



AD Knowledge Portal

Controlled-Access Data Use Certificate INSTRUCTIONS

Data contributed to the [AD Knowledge Portal](#) (including the [AD CDCP Hub](#)) is made available under a tiered system designed to protect the privacy and confidentiality of study participants. Some data are available under Controlled Access to comply with ethical guidelines for protection of human subjects. Controlled Access data requires users to request access and/or agree to terms of use prior to accessing the data from Synapse. All individual level Human data are available through Controlled Access and require the submission of this DUC. **Individual level Human data cannot be redistributed.**

Investigators wishing to use the Controlled-Access data (“Data”) must:

1. Maintain an active account on Synapse: <http://www.synapse.org>
2. Provide the name of the research project’s project lead/principal investigator, institutional affiliation, and a brief description of their intended data use which will be posted on the AD Knowledge Portal researcher community page.
3. Submit an Intended Data Use statement (IDU) written in English, describing the following information (up to 500 words).
 - **The names of the studies being requested.** A full list of study names in the AD Knowledge Portal can be found [here](#).
 - Objectives of the proposed research
 - Study design and analysis plan
4. Agree to comply with all Data Access Terms and Conditions, and any specific data use limitations by submitting the Data Use Certificate below co-signed by an authorized Signing Official from their institution. Signing Officials must:
 - Have oversight authority over the data requester.
 - Be responsible for ensuring appropriate and ethical use of the Data by the data requester.
 - Not be a member of the study team (e.g., not the Project Lead, not a Data Requester, and not the Principal Investigator).
5. Provide the list of collaborators (including name and Synapse username) who will be accessing these data to perform the proposed research. If a collaborator is from a different institution than the Principal Investigator, that individual must complete a separate data access request.

Data access will be granted for one year. Investigators can apply to extend/renew access to these data to complete the approved research.

To extend/renew access to these data, investigators must fulfill all the following requirements:

1. Review and update your Intended Data Use Statement. Describe the research performed with these data by the approved users in the past year as well as the intended use of the data for the next year (1-3 paragraphs).
2. Update your list of collaborators (including name and Synapse username) who will be accessing these data to perform the proposed research.

3. Confirm continued agreement with all Data Access Terms and Conditions, and any specific data use limitations.
4. Indicate any publications that resulted from your use of the data.

Please apply for data access or extension/renewal, and upload required documents using [the Synapse Data Access system](#). Following approval, the individual who submitted the application will receive a confirmation email with instructions to log on to Synapse and confirm their agreement to any specific data use terms as applicable. The requester/submitter is responsible for ensuring that annual updates are submitted and that all investigators adhere to these terms. Additional investigators may be added to an application throughout the duration of the study through [the Synapse Data Access system](#).

Please note that the original request submitter must submit any changes or progress reports on behalf of their research group. Access requests cannot be transferred from the original request submitter to another data requester included on the access request application. Sage Bionetworks also cannot submit any updates or progress reports on behalf of the original request submitter. If the original request submitter is unable to conduct the update, the request will need to be closed out, and a new data request will need to be submitted by another individual from the institution.

Controlled Data may not be redistributed. Upon completion of the project or termination of data access permissions, users are required to erase all locally stored copies of the data. Any misuse of data will result in termination of access/use privilege to these data on Synapse. In addition, misuse will be reported to the lead investigator and their institution as well as to the Data Contributor. If an investigator changes institution, (s)he will submit a new Data Use Certificate signed by an authorized official from the new institution.

By using Synapse, investigators agree to the Synapse Terms of Use. More information describing the data governance process on Synapse is available at:

<https://help.synapse.org/docs/Synapse-Governance.2004255211.html>.

Please continue onto the next page.



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AD Knowledge Portal Controlled Access Data Use Certificate

In this document “You” refers to the data requester.

The [AD Knowledge Portal](#) is hosted on Sage Bionetworks Synapse platform. Individuals wishing to access the Controlled-Access data (“Data”) must [register on Synapse](#) and agree to the following Data Access Terms and Conditions.

Data Access Terms and Conditions

1) Research Use

- a) You agree to use the Data exclusively for the research purpose(s) described in your Intended Data Use Statement (IDU), and in accordance with applicable federal, state, local, and tribal laws, regulations, and any relevant institutional policies including IRB/ethics oversight. Any other use of the Data is prohibited.
- b) You agree to only use the dataset(s) necessary to conduct the research described in your IDU.
- c) You further agree to respect any research use limitations identified by the Data Contributor(s) and indicated with the Data description.

2) Confidentiality and Data Security

- a) You agree to keep the Data confidential and not to distribute it in any form to any entity or individual other than to collaborators who have signed a Data Use Certificate subject to applicable law.
- b) You agree to protect and retain control over the Data and follow appropriate physical and electronic security protection measures.
- c) You agree not to use the Data, or any other information, to identify or contact individuals from whom Data were collected.
- d) You agree to destroy all local copies of the Data as soon as the research project(s) have been concluded.
- e) You agree to report any misuse or data release, intentional or inadvertent, to the Synapse Access and Compliance Team (ACT) within 5 business days by emailing act@sagebase.org.

3) Dissemination of Research Results and Acknowledgment

- a) You agree to have your IDU describing the overarching research objectives and design posted on the AD Knowledge Portal researcher community page, with the affiliation and name of the lead investigator.

- b) You agree to submit an annual progress update or project closure report.
- c) In recognition of the effort that Data contributor(s) made in obtaining the Data, should you wish to publish your results, based in whole or part on an analysis of these Data, you agree to acknowledge the Data Contributor(s) and the source of these Data on Synapse per the instructions and acknowledgement statement(s) provided with the Data.

4) The Data Contributor retains ownership of the Data

- a) Data Contributor shall retain ownership of any rights it may have in the Data, and Data Recipient does not obtain any rights in the Data other than as set forth herein. Data Recipient shall not license or otherwise transfer the Data except as authorized by this Agreement.
- b) The Data is “AS IS” and Data Contributor makes no representations or warranties, expressed or implied, regarding the Data, including but not limited to the marketability, accuracy, reliability, completeness, use or fitness for any particular purpose, results obtained from use, or that such Data do not infringe upon any third party property rights. Further, to the extent permitted by law Data Contributor shall not be liable for special consequential or incidental damages which may arise from Data Recipient’s use, storage, disclosure, or disposal of Data.

5) Data requester and Signing Official*

- a) You understand that by using Synapse, you agree to the general Synapse Terms of Use and guiding principles for responsible research as described in the [Synapse Governance documents](#).
- b) You agree that if you change institutions, you will submit a new Data Use Certificate signed by an authorized official from your new institution.
- c) You and your Institutional Signing Official certify your agreement to the principles, policies and procedures for use of these Data as articulated in this document.

Failure to comply with the terms of this Data Use Certificate may result in termination of all current data access and/or suspension of the PI and all associated key personnel and collaborators from submitting new Data Access Requests for a period to be determined. Repeated violations or unresponsiveness to Sage requests may result in further measures.

* The Signing Official is somebody with oversight authority over the data requester and who is responsible for ensuring appropriate and ethical use of the Data by the data requester.

AGREED by the parties through their authorized signatures.

SIGNING OFFICIAL (Required, see Instructions)

Name: Karissa Barthelson

Official/Professional Title: Dr

Institutional/Official Email: karissa.barthelson@flinders.edu.au

Institution: Flinders University

Signature: 

Date: 16/5/25

PRINCIPAL INVESTIGATOR (Required)

Name: Karissa Barthelson

Official/Professional Title: Dr

Email: karissa.barthelson@flinders.edu.au

Synapse Username: karissa

Signature: 

Date: 16/5/25

List your Collaborators on the next page. All collaborators must be from the same institution.

No other collaborators will access the data

Other Data Requester(s) from the same Institution

Signature	Printed Name	Synapse Username	Date

Please complete your data access request, with your project description or Intended Data Use Statement (in English) and upload this signed form using the [Synapse Data Access system](#).