

Synapse Privacy Policy

Last updated: March 18, 2013

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| Introduction | <p>Sage Bionetworks is driving a systems change in data-intensive healthcare research by enabling a collective approach to information sharing and analysis. Sage Bionetworks is building a broadly accessible computational 'Commons' platform ("Synapse" or the "Service") where de-identified datasets can be shared with researchers to co-analyze, learn from and improve knowledge of health and disease.</p> <p>This Privacy Policy explains how Sage Bionetworks aims to protect personal information received, used and disclosed in connection with website visitors and registered users of Synapse ("Users"). We also describe how we protect the information uploaded and shared by users or data contributors on the Service.</p> <p>While we are generally responsible for the processing of personal information described in this Privacy Policy, Sage Bionetworks only acts as steward for the data, tools and analyses available through Synapse. Users or data contributors are responsible for the processing of information submitted to or shared between users through Synapse. The complete Governance process under which data is used and shared within Synapse represents a committed effort to safeguard the security and protect data in Synapse. This Privacy Policy is incorporated by reference into, and is subject to the provisions of, the Synapse Terms and Conditions of Use</p> |
| Information We Collect | <p>Through your use of this site, you may provide to us and we may collect personal information. By personal information we mean "any information relating to an identified or identifiable (directly or indirectly) natural person." The different types of personal information that we collect are:</p> <p>User data: In general, visitors can browse Synapse without registering on the website. However, some sections of Synapse and access to some content will be granted only to registered users for research, statistical and training purposes. We collect personal information for registration and authentication, including name, email address, username, password and any other information entered voluntarily by users such as company or organization name, title, postal address, telephone number, interests, and field of research. Users may elect to link their Synapse profile to other social media accounts. In this case the amount of visible information will depend on the privacy settings of these accounts. By authorizing us to connect with a social media account, you authorize us to access and store all information that the social media service makes available to us in accordance with your consent, and to use and disclose it in accordance with this Privacy Policy. We do not verify the accuracy of any data provided by users other than the fact that his/her email address is valid. To the extent you contact us, we may also keep a</p> |

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| | <p>record of that correspondence or communication, including any personal information contained therein.</p> <p>Web data: Like most websites we collect technical information on how visitors and registered users use the site. 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 about this type of data collection consult the COOKIE section.</p> <p>User activities data: Projects in Synapse Commons are meant to be developed collaboratively. Any registered user (not otherwise restricted from doing so) can share project content with other registered users by creating, uploading, editing and analyzing information into shared project workspaces stored in Synapse Commons. By doing so users create a record of their activities and they are identified as the author of these activities. These interactions reveal a contributor's chosen user name and possibly other personal information voluntarily provided by users such as posts, comments, research details and interests, as well as contact information.</p> <p>Project content: Synapse Commons collects and stores project content such as sequenced genomic, molecular and/or phenotypic data ("Biological Data") of human participants that is submitted to the site as well as other information users contribute to shared project workspaces.</p> <p>Content posted on Synapse is the responsibility of its contributor. All human Biological Data must be de-identified by the contributor per the HIPAA privacy rule standards for de-identification set forth in 45 CFR 164.514(b), prior to being included in the Synapse Commons. Contributors must take reasonable steps to ensure that all Biological Data derived from human samples is key-coded and de-identified such that it no longer constitutes personal information. In particular, contributors must remove any information that would enable Sage Bionetworks or a third party to directly associate any Biological Data with a specified individual. To the extent that submitted Biological Data is still personal information under applicable privacy laws, we protect this information as required by applicable law.</p> <p>Data contributor and participants whose data is being analyzed must carefully review the Synapse Commons Data Use Procedure that provides additional information on how Biological Data is shared. Data Contributor assumes responsibility for the data published or shared through Synapse and declares that (s)he has the right to communicate or broadcast them and that (s)he has obtained all necessary permissions and, where legally required, prior specific, informed and freely given consents from the data participants from which the Biological Data is derived prior to submitting the data to Synapse.</p> <p>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</p> |
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| | staff, as described in the Synapse Terms and Conditions of Use . |
| Use of Information We Collect | <p>We limit the use of user data to purposes that serve the Synapse Commons community.</p> <p>User data: Sage Bionetworks requires user registration to contribute and access content of Synapse Commons. We use that type of information for:</p> <ul style="list-style-type: none"> - Authentication - Administering your account - Responding to user requests, questions and concerns - Assessing suitability of user activity and compliance with Synapse Governance - Preventing or remedying abusive activities - 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 <p>User activities data: We use personal user activities data for the foregoing activities, as well as to:</p> <ul style="list-style-type: none"> - Enhance transparency in Data use - Foster open collaborations - Enhance user accountability <p>Contributions and activities conducted within Synapse Commons may be reviewed, copied or reused by other Synapse users with few restrictions as defined in the Synapse Terms and Conditions of Use and the Synapse Commons Data Use Procedure. Sage Bionetworks encourages dialogue and feedback from Users through a web interface where concerns, issues and suggestions can be posted, reviewed and assessed by the community. Usernames are associated with these comments. In addition, Users can use the “flag” link when they wish to keep their comments confidential.</p> <p>Sage Bionetworks will perform periodic audits of the Synapse Commons to assess the practices within the analytical environment and to confirm compliance with Synapse Governance process. The Access and Compliance Team (ACT) and Sage Bionetworks Ethics Advisory Team (SB-EAT) will review results of such audits. The username or IP address of user may be used to identify source(s) of abusive activities such as vandalism, harassment of other users or disruptive behavior. This information may be shared with users whose projects are affected by the behavior, ethics board or institutional authorities.</p> |

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| | <p><u>Web data:</u> We use web data for the following purposes:</p> <ul style="list-style-type: none"> - 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 <p><u>Project content:</u> We are generally not responsible for the processing of Biological Data submitted to or shared between users through Synapse - data contributors are responsible for the processing of these data. However, in some limited situations, we may access or use such data as described in our Synapse Commons Data Use Procedure. This includes uses that:</p> <ul style="list-style-type: none"> - Facilitate data contributions in our tiered systems - 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 <p>We do not re-identify de-identified information.</p> |
| Information Sharing | <p>We do not sell or otherwise disclose personal information we collect about you, except as described here.</p> <p>Sage Bionetworks acts as steward for the biological data, tools and analyses available through Synapse. Underlying the willingness of patients to provide data and of researchers to engage in scientific collaborations is the expectation that all results from biological data sharing and co-analysis will be published within the platform for the benefit of everyone as defined in the Synapse Terms and Conditions of Use and the Synapse Commons Data Use Procedure. In addition, we may share personal information as follows:</p> <p><u>Service Providers:</u> We may rely on various third-party service providers and contractors to provide services that support the Synapse services and our operations, including third-party vendors and hosting partners that provide the necessary hardware, software, networking, storage, and related technology</p> |

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| | <p>required to operate and maintain Synapse.</p> <p>Such third parties may have access to personal information for the purpose of performing the service for which they have been engaged. We require them to agree to implement reasonable safeguards to guarantee the security and confidentiality of the data, and to process the data only for the purposes of performing tasks on our behalf and in accordance with our instructions. We do not authorize service providers to use or disclose the data, except as necessary to perform services on our behalf or to comply with legal requirements.</p> <p>Statistical and Aggregate Information: In accordance with applicable law, we may share aggregated and statistical information with third parties for analysis.</p> <p>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, data 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. We may also disclose information when disclosure is required by applicable law.</p> <p>Business Transfers: In the event that 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 Bionetwork's business, assets, or stock, personal information may be transferred to a third party. In such case we will take reasonable steps to direct the transferee that the data use will remain subject to this Privacy Policy and that individuals concerned can address any inquiries regarding the processing of their personal information directly to the transferee.</p> |
| Your Rights | <p>You may request to access, update, correct or delete the personal information you provide to us by contacting us as described below under "Contact Us". If you completely delete all such information, then your account may become deactivated. If you would like us to delete your account in our system, please contact the Access and Compliance team at ACT@sagebase.org with a request that we delete your personal information from our database. We will honor your request as required by applicable law.</p> <p>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</p> |

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| | <p>email at synapseInfo@sagebase.org with the word “remove” in the subject header, and we will remove your details from our mailing list.</p> <p>Please address any queries related to the use of Biological Data pertaining to you to the person or organization responsible for collecting, de-identify and uploading the data (e.g., doctor, researcher, hospital, lab, research centre, or similar organization).</p> |
| Information Security | <p>Sage Bionetworks maintains organizational, technical, and administrative measures designed in an effort to protect the information we collect, store or otherwise process in connection to Synapse against accidental, unlawful, or unauthorized access destruction, disclosure, misuse, alteration, or loss. This includes reasonable information technology procedures implemented in an effort to safeguard information and prevent improper access. The data security measures are a combination of Privacy-Enhancing Technologies (PET) options and policies/processes for data handling. PET options include user login requirement, data and communication encryption via Secure Sockets Layers (SSL) when transmitting data or command and firewalls for both ingress and egress. By using Synapse, users agree to be bound by all terms of the Synapse Governance.</p> |
| Data retention: | <p>We retain the personal information for as long as necessary to provide our services and to fulfill any other purposes for which the data was initially collected, unless otherwise required by applicable law.</p> <p>Users may choose to deactivate their accounts. Subject to applicable law, the record of user’s activities performed while the account was active will be maintained after the account is closed, if required by law or for legitimate business purposes for a certain period after the deletion of the account.</p> |
| Cookies | <p>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 through the use of 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.</p> <p>Cookies can help us determine whether a user has visited our website before or is a new visitor, identify site features in which users have the greatest interest, and save user preferences while they are visiting our site. In particular, Synapse uses cookies for the following purposes:</p> <ul style="list-style-type: none"> - 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 |

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| | <ul style="list-style-type: none"> - To maintain user authentication when navigating between Synapse and Get Satisfaction, the community support environment for Synapse. - To verify user authorization to pull basic profile information from his/her selected social media profile (such as LinkedIn). This cookie expires 5 minutes after its creation. <p>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.</p> |
| Sage Bionetworks Adaptive Policies | <p>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. Policy changes will be done in coordination with the Ethics Advisory Team. New policies and/or amendments will be submitted to Users and must be agreed to in order for such Users' continued use of Synapse.</p> <p>We will also notify you of any material changes to this Privacy Policy by posting the revised policy on the Synapse site and identify the date of last update at the top of this page. We encourage you to periodically review this page to ensure continuing familiarity with the most current version of our Privacy Policy. Any material changes to our Privacy Policy will become effective 30 days upon our posting of the revised Privacy Policy on the Site. If you do not refuse their acceptance in writing before they become effective, this shall mean that you have accepted the revised Privacy Policy then in effect. Your use of the Service after a change is effective will be governed by the revised Privacy Policy.</p> |
| Data transfers | <p>Although you may access Synapse from a location outside of the United States, any personal information collected in connection with Synapse may be transferred to, processed, and stored within the United States. The United States may not have the same data protection framework as the country from which you may be using Synapse. When we transfer your data to the United States, we will protect your personal data as described in this Privacy Policy, and comply with applicable legal requirements providing adequate protection for the transfer of personal data from your country to the United States.</p> |
| Links to Other Websites | <p>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</p> |

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| | content of these sites, any products or services that may be offered through these sites, the data processing activities that are conducted via those 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 the Synapse Terms and Conditions of Use or Data Use Procedure will be reported to the user's institutional official, if applicable. Sage Bionetworks has no responsibility to 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. Users and their institutions, if applicable, will be fully and solely responsible for all such breaches, violations and their consequences. |
| Contact Us | <p>If you have any questions, comments, or concerns regarding this Privacy Policy, please contact us by email at ACT@sagebase.org, or by writing us at:</p> <p>Sage Bionetworks Attn: ACT 1100 Fairview Ave N. M1-C108 Seattle WA 98109-1024</p> <p>Please address any queries related to the use of Biological 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 centre, or similar organization).</p> |