

# Interactive tools for researchers

The new NACC web-based query system and more

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Fall ADC Meeting  
October 11, 2014

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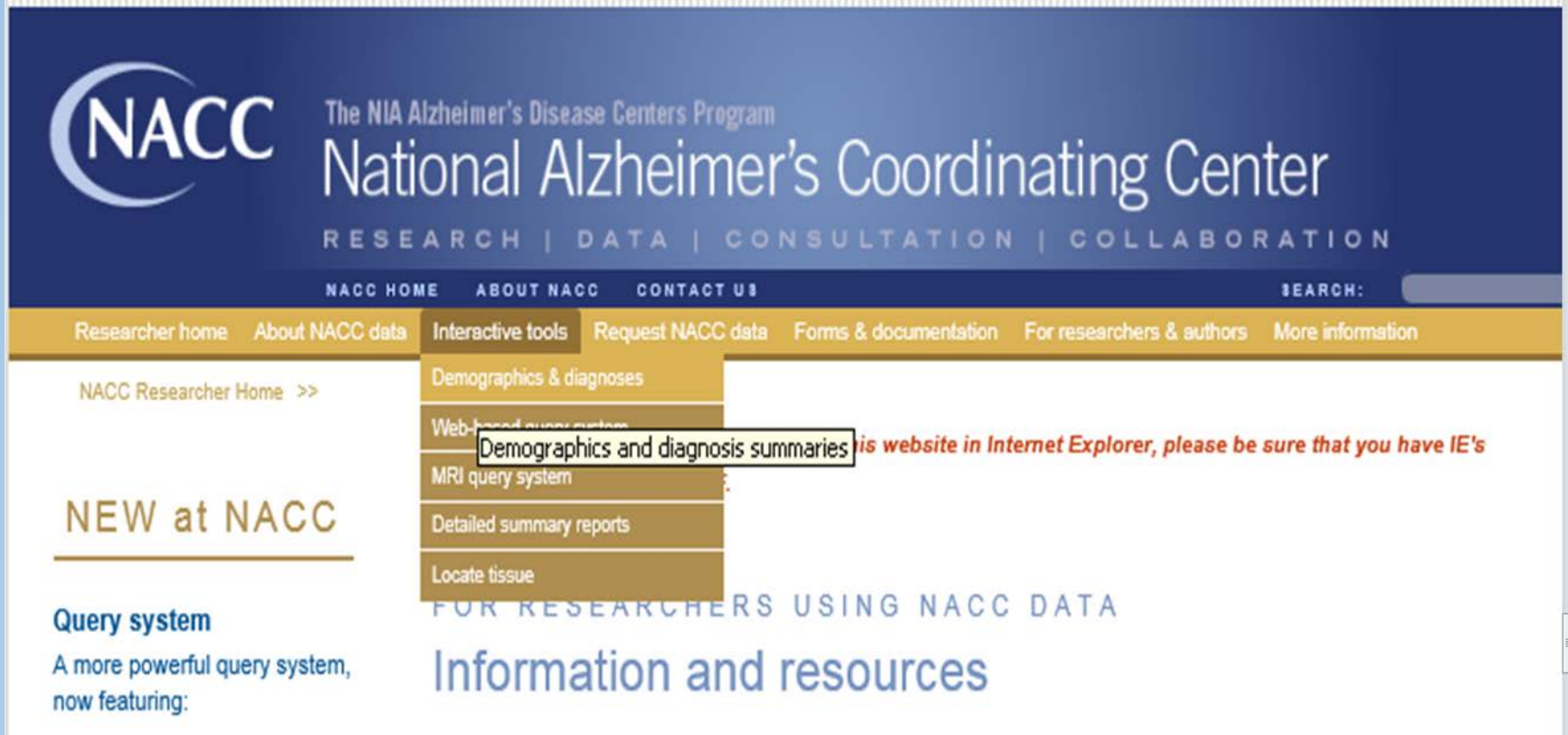


# Interactive Tools

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- Demographics and diagnoses tables
- Web-based query system
- MRI query system

# Demographics and diagnoses summary tables



The screenshot shows the NACC website interface. At the top, the NACC logo is on the left, followed by the text 'The NIA Alzheimer's Disease Centers Program' and 'National Alzheimer's Coordinating Center'. Below this is the tagline 'RESEARCH | DATA | CONSULTATION | COLLABORATION'. A navigation bar contains links for 'NACC HOME', 'ABOUT NACC', and 'CONTACT US', along with a search box. A secondary navigation bar lists various resources: 'Researcher home', 'About NACC data', 'Interactive tools', 'Request NACC data', 'Forms & documentation', 'For researchers & authors', and 'More information'. A dropdown menu is open under 'Interactive tools', listing 'Demographics & diagnoses', 'Web-based query system', 'MRI query system', 'Detailed summary reports', and 'Locate tissue'. The 'Demographics & diagnoses' item is highlighted with a white box. Below the dropdown, there is a red warning message: 'This website in Internet Explorer, please be sure that you have IE's'. On the left side of the page, there is a section titled 'NEW at NACC' with a sub-section 'Query system' and the text 'A more powerful query system, now featuring:'. At the bottom of the page, there is a section titled 'FOR RESEARCHERS USING NACC DATA' and 'Information and resources'.

[https://www.alz.washington.edu/WEB/research\\_home](https://www.alz.washington.edu/WEB/research_home)



The NIA Alzheimer's Disease Centers Program

# National Alzheimer's Coordinating Center

RESEARCH | DATA | CONSULTATION | COLLABORATION

[NACC HOME](#) [ABOUT NACC](#) [CONTACT US](#)

SEARCH:

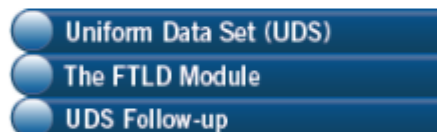
[Researcher home](#) [About NACC data](#) [Interactive tools](#) [Request NACC data](#) [Forms & documentation](#) [For researchers & authors](#) [More information](#)

[NACC Researcher Home](#) >> [Interactive tools & tables](#) >> [Demographics & diagnosis summaries](#)

## Demographics and diagnosis summaries

Use the links below to display tables summarizing the demographics and diagnoses data for NACC's research data sets. The tables are displayed in an easy-to-read, printable, one-page PDF format.

All data presented are as of the most recent data freeze at NACC.



To view more specialized frequency tables and cross-tabulations of NACC data, please explore the NACC web-based query system, or submit a data request:

- [Web-based query system](#)
- [Request a custom data file](#)
- [Request a custom data table](#)



NACC is funded by the National Institute on Aging (UO1 AG016976) and located in the Department of Epidemiology at the University of Washington School of Public Health, Walter A. Kukull, Ph.D., Director. Copyright© 2010 University of Washington.



Table 1. UDS subject demographics by cognitive status

	UDS subjects									
	Normal cognition		Impaired, not MCI		MCI		Dementia		All n	
	n	%	n	%	n	%	n	%		
<b>Age (y)</b>										
<65	2026	19%	257	19%	688	13%	2074	15%	5045	
65-84	6982	65%	911	68%	3510	67%	8656	63%	20059	
>=85	1660	16%	175	13%	1027	20%	2987	22%	5849	
Mean (SD)	73.2	(11.3)	73.0	(10.4)	75.8	(10.1)	76.0	(10.6)	74.9	
<b>Education (y)</b>										
<=12	2091	20%	408	30%	1551	30%	4982	36%	9032	
13-16	4532	42%	522	39%	2119	41%	5216	38%	12389	
>=17	3993	37%	409	30%	1525	29%	3391	25%	9318	
Missing	52	<1%	4	<1%	30	<1%	128	<1%	214	
<b>APOE ε4</b>										
No ε4 allele	5468	51%	652	49%	2066	40%	4475	33%	12661	
1 copy of ε4 allele	2070	19%	255	19%	1107	21%	3945	29%	7377	
2 copies of ε4 allele	200	2%	21	2%	185	4%	1026	7%	1432	
Missing or unknown or not assessed	2930	27%	415	31%	1867	36%	4271	31%	9483	
<b>Number of visits</b>										
1	2689	25%	417	31%	2036	39%	4838	35%	9980	
2	2021	19%	221	16%	1099	21%	2835	21%	6176	
>=3	5958	56%	705	52%	2090	40%	6044	44%	14797	
Mean (SD)	3.6	(2.4)	3.2	(2.1)	2.7	(2.0)	2.8	(1.9)	3.0	
<b>Total</b>	<b>10668</b>		<b>1343</b>		<b>5225</b>		<b>13717</b>		<b>30953</b>	

Data are from the most recent visit as of September 1, 2017.

For more information, visit <https://www.alz.washington.edu>

Table 2. Neuropathologic features <sup>1</sup>

	NP + UDS subjects	
	n	%
Thal phase for amyloid plaques <sup>2</sup>		
Phase 0	16	10%
Phase I-II	13	8%
Phase III	6	4%
Phase IV-V	105	68%
Missing or unknown or not assessed	14	9%
Not collected, previous form version	(3060)	

Normal cognition	336	10%
Impaired, not MCI	45	1%
MCI	266	8%
Dementia	2567	80%
<b>Total</b>	<b>3214</b>	

White matter rarefaction <sup>2</sup>	94	61%
Any Lewy body pathology	1003	31%
Any FTLD pathology	707	22%
<b>Total</b>	<b>3214</b>	

<sup>1</sup> Row data are not mutually exclusive

<sup>2</sup> Collected in NP Form version 10 only. Column percent calculated from total v10 NP forms (n=154)

<sup>1</sup> At last UDS visit prior to death

Data as of September 1, 2014

For more information, visit <https://www.alz.washington.edu>

# Web-based query system

The screenshot displays the NACC website interface. At the top, the NACC logo is followed by the text "The NIA Alzheimer's Disease Centers Program National Alzheimer's Coordinating Center". Below this, a navigation bar includes links for "RESEARCH | DATA | CONSULTATION | COLLABORATION" and "NACC HOME ABOUT NACC CONTACT US". A search bar is also present. The main content area features a sidebar on the left with sections for "NEW at NACC", "Query system", "Research structural MRI", and "Project using NACC data wins Hirano Award". The main content area has a "Web-based query system" section with a dropdown menu and a "Quick links" section with buttons for "Forms & documentation", "Description of the database", "Demographics & Dx summaries", and "Ongoing & completed research". A "Free consultation available" section is also present.

**NACC** The NIA Alzheimer's Disease Centers Program  
**National Alzheimer's Coordinating Center**  
RESEARCH | DATA | CONSULTATION | COLLABORATION  
NACC HOME ABOUT NACC CONTACT US SEARCH:

Researcher home About NACC data Interactive tools Request NACC data Forms & documentation For researchers & authors More information

NACC Researcher Home >>

## NEW at NACC

### Query system

A more powerful query system, now featuring:

- Cross-tabulations of UDS and NP data
- FTLD Module data
- User-friendly drop-down menus
- NACC derived variables

[Try it here ...](#)

### Research structural MRI

Image files now available for a subset of UDS subjects

[More details ...](#)

### Project using NACC data wins Hirano Award

A presentation featuring NACC data won the 2014 Hirano Award from the American Association of Neuropathologists

[Read more ...](#)

Demographics & diagnoses  
Web-based query system  
MRI query system  
Detailed summary reports  
Locale Issue

**Web-based query system**

## FOR RESEARCHERS USING NACC DATA

## Information and resources

The National Alzheimer's Coordinating Center (NACC), established in 1999, maintains a cumulative database including clinical evaluations, neuropathology data when available, and now MRI imaging. **NACC invites researchers throughout the AD community to take advantage of this valuable resource.**

The data are contributed by the 34 past and present Alzheimer's Disease Centers (ADCs) supported by the U.S. National Institute on Aging/NIH, where all enrolled subjects undergo a standardized evaluation. The clinic-based population includes subjects with Alzheimer's disease and related disorders, as well as cognitively normal subjects and those with MCI.

The NACC database comprises several standardized clinical and neuropathology data sets, all of which are freely available to the research community. **No password or account is required**, and no affiliation with the NIA Alzheimer's Disease Centers is needed.

### Quick links

Try these links for a quick look at NACC's resources. To explore the site in greater depth, use the drop-down menus above.

- Forms & documentation
- Description of the database
- Demographics & Dx summaries
- Ongoing & completed research

### Free consultation available

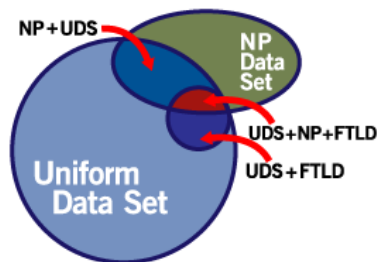
When you request NACC data, NACC research scientists can save you time, providing help with:

- *Checking a project's feasibility with NACC data*
- *Creating a custom file for data analysis*
- *Specifying variables*
- *Statistical methods*
- *Data analysis*

Email NACC for more information.

## Web-based query system

With NACC's direct query system, you can create frequency tables of data from the Uniform Data Set, the Neuropathology Data Set, and the FTLD Module. 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 as rough, preliminary numbers; for publication purposes, a more detailed data request is required.



This diagram illustrates the relationships among the Uniform Data Set (UDS), NP Data Set, and FTLD Module, as well as the relative numbers of subjects. Not shown: the Minimum Data Set (MDS).

Many data elements used in NACC's direct query system are derived or calculated variables that describe a combination of data elements taken directly from the UDS forms (e.g., "Age at initial visit" is derived from the subject's birth year and month and the date of the initial UDS visit).

*NOTE: Data collected using version 10 of the Neuropathology Form will be available soon. NP data sample size may be underestimated.*

There are three steps to creating a frequency table: first, choose the subjects you want to include; next, select the variable(s) you want to see for those subjects; finally, choose the type of output you want (web or PDF).

### Step 1: Select the subject inclusion criteria:

**OPTION A — Use a subset of the UDS:** In the columns below, choose one to three criteria, specifying the relationship between them as "AND" or "OR" (choose "N/A" if you don't want to apply any criterion for a particular column).

Please note that when three criteria are selected using a combination of AND and OR, the criteria are applied to the data in the following order:

**Scenario 1:** [Criterion 1 OR (Criterion 2 AND Criterion 3)]

**Scenario 2:** [(Criterion 1 AND Criterion 2) OR Criterion 3]

**OPTION B — Use all of the UDS:** If you don't want to focus on a specific sub-population (e.g., <65-year-olds), click "Next" to go directly to Step 2; in this case, your table will include all UDS subjects.

<b>CRITERION #1</b>	<input type="radio"/> and	<b>CRITERION #2</b>	<input type="radio"/> and	<b>CRITERION #3</b>
<input checked="" type="radio"/> INCLUDE ALL UDS SUBJECTS (no criteria)	<input type="radio"/> or	<input checked="" type="radio"/> INCLUDE ALL UDS SUBJECTS (no criteria)	<input type="radio"/> or	<input checked="" type="radio"/> INCLUDE ALL UDS SUBJECTS (no criteria)
	<input checked="" type="radio"/> n/a		<input checked="" type="radio"/> n/a	



# Step 1: Select subject inclusion criteria

**OPTION B — Use all of the UDS:** If you don't want to focus on a specific sub-population (e.g., <65-year-olds), click "Next" to go directly to Step 2; in this case, your table will include all UDS subjects.

## CRITERION #1

INCLUDE ALL UDS SUBJECTS  
(no criteria)

– OR – choose from options below:

AGE OF PARTICIPANT

COGNITIVE STATUS

AGE OF ONSET of cognitive decline

SEX

RACE

HISPANIC ETHNICITY

NUMBER OF VISITS

APOE (number of E4 alleles)

GENOTYPE AVAILABLE AT ADGC

FTLD MODULE DATA AVAILABLE

NP DATA AVAILABLE

and  
 or  
 n/a

## CRITERION #2

INCLUDE ALL UDS SUBJECTS  
(no criteria)

– OR – choose from options below:

AGE OF PARTICIPANT

COGNITIVE STATUS

AGE OF ONSET of cognitive decline

SEX

RACE

HISPANIC ETHNICITY

NUMBER OF VISITS

APOE (number of E4 alleles)

GENOTYPE AVAILABLE AT ADGC

FTLD MODULE DATA AVAILABLE

NP DATA AVAILABLE

and  
 or  
 n/a

## CRITERION #3

INCLUDE ALL UDS SUBJECTS  
(no criteria)

– OR – choose from options below:

AGE OF PARTICIPANT

COGNITIVE STATUS

AGE OF ONSET of cognitive decline

SEX

RACE

HISPANIC ETHNICITY

NUMBER OF VISITS

APOE (number of E4 alleles)

GENOTYPE AVAILABLE AT ADGC

FTLD MODULE DATA AVAILABLE

NP DATA AVAILABLE

NEXT >>>

# Step 2: Select row and column variables

Select the visit for the row and column data (if applicable). Indicate whether the table should use data from the subjects initial clinic visit or their most recent visit. You must select a visit from which to output data for data not designated as CS\*. Longitudinal variables selected to cross-tabulate with FTLD Module variables will default to the associated UDS+FTLD Module visit.

\*CS = Cross-sectional (e.g., "Education" or "Age of onset of cognitive decline"): data values are the same for all visits.

<p><b>ROW VARIABLE</b></p> <p><input checked="" type="radio"/> NO ROW VARIABLE</p> <p>SUBJECT DEMOGRAPHICS AND VISIT CHARACTERISTICS REPORTED SUBJECT HEALTH HISTORY / FAMILY HISTORY ASSESSMENTS, EXAMS, AND EVALUATIONS CLINICIAN DIAGNOSIS AND COGNITIVE STATUS GENETICS AND BIOMARKERS NEUROPATHOLOGY FTLD MODULE</p> <p><b>VISIT FOR ROW DATA</b></p> <p><input checked="" type="radio"/> N/A (Chosen data element is cross-sectional) <input type="radio"/> INITIAL VISIT <input type="radio"/> MOST RECENT VISIT</p>	<p>by</p>	<p><b>COLUMN VARIABLE</b></p> <p><input checked="" type="radio"/> NO COLUMN VARIABLE</p> <p>SUBJECT DEMOGRAPHICS AND VISIT CHARACTERISTICS REPORTED SUBJECT HEALTH HISTORY / FAMILY HISTORY ASSESSMENTS, EXAMS, AND EVALUATIONS CLINICIAN DIAGNOSIS AND COGNITIVE STATUS GENETICS AND BIOMARKERS NEUROPATHOLOGY FTLD MODULE</p> <p><b>VISIT FOR COLUMN DATA</b></p> <p><input checked="" type="radio"/> N/A (Chosen data element is cross-sectional) <input type="radio"/> INITIAL VISIT <input type="radio"/> MOST RECENT VISIT</p>
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Next >>>

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# Web-based query table output

NACC Query System: UDS Subjects

APOE genotype (ROW) by Cognitive status at UDS visit (COLUMN)

UDS Subjects Selected by number of visits >= 3 and NP data available

	Cognitive status at UDS visit				All
	Normal cognition	Impaired not MCI	MCI	Dementia	
APOE genotype					
e3,e3	103	12	73	434	622
e3,e4	20	7	24	334	385
e3,e2	34	0	16	55	105
e4,e4	1	0	2	97	100
e4,e2	3	0	2	24	29
e2,e2	1	0	0	1	2
Missing or unknown or not assessed	17	3	12	138	170
All	179	22	129	1083	1413

Row data from NACC derived variable [NACCAPOE](#)

Column data from NACC derived variable [NACCUDSD](#), most recent visit data

Created on October 1, 2014

Data as of September 1, 2014

[www.alz.washington.edu](http://www.alz.washington.edu)

New Query>>>

# MRI query system

## Step 1: Select MRI inclusion criteria

**CRITERION #1**

INCLUDE ALL MRIs  
(no criteria)

and  
 or  
 n/a

– OR – choose from options below:

SCAN TYPE

MAGNETIC FIELD STRENGTH

MANUFACTURER

MRI DURING UDS FOLLOW-UP

**CRITERION #2**

INCLUDE ALL MRIs  
(no criteria)

and  
 or  
 n/a

– OR – choose from options below:

SCAN TYPE

MAGNETIC FIELD STRENGTH

MANUFACTURER

MRI DURING UDS FOLLOW-UP

**CRITERION #3**

INCLUDE ALL MRIs  
(no criteria)

– OR – choose from options below:

SCAN TYPE

MAGNETIC FIELD STRENGTH

MANUFACTURER

MRI DURING UDS FOLLOW-UP

NEXT >>>

# MRI query system

## Step 2: Select subject inclusion criteria

### CRITERION 4

No criteria/All UDS subjects  
Clinician diagnosis and cognitive status  
CDR Global Score  
Age at MRI  
Sex(CS)  
Race(CS)  
APOE (number of E4 alleles)(CS)  
ADGC data available (CS)  
FTLD Module data available(CS)  
NP data available (CS)

n/a  
 and  
 or

### CRITERION 5

No criteria/All UDS subjects  
Clinician diagnosis and cognitive status  
CDR Global Score  
Age at MRI  
Sex(CS)  
Race(CS)  
APOE (number of E4 alleles)(CS)  
ADGC data available (CS)  
FTLD Module data available(CS)  
NP data available (CS)

n/a  
 and  
 or

### CRITERION 6

No criteria/All UDS subjects  
Clinician diagnosis and cognitive status  
CDR Global Score  
Age at MRI  
Sex(CS)  
Race(CS)  
APOE (number of E4 alleles)(CS)  
ADGC data available (CS)  
FTLD Module data available(CS)  
NP data available (CS)

Next >>>

# MRI query output

Structural MRIs for UDS subjects

## NACC MRI query results

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### YOUR CRITERIA

In your query of 10/2/2014, you requested all available image files for:

MRIs selected by: MRI Type of T1 and

UDS subjects selected by: ADGC data available

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### YOUR TOTALS

Total MRI files at NACC..... 1720

Total MRI files meeting your query criteria..... 302

Unique UDS subject IDs with MRI files meeting criteria..... 187

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### YOUR DOWNLOAD

Following is a sample of MRI files meeting your criteria:

Obs	NACC Subject ID	MRI Date	Download MRI (.zip files)
1	NACC001959	02/19/2009	<a href="#">Click Here to Download MRI</a>
2	NACC002865	11/10/2005	<a href="#">Click Here to Download MRI</a>
3	NACC005166	05/10/2010	<a href="#">Click Here to Download MRI</a>
4	NACC005230	02/08/2011	<a href="#">Click Here to Download MRI</a>
5	NACC010525	02/24/2009	<a href="#">Click Here to Download MRI</a>
6	NACC016412	07/24/2007	<a href="#">Click Here to Download MRI</a>
7	NACC018587	06/25/2009	<a href="#">Click Here to Download MRI</a>
8	NACC019731	06/04/2012	<a href="#">Click Here to Download MRI</a>
9	NACC020811	03/18/2010	<a href="#">Click Here to Download MRI</a>
10	NACC032872	03/05/2009	<a href="#">Click Here to Download MRI</a>

To obtain all the image files meeting your criteria, please submit a data request.

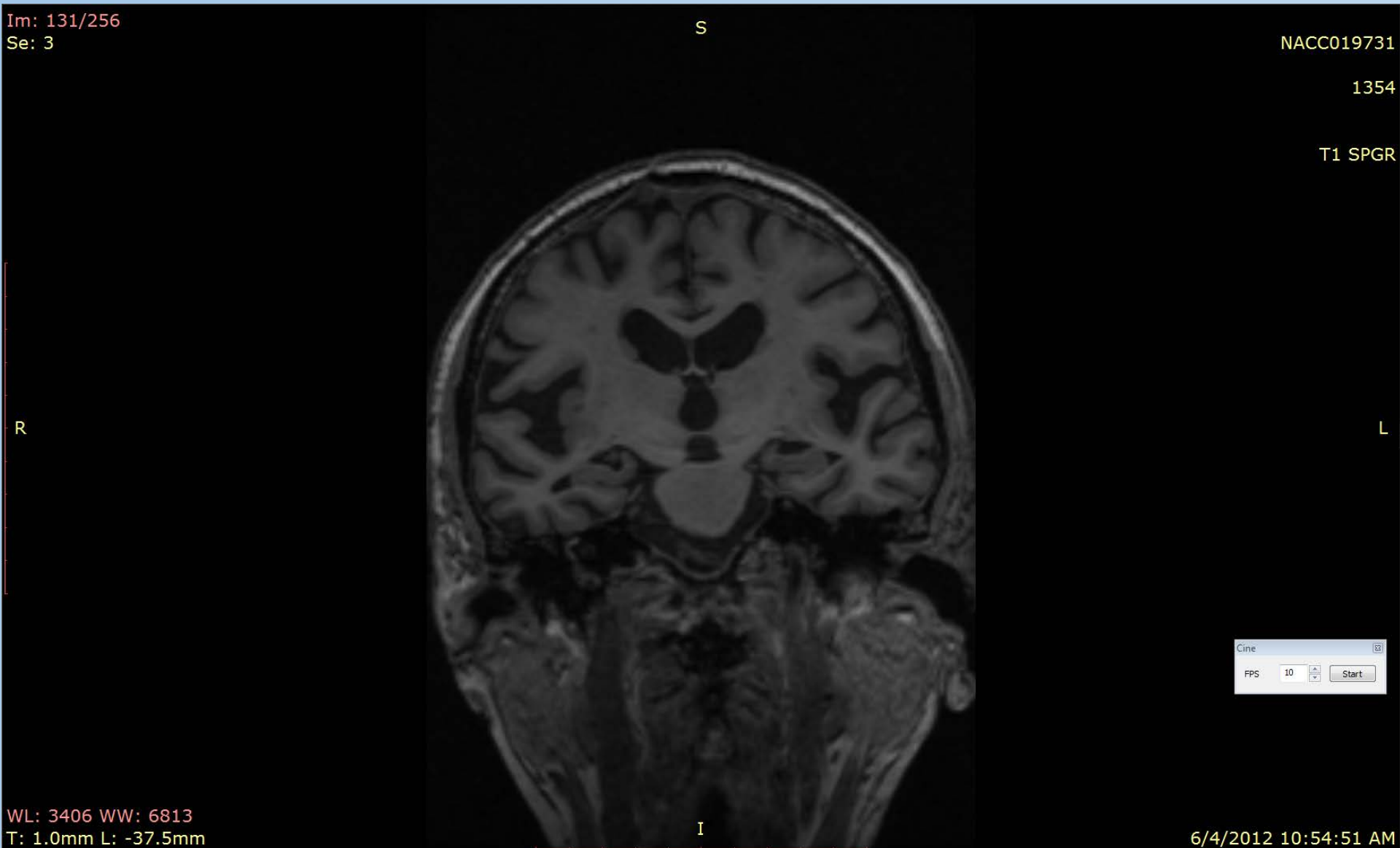
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### OBTAIN THE SOFTWARE NEEDED TO VIEW YOUR DOWNLOAD

Visualization software is required to view DICOM MRIs. Many software packages are available on the web as freeware or free trials and can be located by doing a web search for "DICOM viewer".



# MRI query – sample MRI



# Conclusion

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- New tools available on Researcher's side of NACC website

[https://www.alz.washington.edu/WEB/researcher\\_home.html](https://www.alz.washington.edu/WEB/researcher_home.html)

- Work in progress for query system
  - adding Neuropathology Form v10 data

- Feedback and questions

[naccmail@uw.edu](mailto:naccmail@uw.edu) (NACC)

[kbristow@uw.edu](mailto:kbristow@uw.edu) (Kate)

206-616-0254

- Many thanks to Mark Bollenbeck and Duane Beekly





Thank you