

The *All of Us* Research Program Privacy Statement (Draft)

1. Overview

The *All of Us* Research Program respects the privacy of our users. This Privacy Statement describes the types of information we may collect from you or that you may provide, and how we are storing, using and protecting that information. The researcher data is collected and stored by the *All of Us* Research Program's Data and Research Center housed at Vanderbilt University Medical Center (VUMC). VUMC is the data controller and processor of your data, and you can contact the data protection officer at any time using the contact information provided in this Privacy Statement. In this Privacy Statement, “we” refers to VUMC as the data processor, and “you” refers to the entity that is the “researcher”.

Changes to the Privacy Statement may be made at any time to be consistent with updates in our resources and services, or to laws and regulations that the *All of Us* Research Program and VUMC must abide by. If there are significant changes to the Privacy Statement, we will alert you to the changes, either through an *All of Us* Research Program resources email, posting to the *All of Us* Research Hub website, and/or through other means. If you use the services after any changes to the Privacy Statement has been posted, that means you agree to all of the changes. Use of information we collect now is subject to the Privacy Statement in effect at the time such information is collected.

2. Your information

We collect several types of information from you either directly, when register for an *All of Us* Researcher Workbench account, or automatically when you use the *All of Us* Researcher Workbench. Data may be used for a variety of ways, including for your account creation and personalization, to ensure appropriate use of the *All of Us* Research program data and platform, and to gather information about usage trends in order to improve our data and resources. The specific information we collect about you is outlined below.

2.1 Information collected directly from you

We may collect information directly from you for the purposes of identity verification, account registration, and for billing purposes. Your data is stored in encrypted Google cloud-based databases that are protected by the *All of Us* Research Program's security infrastructure, in compliance with applicable laws and regulations including the [General Data Protection Regulation \(GDPR\)](#). Only you, authorized staff and consortium members of the *All of Us* Research Program have access to your data; all access is tightly regulated.

The details of the information we collect, use, and length of storage is as follows:

2.1.A. Identity Verification Information

As part of the registration process for requesting access to *All of Us* Research Program data, we may collect your name, date of birth, identification associated with state or country-issued official identification document such as a Passport or Driver's License and Selfie. This information is collected by [Idology](#), a third-party electronic identity verification service. Idology stores this information for a period of 14 days for the sole purpose of verification of your identity, and then deletes it. We do not store this information ourselves. Alternatively, if you have an eRA Commons Account, we may also collect your eRA Commons Account ID as part of identity verification.

2.1.B. Personal information for registration and description of Research Purpose

As part of registration for access to *All of Us* Research Program data, we collect contact information, information regarding your employment and institutional affiliation, your professional role, your full address, your email and demographic information, including but not limited to, race/ethnicity, age, gender, education, and disability status. This information is stored as part of your profile, and you can update this information at any time by logging into your *All of Us* account.

Your contact information may be used by the program for communication purposes by the program, including sending you our newsletter or program updates by email. This information will not be distributed or sold for advertising or solicitation for goods and services. The description of research purpose that you provide may be used by the Resource Access Board of the *All of Us* Research Program for review and oversight. Demographic data that you may provide, as well as information regarding your state and country of residence, education and institutional affiliation, may be used at aggregate level for program assessment of researcher diversity and other researcher-related metrics. None of this information is used to make decisions regarding your access to the *All of Us* Research Program data.

For every project that you access the *All of Us* Research Program data, you will be asked to create a project-specific Research Workspace within the *All of Us* Researcher Workbench. You will be required to provide the research purpose for which you are accessing the *All of Us* data within that workspace. In order to comply with the [21st Century Cures Act \[Section 2011: Precision Medicine Initiative; subsection d\(6\)\]](#), and for transparency with the Research participants regarding the use of their data, your name, institutional affiliation and/or employment information, and the research purpose description you have provided will be displayed publicly on the *All of Us* Research Program Research Hub website. If you have any publications resulting from the use of *All of Us* Research Program data or resources, you will be required to disclose those to the program. Your publications will also be displayed publicly on the Research Hub Website to inform the *All of Us* Research participants. This information will be accessible in the Research Hub website indefinitely even after you delete your profile and stop accessing the *All of Us* data as an authorized researcher of the *All of Us* Research Program.

2.1.C. Billing information

The use of the compute resource in the *All of Us* Researcher Workbench may incur costs, and we may collect your billing information to charge you for your use of the compute resource. This information is collected by Google Cloud Platform (GCP), and handled separately by GCP. We do not store or access this information. Your billing information is retained until you update or delete the information. None of your historical billing information is retained.

2.2 Information collected as part of your use of the All of Us Researcher Workbench

We may collect information automatically as part of using the *All of Us* Researcher Workbench. The details of the information we collect, use, and length of storage is as follows:

2.2.A. Logs of database queries and data use

As you use our resources, we may collect information about the database queries you run, and files you upload into or download from the Researcher Workbench. Logs of your queries, and upload/download activity will be used for audit purposes and may be retained indefinitely. This information may be shared with members or groups within the *All of Us* Research Program as part of audit and oversight of data use, or to resolve or address regarding privacy or security policy violations.

2.2.B Account activity browsing patterns and cookies

We may also collect data about your browsing and resource-use patterns and other information collected through cookies, Google Analytics or other technology. Your browsing patterns may be used to improve security, enhance your user experience, or as aggregate data to update and improve the resource. Data that is used for improving resource functionalities are limited to anonymized use patterns. These data are stored for up to 30 days.

Cookies are non-personally identifying information that are placed on your device that allows us to recognize and remember you (keep you signed in), and to improve your experience using our services (by understanding your browsing patterns). We do not use cookies for advertising purposes. Cookies do not harm your computer and do not contain any viruses. Disabling cookies may limit the functionality of this website.

When you use the program's Researcher HelpDesk to report issues, ask questions or communicate through a researcher forum, your name and email address, along with the issues that you report may be collected and shared with the appropriate bodies in the program for resolving the issues you report and communicating back with you.

The data collected from your use of the resource is often accompanied by metadata such as your Workspace ID or User ID and the date or timestamp associated with your activity.

2.3 How third party services use your information

As stated previously, some of your data may be collected or accessed by third party services (ie. Google Cloud Platform for billing and Idology for identity verification). The third party access is strictly regulated under program contracts that align with this Privacy Statement. Any use of your information for purposes other than providing the services specified in the contracts between the program and the third party services, and as outlined in this Privacy Statement, are strictly prohibited.

2.4 User rights and limitations

By registering for access to *All of Us* data, you are agreeing to the *All of Us* Research Program Privacy Statement outlined in this document, including your rights and limitations thereof, as a data user. You may change or update your personal profile information at any time by logging into your *All of Us* account. You may prevent further data collection by deciding to leave the *All of Us* Research Program and deleting your user account. However, any data already collected will be retained for programmatic audits of data use. Your name, institutional affiliation and purpose for data access provided for any project workspaces you may have created will continue to be accessible in the *All of Us* Research Hub website. This is based on the legitimate interest of enabling programmatic audit against potential data privacy or security incidents, and for the purpose of transparency to the *All of Us* Research Participants regarding the use of their data.

3. Information for EEA Researchers (GDPR)

If you are located in the European Economic Area (EEA) or other nation, please note that the regulations that apply to our processing of your data may be different from the laws in your jurisdiction. The following provisions regarding the General Data Protection Regulation (GDPR) apply to you if you are an EEA citizen or resident. GDPR provisions apply to ‘personal data’, meaning any information of yours that can directly or indirectly identify you.

3.1 Your rights under GDPR

The GDPR provides you the following rights in order to maintain key transparency regarding what the *All of Us* Research Program does with your data. Rights of GDPR are not absolute. Under certain circumstances, rights may not be granted.

Right to be informed:

You have the right to be informed how your personal data is used, which is outlined in this Privacy Statement.

Right to access and Right to rectification:

You have the continued ability to access, change and modify information about yourself that you provide to the program, which you are able to do directly by logging into your Researcher Workbench account and accessing your profile.

Right to be erasure, Right to restrict or object to processing:

As outlined above, on the basis of the legitimate interest of maintaining transparency with the program's research participants, once you register to become an authorized user, your information cannot be removed from the *All of Us* Research Hub website. In the interest of protecting the data contributed to the program by our participants, we may retain your personal data, logs of your activity and database queries in the Researcher Workbench for the purpose of audit in the event of a privacy or security breach incident. Your data cannot be deleted, restricted, or stopped from being processed.

3.2. Contact information

Your personal information is processed and stored by VUMC for the *All of Us* Research Program. To communicate with the data protection officer regarding the control and/or processing of your data, please contact the VUMC Data Privacy Office at support@researchallofus.org or +1 (830) 541-7648.