

Appendix C: Website Privacy Policy

Summary of Our Privacy Policy

The COVID Recovery Corps 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 COVID Recovery Corps study is committed to protecting the privacy of the users of the website. This privacy policy tells what we will do with the information we collect from you through the website.

Data We Collect From You

Who You Are (User Information)

Information collected during the informed consent and account creation process, and any correspondence, you have with us. For example, this could be your name, email and any other contact information you shared with us.

Where you go on the Website (Usage Data)

Technical data on the different pages you visit on the study website. For example, we may collect the date and time when you visit the study's homepage.

Why We Collect This Data

We collect this data to maintain and improve the website, and to be able to correspond with you. We also collect this data to adhere to state and federal laws and prevent and deal with cases of abuse or fraud.

How We Process Information

We process the information we collect through the COVID Recovery Corps website. Here are the steps we will take to process your information:

We will separate your account information like your name and email address from your study data like your answers to the surveys. We will assign you a random study code. We will add this code to your study data. The key that links this code to your name is kept in a separate, secure location.

We will combine your coded study data (without your name) with the coded study data from other people in the COVID Recovery Corps research study. We will use this combined data for our research.

We will store the COVID Recovery Corps research data we collect on Synapse. Synapse is a cloud-based research platform. Researchers from the sponsor, the study team and researchers' partners will access and analyze data. We may report the results of our research through blogs or scientific publications. Your name will not appear in the results we report.

To Whom/When We Disclose Data

We use the services of third-party vendors. We mandate that all service providers put measures in place to protect and secure your data. They are not allowed to use or share

your personal information outside the scope of their work on the website. We may be required to share your personal information for legal purposes.

How Long We Keep This Data

User Information

Information retained for as long as the user's account is active. Users may edit their information or remove their information by withdrawing from the study in the profile settings.

Usage and Activity Data

Data will be retained and archived indefinitely for auditing and compliance purposes.

Cross-Border Transfer of Data

The Synapse platform and the study data may be accessed by users outside the United States.

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 and Choices

You may access, update, correct or deactivate your account. To comply with our contractual obligations, your usage and activity data are parts of our permanent records.

How to Contact Us

You can contact our Data Protection Officer (DPO) at privacyofficer@sagebionetworks.org.

This is a summary of the COVID Recovery Corps study privacy policy. Please read further for more detailed information.

Privacy Policy

Version: 1.0 04.May.2020

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The COVID Recovery Corps study is committed to protecting the privacy of the users of the website. This privacy policy tells what we will do with the information we collect from you through the website.

This privacy policy explains how we protect personal information (“personal data”) received, used and disclosed by users. 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.

Please read this Privacy Policy carefully. By using the study website, you agree to this Privacy Policy.

Information We Collect

When you use the website, you may provide to us and/or we may collect personal information about you and your activity on the website. “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).

We collect information about you in the following ways:

User Information

We collect the following personal information during the account creation process:

- Your name
- Your email or mobile phone number

We also collect information when you update/change your account and when you contact us. If you send us an email or otherwise communicate with us, we may keep a copy of that communication.

Usage Data

Like most websites, we collect technical information on website usage. We may use cookies and similar technologies to record information such as but not limited to: date, time, pages and tools you used, your browser/client type, IP addresses, how you navigate the website, how you have found the website on the internet, and other service usage patterns.

How We Use the Information We Collect

We will use your personal information only as we describe here.

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

How We Disclose Information

We do not sell, lease or otherwise disclose the information we collect about you, except as described here. We share user's information in the following ways:

Service Providers

We may rely on third-party 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 third-party 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.

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
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 privacypolicy@sagebionetworks.org with the word “remove” in the subject header, and we will remove your contact details from our mailing list.

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.

User Information Retention

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.

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.

Changes to Our Privacy Policy

We may change this privacy policy from time to time. Any changes will be posted on this page with an updated revision date. In the event that any changes to this privacy policy materially alter your rights or obligations under this privacy policy, we will make reasonable efforts to notify you.

Contact

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.

Versions

Version 1: May 04, 2020