



# Synapse Privacy Policy

Effective Date: May 25, 2018

[Introduction & Definitions](#)

[Information We Collect](#)

[Project Content](#)

[Use of Information We Collect](#)

[Information Sharing](#)

[Your Rights](#)

[Information Security](#)

[Data Retention](#)

[Cookies](#)

[Sage Bionetworks Adaptive Policies](#)

[Data Transfers](#)

[Links to Other Websites](#)

[Violation Consequences](#)

[Contact Us](#)

## Introduction & Definitions

Sage Bionetworks is helping researchers worldwide do better science together by enabling a collective approach to information sharing and analysis. We (Sage Bionetworks) have built a computational platform ("Synapse") where researchers can share de-identified datasets to co-analyze, learn from, and improve knowledge of health and disease. Sage Bionetworks acts as steward for the content available through Synapse. Synapse Users are responsible for the processing of the Data they submit to and/or share through Synapse.

This Privacy Policy explains how we protect personal information received, used, and disclosed by data contributors and users (collectively, "Registered Users" or "Users") and non-registered users ("Visitors") of Synapse.

Synapse can house genomic, molecular, phenotypic, and/or other data from human or non-human sources and other information contributed to project workspaces (collectively "Data"). Synapse also houses information ("Information") about Users and Visitors.

The governance process under which Data is used and shared within Synapse represents our (Sage Bionetworks') committed effort to safeguard the security and protect Data in Synapse. Please read this Privacy Policy carefully. By using Synapse, you agree to the Synapse governance framework, including this Privacy Policy.

## Information We Collect

When you use Synapse, you may provide to us and/or we may collect personal information about you and your activity on Synapse. Personal Information is any information that reasonably can be linked to you such as your name and contact information.

In general, Visitors can browse the Synapse content in the public Synapse Commons (the 'Commons') without registering for a Synapse account. We collect Information from Visitors and Users of Synapse:

Web data: Like most websites, we collect technical information on how Visitors and Users use Synapse. Such information includes date, time, pages and services consulted, browser or client type, IP addresses, how you have found our site on the Internet, and other Service usage patterns. For details, please read the COOKIE section of this Privacy Policy.

Some sections of Synapse and access to some content are granted only to Registered Users. The types of Information we collect from Registered Users are:

User information: We collect Information that you provide to us for account registration and authentication, including but not limited to your name, email address, username and password. We also collect Information when you update or change your account, participate in our public project forums, and send us email messages. If you send us email or otherwise communicate with us, we may keep a copy of that communication. We may also collect documentation intended to verify User's credentials such as letter from signing official, notary or other official documents which may contain Personal Information. Non-personally identifiable sections of these documents may be snapshotted and User's qualification status may be displayed publicly as part of the User profile.

Linked accounts: Any Registered User may elect to link their Synapse profile to their social media account(s) (e.g. LinkedIn) or researcher credentialing web services (e.g., ORCID). If a user chooses to link their account(s), the amount of visible information posted on User's Synapse profile will depend on the privacy settings of those outside accounts. By authorizing Synapse to connect with an outside account, you authorize Sage Bionetworks to access and store all information that that service makes available to us in accordance with your consent, and to use and disclose it as we describe in this Privacy Policy.

User activity information: Projects hosted on Synapse are meant to be developed collaboratively. Any User not otherwise restricted from doing so can share project content with other Users by creating, uploading, editing, and analyzing Data into shared project workspaces on Synapse. By doing so Users create a record of their activities and they are identified as the author of these activities ("User Activity Information"). These interactions reveal usernames and possibly other personal information voluntarily provided by Users, such as posts, comments, research details and interests, as well as contact information. We may collect and display aggregate User Activity Information as part of a public page.

Forum information: Sage Bionetworks encourages dialogue and feedback from Users through a web interface forum where concerns, issues and suggestions can be posted, reviewed, and assessed. Usernames are associated with these comments. Information that you post on public forums are publicly

available. You should not include information of a personal or sensitive nature, whether related to you or another person, on a forum.

For details about retention of personally identifiable information consult the DATA RETENTION section.

## Project Content

Project Content posted on Synapse is the responsibility of its contributor.

Contributors must take reasonable steps to ensure that all Data derived from human samples is key-coded and de-identified such that it no longer constitutes personal information. In general, human Data must be de-identified by the data contributor (or verified as being already de-identified) prior to being included in Synapse using the United States Health Insurance Portability and Accountability Act of 1996 (“HIPAA privacy rule” or “HIPAA”) standards for de-identification set forth in U.S. 45 CFR 164.514(b) and any applicable laws and regulations. Limited identifiers are sometime allowed to be included with the Data when unambiguously approved by the Data subjects or by an Institutional Review Board (IRB) or similar ethics committee.

Synapse Users must be Synapse Certified to contribute Data on Synapse. Data contributors assume responsibility for the Data they publish or share through Synapse and declare that they have the right to communicate or broadcast these Data. They have obtained all necessary permissions and, where legally required, prior specific, informed, and freely given consents from the participants from which the Data is derived prior to submitting the Data to Synapse.

Sage Bionetworks does not guarantee the accuracy, integrity, or quality of Synapse project content and is not liable for the content posted by non-Sage Bionetworks staff, as described in the Synapse Terms and Conditions of Use.

## Use of Information We Collect

We will use Visitor and User Information only as we describe here:

User data: Sage Bionetworks requires User registration to contribute and access Synapse content. We use the Information we request as part of the registration process for:

- Authentication
- Administering your account
- Responding to User requests, questions, and concerns
- Assessing suitability of User activity and compliance with Synapse governance
- Assessing User comprehension to confer or rescind certain rights and access privileges to User accounts
- Preventing or remedying abusive activity
- Operating, maintaining, enhancing, and providing all features of Synapse
- Enhancing and improving Synapse, and developing new features, products, and functionality

- Sending marketing communications such as newsletters and other materials that may be of interest to Users

Survey information: We use surveys to:

- Assess comprehension of Synapse governance policies and procedures
- Enhance and improve Synapse
- Develop new features, products, and functionality

User activity information: We also use User activity information to:

- Enhance transparency in Data use
- Foster open collaborations
- Enhance User accountability

Contributions and activity conducted within Synapse may be reviewed, copied, or reused by other Synapse Users as described in the Synapse Terms and Conditions of Use and the Synapse Commons Data Use Procedure.

Sage Bionetworks will perform periodic audits to assess the practices within the Synapse Commons analytical environment and to confirm compliance with Synapse governance process. The Access and Compliance Team (ACT) and, as needed, an independent Institutional Review Board (IRB) and/or legal counsel will review results of these audits. The username and/or IP address of the User may be used to identify source(s) of abusive activity such as vandalism, harassment of other Users, or disruptive behavior. This Information may be shared with Users whose projects are affected by the behavior, additional IRB/ethics boards, legal counsel, and/or outside institutional authorities.

Web data: We use web data for the following purposes:

- Learning what Synapse features are most attractive to Users
- Maintaining, securing, and enhancing the Synapse Service
- Detecting and remedying disruptions in our systems
- Performing statistical analysis of usage patterns
- Operating, maintaining, enhancing, and providing all features of Synapse
- Enhancing and improving Synapse, and developing new features, products, and functionality

Project content: We may access project content that Users have uploaded to Synapse as described in our Synapse Commons Data Use Procedure. We will not attempt to re-identify de-identified Data. We may use project content to:

- Facilitate Data contributions in our tiered system
- Assist review of data contributions by our Sage Bionetworks Access Compliance Team (ACT)
- Audit Data use to verify compliance with the Synapse Terms and Conditions of Use.
- Assist data contributors with their review submissions to an ethics committee or an independent Institutional Review Board (“IRB”)

- Improve Data storage on the platform
- Enhance research collaboration and interaction between Users

## Information Sharing

We do not sell or otherwise disclose Information we collect about you, except as described here. We may share Users' Information in the following ways:

Service Providers: We may rely on third-party vendors or partners to provide the necessary hardware, software, networking, storage, and related technology required to operate, support, and maintain Synapse. We will give them the Information they need to do their work, including Users' Personal Information if necessary. We require them to agree to implement reasonable safeguards to keep Users Information confidential and secure, and to process this Information only for performing tasks on our behalf in accordance with this Privacy Policy and our instructions. We do not authorize service providers to use or disclose Users' Information, except as necessary to perform services on our behalf or to comply with legal requirements.

Statistical and Aggregate Information: In accordance with applicable law, we may share aggregated and statistical information derived from Users' Information with third parties for analysis.

Compliance with Laws: Subject to applicable law, we may disclose User Information to comply with a legal obligation or when we have reason to believe that disclosing this Information is necessary to (i) identify, contact, or bring legal action against someone who may (either intentionally or unintentionally) be causing injury to or interference with our rights or property, Users of Synapse, participants, or anyone else who could be harmed by such activities, (ii) take precautions against liability, (iii) investigate and defend ourselves against any third-party claims or allegations, (iv) protect the security or integrity of Synapse or any facilities or equipment used to make Synapse available, or (v) protect our property or other legal rights (including, but not limited to, enforcement of our agreements), or the rights, property, or safety of others.

Business Transfers: If Sage Bionetworks goes through a management or business transition such as 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 or delete the Information you provide to us by contacting us as described below under "Contact Us". 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. Contact the Access and Compliance team at [ACT@sagebase.org](mailto:ACT@sagebase.org) to request that we deactivate your Synapse account. We will honor your request as required by applicable law.

You may opt-out of receiving marketing communications from us by clicking on the “unsubscribe” link included in each such communication or by notifying us by email at [synapseInfo@sagebase.org](mailto:synapseInfo@sagebase.org) with the word “remove” in the subject header, and we will remove your contact details from our mailing list.

If you are a research participant, please address any queries related to the use of Data pertaining to you to the person or organization responsible for collecting, de-identifying, and uploading the Data (e.g., doctor, researcher, hospital, lab, research center, or similar organization).

## Information 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 Synapse 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. Nevertheless, no environment is 100% secure. There is some risk that an unauthorized third party may find a way to circumvent our security systems. Users are responsible for protecting the security of their Synapse login information.

## Data Retention

We retain 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 retain personally identifiable information related to authentication of user identity only for as long as is necessary for authentication.

Users may choose to deactivate their accounts which will make their profile information invisible to other Synapse users. 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 comply with our legal obligations, resolve disputes, and enforce our agreements and policies.

## Cookies

Sage Bionetworks may use cookies to help track User activity on Synapse and enhance the functionality of our site. A cookie is a small file containing a string of characters that is sent to your computer when you visit a website. The information that we may collect using cookies is of technical nature and may include, for example, dates and times of website visits, and visited URLs. We do not use any advertising or behavioral cookies.

Cookies can help us determine whether a Visitor or User has visited our website before or is a new visitor, identify site features in which Visitors/Users have the greatest interest, and save User preferences while they are visiting our site. Synapse uses cookies for the following purposes:

- To keep the User’s authentication token in their browser between sessions (expires after 24 hours).

- To store the current and last visited place in the website such that we can redirect Users to the last page visited upon subsequent login

You have the choice to refuse all cookies, to stop accepting new cookies, to be notified when you receive a new cookie, and to disable existing cookies by using the privacy settings of your browser. The help section of all major browsers will tell you how you can block or delete cookies from your system. If you choose to reject cookies from our site, you may be unable to use certain services, features, and functionality.

## Sage Bionetworks Adaptive Policies

Sage Bionetworks policies may be modified, supplemented, or replaced to address emerging issues based on Users' input, audit results, evolving social and regulatory contexts, or other concerns. Any policy update will be effective immediately upon posting on Synapse.

We will notify Visitors and Users of any material changes to this Privacy Policy by posting a notice on the Synapse homepage and by indicating the update date on the first page of this policy. We encourage you to periodically review this page to ensure continuing familiarity with the most current version of our Privacy Policy. Once a revised Privacy Policy is effective, your use of the Service will be governed by the revised Privacy Policy.

## Data Transfers

Although you may access Synapse from a location outside of the United States, Synapse is primarily operated and managed within the United States. Personal Information on Synapse may be transferred to, processed, and stored in the United States or other countries that may not have the same data protection framework as the country from which you may be using Synapse. When we transfer Information and Data, we will protect the Information and Data as described in this Privacy Policy.

## Links to Other Websites

This site may provide links to third party websites for your convenience and information. These websites operate independently from Sage Bionetworks and are not under our control. Linked sites may have their own privacy policies, which we strongly suggest you review if you visit them. We are not responsible for the content of these sites, any products or services that may be offered through these sites, the data processing activities that are conducted via these sites, or any other use of these sites.

## Violation Consequences

Intentional or unintentional violation of this Privacy Policy, the Synapse Commons Data Use Procedure, or the Terms and Conditions of Use will result in termination of current and future access to the Synapse Commons. Any breach of obligations under this Privacy Policy, the Synapse Terms and Conditions of Use or the Data Use Procedure will be reported to the Visitor's/User's institutional official, if applicable. Sage Bionetworks has no responsibility to Visitors, Users, institutions or any third party for the breach or violation of this Privacy Policy, the Synapse Commons Data Use Procedure, or the Terms and Conditions

of Use by Users. Visitors/Users and their institutions, if applicable, will be fully and solely responsible for all such breaches, violations, and their consequences.

## Contact Us

If you have any questions, comments, or concerns regarding this Privacy Policy, please contact us by email at [ACT@sagebase.org](mailto:ACT@sagebase.org), or by writing us at:

Sage Bionetworks  
Attn: ACT  
2901 3<sup>rd</sup> Avenue  
Seattle, WA 98121

If you are a research participant, please address any queries related to the use of Data pertaining to you to the person or organization responsible for collecting, de-identifying, and uploading the Data (e.g. doctor, researcher, hospital, lab, research center, or similar organization).

t: (206) 667-2102

f: (206) 667-2062

w: [www.sagebionetworks.org](http://www.sagebionetworks.org)