approved study design. We refer to these searches as **queries**. The results of a study-linked query will include a list containing de-identified **data file identification numbers** of members whose Shared Data is a match for the query. Based on these results, a subset of aggregated, de-identified Shared Data is populated in a private, secured compute environment controlled by LunaDNA, which we refer to as a **sandbox**, in order to complete the analysis required by the study design.



In the event of a change in control or ownership of LunaDNA or our manager, LunaPBC, the new controlling or owning party will have the same rights to your Shared Data as provided in this Consent Agreement as LunaDNA and LunaPBC have.

3. Your data is owned by you. You may revoke your consent at any time. At any time after you provide Shared Data or Personal Data to LunaDNA, you can decide to revoke your consent, purge some or all of your data, and even delete your account completely from our databases. If you revoke your consent or delete your account, your data will be permanently removed, or purged, from our database (subject to retaining an archival copy if, and for so long as, required by law), and this Consent Agreement relating to that data will automatically terminate. If you choose to purge some or all of your data, LunaDNA will immediately prevent that data from being found in any new queries for researchers. LunaDNA will also determine if your Shared Data is at that time available to any researchers in a sandbox.

The process to remove your Shared Data from all relevant sandboxes may take up to 30 days. Once your Shared Data is removed from the sandbox(es), the researchers may be able to determine that a subset of the data previously available to them has been removed and may be able to determine a specific data file identification number associated with data that was removed. This data file identification number does not include your name or other Personal Data.

It is possible that a researcher will have created a record of your data file identification number or of aggregated data including your Shared Data that was available in the researcher's sandbox area prior to your revocation of consent or purging of relevant Shared Data. Any research that has been completed or published using your Shared Data prior to you revoking your consent for the use of that data or purging that data from our database will not be affected by your decision to purge data or revoke consent.

4. You can opt-in or opt-out to participate directly in research studies. As a member, you may opt-in to learn about specific studies where the researcher may require direct participation of a Member. Once you've evaluated such a request you may choose to participate directly in research studies.

If you opt-in, a researcher may invite you to participate directly in a research study using an automated process which does not grant the researcher access to any of your Personal Data. In other words, even if you opt-in to learning about research studies, you will remain anonymous to the interested researcher unless you agree to participate in the study and share your identity.

You can opt-in or opt-out of being contacted for such participation during your registration or at any time in settings. You will be able to access these settings after completing the sign-up process. The default selection is opt-out (or "no"). If you choose to opt-in, you will need to manually update this selection.

5. You can opt-in or opt-out to receive communications from any Communities you join in LunaDNA. As a member, you have the option to join Communities within LunaDNA (e.g. registries, health groups, etc.). If you choose to opt-in to communications from a Community you join, you are agreeing to allow the Community to contact you using the same automated process used by researchers (see #4 above).

What studies will LunaDNA support?

Our manager, LunaPBC, intends to contract with researchers to query the LunaDNA platform for research and discovery studies. These studies may focus on specific diseases or conditions (for example, diabetes, cardiovascular disease), wellness, and longevity (that is, preventing disease and living longer

lives). As noted above, researchers conducting these studies will be provided access only to the de-identified, aggregated Shared Data associated with results of their queries. They will not have direct access to your Personal Data without your explicit acceptance.



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What can I do to contribute more to the LunaDNA community?

People's health and environment changes over time. One of LunaDNA's goals is to help and encourage you and other members to remain active in research by contributing more Shared Data over time. LunaPBC will inform LunaDNA members of ongoing studies powered by our members' data, which will help you see the value created through member contributions towards improving health and quality of life. To further our community's goal, we encourage you to regularly contribute Shared Data with LunaDNA and to check-in periodically to learn about how your Shared Data is making a difference.

Risks and Benefits to Consider

Sharing your data with LunaDNA has some risks that you should understand. We make significant efforts to protect against these risks. However, it's still important for you to know about them.

By opting in to receive invitations to engage directly with researchers, you may directly or indirectly learn information about your genetic or lifestyle risk for certain diseases or conditions that you were unaware of previously. For example, a researcher may be recruiting participants for a breast cancer study. Even though the researcher's interest in your data does not necessarily mean you have or are at increased risk for breast cancer, it may cause you to have concerns about whether or not they selected your data based on something they know about you and breast cancer. You will need to decide if this is information you are interested in potentially learning or thinking about yourself. Some of this information could also be relevant to your family because people with the same parents and ancestors may share genetic risk factors (that is, changes in or attributes of your DNA that may cause a disease or condition either now or in the future). If you do not want to learn this type of information, you should opt-out of receiving invitations from LunaDNA to engage directly with research partners in your profile page.

Protecting the privacy and security of your Shared Data and Personal Data is foundational to LunaDNA. We strive to apply the industry's best practices and state-of-the-art technology to protect your information, including those identified under "Security & Privacy Measures" in our **Privacy Policy** (<https://support.lunadna.com/support/solutions/articles/43000040805-lunadna-privacy-policy>). But neither we, nor anyone else, can completely guarantee the long-term security of data. While we have implemented numerous precautions and protections intended to avoid the potential for researchers or other third parties to learn the identity of you or any other community member who contributed Shared Data to us, we cannot provide an absolute assurance that a researcher or other third party, including hackers, will never be able to circumvent our safeguards and learn or verify your identity or some or all of your contributed data. We know that, especially when your genomic information is included, it is possible for you to be re-identified. We will monitor the effectiveness of our security procedures to identify and resolve any discovered threats of de-identification and use reasonable technical, physical, and administrative controls to protect Personal Data and Shared Data from unauthorized access or disclosure and to ensure the appropriate use of this information.

Changes to This Consent Agreement

LunaDNA cannot foresee all of the potential applications of the data we collect, particularly in a rapidly developing field such as genomics and medical research. Therefore, except as indicated below, LunaDNA reserves the right to update this Consent Agreement from time-to-time. Before implementing any changes, LunaDNA will first notify you of the proposed changes at least 30 days before their effectiveness to provide you with the opportunity to revoke this LunaDNA consent, purge some or all of your data, or even delete your account completely from our databases if you do not want your data to be bound by the revised terms. If you do not take one of those actions after receiving notice of those

proposed changes, to the maximum extent permitted by applicable law, you agree that you will be bound by the new terms when they become effective. None of the changes to this Consent Agreement may, without your explicit consent, adversely affect your basic right to revoke this LunaDNA consent, to purge some or all of your data, or to delete your account completely from our databases.



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You are responsible for ensuring that your contact information (i.e., email listed on your profile page) remains up to date and valid.

Without limiting the prior paragraph, this Consent Agreement (including the Privacy Policy in its current form) applies to both current and prior contributions of Shared Data or Personal Data, and to the extent it is inconsistent with any prior Consent Agreement you have signed (including the Privacy Policy provided at that time) in connection with prior Shared Data or Personal Data contributions, including any amendments to such Consent Agreement (and Privacy Policy)), you agree that this Consent Agreement (and this Privacy Policy) will govern our use of those prior data contributions after the date you sign this Consent Agreement.

When you accepted this Consent Agreement, you agreed to be legally bound by the above terms, including the **Privacy Policy** (<https://support.lunadna.com/support/solutions/articles/43000040805-lunadna-privacy-policy>) and **Terms of Use** (<https://support.lunadna.com/support/solutions/articles/43000454664-lunadna-terms-of-use>). You are also agreeing to use this electronic consent form (also called **eConsent**) to grant your consent, with the same legal effect as if you had signed and sent us a paper form.

When you download the Consent Agreement from your account you will see this information: Accepted by [member's username or full name if available] on [timestamp]

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