

# *All of Us Research Program*

## **Researcher Workbench Terms of Use and Privacy Statement**

The *All of Us Research Program* (the “**All of Us Program**”) is part of an effort to advance individualized healthcare by enrolling one million or more participants to contribute their health data and developing custom tools and software to help researchers analyze that data. The goal of the *All of Us Program* is to speed up health research discoveries, enabling new kinds of individualized health care. Among the resources developed in connection with the *All of Us Program* is the Researcher Workbench, which is a platform and collection of tools through which researchers can access registered tiered data, workspaces, and tools such as a cohort builder, and an interactive notebook (the “**Workbench**”).

These Terms of Use (“**Terms**”) describe the terms and conditions that govern how Vanderbilt University Medical Center (“**VUMC**,” “**We**,” or “**Us**”) makes the Workbench available to users that meet the *All of Us Program* Workbench requirements, complete the registration process and are approved to access the Workbench (“**Users**”). These Terms, the *All of Us Program* Privacy Statement (“**Privacy Statement**”) and any applicable Third Party Terms referenced below govern use of the Workbench by each User, including you (“**You**”). Additionally, the *All of Us Program* Data User Code of Conduct (“**Data User Code of Conduct**”) describes how You can and cannot use the *All of Us Program* data, which includes any data that is made available through the Workbench.

PLEASE READ THESE TERMS CAREFULLY. BY CLICKING BELOW, CONTINUING WITH THE REGISTRATION PROCESS, OR ACCESSING AND/OR USING ANY PORTION OF THE WORKBENCH, YOU AGREE TO COMPLY WITH, AND YOU ARE BOUND BY, THESE TERMS. IF YOU DO NOT AGREE TO THESE TERMS, YOU MAY NOT ACCESS OR USE THE WORKBENCH IN ANY MANNER, AND YOU MUST EXIT THE REGISTRATION PROCESS.

### **1. Your Workbench Account.**

**1.1 Registration.** To access the Workbench (including any data, content, tools, software or other resources available through the Workbench), You must complete the registration process that is required for the appropriate tier of data You are seeking to access. Any data or information that You provide to Us in connection with application for registration must be true, current and complete. If any of Your data or information changes, You are responsible for promptly updating it on your personal profile page for the Workbench.

**1.2 Account Login ID and Password.** As part of the registration process, You will set Your account access login ID and password. Do not share Your login ID, password or other account information with anyone. It is Your responsibility to maintain the confidentiality of Your account

information. You are solely responsible for any use of Your account or Your account access information.

**1.3 No Shared or Group Accounts Permitted.** Your access to the Workbench, including any resources offered on or through Your account, is only for Your individual use and no other person's use. You may not allow any other person to pose as You in connection with the Workbench or use Your account information. You may not use any other User's account information. Shared or group accounts are prohibited.

**1.4 Privacy Statement.** As part of Your registration, account creation and use of the Workbench, We and/or Our providers may collect some data from You or about You and Your use of the Workbench. Our collection of that data, and how it is used, stored and shared is outlined in Our Privacy Statement.

**1.5 Unauthorized Access.** You agree to notify us immediately if You suspect or learn of any unauthorized access to Your account or compromise of Your account access information, or any other unauthorized use or security incidents related to the Workbench or the *All of Us Program*, (including any other User's use of the Workbench or content for an unauthorized purpose). If you experience any login issues or security concerns, please contact our technical support staff at [support@researchallofus.org](mailto:support@researchallofus.org).

## **2. Use of Workbench.**

**2.1 Conduct.** You are solely responsible for Your conduct related to the Workbench and the *All of Us Program*, and for any content (such as external data or software) that You upload, post or otherwise send to the Workbench ("**Your Content**"). You must ensure that you have the rights and permissions to upload and use Your Content on the Workbench as contemplated by these Terms. You are solely responsible for maintaining backups of Your Content. Neither We nor our licensors or providers will be responsible for or have any liability for any loss or corruption, or unauthorized access to Your Content, or for the security of Your Content. You must use Workbench and any content, data, tools or other resources provided by Us or available through the Workbench in compliance with all laws, and solely for internal, non-commercial research conducted by You for the non-commercial purpose that You disclose to Us when You register for the Workbench or create a workspace for a project. Neither We, nor any third party licensor, provider or contractor, have any obligation or responsibility with respect to Your Content, or Your use of the Workbench or resources available through the Workbench.

**2.2 Restrictions.** You may not circumvent or attempt to circumvent (or allow any person to circumvent) the security and access control measures of the Workbench or any of Our sites or services. Use of the Workbench or any of the public forums or other aspects of the *All of Us Program* for the marketing of goods or services is prohibited. We do not endorse or express any opinion with respect to Your Content or Your activities, and You may not suggest or imply that We do or that You or Your products or services are in any way affiliated with Us or the *All of*

*Us Research Program.* You may not use or upload any content that infringes upon any third-party rights, including copyright, trademark, patent, trade secret, moral rights, privacy rights, right of publicity or any other intellectual property or proprietary rights. You may not use the Workbench in any manner that is unlawful, harassing, abusive, threatening, harmful of another's privacy, vulgar, defamatory, false, misleading, libelous, pornographic, obscene, offensive, promotes racism, bigotry, xenophobia, hatred, or physical harm of any kind against any group or individual, or is otherwise objectionable.

**2.3 Monitoring.** We may monitor, review and audit Your account activity to ensure compliance with these Terms and Your other agreements and applicable policies related to the *All of Us Research Program*. If there are findings of violation, or suspected violation, of these Terms, *All of Us* Data User Code of Conduct or other applicable agreement or policy, We reserve the right, in our sole discretion, to suspend or terminate Your account and/or implement other sanctions or corrective measures. Violations or perceived violations of our *All of Us* user agreements may be reported to law enforcement or appropriate individuals.

**2.4 Confidentiality.** You acknowledge that the Workbench (including any data, content, tools, software or other resources available through the Workbench) may include confidential or proprietary information. Except as expressly authorized in an applicable Data User Code of Conduct, You agree to keep the Workbench confidential and to not disclose it (or any part of it) to any third party, except for portion that: (i) is publicly available through no fault of You; (ii) You receive from somebody else without a confidentiality obligation; (iii) You independently develop without use of any portion of the Workbench.

### **3. Reservation of Rights.**

**3.1 Generally.** Except for the limited permission to use the Workbench described in these Terms, We and, where applicable, Our licensors and providers, own and retain all right, title and interest in and to the Workbench (including any resources available through the Workbench) and all derivative works thereof (regardless of by whom prepared), and all related intellectual property and proprietary rights. Nothing in these Terms shall be construed to confer any rights by implication, estoppel, or otherwise as to any data, technology, patent rights, copyrights or other rights of Ours, Our licensors, or any other entity, whether existing now or in the future, and whether or not related to the Workbench (except for the limited permission described in these Terms). Under no circumstances may You: (i) reverse engineer, decompile or disassemble the Workbench or any software or other technology provided through, or used to deliver or display the Workbench, or any portion of it, or attempt to engage in any of such activities; (ii) transmit the Workbench (including any resources available through the Workbench) or otherwise permit it to be publicly accessible over a network, by any means, including but not limited to through the Internet or in the operation of a service bureau; (iii) remove, obscure or alter any disclaimers, or notices, including without limitation, copyright notice, trademark or other proprietary rights notices displayed or contained within the Workbench (including any resources available through the Workbench); or (iv) modify or create any derivative work of any Workbench or any part thereof. However, should you create any derivative works based on the

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**3.2 Trademarks.** The *All of Us Research Program* trademarks, logos, copyrighted works, text, graphics, logos, button icons, images, audio/video clips that are displayed on, or available through, the Workbench are the property of Us or Our licensors and may not be used in any manner without the prior written consent of Us or the licensor(s). Additionally, You may not use the name, mark, logo or other indicia of VUMC, Vanderbilt University or any of their affiliates in any public manner, or in any promotional or marketing materials (including, without limitation, on any website), or for any purposes whatsoever without Our prior written consent. Misuse of any of the trademarks is strictly prohibited.

**3.3 Third Party Materials.** The Workbench and any of Our services and resources may reference, contain, link, refer, or otherwise consist of content, software, services or other resources that are provided by third parties, including, but not limited to, the National Institutes of Health and the Centers for Disease Control and Prevention, The Broad Institute, Inc. and Verily Life Sciences LLC. Your use of such third party resources is subject to the terms of the third party provider of those services (which may be updated from time to time), including, but not limited to, the terms located at <https://app.terra.bio/#terms-of-service> (“**Third Party Terms**”). The content represented from various third-party sources does not necessarily belong to Us or the *All of Us Research Program*, and We have no responsibility for that content. Links that are provided to third party resources are provided to You only as a convenience. If you have questions or issues relating to third-party content, you should direct those to the sources of that content, not to Us or the *All of Us Research Program*.

**4. Term and Termination.** These Terms shall be effective until expiration of the projects for which You successfully registered. Either You or We may terminate Your use of the Workbench at any time for any reason with no obligation or liability of any kind for such termination. Additionally, Your permission to access the Workbench will automatically terminate in its entirety if you breach these Terms. Upon termination of Your permission to access the Workbench, you must immediately cease use of the Workbench and Your Content is subject to deletion. Sections 2-8 shall survive expiration or termination of these Terms.

## **5. Disclaimers.**

**5.1 Availability; Changes.** We reserve the right to modify or discontinue, temporarily or permanently, functions and features of the Workbench. You understand that You use, download or access, or otherwise are obtaining, tools, content or data through the Workbench at Your own discretion and risk, and there is no assurance of continued availability. We will make reasonable efforts to notify you of any planned downtime but reserve the right to suspend access without notice for updates, maintenance, or to address potential security or other issues.

**5.2 Disclaimer.** THE WORKBENCH, ANY RESOURCES AVAILABLE THROUGH THE WORKBENCH AND THE *ALL OF US PROGRAM* ARE PROVIDED “AS IS” WITHOUT

WARRANTY OR REPRESENTATION OF ANY KIND, WHETHER EXPRESSED OR IMPLIED. WE HEREBY DISCLAIM ALL WARRANTIES AND REPRESENTATIONS, EXPRESS OR IMPLIED, INCLUDING, BUT NOT LIMITED TO, ANY IMPLIED WARRANTY OF MERCHANTABILITY, NON-INFRINGEMENT, FITNESS FOR A PARTICULAR PURPOSE, AND FREEDOM FROM VIRUSES OR MALWARE.

**5.3 Limitation.** TO THE MAXIMUM EXTENT PERMITTED BY LAW, IN NO EVENT SHALL WE, OR OUR AFFILIATES, LICENSORS OR PROVIDERS, BE LIABLE FOR ANY DIRECT, INDIRECT, INCIDENTAL, SPECIAL, PUNITIVE, EXEMPLARY OR CONSEQUENTIAL DAMAGES (INCLUDING, WITHOUT LIMITATION PERSONAL INJURY, WRONGFUL DEATH, INTERRUPTION OF SERVICE OR LOSS OF DATA, LOSS OF USE, LOSS OF BUSINESS, PROFITS OR REVENUE) HOWEVER CAUSED AND ON ANY THEORY OF LIABILITY, WHETHER IN WARRANTY, CONTRACT, STRICT LIABILITY, OR TORT (INCLUDING NEGLIGENCE OR OTHERWISE) ARISING FROM OR RELATED TO THESE TERMS, THE WORKBENCH OR THE *ALL OF US PROGRAM*, EVEN IF ADVISED OF THE POSSIBILITY OR LIKELIHOOD OF SUCH DAMAGE. TO THE EXTENT CERTAIN JURISDICTIONS RESTRICT ANY OF THE ABOVE LIMITATIONS OF LIABILITY, SUCH LIMITATIONS SHALL NOT APPLY IN SUCH JURISDICTIONS TO THE EXTENT OF SUCH RESTRICTIONS. You are solely responsible for determining the appropriateness of using the Workbench, and you assume all risks and responsibilities associated with use of the Workbench and the resources available through the Workbench.

**6. Revision of Terms.** These Terms constitute the entire agreement between You and Us with respect to the Workbench (except as otherwise expressly provided herein) superseding all other prior agreements that might exist. We may revise the Terms at any time by posting the revised Terms through the Workbench or otherwise notifying You. All revised Terms are automatically effective as soon as they are posted or provided. Your continued use of the Workbench constitutes Your agreement to be bound by the revised Terms.

**7. General Provisions.** You may not assign or transfer Your rights or obligations under these Terms without Our prior written consent. Any other assignment or transfer by You is void. If any provision of these Terms is held invalid or unenforceable, such provision shall, to that extent, be deemed omitted, and the balance of these Terms will be enforceable in accordance with its own terms. These Terms are governed by the laws of Tennessee without regard to principles of conflicts of laws, and the state and federal courts sitting in Nashville, Tennessee shall have proper and exclusive jurisdiction and venue over any disputes arising from or relating to these Terms or any Program. If You do not comply with these Terms, and We do not take immediate action, We do not relinquish or waive any rights to take action in the future.

## **The *All of Us* Research Program Privacy Statement**

## **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 you register for an *All of Us* Researcher Workbench account, or automatically when you use the *All of Us* Researcher Workbench. Data may be used in 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 and use, as well as 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, and identification associated with state or country-issued official identification documents 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, 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 the 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 the 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 through the *All of Us Research Program*, 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 Program* 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 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 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](mailto:support@researchallofus.org) or +1 (830) 541-7648.