NATIONAL ALZHEIMER'S COORDINATING CENTER

Guide to the online query system

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Introduction

Query system applications

With NACC's query system, you can create frequency tables of data from:

- the Uniform Data Set
- the FTLD Module
- Genetics data
- Imaging data
- the Neuropathology Data Set

These tables can help you determine quickly whether NACC is likely to have the subjects you're looking for in numbers sufficient to address your research question.

> **PLEASE NOTE** that these should be used only as rough, preliminary numbers. For publication purposes, or if your query requires more detailed information, please make a custom data request.

How to use the query system

Creating a frequency table is simple. Depending on your specific interests, you can make variable selections for **row** only; **row** and **column**; or **row, column,** and **page**. (Note that some variables are available only as a row option or only as row or column.) **Page** will generate a separate table for each output category of a query selection. For example, selecting "Sex" for page will generate one table for men and another table for women.

After making your selections, click "SUBMIT" to create a table or "RESET" to clear your selections and start over.

About this guide

This guide is intended to be the initial resource for researchers using NACC's online query system. It provides detailed information on the query selection categories, including the source variable(s) and source document(s). This will allow you to easily link the query selection categories to their original data source. The source documents for NACC data are described on the next page.

Source documents for NACC data

For more information about the data elements, please consult the linked references below. In the pages that follow, these are referred to by their abbreviations in blue.

RDD-UDS **Researcher's Data Dictionary – Uniform Data Set**
Brings together information for the original data-collection instruments for all past and current UDS form versions.

DED-UDS v3 **Data Element Dictionary – Uniform Data Set v3**
Defines every variable in a given form in the order in which it appears from version 3.0 of the UDS.

DED-FTLD v2 **Data Element Dictionary – FLTD Module v2**
Defines every variable in a given form in the order in which it appears from version 2.0 of the FTLD Module

RDD-NP **Researcher's Data Dictionary – Neuropathology Data Set**
Brings together information from all the original data-collection instruments (Coding Guidebooks and Forms) for all past and current versions of the NP Form.

DED-CSF **Data Element Dictionary – CSF Biomarker Data Set**
Includes data on UDS participants who have CSF values for A-beta, P-tau, and T-tau.

RDD-Imaging **Researcher's Data Dictionary – Imaging Data**
Includes MRI and PET variables (e.g., year of MRI scan, year of amyloid PET scan) associated with DICOM files stored at NACC. Also included are MRI variables that provide volume values (e.g., hippocampal volume) for the subset of DICOM files stored at NACC for which volumetric analysis has been completed.

RDD-Genetics **Researcher's Data Dictionary – Genetic Data**
Describes variables that contain either genetic data (APOE genotype) or information about the availability of genetic data that can be obtained, by request, from the Alzheimer's Disease Genetics Consortium (ADGC), the National Institute of Aging Genetics of Alzheimer's Disease Data Storage Site (NIAGADS), or the Database of Genotypes and Phenotypes (dbGaP).

Query selection categories

PARTICIPANT'S FOLLOW-UP CHARACTERISTICS

UDS visits completed

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAVST *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Categorizes RDD-UDS variable NACCAVST (total number of all UDS visits made)
Output categories	1 visit 2 visits ≥3 visits

PARTICIPANT DEMOGRAPHICS

Age

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	NACCAGE *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Categorizes RDD-UDS variable NACCAGE (participant's age at visit)
Output categories	<60 60-69 70-79 80-89 ≥90

Sex

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	SEX *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	Male Female

Race

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCNIHR *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	White Black or African American American Indian or Alaskan Native Native Hawaiian or Pacific Islander

	Asian
	Multiracial
	Unknown or ambiguous

Hispanic ethnicity

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	HISPANIC *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	Yes
	No
	Unknown

Primary language

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	PRIMLANG *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	English
	Spanish
	Mandarin
	Cantonese
	Russian
	Japanese
	Other primary language
	Unknown

Years of education

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	EDUC *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Categorizes RDD-UDS variable EDUC (years of education)
Output categories	≤12 years
	13-16 years
	>16 years

CLINICAL DEMENTIA RATING (CDR)

Global CDR

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	CDRGLOB *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	0.0 — no impairment
	0.5 — questionable impairment
	1.0 — mild impairment
	2.0 — moderate impairment
	3.0 — severe impairment

CDR – Behavior, comportment, and personality

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	COMPORT *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	0.0 — no impairment 0.5 — questionable impairment 1.0 — mild impairment 2.0 — moderate impairment 3.0 — severe impairment Not collected/unknown

CDR – Language

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	CDRLANG *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	0.0 — no impairment 0.5 — questionable impairment 1.0 — mild impairment 2.0 — moderate impairment 3.0 — severe impairment Not collected/unknown

COGNITIVE STATUS

Cognitive status

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	NACCUDSD *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	Normal cognition Impaired not MCI MCI Dementia

PRIMARY CLINICAL DIAGNOSIS

Primary clinical diagnosis

Cross-sectional or visit-based	Visit-based — initial visit or most recent visit
Source variable(s) (source document(s))	NACCETPR *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Edited original NACCETPR variable to include individuals with normal cognition
Output categories	Alzheimer's disease (AD) Lewy body disease (LBD) Multiple system atrophy (MSA)

Progressive supranuclear palsy (PSP)
Corticobasal degeneration (CBD)
FTLD with motor neuron disease (e.g., ALS)
FTLD, other (e.g., bvFTD, PPA)
Vascular brain injury or vascular dementia including stroke
Essential tremor
Down syndrome
Huntington's disease
Prion disease (CJD, other)
Traumatic brain injury (TBI)
Normal-pressure hydrocephalus (NPH)
Epilepsy
CNS neoplasm
Human immunodeficiency virus (HIV)
Other neurologic, genetic, or infectious condition
Depression
Bipolar disorder
Schizophrenia or other psychosis
Anxiety disorder
Delirium
Post-traumatic stress disorder (PTSD)
Other psychiatric disease
Cognitive impairment due to alcohol abuse
Cognitive impairment due to other substance abuse
Cognitive impairment due to systemic disease or medical illness
Cognitive impairment due to medications
Cognitive impairment for other/unknown reasons (i.e., written-in values)
Normal cognition

FTLD MODULE

FTLD module visits completed

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source documents(s))	Created for query system
Changes to source variable for query system	N/A
Additional details	N/A
Output categories	0 visits 1 visit ≥2 visits

Participant/family has known FTLD mutation (MAPT, PGRN, C9ORF72, FUS)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	FFTDMUT *(DED-UDS V3)* FTDPMUT *(DED-FTLD V2)*
Changes to source variable for query system	Yes

Additional details	Combines responses from FFTDMUT and FTDPMUT from the most recent visit where the variables are non-missing data.
Output categories	MAPT PGRN C9ORF72 FUS Other FTLD mutation No mutation/unknown

FTLD type, most recent FTLD module visit

Cross-sectional or visit-based	Visit-based — most recent FTLD visit
Source variable(s) (source document(s))	NACCFTD *(RDD-UDS)* NACCUDSD *(RDD-UDS)* CORTIF *(RDD-UDS)* PSPIF *(RDD-UDS)* FTLDMOIF *(RDD-UDS)* FTLDNOIF *(RDD-UDS)* FTDIF *(RDD-UDS)* PPAPHIF *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Ascertained FTLD type from CORTIF, PSPIF, FTLDMOIF, FTLDNOIF, FTDIF, and PPAPHIF from the most recent FTLD Module visit, accounting for cognitive status, for UDS participants with one or more FTLD Module visits completed.
Output categories	CBD (normal cognition, MCI, or dementia) PSP (normal cognition, MCI, or dementia) FTLD with motor neuron disease (e.g., ALS) (normal cognition, MCI, or dementia) FTLD other (e.g., bvFTD, PPA) (MCI or dementia) Non-FTLD MCI or dementia (e.g., AD) Normal cognition and no FTLD No FTLD Module visits

GENETICS

APOE genotype available at NACC

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAPOE *(RDD-GENETICS)*
Changes to source variable for query system	Yes
Additional details	Indicator of APOE genotype availability at NACC
Output categories	Yes No

APOE genotype

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAPOE *(RDD-GENETICS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	e3e3 e3e4 e3e2 e4e4 e4e2 e2e2 Missing/unknown/not assessed

Number of APOE e4 alleles

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCNE4S *(RDD-GENETICS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	No e4 allele 1 copy of e4 allele 2 copies of e4 allele Missing/unknown/not assessed

Participant or family has known AD mutation (APP, PS1, PS2)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAM *(RDD-UDS)*
Changes to source variable for query system	Yes
Additional details	Participant or family has known AD mutation
Output categories	APP PSEN-1 PSEN-2 Other AD mutation No mutation/unknown

Participant/family has known FTLD mutation (MAPT, PGRN, C9ORF72, FUS)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	FFTDMUT *(DED-UDS V3)* FTDPMUT *(DED-FTLD V2)*
Changes to source variable for query system	Yes
Additional details	Combines responses from FFTDMUT and FTDPMUT from the most recent visit where the variables are non-missing data.
Output categories	MAPT PGRN C9ORF72 FUS Other FTLD mutation No mutation/unknown

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

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	ADGCGWAS *(RDD-GENETICS)* ADGCRND *(RDD-GENETICS)* ADGCADSP *(RDD-GENETICS)*
Changes to source variable for query system	Yes
Additional details	Indicator of whether genetic data and/or samples are available, and from where.
Output categories	Genotype data available at ADGC Genotype data available at NIAGADS Exome sequencing data available from dbGaP/ADSP DNA sample available at NCRAD Total participants in UDS

CSF

CSF biomarker data available at NACC (A-beta, p-tau, t-tau)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	CSFABETA *(DED-CSF)* CSFPTAU *(DED-CSF)* CSFTTAU *(DED-CSF)*
Changes to source variable for query system	Yes
Additional details	Indicator of CSF biomarker data availability at NACC (A-beta, p-tau, t-tau)
Output categories	Yes No

IMAGING

At least one MRI available for download — by scan type

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCMRI *(RDD-IMAGING)* MRIT1 *(RDD-IMAGING)* MRIT2 *(RDD-IMAGING)* MRIFLAIR *(RDD-IMAGING)* MRIDTI *(RDD-IMAGING)*
Changes to source variable for query system	Yes
Additional details	Indicator of at least one MRI available at NACC
Output categories	No MRI available for download At least one MRI available for download, any type At least one T1 available for download At least one T2 available for download At least one FLAIR available for download At least one DTI available for download Total participants in the UDS

Longitudinal MRIs available for download — by scan type

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCMRI *(RDD-IMAGING)* MRIT1 *(RDD-IMAGING)* MRIT2 *(RDD-IMAGING)* MRIFLAIR *(RDD-IMAGING)* MRIDTI *(RDD-IMAGING)*
Changes to source variable for query system	Yes
Additional details	Indicator of longitudinal MRIs available at NACC
Output categories	No MRI available for download, or MRI available for download but not available longitudinally Longitudinal MRIs available for download, any type Longitudinal T1 available for download Longitudinal T2 available for download Longitudinal FLAIR available for download Longitudinal DTI available for download Total participants in the UDS

Calculated summary MRI volume data available — at least one visit, longitudinal

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCMVOL *(RDD-IMAGING)*
Changes to source variable for query system	Yes
Additional details	Indicator of calculated summary MRI volume data available (calculations done by IDeA Lab at University of California, Davis)
Output categories	Calculated summary MRI volume data available for at least one visit Longitudinal calculated summary MRI volume data available Calculated summary data not available Total participants in the UDS

Calculated summary MRI volume data available – by brain region

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCICV *(RDD-IMAGING)* NACCBRNV *(RDD-IMAGING)* GRAYVOL *(RDD-IMAGING)* WHITEVOL *(RDD-IMAGING)* WMHVOL *(RDD-IMAGING)* NACCWMVL *(RDD-IMAGING)* CSFVOL *(RDD-IMAGING)* HIPPOVOL *(RDD-IMAGING)* FRONTGRY *(RDD-IMAGING)* FRONTWHT *(RDD-IMAGING)* FRONTCSF *(RDD-IMAGING)* OCCIPGRY *(RDD-IMAGING)* OCCIPWHT *(RDD-IMAGING)*

	OCCIPCSF *(RDD-IMAGING)* PARGRY *(RDD-IMAGING)* PARWHT *(RDD-IMAGING)* PARCSF *(RDD-IMAGING)* TEMPGRY *(RDD-IMAGING)* TEMPWHT *(RDD-IMAGING)* TEMPCSF *(RDD-IMAGING)*
Changes to source variable for query system	Yes
Additional details	Calculated summary MRI volume data available by brain region (calculations done by IDeA Lab at University of California, Davis)
Output categories	Total intracranial volume available Total brain volume available Total volume of gray matter available Volume of white matter excluding WMH available Volume of white matter hyperintensities available Total white matter volume available Volume of intracranial CSF available Volume of hippocampus available Volume of frontal lobe gray matter available Volume of frontal lobe white matter available Volume of frontal lobe CSF available Volume of occipital lobe gray matter available Volume of occipital lobe white matter available Volume of occipital lobe CSF available Volume of parietal lobe gray matter available Volume of parietal lobe white matter available Volume of parietal lobe CSF available Volume of temporal lobe gray matter available Volume of temporal lobe white matter available Volume of temporal lobe CSF available Total participants in the UDS

Age at first MRI available for download

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCMRIA *(RDD-IMAGING)*
Changes to source variable for query system	Yes
Additional details	Birth month and birth year are required elements in the UDS; however, birth day is not collected. To calculate age at MRI, birth day is set to 1 for all UDS participants, and NACCMRIA is computed as MRI date minus birth date.
Output categories	<60 60-69 70-79 80-89 ≥90

At least one amyloid PET available for download

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	Created for query system
Changes to source variable for query system	Not applicable
Additional details	N/A
Output categories	Yes No

NEUROPATHOLOGY DATA

Neuropathology data available

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAUTP *(RDD-UDS)*
Changes to source variable for query system	No
Additional details	N/A
Output categories	Yes No — deceased, no autopsy data Not applicable, participant not deceased

Alzheimer's disease neuropathology present

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCNEUR *(RDD-NP)* NACCBRAA *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Combines data from variables NACCNEUR (density of neocortical neuritic plaques, or C score) and NACCBRAA (Braak stage for neurofibrillary degeneration, or B score) to determine presence of Alzheimer's disease neuropathology (moderate to frequent neuritic plaques and Braak stage III-VI)
Output categories	Yes No Not assessed/missing/unknown Deceased, no autopsy data Participant not deceased

Thal phase (A score)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NPTHAL *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Thal phase for amyloid plaques (A score)
Output categories	Phase 0 (A0) Phase 1 (A1) Phase 2 (A1) Phase 3 (A2) Phase 4 (A3) Phase 5 (A3)

	Not assessed/missing/unknown
	Deceased, no autopsy data
	Participant not deceased

Braak neurofibrillary stage (B score)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCBRAA *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Braak stage for neurofibrillary degeneration (B score)
Output categories	Stage 0, AD-type neurofibrillary degeneration not present (B0) Stage I (B1) Stage II (B1) Stage III (B2) Stage IV (B2) Stage V (B3) Stage VI (B3) The presence of tauopathy (other than aging/AD) precludes Braak staging Not assessed/missing/unknown Deceased, no autopsy data Participant not deceased

Neuritic plaque score (C Score)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCNEUR *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Density of neocortical neuritic plaques (CERAD score) (C score)
Output categories	No neuritic plaques (C0) Sparse neuritic plaques (C1) Moderate neuritic plaques (C2) Frequent neuritic plaques (C3) Not assessed/missing/unknown Deceased, no autopsy data Participant not deceased

Alzheimer's disease neuropathology change (ADNC score)

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NPADNC *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	NIA-AA Alzheimer's disease neuropathologic change (ADNC) (ABC score)
Output categories	Not AD Low ADNC Intermediate ADNC High ADNC Not assessed/missing/unknown

	Deceased, no autopsy data Participant not deceased

Cerebrovascular pathology — by type

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCAMY *RDD-NP* NACCINF *RDD-NP* NACCMICR *RDD-NP* NACCHEM *RDD-NP* NACCARTE *RDD-NP* NACCNEC *RDD-NP* NACCAVAS *RDD-NP* NPART *RDD-NP* NPOANG *RDD-NP* NPVOTH *RDD-NP* NPWMR *RDD-NP* NPPATH *RDD-NP*
Changes to source variable for query system	Yes
Additional details	Indicates the presence of cerebrovascular pathologies
Output categories	Cerebral amyloid angiopathy Infarcts and lacunes Microinfarcts Hemorrhages and microbleeds Arteriolosclerosis Laminar necrosis Other vascular pathology No vascular pathology Total UDS participants with NP data Total UDS participants without NP data

Hippocampal sclerosis

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NPHIPSCL *(RDD-NP)* NPSCL *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Combines data from NPHIPSCL (hippocampal sclerosis (CA1 and/or subiculum)) and NPSCL (medial temporal lobe sclerosis present (including hippocampal sclerosis)) to determine presence of hippocampal sclerosis.
Output categories	Yes No Not assessed/ missing/unknown Deceased, no autopsy data Participant not deceased

Lewy body disease pathology — by region

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCLEWY *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Presence of Lewy body disease pathology
Output categories	No Lewy body pathology Brainstem-predominant Limbic (transitional) or amygdala-predominant Neocortical (diffuse) Lewy bodies present, but region unspecified or found in the olfactory bulb Not assessed/missing/unknown Deceased, no autopsy data Participant not deceased

FTLD neuropathology — by type

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCPICK *(RDD-NP)* NACCCBD *(RDD-NP)* NACCPROG *(RDD-NP)* NPFRONT *(RDD-NP)* NPTAU *(RDD-NP)* NPFTD *(RDD-NP)* NPFTDNO *(RDD-NP)* NPALSMND *(RDD-NP)* NPFTDSPC *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	Combines data from the following to determine presence of FTLD neuropathology: • NACCPICK (Pick's, or PiD) • NACCCBD (corticobasal degeneration, or CBD) • NACCPROG (progressive supranuclear palsy, or PSP) • NPFRONT (frontotemporal dementia and parkinsonism with tau-positive or argyrophilic inclusions) • NPTAU (other tauopathy) • NPFTD (FTD with ubiquitin-positive or tau negative inclusions) • NPFTDNO (FTD with no distinctive histopathology present) • NPALSMND (ALS/motor neuron disease, or MND) • NPFTDSPC (FTD not otherwise specified present)
Output categories	FTLD-tau FTLD-TDP FTLD-other Total UDS participants with NP data Total UDS participants without NP data

No major neuropathologic change present

Cross-sectional or visit-based	Cross-sectional
Source variable(s) (source document(s))	NACCBRNN *(RDD-NP)*
Changes to source variable for query system	Yes
Additional details	No major neuropathologic change present is defined as meeting all of the following criteria: • Braak stage 0 (AD-type neurofibrillary degeneration not present), I, or II • No amyloid pathology • No or mild vascular pathology • No Lewy bodies • No other pathology (e.g., FTLD-TDP, FTLD-tau, tangle-only dementia, prion disease, etc.)
Output categories	Yes No At least one required variable is not assessed/missing/unknown Deceased, no autopsy data Participant not deceased