

Agora Terms and Conditions of Use

Effective Date: July 19, 2018

Summary of Key Provisions

By using Agora, you agree to the Terms and Conditions of Use listed below. Here is a summary of several key provisions of those Terms and Conditions. Be certain to read the full Terms and Conditions of Use in detail; in the event of any conflict or inconsistency between this summary and the full Terms and Conditions, the full Terms and Conditions will govern.

You agree to the following Agora Operating Ethics Principles:

- Act ethically and responsibly.
- Protect and respect data participant's privacy and confidentiality.
- Take full responsibility for your use of data, software, and other Agora content.
- Share content only when you have the authority to do so and sharing does not violate any applicable laws or contracts.
- Not hack Agora.
- Abide by all applicable laws and regulations.

When using Data on Agora, you must:

- Respect intellectual property rights of others
- Acknowledge contributors in all presentations.

Sage Bionetworks wants you to know that:

- Use of Data in Agora is governed by these **Terms and Conditions of Use and the Agora Privacy Policy**.
- We will **remove Content** if we deem it inappropriate.
- These Terms and Conditions of Use apply to, but we otherwise do not monitor, Data and Content contributed to **Private Workspaces**.
- We respect the intellectual property rights, including copyrights, patents, trade secrets, and trademarks, of others, and ask you to do the same.
- You must be **13 years or older** to use Agora. European residents under the age of sixteen (16) shouldn't use Agora without verified parental consent.
- We take **no responsibility or liability for any Content** that has been posted to Agora.

Agora Terms and Conditions of Use

Welcome to Agora, a service operated by Sage Bionetworks, an IRS 501(c)(3) public charity ("**Sage Bionetworks**," "**we**," or "**us**"). These Terms and Conditions of Use ("**Terms**") are a binding legal agreement between you and Sage Bionetworks regarding your use of Agora, Sage Bionetworks' web-based platform

for providing access to analytical results and analyses from the Accelerating Medicine Partnership Alzheimer's Disease research consortia ("**Agora**" or the "**Service**").

Please read these Terms carefully. By using Agora, or downloading or using any genomic, molecular, phenotypic and/or other data from human or non-human sources ("**Data**"), any algorithms, tools, and other software code in source or object form ("**Software**"), or any other information and content (such content, including Software, is referred to in these Terms as "**Content**") available on or through Agora, you agree to be bound by these Terms and use Agora and all Data and Content in compliance with these Terms. If you are using the Service on behalf of a company or other legal entity, you represent and warrant that you have the legal authority to bind such company or entity to these Terms.

In addition, when using certain features of Agora, you also will be subject to the guidelines, terms, and agreements applicable to such features ("**Policies**"). For example, the Agora [Privacy Policy](#) describes the personal information Sage Bionetworks collects in connection to Agora, and how we use and disclose such information. All such Policies, including the Agora Privacy Policy are incorporated by reference into these Terms. If these Terms are inconsistent with any Policy, the terms in the Policy will control to the extent of the inconsistency.

We may periodically make changes to these Terms and will identify the date of last update. We will post the updated Terms on Agora. Changes to the Terms will be effective upon being posted on Agora, except as set forth below. Material changes to these Terms will be effective 30 days from posting of such change ("**Effective Date**"). We encourage you to review the most recent version of the Terms frequently and remain informed of any changes to these Terms. If you continue to use Agora after we modify these Terms, you will be deemed to have consented to terms of the modified agreement for your use of Agora as of the date of the modification. If you do not agree to any provision of these Terms, you must not use Agora.

1. Eligibility

You must be 13 years of age or older to use Agora. Use of Agora is void where prohibited. You represent and warrant that any information you submit to the Services or otherwise to Sage Bionetworks, during registration or otherwise, is true and accurate, that you are 13 years of age or older, and that you are fully able and competent to enter into and abide by these Terms. European residents under the age of 16 shouldn't use Agora without verified parental consent.

2. Fees; No Refunds

Access to the Service presently is provided to you free of charge. Sage Bionetworks reserves the right to implement fees or change the fees for Agora, or portions thereof, at any time by providing you 30 days prior written notice on Agora or otherwise. If you do not wish to pay these fees, you will be able to terminate your use of Agora.

3. Access to and Use of Data and other Content

a. Overview

Agora gives data users access to Content. Subject to applicable law, Sage Bionetworks takes no responsibility and assumes no liability for any Content posted, stored, or uploaded, or for any loss or damage to any Content. We reserve the right, and have discretion, to remove and screen any Content posted, stored, or transmitted on or through Agora at any time and without notice.

b. Agora Data Content, Access and Use Procedures

These Terms and Conditions of Use, and the [Agora Privacy Policy](#) govern all use of Content on Agora. All use of Data on Agora must comply with these Terms and Conditions of Use and the Agora Privacy Policy.

Without limiting the generality of the foregoing, your access to and use of certain types of Data may be subject to additional terms and conditions that you will be required to agree to before receiving access to such Data.

All Materials accessible through Agora is for informational purposes only. Content is not a substitute for professional advice on any matter, medical or otherwise. Always seek the advice of a qualified health professional. Sage Bionetworks does not recommend or endorse any treatment, institution, professional, physician, product, procedure, or other information that may be mentioned through Agora.

4. Use Restrictions

In your use of Agora, you agree **not to**:

- a. Publish, present or otherwise disclose Data or results from analysis of Data obtained through Agora without properly attributing the Data source using the language provided by the Data contributor of that Data set;
- b. Use or attempt to use the Data or other Content to harm, marginalize, or discriminate against individuals or populations, whether in insurance, employment, or other manners;
- c. Identify, or make any attempt to identify, any individual humans to which any Data pertains;
- d. Create a false identity, impersonate another person or entity in any way, or falsely imply that any third-party service is associated with Agora;
- e. Upload or otherwise transmit to or through Agora any information, Content, or materials that infringes, misappropriates, or violates any intellectual property right, including patent, trademark, trade secret, copyright, privacy and confidentiality rights, or other rights of any party, including by incorporating any such material in User Materials;
- f. Upload or otherwise transmit to or through Agora any User Materials that violate, or cause us or our affiliates to violate, any applicable law, regulation, or order of any governmental authority in any jurisdiction;
- g. Upload or otherwise transmit to or through Agora any unlawful, harmful, harassing, defamatory, threatening, vulgar, sexually explicit, hateful or otherwise objectionable User Materials of any kind,

or any User Materials that can cause harm or delay to Agora or computers or networks of any kind;

- h. Upload or otherwise transmit any trade secrets or information for which you have any obligation of confidentiality or professional secrecy;
- i. Upload or otherwise transmit any unsolicited or unauthorized advertising, promotional materials, junk mail, spam, or any other form of solicitation (commercial or otherwise);
- j. Restrict, discourage or inhibit any person from using Agora;
- k. Undertake, cause, permit or authorize the modification, creation of derivative works, translation, reverse engineering, decompiling, disassembling or hacking of any aspect of Agora or any part thereof, or attempt to do any of the foregoing, except and solely to the extent permitted by these Terms, the authorized features of Agora, or by law, or otherwise attempt to use or access any portion of Agora other than as intended by us;
- l. Reproduce, distribute, publicly display, publicly perform, sell, trade, resell or exploit any portion of Agora, use of Agora, access to Agora or Content obtained through Agora, for any purpose other than expressly permitted by these Terms, including, by way of example and not limitation, by doing or engaging in any of the following without our express written consent:
 - i. framing, embedding and/or passing off Data or Content obtained from Agora in such a manner as to present it as originating from a source other than Agora;
 - ii. altering or bypassing any Software or other mechanisms through which Agora or any of its Data or Content is made available; and
 - iii. using any trademarks, service marks, design marks, logos, photographs or other Content belonging to us or obtained from Agora.
- m. Gain unauthorized access to Agora, or to other computers or websites connected or linked to Agora;
- n. Post, transmit or otherwise make available any virus, worm, spyware or any other computer code, file or program that may or is intended to damage or hijack the operation of any hardware, Software or telecommunications equipment, or any aspect of Agora or communications equipment and computers connected to Agora;
- o. Remove, disable, damage, circumvent or otherwise interfere with any security-related features of Agora, features that prevent or restrict the use or copying of any part of Agora or any Data or Content on Agora, or features that enforce limitations on the use of Agora or any Data or Content on Agora;
- p. Use any scraper, spider, robot or other automated means of any kind to access Agora, except and solely to the extent permitted by these Terms and the features of Agora, deep-link to any feature or any Data or Content on Agora, bypass our robot exclusion headers or other measures we may use to prevent or restrict access to Agora;
- q. Use excessive bandwidth, whether through our API or otherwise, and as determined by us in our sole discretion, on the Service (if your bandwidth usage significantly exceeds the average bandwidth usage of other Agora users, as determined by us in our sole discretion, we reserve the right to immediately disable or throttle your usage until you can reduce your bandwidth consumption);
- r. Interfere with or disrupt Agora, networks or servers connected to Agora or violate the regulations, policies or procedures of such networks or servers;

- s. Intentionally or unintentionally violate any applicable federal, state or other applicable local laws or regulations, including privacy laws and regulations, or these Terms;
- t. Upload or otherwise transmit any User Materials that, in our sole judgment, is objectionable, restricts or inhibits any person or entity from using or enjoying Agora or any portion thereof, or that may expose us or our users to harm or liability of any nature; or
- u. Assist or permit any persons in engaging in any of the activities described above.

Additionally, you acknowledge the following in connection with your use of the Service:

- a. We use third-party vendors and hosting partners to provide the necessary hardware, Software, networking, storage, and related technology required to operate Agora, as further specified in our Agora Privacy Policy.
- b. Subject to applicable law, technical processing and transmission of Agora, including Data, Software, and other Content made available thereon, may be unencrypted and involve (i) transmissions over various networks and (ii) changes to conform and adapt to technical requirements of connecting networks or devices.

5. Modifications to Agora

We reserve the right to modify, discontinue, and restrict, temporarily or permanently, all or part of Agora (including, without limitation, any Content or Data available on or through Agora) without notice in our sole discretion. Neither we nor our suppliers or licensors, nor any other Agora users, will be liable to you or to any third party for any modification, discontinuance, or restriction of Agora or any deletion of any Content or Data stored on, or otherwise associated with, your account on Agora.

6. Feedback

Any materials, including but not limited to comments, suggestions, identifying potential errors and improvements, ideas, or other information, provided by you in the form of email or other submissions to us (collectively, "**Feedback**"), are non-confidential (notwithstanding any notice to the contrary you may include in any accompanying communication) and you hereby grant to us and our subsidiaries and affiliates a nonexclusive, royalty-free, perpetual, irrevocable, and fully sub-licensable right to use your Feedback for any purpose without compensation or attribution to you. Where required by applicable law or regulation, Sage Bionetworks will respect any privacy restrictions applicable to Feedback you communicate to us.

7. Copyright Infringement

We respect the intellectual property rights of others, and ask you to do the same. It is our policy to terminate the access privileges of those who infringe the intellectual property rights of others. If you believe that your work has been posted on Agora in a way that constitutes copyright infringement, please contact us at the address below and provide the following information: (a) an electronic or physical signature of the person authorized to act on behalf of the owner of the copyright interest; (b) a description of the copyrighted work that you claim has been infringed, and identification of the time(s) and date(s) the material that you claim is infringing was displayed on Agora; (c) your address, telephone

number, and email address; (d) a statement by you that you have a good faith belief that the disputed use is not authorized by the copyright owner, its agent, or the law; and (e) a statement by you, made under penalty of perjury, that the above information in your notice is accurate and that you are the copyright owner or authorized to act on the copyright owner's behalf.

Our designated agent for notice of copyright infringement can be reached at:

Sage Bionetworks
ATTN: Diane Gary
2901 Third Avenue
Seattle, WA 98121
diane.gary@sagebase.org

8. Trademarks

"Sage Bionetworks," "Agora," "SageBio," "Sage Bionetworks Commons," the Agora logo, the Sage Bionetworks logo, and any other product or service name or slogan contained on Agora are trademarks or registered trademarks of Sage Bionetworks and its suppliers or licensors, and may not be copied, imitated or used, in whole or in part, without the prior written permission of the applicable trademark holder. All other trademarks, registered trademarks, product names and company names or logos mentioned on Agora are the property of their respective owners. Reference to any products, services, processes or other information, by trade name, trademark, manufacturer, supplier, or otherwise, does not constitute or imply endorsement, sponsorship, or recommendation thereof by us, or vice versa.

9. Ownership

We, our affiliates, and our suppliers and licensors own all right, title, and interest, including all intellectual property rights, in and to Agora. Except for those rights expressly granted in these Terms, no other rights are granted, either express or implied, to you.

10. Third-Party Content

Agora may contain links to Web pages and content of third parties ("**Third-Party Content**") as a service to those interested in this information. We do not monitor, endorse, or adopt, or have any control over, any Third-Party Content. We undertake no responsibility to update or review any Third-Party Content and can make no guarantee as to its accuracy or completeness. Subject to applicable law, under no circumstances will Sage Bionetworks be liable in any way for or in connection with any third party content.

Additionally, if you follow a link or otherwise navigate away from Agora, please be aware that these Terms will no longer govern, other than with respect to Content you have obtained on Agora, with respect to your activities off of Agora. You should review the applicable terms and policies, including privacy and

data gathering practices, of any Third-Party Content provider to which you navigate from Agora. You access and use Third-Party Content at your own risk.

11. Indemnification

Subject to applicable law, you will defend, indemnify, and hold harmless Sage Bionetworks, its subsidiaries, affiliates, and their respective directors, officers, agents, employees, licensors, and suppliers from and against all costs, damages, expenses, and liabilities (including, but not limited to, reasonable attorneys' fees) arising out of or related to your use of the Service, your violation of these Terms, or your violation of any rights of a third party (or, solely to the extent that such a limitation may be required under applicable law, from and against any of the foregoing costs, damages, expenses, and liabilities to the extent reasonably foreseeable), except to the extent arising from the gross negligence or willful misconduct of Sage Bionetworks.

12. Disclaimer of Warranties

SUBJECT TO APPLICABLE LAW, THE SERVICE (INCLUDING ITS CONTENT AND DATA), ANY USER MATERIALS, AND ANY THIRD-PARTY CONTENT, SOFTWARE, SERVICES OR APPLICATIONS MADE AVAILABLE ON OR THROUGH OR IN RELATION TO THE SERVICE, ARE PROVIDED ON AN **"AS IS," "AS AVAILABLE," "WITH ALL FAULTS"** BASIS WITHOUT REPRESENTATIONS OR WARRANTIES OF ANY KIND, EITHER EXPRESS OR IMPLIED, INCLUDING BUT NOT LIMITED TO IN TERMS OF CORRECTNESS, ACCURACY, RELIABILITY, OR OTHERWISE, OTHER THAN THOSE THAT ARE REQUIRED BY APPLICABLE LAW. YOUR USE OF THE SERVICE, INCLUDING, WITHOUT LIMITATION, YOUR USE OF ANY CONTENT OR DATA ACCESSIBLE ON OR THROUGH THE SERVICE (INCLUDING USER MATERIALS), IS AT YOUR SOLE RISK.

TO THE FULLEST EXTENT PERMISSIBLE PURSUANT TO APPLICABLE LAW, SAGE BIONETWORKS AND ITS OFFICERS, DIRECTORS, LICENSORS, AND SUPPLIERS, HEREBY DISCLAIM ALL EXPRESS, IMPLIED AND STATUTORY WARRANTIES OF ANY KIND, INCLUDING BUT NOT LIMITED TO THE IMPLIED WARRANTIES OF MERCHANTABILITY, FITNESS FOR A PARTICULAR PURPOSE, AND NON-INFRINGEMENT. NO ADVICE OR INFORMATION, WHETHER ORAL OR WRITTEN, OBTAINED BY YOU FROM SAGE BIONETWORKS, ANY EMPLOYEE OR REPRESENTATIVE OF SAGE BIONETWORKS OR THROUGH THE SERVICE WILL CREATE ANY WARRANTY NOT EXPRESSLY STATED IN THESE TERMS. SAGE BIONETWORKS AND ITS OFFICERS, DIRECTORS, LICENSORS, AND SUPPLIERS DO NOT WARRANT THAT THE SERVICE OR ANY PART THEREOF, OR ANY CONTENT OR DATA (INCLUDING USER MATERIALS) AVAILABLE THROUGH THE SERVICE, WILL BE SECURE, UNINTERRUPTED, OR FREE OF ERRORS, VIRUSES OR OTHER HARMFUL COMPONENTS, AND DO NOT WARRANT THAT ANY OF THE FOREGOING WILL BE CORRECTED. YOU UNDERSTAND AND AGREE THAT YOU USE, ACCESS, DOWNLOAD, OR OTHERWISE OBTAIN CONTENT AND DATA (INCLUDING USER MATERIALS) THROUGH THE SERVICE AT YOUR OWN DISCRETION AND RISK AND THAT YOU WILL BE SOLELY RESPONSIBLE FOR ANY DAMAGE TO YOUR PROPERTY (INCLUDING YOUR COMPUTER SYSTEM USED IN CONNECTION WITH THE SERVICE) OR LOSS OF DATA THAT RESULTS FROM THE DOWNLOAD OR USE OF SUCH MATERIAL OR DATA.

ADDITIONALLY, SAGE BIONETWORKS AND ITS LICENSORS AND SUPPLIERS MAKE NO REPRESENTATION OR WARRANTY REGARDING THIRD-PARTY INTELLECTUAL PROPERTY RIGHTS (INCLUDING, WITHOUT LIMITATION, RIGHTS UNDER PATENTS) THAT MAY APPLY TO THE USE OF ANY CONTENT OR DATA (INCLUDING USER MATERIALS) AVAILABLE ON OR THROUGH AGORA.

YOU MUST NOT MAKE ANY REPRESENTATION OR WARRANTY ON BEHALF OF AGORA OR ANY OTHER AGORA USER REGARDING AGORA OR ANY DATA, SOFTWARE, OR OTHER CONTENT THAT YOU OBTAIN ON AGORA, EXCEPT TO THE EXTENT AS MAY BE EXPLICITLY PERMITTED BY A AGORA USER WITH RESPECT TO DATA, SOFTWARE, OR OTHER CONTENT PROVIDED BY SUCH AGORA USER.

SOME JURISDICTIONS MAY PROHIBIT A DISCLAIMER OF WARRANTIES AND YOU MAY HAVE OTHER RIGHTS THAT VARY FROM JURISDICTION TO JURISDICTION.

13. Limitation of Liability

TO THE FULLEST EXTENT PERMISSIBLE PURSUANT TO APPLICABLE LAW, SAGE BIONETWORKS OR ITS OFFICERS, DIRECTORS, LICENSORS, OR SUPPLIERS WILL NOT BE LIABLE TO ANY PARTY UNDER THESE TERMS OR OTHERWISE FOR ANY INDIRECT, INCIDENTAL, SPECIAL, CONSEQUENTIAL, OR EXEMPLARY DAMAGES ARISING OUT OF OR IN CONNECTION WITH THE USE OR ACCESS OF OR INABILITY TO USE OR ACCESS THE SERVICE OR ANY CONTENT OR DATA (INCLUDING USER MATERIALS) MADE AVAILABLE THROUGH THE SERVICE, INCLUDING, WITHOUT LIMITATION, DAMAGES FOR LOSS OF PROFITS, GOODWILL, USE, DATA, OR OTHER INTANGIBLE LOSSES (EVEN IF SAGE BIONETWORKS OR ANY SUPPLIER OR LICENSOR HAS BEEN ADVISED OF THE POSSIBILITY OF THESE DAMAGES).

TO THE FULLEST EXTENT PERMISSIBLE PURSUANT TO APPLICABLE LAW, THE MAXIMUM TOTAL LIABILITY OF SAGE BIONETWORKS AND ITS SUPPLIERS AND LICENSORS TO YOU FOR ALL CLAIMS UNDER THESE TERMS OR OTHERWISE IN CONNECTION WITH THE SERVICE AND ANY CONTENT OR DATA (INCLUDING USER MATERIALS), WHETHER IN CONTRACT, TORT, OR OTHERWISE, IS \$50. THIS SECTION 16 DOES NOT EXCLUDE OR LIMIT THE LIABILITY OF SAGE BIONETWORKS FOR ANY LIABILITY THAT CANNOT BE LIMITED OR EXCLUDED BY LAW, INCLUDING, IN CERTAIN JURISDICTIONS, LIABILITY FOR FRAUD OR FOR DEATH OR PERSONAL INJURY RESULTING FROM NEGLIGENCE OF SAGE BIONETWORKS

APPLICABLE LAW MAY NOT ALLOW THE LIMITATION OR EXCLUSION OF LIABILITY OR INCIDENTAL OR CONSEQUENTIAL DAMAGES, SO THE ABOVE LIMITATIONS OR EXCLUSIONS IN THIS SECTION MAY NOT APPLY TO YOU. IN SUCH CASES, YOU AGREE THAT BECAUSE SUCH WARRANTY DISCLAIMERS AND LIMITATIONS OF LIABILITY REFLECT A REASONABLE AND FAIR ALLOCATION OF RISK BETWEEN YOU AND SAGE BIONETWORKS, AND ARE FUNDAMENTAL ELEMENTS OF THE BASIS OF THE BARGAIN BETWEEN YOU AND SAGE BIONETWORKS, SAGE BIONETWORKS' AND ITS LICENSORS' AND SUPPLIERS' LIABILITY WILL BE LIMITED TO THE MAXIMUM EXTENT PERMITTED BY LAW.

EACH PROVISION OF THESE TERMS THAT PROVIDES FOR A LIMITATION OF LIABILITY, DISCLAIMER OF WARRANTIES, OR EXCLUSION OF DAMAGES IS TO ALLOCATE THE RISKS UNDER THESE TERMS

BETWEEN THE PARTIES. THIS ALLOCATION IS AN ESSENTIAL ELEMENT OF THE BASIS OF THE BARGAIN BETWEEN THE PARTIES. EACH OF THESE PROVISIONS IS SEVERABLE AND INDEPENDENT OF ALL OTHER PROVISIONS OF THESE TERMS. THE LIMITATIONS IN THIS SECTION WILL APPLY EVEN IF ANY LIMITED REMEDY FAILS OF ITS ESSENTIAL PURPOSE TO THE EXTENT PERMITTED BY APPLICABLE LAW.

14. Electronic Communications

To the extent authorized by applicable law, by using the Service, you consent to receiving electronic communications from us. These communications may include notices about your account and information concerning or related to the Service. You agree that any notices, agreements, disclosures, or other communications that we send to you electronically will satisfy any legal communication requirements, including that such communications be in writing. If you are located in the European Union, we will not send you marketing communications by electronic means unless authorized by law or provided that we have obtained your prior opt-in consent.

15. General Legal Notices

Our failure to act in a particular circumstance does not waive our ability to act with respect to that circumstance or similar circumstances. Any provision of these Terms that is found to be invalid, unlawful, or unenforceable will be severed from these Terms, and the remaining provisions of these Terms will continue to be in full force and effect. The section headings and titles in these Terms are for convenience only and have no legal or contractual effect. Any provision in these Terms that by its nature should survive the termination of your license to access the Service or any termination of these Terms (including, without limitation, provisions governing indemnification, limitations on liability, disclaimers of warranty, and ownership of intellectual property) will continue to remain in full force and effect after any such termination.

To the extent permitted by applicable law, these Terms are governed by the laws of the State of Washington, excluding conflicts of law principles, and any controversy or claim arising out of or relating to the Service or these Terms must be commenced within one year after the claim arose and will be settled by binding arbitration in accordance with the commercial arbitration rules of the American Arbitration Association. Any such controversy or claim will be arbitrated on an individual basis, and will not be consolidated in any arbitration with any claim or controversy of any other party. The arbitration will be conducted in King County, Washington and judgment on the arbitration award may be entered into any court of competent jurisdiction. The award of the arbitrator will be final and binding upon the parties without appeal or review except as permitted by Washington law. Either party may seek any interim or preliminary injunctive relief from any court of competent jurisdiction, as necessary to protect the party's rights or property pending the completion of arbitration. If, under local law, you are able to bring a claim in the court of a country other than the U.S., the laws of the State of Washington, excluding conflicts of law principles, will apply to the claim.

These Terms, including all Policies, constitute the entire agreement between you and Sage Bionetworks concerning Agora, as well as all Content and Data available on or through Agora. These Terms supersede

all prior agreements or communications between you and Sage Bionetworks regarding the subject matter of these Terms.

19. Questions & Contact Information

If you have any questions or concerns about the Service, or these Terms, you may contact Sage Bionetworks by email at diane.gary@sagebase.org or write us at:

Sage Bionetworks
ATTN: Diane Gary
2901 Third Avenue
Seattle, WA 98121

Agora Privacy Policy, Effective Date: July 19, 2018

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 web-based platform (“Agora”) where researchers can access data and analyses to co-analyze, learn from, and improve knowledge of health and disease. Sage Bionetworks acts as steward for the content available through Agora. Agora Users are responsible for the processing of the Data they submit to and/or share through Agora.

This Privacy Policy explains how we protect personal information received, used, and disclosed by users (“Visitors”) of Agora.

Agora can house genomic, molecular, phenotypic, and/or other data from human or non-human sources and other information (collectively “Data”). Agora also houses information (“Information”) about Users and Visitors.

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

Information We Collect

When you use Agora, you may provide to us and/or we may collect personal information about you and your activity on Agora. 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 content in Agora. We collect Information from Visitors and Users of Agora:

Web data: Like most websites, we collect technical information on how Visitors and Users use Agora. 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 Agora 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 Agora 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 Agora profile will depend on the privacy settings of those outside accounts. By authorizing Agora 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 Agora 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 Agora. 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 Agora 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 Agora 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.

Agora Users must be Agora Certified to contribute Data on Agora. Data contributors assume responsibility for the Data they publish or share through Agora 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 Agora.

Sage Bionetworks does not guarantee the accuracy, integrity, or quality of Agora project content and is not liable for the content posted by non-Sage Bionetworks staff, as described in the Agora 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 Agora 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 Agora 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 Agora
- Enhancing and improving Agora, 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 Agora governance policies and procedures

- Enhance and improve Agora
- 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 Agora may be reviewed, copied, or reused by other Agora Users as described in the Agora Terms and Conditions of Use.

Sage Bionetworks will perform periodic audits to assess the practices within Agora analytical environment and to confirm compliance with Agora 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 Agora features are most attractive to Users
- Maintaining, securing, and enhancing the Agora Service
- Detecting and remedying disruptions in our systems
- Performing statistical analysis of usage patterns
- Operating, maintaining, enhancing, and providing all features of Agora
- Enhancing and improving Agora, and developing new features, products, and functionality

Project content: We may access project content that Users have uploaded to Agora. 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 Agora 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 Agora. 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 Visitors' and 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 Agora, 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 Agora or any facilities or equipment used to make Agora 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 to request that we deactivate your Agora 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 Agora@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 Agora 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 Agora 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 Agora 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 Agora 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. Agora 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 Agora.

We will notify Visitors and Users of any material changes to this Privacy Policy by posting a notice on the Agora 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 Agora from a location outside of the United States, Agora is primarily operated and managed within the United States. Personal Information on Agora 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 Agora. 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 or the Terms and Conditions of Use will result in termination of current and future access to Agora. Any breach of obligations under this Privacy Policy, the Agora 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 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, or by writing us at:

Sage Bionetworks
Attn: ACT
2901 3rd 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