

1. Accessing NCRAD ADC Catalog

- a. The NCRAD ADC Catalog can be accessed on the NCRAD website in the Accessing Biospecimens and Data section at [https://www.ncrad.org/accessing\\_data.html](https://www.ncrad.org/accessing_data.html).

## Accessing Biospecimens and Data

In order to ensure that researchers have the most accurate information, the National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD) is continually updated with new information. At the time data is requested, NCRAD will provide the researcher with the most current information. Therefore, NCRAD encourages all researchers to request an updated set of variables prior to publication and implementation of analyses involving samples acquired from the Repository. While every effort is made to verify all data and information, NCRAD cannot be responsible for any errors or omissions in the distributed data.

Cohort	Population	Genomic DNA	Cell Line DNA	RNA	Plasma	Serum	LCLs	PBMCs	CSF
4RTNI-2	CBD, PSP, o/vPSP, or healthy controls	✓		✓	✓	✓		✓	✓
ADNI	AD Cases, Controls, MCI	✓	✓	✓			✓		
AA Genetics	AD Cases, Controls		✓				✓		
ADCs	AD and other dementia cases, Controls, MCI	✓	✓					✓	



- b. Upon clicking on the ADC cohort, you will be directed to a detailed box that will link you to the ADC catalog.

**ADCs** Top

The Alzheimer's Disease Centers (ADCs) are funded at major medical institutions across the United States. Researchers at these Centers are working to translate research advances into improved diagnosis and care for people with Alzheimer's disease while focusing on the program's long-term goal—finding a way to cure and possibly prevent Alzheimer's.

**Study Subjects**

Although each center has its own area of emphasis, a common goal of the ADCs is to enhance research on Alzheimer's disease by creating a network that shares new ideas and research results. The clinic-based population includes subjects with Alzheimer's disease and related disorders, as well as cognitively normal subjects and those with MCI.

**Available Data**

The National Alzheimer's Coordinating Center (NACC) maintains a cumulative database including clinical evaluations, neuropathology data when available, and MRI Imaging. The NACC database comprises several standardized clinical and neuropathology data sets, all of which are freely available to the research community.

**Available Biospecimens**

Genomic DNA from blood or brain tissue, Cell Line DNA from LCLs, PBMCs from select subjects

[Price Structure](#) | [Catalog](#) | [Request Access to Biospecimens](#)

- c. Researchers must complete a web-based Data Agreement to obtain a username and password to the restricted catalogs.

## Data Agreement

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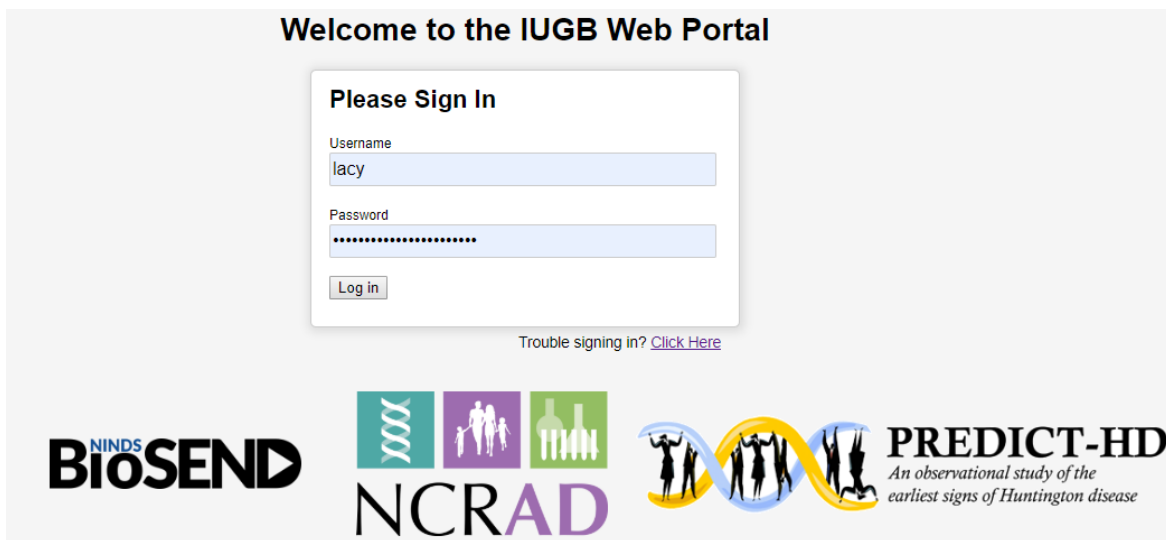
I request access to data housed at the National Cell Repository for Alzheimer’s Disease (NCRAD) for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

### Section I: Access, Use, and Safeguards

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- A. I will receive de-identified data and will not attempt to establish the identity of, or attempt to contact any of the subjects with data in NCRAD.
- B. I will not attempt to identify any specific study sites, unless NCRAD has approved such identification as part of my project’s protocol.
- C. I understand that distributing these data to a third party is prohibited, and therefore I will not distribute these data beyond the uses outlined in this agreement. A third party is defined as anyone who is not a collaborator or co-author on the analyses defined in my proposal.
- D. I will require anyone on my team who uses the data, or anyone with whom I share these data, to comply with this Data Agreement.
- E. I will accurately provide the requested information about persons who will use the data and analyses that are planned using these data.
- F. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting and using these data.
- G. I understand that any data I download may change as new quality assurance measures are implemented and data records are updated.
- H. I will ensure that Investigators who utilize data obtained from NCRAD use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
- I. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 15 days of becoming aware of such use or disclosure.

- d. After obtaining a username and password from the NCRAD staff, researchers will be able to log directly into the specimen catalog to review a subset of data.



- e. The catalog system is designed to allow researchers to determine which sample collections best fit their research needs and perform feasibility checks before applying for or requesting the samples. The researcher will have the option to download their selected sample set and include that with their application.

NACC Fields in NCRAD Limited Data Set	
NACCID	DICOM image file available?
Sex	Global CDR at Last Visit
Ethnicity	Cognitive Status at Last Visit
Race	Diagnosis at Last Visit
Years of Education	Deceased?
Total Visits	Age at Death
Initial Visit Age	Autopsy Available
Global CDR at Initial Visit	Braak Stage
Cognitive Status at Initial Visit	CERAD Score
Diagnosis at Initial Visit	

NCRAD Biospecimen Fields
Specimen Type
Specimen Quantity
Quantity UOM
Specimen Count
Additional Stock
Concentration
260/280 Ratio
DNA Source
Specimen Type
Specimen Quantity

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- f. Researchers can use the sidebar to filter for the specific samples that meet their request criteria. When the categories on the left are selected, they will appear in the dataset to the right. Variables can be chosen by range of numbers, such as age, or text options, such as baseline diagnosis.

ADC Catalog		Dictionary	Join Data	Selection	Download	Help	Tour
Column Filter Search		NACCID	Specimen Type				
20527	NACC031676	DNA					
20590	NACC046061	DNA					
20589	NACC468633	DNA					
20551	NACC722051	DNA					
20722	NACC815678	DNA					
20873	NACC404251	DNA					
20725	NACC793322	DNA					
20878	NACC165757	DNA					
23500	NACC666455	DNA					
23359	NACC928893	DNA					
23361	NACC968763	DNA					
20881	NACC394961	DNA					
23353	NACC987523	DNA					
23421	NACC528063	DNA					
21409	NACC835931	DNA					
21412	NACC032271	DNA					
21486	NACC611039	DNA					
20728	NACC333002	DNA					
21603	NACC148948	DNA					
22202	NACC843246	DNA					
23381	NACC601145	DNA					

- g. Researchers can individually select the samples they want, which highlights the selection in blue. They can also use the selection tool at the top to select all, none, or invert their selection.

ADC Catalog		Dictionary	Join Data	Selection	Download	Help	Tour
Column Filter Search		NACCID	Specimen Type	Specimen Quantity	Quantity UOM	Specimen Count	Last Diagnosis
20527	NACC031676	DNA	5	ug	154	Alzheimer's disease (AD)	
20590	NACC046061	DNA	5	ug	128	Alzheimer's disease (AD)	
20589	NACC468633	DNA	5	ug	222	FTLD, other	
20551	NACC722051	DNA	5	ug	2	Alzheimer's disease (AD)	
20722	NACC815678	DNA	5	ug	50	Alzheimer's disease (AD)	
20873	NACC404251	DNA	5	ug	828	Alzheimer's disease (AD)	
20725	NACC793322	DNA	5	ug	78	Alzheimer's disease (AD)	
20878	NACC165757	DNA	5	ug	772	Not applicable, not cognitively impaired	
23500	NACC666455	DNA	5	ug	230	FTLD, other	
23359	NACC928893	DNA	5	ug	180	Not applicable, not cognitively impaired	
23361	NACC968763	DNA	5	ug	126	Alzheimer's disease (AD)	

- h. Researchers will have the option to download the entire dataset, just the filtered specimens, or their selected specimens. An excel file will download to the desktop.

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### 2. Links with NIAGADS

a. Samples with genetic data at NIAGADS are hyperlinked directly to the ADC Catalog for the dataset.

NACCID	Specimen Type	Specimen Quantity	Quantity UOM	NIAGADS Dataset
NACC044350	DNA		5 ug	<a href="#">NG00024</a>
NACC245215	DNA		5 ug	<a href="#">NG00024</a>
NACC059326	DNA		5 ug	<a href="#">NG00024</a>
NACC677294	DNA		5 ug	<a href="#">NG00024</a>
NACC047473	DNA		5 ug	<a href="#">NG00024</a>
NACC073844	DNA		5 ug	<a href="#">NG00024</a>
NACC421833	DNA		5 ug	<a href="#">NG00024</a>
NACC333907	DNA		5 ug	<a href="#">NG00070</a>
NACC436597	DNA		5 ug	<a href="#">NG00024</a>
NACC868764	DNA		5 ug	<a href="#">NG00024</a>

b. Indication of NCRAD sample available in NIAGADS dataset

The screenshot shows the NIAGADS INQuery interface. On the left, there is a sidebar with a 'Fields' tab and a list of fields to be displayed, including 'ncrad\_sample'. The main area shows a table of samples with columns: NIAGADS\_ID, subject\_id, niagads\_data, ncrad\_sample, cohort, dx, sex, race, ethnicity, apoe, mmse, braak, and autopsy. The 'ncrad\_sample' column contains 'Yes' for all listed samples, indicating that NCRAD data is available for these samples. The interface also includes search and query options at the top.

### 3. Link at NACC to NCRAD

a. Within NACC UDS Query, select “Genomic data/DNA samples available outside of NACC”.

FTLD type, most recent FTLD module visit	<input type="radio"/>	<input type="radio"/>	
<b>+ Genetics</b>			
<i>Available as:</i>	<b>ROW</b>	<b>COLUMN</b>	<b>PAGE</b>
APOE genotype available at NACC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
APOE genotype	<input type="radio"/>	<input type="radio"/>	
Number of APOE e4 alleles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Subject/family has known AD Mutation (APP, PS1, PS2)	<input type="radio"/>	<input type="radio"/>	
Subject/family has known FTLD mutation (MAPT, PGRN, C9ORF72, FUS)	<input type="radio"/>	<input type="radio"/>	
Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)	<input checked="" type="radio"/>	<input type="radio"/>	

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b. Query below shows how many subjects have sample data elsewhere.

NACC Query System: UDS Subjects  
 NOTE: This query used versions 1-3 of UDS data

**These data should be used only as rough, preliminary numbers.  
 For publication purposes, please submit a custom data request**

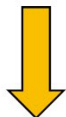
Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)

Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)	Frequency (n)
Genotype data available at ADGC	13187
Genotype data available at NIAGADS	3285
Exome sequencing data available from dbGaP / ADSP	3285
DNA sample available at NCRAD	24818
Total UDS subjects	40031

Data from [Additional genetic data](#)  
 Created on April 22, 2019  
 Data as of March 1, 2019  
[www.alz.washington.edu](http://www.alz.washington.edu)

4. Joining External Data to NCRAD Catalog

a. Click the Join Data button at the top of the screen in the NCRAD catalog. The Join External Data box will appear.



The screenshot shows the NCRAD catalog interface with a 'Join External Data' dialog box open. The dialog box contains the following text:

Select files to join to the catalog. Once joined you can filter results based on the new data

**Note:** You can choose to upload and join multiple files but they all must be selected at the same time. Once one join operation has been performed, this option will be deactivated.

Buttons: Browse... No file selected, Close

The background table shows columns for GUID, ARTFL, LEFFTDS, Specimen Quantity, and Quantity UOM. Rows include subject IDs like 137140, 137102, etc., with corresponding data for ARTFL, LEFFTDS, and specimen details.

b. Select the file to join to the catalog using the Browse button. Be sure the subject ID matches the NACC ID format. Joins work best when files with 50 or less fields (columns) are joined to the ADC Catalog.

This is a close-up of the 'Join External Data' dialog box. It contains the same text as the previous screenshot, but the 'Browse...' button is highlighted with a black border, and the 'No file selected' text is also highlighted. The 'Close' button is visible at the bottom right.