

Privacy Policy

Sage Bionetworks (“Sage Bionetworks,” “we,” or “us”) is a 501(c)(3) nonprofit biomedical research organization in the United States, created to enhance how researchers approach the complexity of human biological information and the treatment of disease.

We have developed a website and mobile application (the “MindKind website” and “MindKind Study App”) to facilitate our MindKind research study (the “Study”). We want to find out if young adults are willing to use a mobile application (the MindKind Study App) to record their mental health. We also want to find out what data youth are willing to share for research and how. This information will help us determine whether data collected via the MindKind Study App can be used to create a global research databank about Mental Health. The Study and the MindKind Study App are designed for users who’ve reached legal age (set between 16 and 21 depending on local laws) and live in a country where the MindKind Study App is available.

Your privacy is important to us. The Privacy Label gives you an overview of Sage’s privacy practices within the MindKind Website and MindKind Study App. 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
- 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 precise device location?..... No
- Do we track your browsing activities on other Apps?..... No
- Do we listen to you using your device microphone? No
- Do we watch you using your device camera?..... No

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/store your study data abroad?Yes, in the US

Privacy Tools and Controls

- Can you control who sees your data? Yes
- Can you ask to access and download your data?Yes
- Do we delete your data when you ask us to do so?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 communications?Yes, if you opt-in

Detailed Privacy Policy

This privacy policy describes our collection of your personal data when you participate in the Study by using the MindKind Website and/or MindKind Study App, our use and disclosure of your personal data, and the steps we take to protect your personal data. “Personal data” means any information relating to an identified or identifiable natural person directly or indirectly.

The entity responsible for the collection and processing of your personal data in the context of the Study, the MindKind Study website and the MindKind Study App is Sage Bionetworks, 2901 Third Avenue North, Suite 330, Seattle, WA 98121, United States.

The study lead in India is:

- Soumitra Pathare, MD, DPM, MRCPsych, PhD - Centre for Mental Health Law and Policy - Indian Law Society, India

The study lead in South Africa are:

- Melvyn Freeman, MA Clin Psych - Higher Health, South Africa
- Zukiswa Zingela, MMed Psych, FCPsych, Department of Psychiatry and Human Behavioral Sciences - Walter Sisulu University, South Africa

The study leads in the UK are:

- Mina Fazel, DM MRCPsych - Medical Sciences Division, Department of Psychiatry, University of Oxford, England
- Tasmin Ford, CBE, FRCPsych, FMedSci - School of Clinical Medicine, Department of Psychiatry - University of Cambridge, England

Your use of the MindKind website and/or MindKind Study App and your participation in the Study are voluntary. By using the MindKind website and/or MindKind Study App and participating in the Study, you consent to the privacy practices described in this privacy policy.

Information We Collect

In general, we collect all information that you give us directly. With your consent, we also collect information passively when you use the MindKind website and/or 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 MindKind.

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 can include your name, email, phone number, and any other information you share with us so we can respond to your support requests, questions, and comments.
- **Eligibility:** We ask questions to verify that it is all right for you to participate in the Study and use the MindKind Study App. The Study is designed for people between the age of 18 (16 in the UK) and 24 years old. We may ask your age to make sure you are old enough to use the App.
- **Informed consent:** The informed consent process explains the MindKind Study. You must consent to join and use the App. We ask questions to confirm your understanding and record your choices. We also collect your electronic signature to confirm your decision.
- **Account creation:** We collect basic account information to create your profile and provide you access to the MindKind Study App. This may include a username, password, and your email address.

What you do when you use the App (“Activity Data”)

Once you join the MindKind study we will collect information about your health and wellness through surveys and other data you provide to us.

Health surveys

As part of the MindKind research study, we will ask you about your mental health and wellness. All of these questions are optional. You can skip any questions you do not wish to answer.

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, screen time and battery statistics. You can decide which forms of passive sensor data you want 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 use the MindKind website or download and use the MindKind Study App. For example, we may collect the date and time when you use the App and

the pages you visit. We do not collect information using cookies, beacons or device fingerprinting.

Why we collect this data

We collect this data to conduct maintain and improve the research study, MindKind website and the MindKind Study 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 MindKind website and/or MindKind Study

App for any of the following:

- Ensuring that the website and/or App is working properly.
- Improving the website and/or App and making it 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 research 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 website and/or App
- Detecting and remedying disruptions in our systems
- Performing statistical analysis of usage patterns
- Operating, maintaining, enhancing, and providing all the features of the website and/or App

How we process the information we collect through the App

We process the information we collect through the MindKind Study 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 research studies We use this combined data for our research.
4. We store the 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 user 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 user login information for as long as the user account is active. 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. We will retain personal information, including your record of consent and account information, and study data for future research for the duration of the MindKind project. If you withdraw from a study, we will delete your personal account data and personal information, but retain the study data that has already been collected. You can also explicitly request that we delete your personal account and study data, and we will honor that request.

How 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 the Study, the MindKind website and/or and MindKind Study App. We required that all service providers process information only for performing tasks on Sage Bionetwork's behalf and to maintain the security and confidentiality of such information by applying adequate technical and organizational measures. We do not permit service providers to use or disclose users' information, except as necessary to the work we ask them to do. MindKind uses the following service providers: ● Amazon Web Services

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 that we believe, in good faith, is appropriate: ●

- To protect ourselves against liability
- To protect ourselves from fraud, abuse, or unlawful uses or activity
- To investigate and defend ourselves against third-party claims or allegations
- To protect the security or integrity of the MindKind Study App, the MindKind website and the Study and any facilities or equipment used to make the MindKind Study App, MindKind website, or Study available
- To protect our property or other legal rights (including, but not limited to, enforcement of our agreements), or the rights, property, or safety of others. We will notify you of any such disclosures.

Business Transfer

If Sage Bionetworks 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.

Statistical and Aggregate Information

We may share aggregate and statistical information derived from user's information with third parties for analysis.

Future Research

As described above in the "How we process the information we collect" section, we will combine your Study data, including survey response and tasks measurements, with those of other Study participants. The combined data will be transferred to Synapse, a computational research platform, for analysis. Researchers from the Study team and its partners accessing data through Sage Synapse (www.synapse.org) will analyze the data and report findings back through blog or scientific publications. This Study may give you options to share your Study data more broadly, with other researchers worldwide, for use in this research and beyond to benefit future scientific research. If you choose to share your data broadly, your coded Study data (without your contact information) will be added to a shared Study dataset on Synapse

and will be made available to qualified researchers who are registered Synapse users and who agree to using 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. 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 MindKind website, MindKind Study App and Study.
- We do not track visitors to the MindKind website and/or MindKind Study App over time and across third party websites or online services to provide targeted advertising, and we do not specifically respond to Do Not Track (“DNT”) signals.

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. Experts in re-identification may be able to reverse our processes and/or attempt to re-identify you if given sufficient cross-reference information. Anonymity cannot be guaranteed.

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 enquiry as required by applicable law.

At any time, you can elect not to grant access to the collection of any mobile phone usage data by de-activating the relevant setting within the MindKind Study App or your mobile device.

You can leave the Study at any time and for any reason. If you would like to do so, you can either contact the contact person in your country listed above or email the study team in the

US at MindKindSupport@sagebionetworks.org. You can also withdraw by selecting the “Withdrawal” button directly from the MindKind Study App. We will close your account and stop collecting new data from you. We will respond to your withdrawal request within 1 month of receiving it. By default, your de-identified, coded study data provided prior to your withdrawal will remain in the Study.

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

To make a request about the personal data we hold about you, or if you have questions about your rights and choices related to the processing of your data, please contact Sage’s Data protection Officer (DPO) at privacyofficer@sagebionetworks.org or write to Sage Bionetworks, Attention: Data Protection Officer, 2901 Third Avenue, Suite 330, Seattle, WA 98121, USA. Please note that while any changes you make will be reflected in active user databases within a reasonable period of time, we may retain all information you submit for backups, archiving, prevention of fraud and abuse, analytics, satisfaction of legal obligations, or where we otherwise reasonably believe that we have a legitimate reason to do so, as permitted by applicable law.

If you are a primary resident of a nation that abides by the General Data Protection Regulation, see the Data Rights Addendum below for more information about your data rights.

Cross-Border Transfer of Your Information

The MindKind Study is being conducted in multiple countries. The data collected in connection with the Study, website and/or App will be transferred to, processed, and stored in the United States. The US may have different personal data protection laws than the country in which you initially provided the information. We may also transfer your data from the United States to other countries or regions in connection with storage and processing of data, fulfilling your requests, and operating the MindKind Study App, website and the Study. In doing so, we comply with applicable legal requirements pertaining to the transfer of personal data to other countries and will protect that information as described in this Privacy Policy.

By using the MindKind Study App or participating in the Study, you will be asked to consent to the transfer of your personal data, including your health information, to countries outside of your country of residence, including to the United States. If you are located outside the United States and choose to join the Study or provide information to us, through the website, App or

other means, you acknowledge and understand that your information will be transferred, processed, and stored in the United States as is necessary.

For participants from India, personal information collected for documenting consent will be securely stored in India. Only de-identified (without name) study data will be stored on the Synapse platform in the United States.

Contact

If you have any questions, comments or requests regarding this privacy policy or our processing of your information, 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 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. We will post updates with a version date. If we make major changes to this privacy policy that alter your rights or obligations under this privacy policy, we will make reasonable efforts to notify you. For example, we may send a message to your email address, if we have one on file, or generate a pop-up or similar notification when you access the MindKind Study App or the Study for the first time after such material changes are made. If you participate in the Study or use the MindKind website, and/or MindKind Study App after the revised privacy policy has become effective, it means that you have read, understood and agreed to the updated version of this privacy policy.

Version V1: April 06, 2021

Version V2: November 09, 2021

General Data Protection Regulation Addendum

As required by law under the General Data Protection Regulation, additional information is being provided to you as a research participant.

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

If you are habitually located in an area that abides by the General Data Protection Regulation, 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 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 App at any time.

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.