

# **Accessing Shared Data Tutorial**

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## **Accessing Shared Data**

## Introduction to Accessing Data in the NIMH Data Archive

Qualified researchers can request access to shared data within the NIMH Data Archive (NDA) free of charge. Once approved, researchers can download, or access in place, their desired data using a variety of tools developed and maintained by NDA.

This tutorial will provide instructions on how to qualify for and request access, as well as how to query the database and download or access the resulting data packages.

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## Acronyms

DAC	Data Access Committee
DAR	Data Access Request
DUC	Data Use Certification
eRA	Electronic Research Administration
FWA	Federal Wide Assurance
NDA	NIMH Data Archive
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
SO	Signing Official

## Create an Account

To access shared data within the NIMH Data Archive (NDA), you need an NDA account. Accounts can be requested directly from the NDA website by submitting the required information. To create an account, follow these steps:

- 1. Create an NDA account here: <a href="https://nda.nih.gov/user/create">https://nda.nih.gov/user/create</a> account.html.
- 2. Please complete the form to create a new account. If you think you may already have an existing NDA account, or have forgotten your username or password, please first try retrieving your NDA credentials here: https://nda.nih.gov/reset\_password.html.
- 3. Click 'Save' once you have completed the form.
- 4. You will receive a confirmation email once your account has been successfully created. After logging into your account, you can edit your NDA profile or request access to shared data in your Data Permissions dashboard. Please contact us at <a href="https://nda.nih.gov">NDAHelp@mail.nih.gov</a> with any questions.

## Data Access Request (DAR)

## Completing a Data Access Request (DAR)

Submitting a Data Access Request (DAR) will generate a Data Use Certificate (DUC). These two submissions are required to access shared data. You must meet the following prerequisites:

- You must be affiliated with an NIH-recognized research institution, defined by registration in the NIH's eRA (Electronic Research Administration) Commons system.
- Your institution must also maintain an active Federalwide Assurance (FWA) with the Office of Human Protections.
- You must have a research-related need to access the data.

If you satisfy each prerequisite, you can complete the DAR to apply for access. To complete and submit your DAR use the following steps:

- 1. Log into your NDA Account by clicking 'My Account' and logging in with your account credentials at <a href="https://nda.nih.gov/">https://nda.nih.gov/</a>.
- 2. Through your NDA profile, access the <u>Data Permissions dashboard</u> and select 'Request Access' under the 'Actions' dropdown menu for the NDA Permission Group to which you are requesting access.

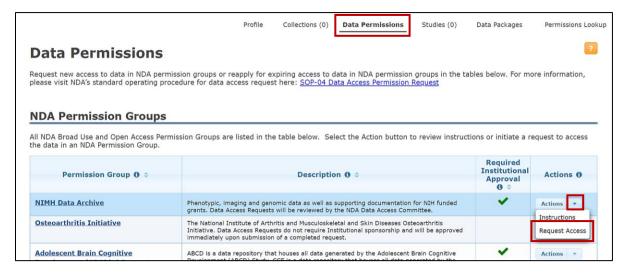


Figure 1: Data Permissions Dashboard

- 3. Read the instructions and use the 'Next' and 'Back' buttons to proceed through the application.
- 4. Provide the title of your research project and your 'Research Data Use Statement'. For the 'Research Data Use Statement', write a description of the proposed research project. Your description is required cover the following criteria:
  - a. Your research question or interest
  - b. The general data you are interested in.
  - c. How the data will be accessed; if data will be downloaded, describe how the data will be managed throughout the course of the proposed research, including the plan for data deletion.
- Select whether any other individuals will access, use, or analyze the data, regardless of position title or data use role. This includes any IT staff who clean or manage the data. Once this is complete, click 'Next'.
   PLEASE NOTE: ALL recipients on a Data Access Request/Data Use Certification must be affiliated with the lead recipient's research institution.

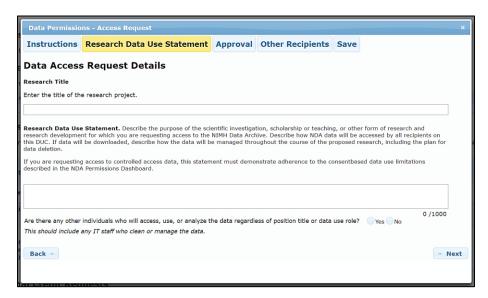


Figure 2: Data Access Request Details

- 6. Select the affiliated institute for the Data Access Request and the Signing Official (SO) who will sign your DUC and Click 'Next'.
- 7. If you indicated that other individuals require access, you will be brought to the 'Other Recipients' section. Here, you can add users from your institution, or you can create a new user to add if they do not yet have an NDA account. Add users accordingly and click 'Next'. **Please note:** The NDA accounts for the 'Other Recipients' need to be affiliated with the same institute as the lead recipient; otherwise, the accounts will not appear in 'Other Recipients' section.



Figure 3: Other Recipients

8. Save your Data Access Request by clicking 'Save'.

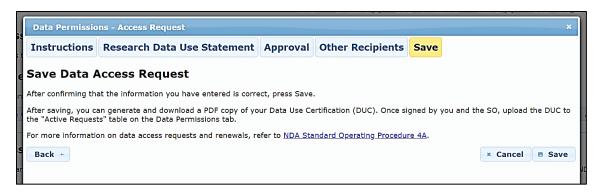


Figure 4: Save Data Access Request

9. Click 'Generate Data Use Certification' to download your DUC, then click 'OK'.



Figure 5: Generate Data Use Certification

10. On your 'Data Permissions' dashboard, you will see your DAR under 'Active Requests'.

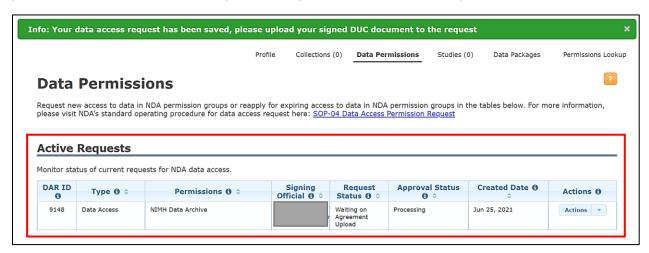


Figure 6: Active Requests

Your request for access to shared data has been saved, **but not submitted**. To complete the process, you will need to have your Data Use Certification **signed by the lead recipient and SO**, then upload it to your DAR.

**Note:** Signing Officials are defined by the assignment of the "SO" role in your institution's eRA Commons profile. The Signing Official for your DAR must be an authorized SO for your institution.

## Editing a Data Access Request (DAR)

Your DAR can be edited if the DAR is not in Request Status "Waiting on DAC Approval".

To edit your request (i.e., change your Research Data Use Statement, change the selected Signing Official, and/or add or remove recipients, etc.):

- 1. Go to your <u>Data Permissions dashboard</u>.
- 2. Locate the active request. Under 'Actions', select 'Edit Request'.



Figure 7: Edit Request

- 3. Make the necessary changes to your Data Access Request, then click 'Save'.
- 4. Generate your Data Use Certification to download your new DUC, then click 'OK'.
- 5. The Request Status will change to "Waiting on Agreement Upload".
- 6. Get your new DUC signed and then upload it to your DAR once complete.

## Signing and Submitting a Data Use Certification (DUC)

The DUC must be signed by both the lead recipient and an authorized Signing Official from the lead recipient's institute. Signatures cannot be typed; they must be either digitally or physically signed.

Once the DUC is generated AND signed:

- 1. Go to your <u>Data Permissions dashboard</u>.
- 2. Then, locate the active request. Under Actions, select 'Upload Signed DUC'.



Figure 8: Actions Dropdown

3. Choose the signed DUC file on your computer and click 'Upload'. It may take a few seconds for the file to upload into our system.



Figure 9: Upload Data Use Certification

4. Once uploaded, a confirmation message will appear. The request status will change to 'Waiting on NDA Admin', and your request will automatically be sent to the NDA Help Desk for review.

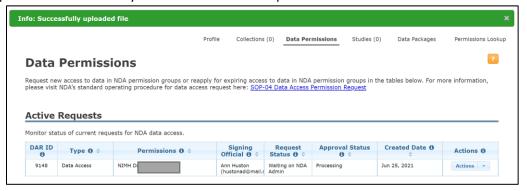


Figure 10: DUC Upload Confirmation

## **Review and Approval of Request**

Once NDA receives a Data Use Certification, it is:

- 1. Checked for completeness.
- 2. Sent to the Data Access Committee (DAC) for review and approval.

This process can take up to 10 business days, and additional clarification of your research plan may be requested. *Ensuring your Research Data Use Statement is clear and complete can help expedite this process.* 

Once approved, access is granted to all personnel listed on the DUC and is valid for one full year.

If any of your collaborating personnel did not have NDA accounts, these will be created upon approval. Once the DAR is approved, the users will be notified via e-mail and prompted to accept the terms and conditions of the Data Use Certification (DUC) upon logging into NDA.

## **Renewing Access**

Once a DAR has been approved, access is valid for one year. After one year, your access will expire and be deactivated unless a renewal request is received and processed prior to expiration. Applying for renewal will become an option 60 days prior to the DAR expiration date. To reapply for access:

- 1. Go to your <u>Data Permissions dashboard</u>.
- 2. In the 'Active NDA Permissions' section, click 'Reapply for Access' in the 'Actions' dropdown menu of the NDA Permission Group you want to renew.

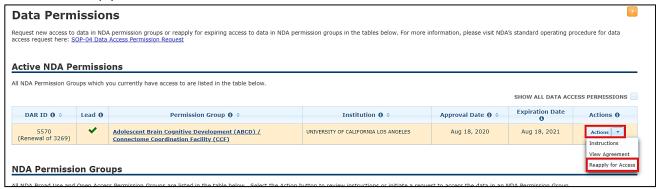


Figure 11: Reapply for Access

3. The process for completing a renewal request is identical to the process for requesting access, with the additional step of providing a brief progress report on the DUC. Recipients requesting the renewal of an expiring Data Use Certification should provide a 'Progress Report' on research conducted with data from the NIMH Data Archive. The 'Progress Report' should also describe any updates to the original 'Research Data Use Statement' and changes to the 'Other Recipients' list on the Data Use Certification. Recipients who conduct a secondary analysis on data shared through the NIMH Data Archive are expected, as part of the DUC Terms of Use, to report their results using the NDA Study feature.

## Adding Recipients to an existing Data Use Certification (DUC)

Lead recipients should add any additional data recipients to a Data Access Request (DAR) before the institutional business official has signed the DUC, and before the request has been reviewed by the NDA Data Access Committee (DAC). To add new data recipients after a DAR has been approved:

- 1. The lead recipient should email the NDA Help Desk at <a href="NDAHelp@mail.nih.gov">NDAHelp@mail.nih.gov</a> with an updated version of the original, active DUC that includes the name(s) and NDA Username(s) for the new data recipient(s), along with the original recipients. The new recipients being added to the DUC will need to <a href="mailto:create an NDA account">create an NDA account</a>.
  - a. The updated DUC must be newly signed by the lead recipient and the institutional Signing Official (SO).
  - b. **Please note:** All recipients on a Data Access Request/Data Use Certification must be affiliated with the lead recipient's research institution.
- 2. NDA will review the updated DUC to ensure that no other changes have been made to the DUC, the two required signatures are present, and the new data recipient(s) are affiliated with the lead recipient's research institution.
- 3. NDA staff will notify the lead recipient when the data recipients have been added to the existing, active DUC. **Please note:** Newly added recipients will be subject to the original expiration date for the DUC.

## Removing Recipients from an existing Data Use Certification (DUC)

Per the DUC terms of use, the lead recipient on a DUC must notify NDA if a recipient is no longer affiliated with the research institution on the DUC. The recipient will be removed from the DUC and their access to the DAR will be revoked. To remove data recipients after a DAR has been approved:

- 1. The lead recipient should email the NDA Help Desk at <a href="MDAHelp@mail.nih.gov">MDAHelp@mail.nih.gov</a> with a request to remove the recipient, providing the Help Desk with the recipient's name and NDA username.
- 2. NDA will revoke that recipient's access to the permission group and remove them from the DUC.
- 3. NDA staff will notify the lead recipient when the data recipient has been removed from the DUC.

## **NDA Query Tools**

### **NDA Search Tool**

The NDA Search tool allows you to look for data or other information in NDA by entering search terms and reviewing or filtering results based on the type of information.



Figure 12: Search Bar

The search results page will display results and provide a summary of information with specified content types. This includes the ability to search results for NDA Studies, NDA Collections, individual data elements, site content pages, and experiment definitions associated with omics or neurosignal recordings data. This is a good tool to see what is available based on key terms used in your search.

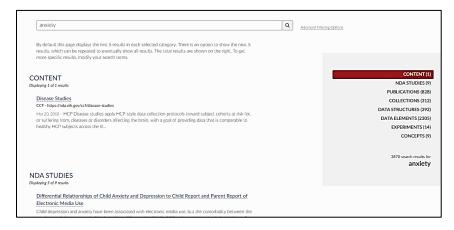


Figure 13: Search Results

## **NDA Query Tool**

## Workspace

Your 'Workspace' is a holding area where you can review your pending filters prior to adding them to your 'Filter Cart'. The first step in accessing data is to select one or more items, then move them into your 'Workspace'. To add items to your 'Workspace':

- 1. Select the search result(s) using the checkbox.
- 2. Click 'Add to Workspace'.
- 3. You will then see it added to your 'Workspace', as seen with the icon in the top right corner.

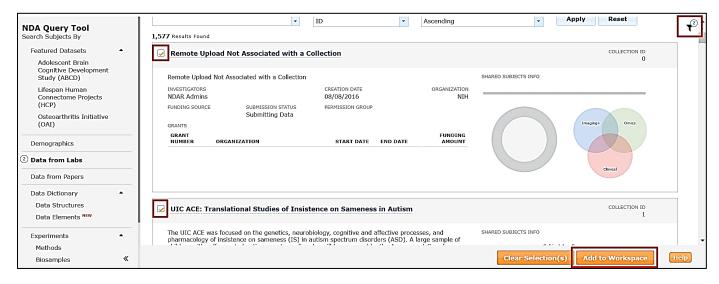


Figure 14: Add to Workspace

#### To view your Workspace:

- 1. Click the workspace icon in the top-right corner.
- 2. Notice that the number of items you have added will appear next to the different sections on the left.

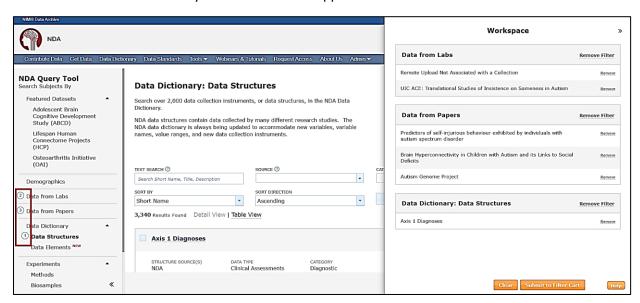


Figure 15: View Workspace

### The Filter Cart

Once queries have been added to your Workspace, the next step is to submit the filters in the workspace to the 'Filter Cart'. This process runs the queries selected, saving the results within a filter cart attached to your account. The 'Filter Cart' is a temporary holder of data, identified by the user through querying or browsing, in which the data from your workspace is filtered.

To submit your query to your 'Filter Cart':

- 1. View your 'Workspace'.
- 2. Click 'Submit to Filter Cart'.

The 'Filter Cart' supports combining multiple filters together and depending on filter type will use "AND" or "OR" logic when combining filters.

Multiple selections from the same filter type will result in those selections being applied with an "OR" condition. For example, if you add an NDA Collection filter with selections for both NDA Collections 2112 and 2563 to an empty Workspace, the subjects from NDA Collection 2112 "OR" NDA Collection 2563 will be added to your Workspace, even if a subject is in both NDA Collections. You can then add other NDA Collections to your Workspace, which further extends the "OR" condition.

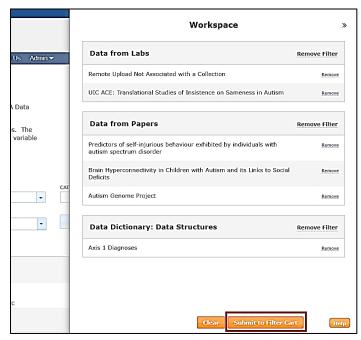


Figure 16: Submit to Filter Cart

## Creating a Package

Once you've used one or more query tools to add a filter(s) to your cart for download, you'll be able to view and edit filters in the cart panel in the upper-right corner of the page. Clicking 'Create Data Package/Add Data to Study' will take you to the 'Data Packaging Page'.



Figure 17: Create Data Package

## **Data Packaging Page**

The Data Packaging Page, also referred to as the 'Landing Page", is where you can view data currently returned by your query. The left panel displays the source Collections of all the data, and the right panel displays a list of all the data structures included. You can check or uncheck Collections and structures to remove or include in this package. An individual must be in both a checked Collection and a checked structure to be included. You can also click 'Find All Subject Data' to drop the existing query and replace it with a 'Query by GUID' filter of all data for all currently included subjects.

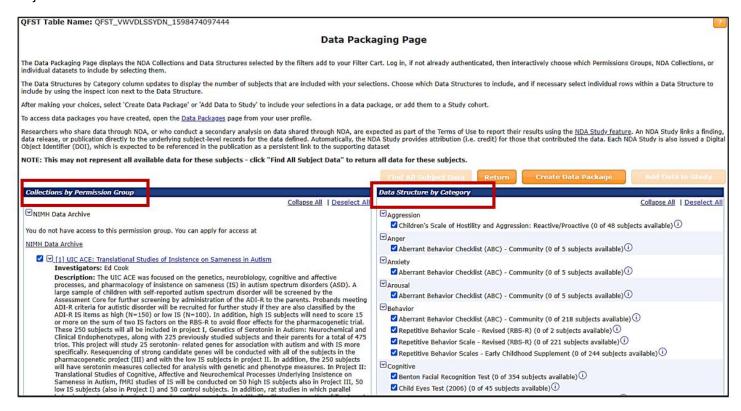


Figure 18: Data Packaging Page

Once you make your selections, click 'Create Package' to name and begin creating your download package. You will have the option to include or exclude associated files. These are associated data files such as omics, EEG, images, etc.

### Data from Labs

The Data from Labs tool serves as a helpful browser of the data organized by its source laboratory into NDA Collections. Each Collection represents one project, typically defined as one grant. By restricting the Collections displayed by organization, funding source, and data source (i.e., ABCD, NDA, ACE, EPINET, etc.), you can browse your subset of interest. You can add an NDA Collection to the cart as a filter from the list using the checkbox on the left of the NDA Collection result.

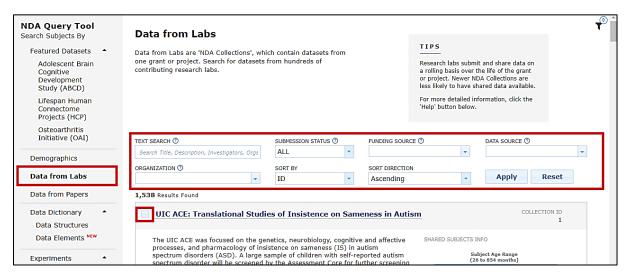


Figure 19: Data from Labs

Within each NDA Collection, there are several tabs to view different information:

- General: Information on the project description, investigator(s), grant, and supporting documentation.
- Experiments: Definitions of any omics, imaging, or neurosignal recordings, and supporting documentation.
- Shared Data: A list of all measures currently shared and number of subjects available for each.
- Publications: Lists of associated publications and associated NDA Studies.
- Data Expected: Displays the expected schedule for the sharing of future data.

Clicking 'Add to Cart' within the NDA Collection will add the entire Collection to your cart as a single filter.

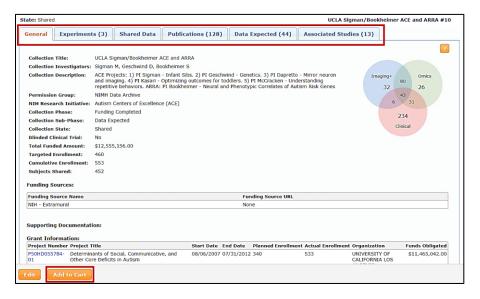


Figure 20: NDA Collection Tabs

## **Data from Papers**

With the Data from Papers tool, you can browse data organized by NDA Study. Each NDA Study represents a publication or other result based on data contained in NDA and serves as a link between the publication and underlying data. You can add an NDA Study to your cart as a filter from the list by clicking the checkbox next to the Study listing, then clicking 'Add New Study' at the bottom-right corner.

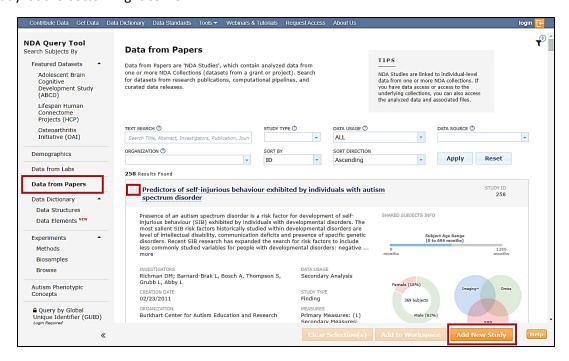


Figure 21: Add New Study

Within the Study you can view general or 'Summary' information, primary and secondary measures, subject cohorts, and other information about the research, including results. You can also add the Study to your cart by clicking 'Download'.



Figure 22: NDA Study

## Search Data Dictionary

The Data Dictionary allows you to view all the data structures currently defined in NDA. Each structure represents a standardized definition of a measure or instrument that researchers use to collect and submit data.

You can select one or more data structures on this page and add them to your cart as one filter. Like in all NDA query tools, the contents of one filter are queried on an "OR" basis, and multiple filters return overlapping results on an "AND" basis.

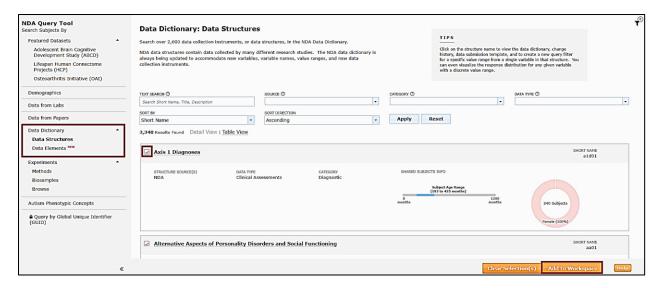


Figure 23: Data Dictionary

You can also click on the title to view the definition. Within each definition are the included data elements, value ranges, descriptions, etc. You can add a data structure to your cart from its definition page as well or click 'Filter' next to an element to view its distribution, then select and apply an element-specific filter.

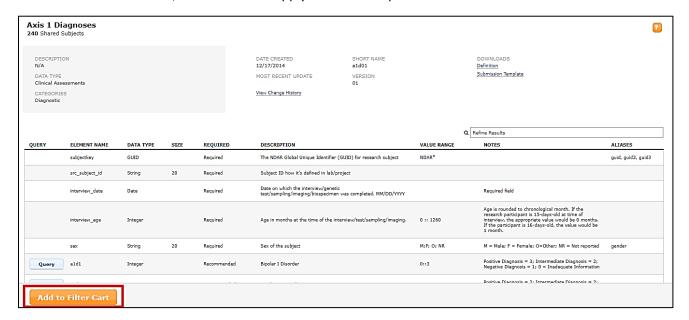


Figure 24: Data Structure - Add to Filter Cart

## **Download Manager**

The Download Manager (Beta) tool is an electron client which was developed with the goal of making the NDA Download Manager (Beta) extremely easy to use. It was completely recoded and relies on a different set of backend tools (which have been documented on our GitHub page).

Once you have initiated your data package creation, you will be presented with the option to launch the Download Manager. Once launched, you can download your data package directly onto your device to a location of your choice. **Please note**: with any package containing omics data or a package over the size limit of 200GB, you will need to use an alternative access method.

If you recently created your package, it may still display as having a status of "Creating Package" when you launch the manager. To update the Download Manager's status use the 'Refresh Queue' button. 'Browse' allows you to select a new download destination. The options at the bottom allow you to stop ongoing downloads, start all selected downloads, and delete or clear packages from the interface. Packages are tied to your account and will persist after you have downloaded them.

View the NDA Tools page for more information and access to the Download Manager User Guide.

#### Cloud Access and miNDAR

NDA Cloud tools are an alternative method to accessing data. All omics data and packages over 200GB must be accessed using these tools; however, these tools also may be used to view other data packages. More information regarding cloud access can be found here.

There are two components to NDA Cloud tools:

- Creating Oracle Databases hosted in Amazon Web Services (AWS) called miniature NDARS (miNDARS) and deploy
  packages to them.
  - Each structure in your package will translate to a table in this database, that you can connect to using provided credentials.
- Manually generating AWS credentials are no longer needed. Instead, you can data NDA by:
  - Creating a "package" on the NDA website. All packages that your user has created will show up in the <u>'Data Packages'</u> portion of your dashboard.
  - Downloading the package using the Download Manager tool. After you create a package on the NDA website, it will show up in the Download Manager tool.
  - Please visit here for the Download Manager User Guide.
  - See <u>here</u> for details on how the new package service works and how to accomplish the same workflows you
    may be using, but with the new service.

### **Federated Access**

NDA has federated with a variety of other repositories to provide a more useful platform for supported research. Federation allows data from other sources to be accessed alongside NDA data, using the NDA infrastructure and many of the query tools described in this tutorial, while preserving the source repository's control over access.

Data from federated partners must be requested directly from those partners, in accordance to their requirements, rather than through the NDA Data Use Certification.