ABCD-ReproNim Data Access Instructions

Where can I find ABCD data?

The NIMH Data Archive (NDA) is comprised of 5 data repositories that are de-identified and contain data consented for broad research use: (1) NIMH Data Archive, (2) Adolescent Brain Cognitive Development (ABCD) Study, (3) Connectome Coordination Facility, (4) NIAAA Data Archive, and (5) Osteoarthritis Initiative.

NDA's ABCD Data Repository houses all data generated by the ABCD Study. Access to NDA Data Repositories is governed by an NIH Data Access Committee.

Who can get access to ABCD data?

From NDA: "NDA users submitting Data Access Requests for Broad Use and Controlled Access Permission Groups **must be sponsored by an NIH recognized institution with a Federalwide Assurance and have a research related need to access NDA data.** NDA users submitting Data Access Requests for Controlled Access Permission Groups must adhere to consent-based data use limitations."

In other words, your institution must have an active Federalwide Assurance (FWA) to be granted access to ABCD data. You can look up your institution's FWA here.

How do I get access to ABCD data?

NDA provides a series of helpful video tutorials for Accessing Shared Data. We recommend that you watch the video tutorials titled "Introduction to Requesting Access", "Create an Account", "Completing a Data Use Certification", "Signing and Submitting a Data Use Certification", and "Review and Approval of Request".

As an alternative to the video tutorials, NDA also provides a series of Standard Operating Procedures to walk you through these processes. We recommend that you read:

SOP-01 NDA Account Request

The purpose of this SOP is to define the steps for requesting a user account to use in accessing shared data in an NDA repository, assisting a project contribute data to the NDA, create GUIDs using participant PII, or any other purpose. A request for an NDA user account is the first step in obtaining access privileges in the NDA system.

SOP-04A Data Access Permission Request – Institutional Sponsorship

The purpose of this SOP is to establish the steps for requesting new or continued access to a subset of shared data available in the NIMH Data Archive (NDA).

I'm submitting a request to create an NDA user account, what should I list as my stated interest in using this account?

NDA user accounts are granted to individuals who have research related interests in gaining access to the shared data located in the NDA repository. For this reason we recommend that you specify a research interest when you submit your account request. Example language for this request is provided below:

> *As a member of Dr. _____'s lab at the University of _____, I am requesting an account to access shared data in the NIMH Data Archive so that I may be able to analyze ABCD data to study _____. I am enrolled as a student in the upcoming ABCD-ReproNim Course (https://www.abcd-repronim.org) and plan to apply the tools and techniques covered in this course to analyze the dataset to answer my scientific questions.*

I'm filling out my NDA Data Use Certification (DUC) - what should I include on my Research Data Use Statement?

Each DUC asks for a **Research Data Use Statement**, which will be reviewed by NDA's Data Access Committee (DAC). NDA recommends that ABCD-ReproNim students include both standard language that reflects our course activities combined with student-specific language that reflects your individual research interests. **Importantly, NDA Data Access is for research purposes, so your DUC request should describe your research activities and should not focus on didactic or educational use.** The DAC does review for responsible data use, so it is helpful to clearly indicate how the data will be managed.

Below is a template for adding a research data use statement to your DUC (please modify based on your research interests). We recommend that you expand the description of your research interests as much as possible so that your expected use of ABCD data is clear to the DAC during their review.

> *I am a researcher in Dr. _____'s lab at the University of _____. Our research involves _____ (area of science) and has access to _____, _____, and _____ (data types and modalities). I am planning on integrating my expertise in these areas to ABCD initiatives to explore _____ (broad research questions) in the ABCD dataset.*
>
> *I will start conducting these analyses as part of the ABCD-ReproNim course (https://www.abcd-repronim.org). In addition to these analyses, I will use the ABCD data to generate new hypotheses prior to the course's Project Week, to better understand the distribution of information, and to appropriately apply techniques and algorithms to this dataset. I will continue to use the data after the course [CHOOSE ONE or MORE FROM BELOW].*
>
> - to answer my scientific questions;
> - to develop new methodological approaches that can be used to improve analyses of such datasets;
> - to integrate these data with my data from my own laboratory
> - to predict outcomes for [addiction, mental health]

Do I need to add the ABCD-ReproNim Organizers to my DUC as external collaborators?

No, the ABCD-ReproNim Organizers have permission to access ABCD through NDA DUCs submitted by their home institutions. It is not recommended that you list these individuals (e.g., Angie Laird, David Kennedy, Satra Ghosh, JB Poline, Jessica Bartley) on your DUC.

What are NDA's terms and conditions for ABCD data access?

You and your institution agree to adhere to the following ABCD data use terms & conditions:

- Use data for research only
- Do not identify participants
- Keep the data secure
- Work only with users on an approved DUC
- Do not distribute data to non-authorized users
- Delete data after use
- Submit your results to an NDA study

Users cannot make individual-level ABCD data available that have not been publicly shared on NDA. This prohibition includes original data, as well as data derived from the original data.

There are penalties for violating these terms of use, and the agreement is valid for one year.

What if I want to publish the results of my ABCD data analysis?

You've analyzed ABCD data and are ready to write a manuscript - congrats! As you move forward, there are three NDA-related responsibilities for you to keep in mind:

First, all publications and presentations must include an acknowledgment statement. Please use the following text provided by the NIH:

> Data used in the preparation of this article were obtained from the Adolescent Brain Cognitive Development (ABCD) Study (https://abcdstudy.org), held in the NIMH Data Archive (NDA). This is a multisite, longitudinal study designed to recruit more than 10,000 children age 9-10 and follow them over 10 years into early adulthood. The ABCD Study is supported by the National Institutes of Health and additional federal partners under award numbers U01DA041048, U01DA050989, U01DA051016, U01DA041022, U01DA051018, U01DA051037, U01DA050987, U01DA041174, U01DA041106, U01DA041117, U01DA041028, U01DA041134, U01DA050988, U01DA051039, U01DA041156, U01DA041025, U01DA041120, U01DA051038, U01DA041148, U01DA041093, U01DA041089, U24DA041123, U24DA041147. A full list of supporters is available at https://abcdstudy.org/federal-partners.html. A listing of participating sites and a complete listing of the study investigators can be found at https://abcdstudy.org/consortium_members/. ABCD consortium investigators designed and implemented the study and/or provided data but did not necessarily participate in analysis or writing of this report. This manuscript reflects the views of the authors and may not reflect the opinions or views of the NIH or ABCD consortium investigators.

(Add the following sentence for a report that uses data from a versioned release) The ABCD data repository grows and changes over time. The ABCD data used in this report came from [NIMH Data Archive Digital Object Identifier (DOI)]. DOIs can be found at [DOI URL].

(Add the following sentence for a report that uses data from the fast track release) The ABCD data repository grows and changes over time. The ABCD data used in this report came from the fast track data release. The raw data are available at https://nda.nih.gov/edit_collection.html?id=2573. Instructions on how to create a NDA study are available at https://nda.nih.gov/training/modules/study.html).

Second, when reporting results, creating a publication, working on any other public disclosure involving ABCD Study data, please use the ABCD word marks or logo marks - you may refer to this guidance for appropriate use. Be sure to use the appropriate acknowledgement language to reference the ABCD Study as the source of the original data.

- Use the full name of the Adolescent Brain Cognitive Development SM Study (word mark) with service mark symbol and the abbreviated title ABCD Study® with registered trademark symbol at least once in an article, publication, webpage, blog post, slide, email, or other document, either the first time it is used or in the most prominent place.

- Use the format below (initial caps, bold type, words followed by service mark SM or registered trademark ®symbol) and be consistent in its use across all documents, webpages, etc.

    - After the initial use, you can use the title or abbreviation (ABCD Study) with no symbols.

Finally, researchers who use ABCD data for secondary analyses are expected to report their results using the NDA Study feature. An NDA Study links a finding, data release, or publication directly to the underlying subject-level records for the outcome measures defined. Each NDA Study is issued a Digital Object Identifier (DOI), which is expected to be referenced in the publication. For more information on creating an NDA Study, watch the tutorial or visit the Data From Papers section of the NDA website and click "Add New Study" to begin.

These policies are described in NDA's Manuscript Preparation page.

How can I stay up-to-date with NDA news and announcements?

You can subscribe to the NIMH Data Archive Newsletter to stay informed of the latest news and information. The most recent information is available in their Spring Newsletter.