

Privacy Policy

The COVID Recovery Corps study (the “Study”) is a collaboration between Sage Bionetworks and Columbia University. The Study is sponsored by the Chan Zuckerberg Initiative. The goal of the Study is to collect information from participants who have been diagnosed or believe they have had COVID-19. Researchers will use this information to better understand how the body fights COVID-19.

The Study is committed to protecting your online privacy. This Privacy Policy explains the personal information we collect about you through the Website (defined below), how we use and share it, and the choices you have regarding this information.

This Privacy Policy applies to visitors to www.covidrecoverycorps.org (the “Website”), including participants in the Study. If you don’t agree with this Privacy Policy, please do not access the Website or participate in the Study.

Data We Collect From You

“Personal information” or “personal data” means any direct information about you such as your name and contact information or indirect information that could be reasonably linked to you such as your device’s internet protocol address (IP Address). When you visit the Website, we collect the following information (collectively, “Personal Data”):

Who You Are (“User Information”)

We collect information that you provide to us during the informed consent and account-creation process , and in any correspondence, you have with us. For example, this could include your name, email and any other contact information you share with us.

Where you go on the Website (“Usage Data”)

Whenever you use any online service, certain information gets created and logged automatically; the same is true when you visit the Website. Technical data on the different pages you visit on the Website. For example, we may collect the date and time when you visit the Website.

Why We Collect This Data

User Information

We use user-reported information for any of the following:

- Authenticating/administering your account
- Responding to user requests, questions, and concerns
- Requesting user feedback to enhance and improve the website
- Sending study communications such as newsletters and other materials that may be of interest to you.

Usage Data

We use usage data for the following purposes:

- Maintaining, securing, and enhancing the website
- Detecting and remedying disruptions in our systems
- Performing statistical analysis of usage patterns
- Operating, maintaining, enhancing, and providing all the features of the website

To Whom/When We Disclose Data

We work with vendors, service providers, and other partners that help us support and maintain the Website by providing services on our behalf.

Vendors/Service Providers

We may rely on vendors and service providers to provide the necessary hardware, software, networking, storage, and related technology required to operate, support and maintain the website. We required that all service providers agree to put in place reasonable security to keep users information confidential and secure, and to process information only for performing tasks on Sage Bionetwork's behalf. We do not permit service providers to use or disclose users' information, except as necessary to their work on the website.

The COVID Recovery Corps website uses the following service providers:

- Amazon Web Services
- Google Analytics

Statistical and Aggregate Information

In accordance with applicable law, we may share aggregate and statistical information derived from users' information with third parties for analysis.

Compliance with Laws

We may be required by law to give your user information in the case of any civil, criminal, administrative, legislative, or other proceedings. We will protect your privacy as much as possible.

Business Transfers

If Sage Bionetworks (website's host) goes through a management or business transition such as a merger, closure, sale, joint venture, assignment, transfer, management reorganization, or other disposition of all or any portion of Sage Bionetworks' business, assets, or stock, information or data may be transferred to a third party. In such cases, we will take reasonable steps to direct the transferee to use the information and data in a manner consistent with this Privacy Policy.

How Long We Keep this Data

We keep the information, including personal information, for as long as necessary to provide our services and to fulfill any other purposes for which the information was initially collected, unless otherwise required by applicable law. For instance, we will keep personally identifiable information related to authentication of user identity only for as long as is necessary for authentication.

Users may edit their information or remove their information by withdrawing from the study in the profile settings. We will retain and archive a record of user's activities performed while the account was active to use for audit purposes, legitimate business purposes, to keep with our legal obligations, resolve disputes, and enforce our agreements and policies.

Information/Data Security

Sage Bionetworks maintains industry standard physical, organizational, technical, and administrative measures to protect the personal identifiable information we collect, store, or otherwise process in connection to the study against accidental, unlawful, or unauthorized access, destruction, disclosure, misuse, alteration, or loss.

The data security measures are a combination of Privacy-Enhancing Technologies (PET) options and policies/processes for data handling. Still, no environment is 100% secure. There is some risk that an unauthorized third party may find a way to circumvent our security systems.

What We Do Not Do

We do not use your personal information for advertising purposes. We do not sell or lease your information.

Your Rights

You may request to access, update, correct, restrict or delete the personal information you provide to us. You also have the right to object to the processing of your personal information under certain conditions. For all such inquiries, we can be reached at the following:

Sage Bionetworks

Attention: Data Protection Officer
2901 Third Avenue, Suite 330,
Seattle, WA 98121
United States of America

privacyofficer@sagebionetworks.org

Upon request, we will provide you with reasonable access to the personal information about you that we hold. If your personal account information is deleted, your account becomes deactivated.

You may opt-out of receiving study communications from us by clicking on the “unsubscribe” link included in each such communication or by notifying us by email at privacyofficer@sagebionetworks.org with the word “remove” in the subject header, and we will remove your contact details from our mailing list.

Cross-Border Transfer of Your Information

Although you may access the website from a location outside of the United States, the website is primarily operated and managed within the United States. When we transfer information and data, we will protect the information and data as described in this Privacy Policy.

How to Contact Us

Sage Bionetworks is the controller of your information when it is collected and processed in the context of our sites and services. Our Data Protection Officer (DPO) is responsible for overseeing what we do with your information and ensuring we comply with applicable data protection laws. Our Data Protection Officer may be contacted by emailing privacyofficer@sagebionetworks.org or by writing to:

Sage Bionetworks

Attention: Data Protection Officer
2901 Third Avenue, Suite 330,
Seattle, WA 98121
United States of America

Updates

We may update our Privacy Policy from time to time to clarify how we collect, process, store, use and disclose information. We want to be as transparent as possible about the changes we make to our Privacy Policy.