

Instructions for Accessing Data Through the CDAS Website

Data and/or images from several studies are available for request through the Cancer Data Access System (CDAS) website. To obtain access to these data/images, you must do the following:

1. Submit a CDAS Project Proposal

If you have not already registered with CDAS, you will need to register using one of the available login services. You will then be asked to fill in your private profile.

Once you are logged in to CDAS, you can submit a project proposal. Submitting a project proposal involves several key requirements:

- You must agree to the Data Use Policies. This includes agreeing not to identify or contact any patients or physicians whose information is contained in the data and to publicly display your research proposal (provided in your request) on this website, to occur once you receive access to the data.
- You must provide your institution and its location.
- You must provide a Principal Investigator (Data Access Requestor) who is a permanent employee of your institution at a level equivalent to, but not limited to, that of an academic professor (e.g., assistant, associate, or non-tenure or tenure-track professor) or senior researcher. This individual cannot be a post-doc, trainee, or lab technician. This individual will register and be responsible for the project, its submission, renewals and close-out.
- You must identify a Signing Official at your institution. A Signing Official (SO) is an individual permanently employed at the institution who is authorized to sign legally binding documents on behalf of the institution. For example, at academic institutions this is typically someone with a high-level position in the Contracts, Licensing, Technology, or Research and/or Programs Administration Department. The CDAS team will contact the SO to have them review the request, renewals and close-out of this project, and have them sign the terms of the Data Transfer Usage Agreement via DocuSign.

- You must list all users who you approve to access the data at your institution. You will be asked to provide their names and institutional e-mail addresses. Additional approved users may be added following project submission. Collaborators from other institutions will need to complete a separate project proposal submission with the same project details.
- You must fill in your Project Details, to include your contact information, including an institutional email, and the name and a brief description of your project (500 words or less).
- Once your project proposal is complete, the Principal Investigator must submit it for review.

2. Project Proposals are Reviewed by CDAS and NCI Staff

All projects are reviewed by CDAS staff followed by the NCI Data Access Committee to determine if you will be given access to the requested data.

CDAS staff will make an initial assessment of whether the data requested are available and necessary to answer your research question(s).

CDAS staff may ask for additional information to determine if your project proposal will be approved. CDAS staff will either pass your project proposal to NCI for a secondary review or will deny the proposal. Once CDAS staff make a determination, you will be notified.

All project proposals are then reviewed by the NCI Data Use Committee, who are part of the senior leadership for each study. The review will determine (1) if your project addresses a scientific question and (2) if the data available through CDAS are appropriate for answering that question. The review will not assess the project's scientific merit, nor will it check to see if another researcher is engaged in a similar project. You may check the list of [Approved Projects](#) to determine if someone else is performing similar research and you may consider contacting them to collaborate on the effort. NCI may request additional information in order to process your project. Once NCI makes a final determination on your project, you will be notified whether your project has been approved or denied.

3. You Must Complete a Data Transfer and Use Agreement (DTUA)

Once NCI approves your project proposal, the Signing Official at your institution will be required to complete a Data Transfer and Use Agreement (DTUA) before you can access the requested data. *(NIH personnel are not required to complete a DTUA but must instead agree electronically to the CDAS Data Use Policies if they have not done so already.)*

DTUAs are required for each research project to protect the confidentiality of the identity of study participants. While already-prepared standard datasets meet the requirements of the HIPAA privacy rule for de-identified datasets by the removal of 18 key identifiers, some risk remains that the data could be used to re-identify participants and exploit that information in some way. The DTUA requires researchers to implement specific safeguards against the discovery of study participants' identities.

In addition, an Agreement is required by HIPAA for certain data available from CDAS. Certain identifiers such as date of diagnosis may be released in a Limited Data Set as specified by HIPAA if they are essential for a specific research project. The DTUA satisfies HIPAA's requirement.

The process for executing a DTUA is as follows:

- CDAS Staff will reach out to the institution's Signing Official to obtain contact information.
- The agreement will be sent to the Signing Official via DocuSign.

Once the DTUA has been executed and the requested data are available, CDAS staff will grant you access to the requested data and you will be notified through the CDAS website. In order to access the requested data:

- Log in to your account.
- Navigate to [My CDAS](#) and click on your project.
- Select "Deliverables" from the menu to see the data for which you have been granted access.

Access will be granted for 12 months, at which time you can submit a request for the project to be extended or the project can undergo close-out procedures.