

# Open Bridge Platform Privacy Policy

*Effective date: 10/30/2023*

Sage Bionetworks (“Sage”, “we,” or “us”) is a 501(c)(3) nonprofit biomedical research organization in the United States.

Sage is deploying a set of app-based validated cognitive assessment tools, Open Bridge, to help identify cognitive changes in adults.

Sage is committed to protecting the privacy of participants in research using Open Bridge. The Privacy Label gives an overview of Sage’s privacy practices related to participation in a research study through use of an Open Bridge website (Open-Bridge-Web) or mobile application (Open-Bridge-App). Throughout this Privacy Policy, when we refer to an Open-Bridge-App or App, this also includes any associated Open-Bridge-Website. To learn more, read the detailed policy below.

## **Privacy Label**

### **Collection of Data**

- Do we collect sensitive categories of data, like health information?.....Yes
- Do we collect passive data from your device? .....Yes, with your consent
- Do we access your contacts, photos, or other personal information stored on your phone? .....No

### **Tracking**

- Do we use cookies? .....No
- Do we collect standard log information? .....Yes
- Do we track your device precise location? .....No
- Do we track your browsing activities on other Apps? .....No
- Do we listen to you using your device microphone when you use the Open-Bridge-Web or Open-Bridge-App?...  
Yes, if you opt-in
- Do we watch you using your device camera when you use the Open-Bridge-Web or Open-Bridge-App?.....  
Yes, if you opt-in

### **Use and Sharing of Data**

- Do we sell or rent your personal information data? .....No
- Do we share your personal information with others? .....Yes, with your consent
- Do we share de-identified aggregate information? .....Yes
- Do we use your data for advertising? .....No
- Do we transfer data abroad? .....Yes

### **Privacy Tools and Controls**

- Can you choose how your data is shared? .....Yes
- Can you ask to access, download or delete your data? .....Yes
- Do we delete your data when you ask us to? .....Yes
- Do we retain your data for as long as we need it unless you request deletion?.....Yes

### **Communication**

- Will we give you notice if we make changes to our Privacy Policy? .....Yes
- Do we send you push notifications? ..... Yes, if you opt-in
- Do we send you marketing communications like invitations to another research? .....Yes, if you opt-in

# **Detailed Privacy Policy**

<b>Detailed Privacy Policy</b>	2
Introduction	2
Information We Collect	2
Why We Collect This Data	4
How We Use the Information we collect	4
How We Process Information	5
How Long We Keep This Data	6
Why We Disclose Information	6
What We Do Not Do	7
How We Protect Information- Data Security	8
Your Rights and Choices	8
Cross-Border Transfer of Your Information	9
Contact	9
Updates to this Privacy Policy	9
Change Log	9
<b>EEA- General Data Protection Regulation Addendum</b>	10

## **Introduction**

Sage is committed to protecting your privacy. This privacy policy tells what we will do with the information we collect from you through Open Bridge. It also tells you about your rights and choices.

**By joining an Open Bridge study and using an Open Bridge study website or App, you agree to this Privacy Policy.**

## **Information We Collect**

“Personal information” or “personal data” means any direct information about you such as your name and contact information. It also means indirect information that could be reasonably linked to you such as your device’s internet protocol address (IP Address) when you connect to a wireless network.

In general, we collect all information that you give us directly. We also collect information passively when you use an Open-Bridge-Web or Open-Bridge-App.

**We will NOT access your personal contacts, photos, text, or email messages on your smartphone. We will only collect information that you give to Open Bridge.**

#### 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.

- Contact information: This could include your name, email, and any other contact information you share with us so we can respond to your support requests, questions, and comments.
- Eligibility: Each Open Bridge study has some inclusion/exclusion criteria. We may ask questions to verify your eligibility to participate in the study. For example, if the study is for people age 25 or older, we will ask your age. We do not knowingly allow people to join a study they are not eligible for.
- Informed consent: When you consent through an Open-Bridge-Web or Open-Bridge-App, we may collect your first and last name, electronic signature, and phone number. If you consent outside an Open-Bridge-Web or Open-Bridge-App, you may receive a code to enter into an Open-Bridge-Web or Open-Bridge-App. This code will be unique to you.
- Account Creation: We collect basic account information to create your profile and provide you access to an Open Bridge study website or App.

#### What you do when you use the Open-Bridge-Web or Open-Bridge-App (“Activity Data”)

Once you join the study, we collect information about your health and wellness through surveys and activities.

- Health Surveys: As part of a research study, we may ask you about your health and wellness. Most of the survey questions are optional. However, some questions may be required to answer. This is because researchers must know the answers as part of the research study.
- Data Imports: We may import information into the Open-Bridge-App. We may ask you to link the Open-Bridge-App

to another App like the Apple health app or Android equivalent. In this way, we may import information from these Apps like your weight, height, the number of steps you take and/or your sleep patterns. Any information that we import is treated the same as the information we collect in the Open-Bridge-App directly.

It is important to note that we do not have control over the privacy policies or practices of other Apps. Depending on the Open Bridge study, you may participate in the research study even if you do not want to link information from other Apps to the Open-Bridge-App.

Location Data: You can opt-in to linking the Open-Bridge-App to your smartphone's GPS (global positioning system). Some studies may use your GPS to capture your movement patterns or capture local weather or air quality. To reduce issues relating to your privacy, we collect only the distance you travel and do not store actual GPS coordinates or precise location.

Passive Sensor Data: You can opt-in to sharing passive sensor data. These are data recorded from sensors on your device. For example, the level of ambient light and background noise, step-count, application usage, and screen time. You can decide which forms of passive sensor data you want to share by adjusting your device settings.

Technical Information and log files ("Usage Data"): Whenever you use any online service, certain information gets created and logged automatically; the same is true when you download and use an Open-Bridge-App or Website. For example, we may collect the date and time when you use the Open-Bridge-App and the pages you visit on the Open-Bridge-App or Website.

## **Why We Collect This Data**

We collect this data to conduct, maintain and improve the research study and the App, to be able to correspond with you and to help recruit more participants over time. We also collect this data to adhere to state and federal laws and prevent and deal with cases of abuse or fraud.

## **How We Use the Information we collect**

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

User Information and Activity Data: In addition to using it for scientific research, we use the information that we collect through the Open-Bridge-Web and Open-Bridge-App for any of the following:

- Ensuring that the Open-Bridge-Web and Open-Bridge-App are working properly.
- Improving the Open-Bridge-Web and Open-Bridge-App and making them easier to use. For example, remembering information you have entered so it does not need to be re-entered.
- Contacting you for administrative purposes or to respond to requests, questions, or concerns.
- Telling you more about other Open Bridge studies or materials that may be of interest to you.

Usage Data: We use usage data for the following purposes:

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

## **How We Process Information**

We process the information we collect through the Open-Bridge-Web and Open-Bridge-App. Here are the steps we take to process your information:

1. We separate your account information like your name and phone number from your study data like your answers to questions.
2. We assign you a random study code. We add this code to your study data. The key that links this code to your name is kept in a separate, secure location.
3. We combine your coded study data (without your name) with the coded study data from other people in this or other Open Bridge research studies We use this combined data for our research.
4. We store the Open Bridge research data we collect on Synapse. Synapse is a cloud-based research platform where researchers from the sponsor, the study team and research partners 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.

## How Long We Keep This Data

We keep your 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 your login information for as long as your account is active. You may edit your profile information or remove your information by withdrawing from the study in the profile settings. At the end of the study, we will stop collecting data, including passive data from you. We will retain and archive a record of your activities performed while your 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.

## Why We Disclose Information

Service Providers: We may work with vendors, service providers, and other partners to provide the necessary hardware, software, networking, storage, and related technology required to operate, support, and maintain Open Bridge studies and Apps. We require 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 the work we ask them to do. Open Bridge uses the following service providers:

- Amazon Web Services: cloud service provider
- Google Firebase Crashlytics: crash reporting tool

Statistical and Aggregate Information: We may share aggregate and statistical information derived from users' information with third parties for analysis.

Compliance with Laws: We may give out information if we are required to do so by law. For example, to comply with state or federal laws, in response to a court order, subpoena, or warrant, or to cooperate with law enforcement or other governmental agencies.

We may give out information:

- To protect ourselves against liability
- To protect ourselves from fraud, abuse, or unlawful activity
- To investigate and defend ourselves against claims or allegations

- To protect the Open-Bridge-Web, Open-Bridge-App and research study
- To protect our rights

Business Transfer: If Sage 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, then Sage's assets, or stock, information or data may be transferred to a third party. The information we have from you may be transferred as a business asset. 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.

Future Research: The Open Bridge study may give you the option to share your coded study data more broadly, with other researchers worldwide, for use in this research and beyond. Your data could benefit future scientific research. If you choose to share your data broadly, your coded study data (responses to questions, activity measurements, etc.) will be added to a shared dataset available to qualified researchers on the Sage Synapse servers ([www.synapse.org](http://www.synapse.org)). This shared dataset will be made available to qualified researchers. Qualified researchers are registered Synapse users who agree to use the data in an ethical manner, to do no harm, and not attempt to re-identify or re-contact you unless you have chosen to allow them to do so. The study team will have no oversight on the future research that qualified researchers may conduct with the coded study data. For more information about our data practices in the context of the Synapse research platform, see the [Synapse Privacy Policy](#).

## **What We Do Not Do**

- We do not sell or lease the information we collect about you without your consent.
- We do not use your personal information for advertising.
- We do not collect information using cookies, beacons, or device fingerprinting.
- We do not access your personal contacts, photos, text, or email messages on your smartphone. We only collect information that you give to the Open Bridge study.

## How We Protect Information- Data Security

Sage Bionetworks maintains industry standard physical, organizational, technical, and administrative measures to protect the personal information we collect, store, or otherwise process in connection to the study. This is to limit risks of 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.

## Your Rights and Choices

You have rights and choices regarding the personal data we collect and maintain about you. You may request access to and receive information about the personal data we maintain about you. You may request to have your personal data rectified, blocked, or deleted if it is incorrect, inaccurate, or outdated. Following your request, we will accommodate your inquiry as required by applicable law.

To make a request about the information we collect from you, you can email Sage's Data Protection Officer (DPO) <[privacyofficer@sagebionetworks.org](mailto:privacyofficer@sagebionetworks.org)> or write to Sage Bionetworks, Attention: Data Protection Officer, 2901 Third Avenue, Suite 330, Seattle, WA 98121, United States of America.

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. We may keep a copy of all the information we collect from you. This is because we have a responsibility to keep backups and archives. We keep backups and archives for reasons like the prevention of fraud and abuse, analytics, and for the satisfaction of legal obligations.

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](mailto:privacypolicy@sagebionetworks.org) with the word "remove" in the subject header, and we will remove your contact details from our mailing list.



If you are habitually located in the EEA, you have certain rights related to the processing of the information we collect from you. While some of these rights apply generally, certain rights apply only in certain limited circumstances. See the GDPR addendum for more information about your data rights.

## **Cross-Border Transfer of Your Information**

Open Bridge is operated and managed from the United States. If you are located outside the United States and choose to join an Open Bridge study or provide information to us, you acknowledge and understand that your information will be transferred, processed, and stored in the United States as is necessary.

We may transfer your information and Open Bridge study data to researchers and partners in countries where you do not live. These countries may have different data protection laws than where you live. If we transfer your information, we will protect the information and data as described in this Privacy Policy.

By using the Open-Bridge-Web or Open-Bridge-App or participating in Open Bridge study, you consent to these types of cross-border transfers of your information.

## **Contact**

If you have any questions, comments or requests, please 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](mailto: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 to this Privacy Policy**

We may update this Privacy Policy from time to time. We will post updates with a revision date. Also, if we make major changes that alter your rights or obligations, we will make reasonable efforts to notify you. For example, we may send you a SMS or put a pop-up notification in the App. If you participate in the study or use the Open BridgeWeb or Open-Bridge-App after we update the Privacy Policy it means you agree to the updated Privacy Policy.

## Change log

June 06, 2022: Added Google Firebase Crashlytic as a Service Provider

October 30, 2023: Updated the name of the application and website

# EEA- General Data Protection Regulation Addendum

As required by the law of the European Union, and its member countries, additional information is being provided to you as a research participant.

For the purpose of EU law, particularly the General Data Protection Regulation (GDPR), the legal basis for the collection and use of your data is your consent as well as scientific research purposes, and the public interest in the research being conducted.

If you are habitually located in the EEA, you have certain rights related to the processing of the information we collect from you. While some of these rights apply generally, certain rights apply only in certain limited circumstances. We will comply with your request to exercise your rights unless we have compelling legitimate grounds to deny your request or we cannot comply with your request for legal reasons. We will respond to your request within 1 month of receiving it.

**You have the right to access your data.** You can write to us at any time asking to know what personal information is being held where and for what purpose.

**You have the right to rectification.** If there is an error in the personal information we collect from you, you have the right to make a request to have it fixed. You can write to us to ask for any incorrect personal data about you to be corrected.

**You have the right to erasure.** You may ask us to delete or remove some or all of your personal data at any time.

**You have the right to restrict processing.** At any time, you can withdraw your consent to our processing of your Personal Data.

**You have the right to data portability.** You can request a copy of your data in usable format.

**You have the right to object.** You can withdraw from providing data to the Open-Bridge-Web or Open-Bridge-App at any time.

V4- 10/30/2023

If you have questions about your rights and choices or would like more information about your rights and choices, you can email [privacyofficer@sagebionetworks.org](mailto:privacyofficer@sagebionetworks.org)