



The NACC report

16 Mar 2013

ADC Directors Meeting

San Diego, CA

Special initiatives

Study	Number of subjects completed	Number of participating Centers
LP survey: Patient experience		
Initial	212	16
Follow-up	140	
FTLD Module*		
In current (freeze) database	96	10
In working database only	45	13

***In addition to these packets from the ADCs, the current database has 13 FTLD packets from the University of Pennsylvania FTLD Center. The UPenn FTLD Center has 4 packets in the working database only.**

Research structural MRI submission system

BIDSS

NACC Biospecimen and Imaging Data Submission System

Research Structural MRI Data Submission System

MRI Home

UPLOAD and PRE-PROCESS FILES

- Quantitative Data
- De-identify Images
- Upload DICOM Image Files
- View Batch Processing Log

WEB DATA ENTRY

ERROR CHECK

FINALIZE DATA

REPORTS

DOWNLOAD DATA

FORMS AND DOCUMENTATION

Sample Center

Welcome to the Research Structural MRI Data Submission System

NACC's structural MRI data submission system is designed to capture and store the following data on UDS Clinical Core subjects:

- Quantitative measures from structural MRI, when available
- DICOM images, when available

Quantitative data may be entered into the system without associated DICOM files, and DICOM images may be uploaded to NACC without associated quantitative data. When both are available, MRI data and DICOM images are linked using subject ID and MRI acquisition date.

Please refer to the "FORMS AND DOCUMENTATION" menu on the left for help in navigating the system and uploading data. For more assistance, contact NACC at NACCmail@uw.edu, or (206) 543-8637.

Data Submission Timing

Submitting MRI data and DICOM files is optional for Centers but highly encouraged. We ask that all data available on UDS subjects be uploaded initially and that subsequent scan sessions be uploaded at least semiannually.

Viewing DICOM Images

Visualization software is required in order 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".

NACC database

Clinical data available	NP data records	Total subjects
MDS* only	10,752	66,127
UDS** (any)	2,406	27,776
Total	13,158	93,903

Numbers as of the March 1, 2013 data archive

***MDS reflects ADC enrollment 1984 – 2005**

****UDS reflects ADC enrollment September 2005 – present**

Note: Some subjects who began in MDS were brought into UDS if they were active and met the ADC's inclusion criteria.

MDS content

- Demographics
- Clinical Dx
- First/Last MMSE
- Neuropathologic Dx (abstracted from report)

- Data elements mapped from different primary data at ADCs, retrospective
- More detailed data must be requested from individual Centers
- Limited research capability

UDS content

- Primary data collection of Clinical Evaluation
 - Testing, examination, evaluation
- Annual follow-up
- Directly usable by researchers
- Links to prospective Neuropathology data

UDS demographics

Characteristic		Data set	Deaths	Autopsy
		UDS (any)	Milestone	NP data
Sex	Male	11,898	2,462	1,333
	Female	15,878	2,116	1,073
Primary race	White	22,440	4,027	2,274
	Black	3,858	412	87
	American Indian or Alaska Native	184	10	2
	Native Hawaiian or other Pacific Islander	17	5	2
	Asian	608	51	21
	Other	548	52	9
	Unknown	121	21	11
	Hispanic	2,157 (7.8%)	207 (4.5%)	88 (3.7%)
Total		27,776	4,578	2,406

Numbers as of the March 1, 2013 data archive

Cognitive status

Clinical category		UDS (any)		Deaths	Neuropath	
Not impaired		9,565	(34%)	561	254	(11%)
MCI or other impaired	Amnestic	3,816	(14%)	380	155	(6%)
	Non-amnestic	1,009	(4%)	105	52	(2%)
	Not MCI	1,201	(4%)	86	33	(1%)
Demented		12,185	(44%)	3,446	1,912	(80%)
Total		27,776		4,578	2,406	

Numbers as of the March 1, 2013 data archive

Primary clinical diagnosis for dementia

Clinical diagnosis	UDS (any)	Deaths	NP
Alzheimer's disease*	9,223	2,355	1,260
Vascular dementia	296	91	48
Dementia with Lewy bodies	633	301	168
Parkinson's disease	178	71	36
FTLD**	1,382	469	303
Other dementia	473	159	97
Total	12,185	3,446	1,912

Numbers as of the March 1, 2013 data archive

*includes probable and possible Alzheimer's

** FTLD includes bvFTD, SD, PPA, CBD, PSP, Picks, and other write-ins indicating a primary FTD diagnosis



Primary clinical diagnosis judged to be the cause of MCI

Clinical diagnosis	UDS (any)	Deaths	NP
Alzheimer's disease*	2,411	188	85
Vascular dementia	291	35	13
Dementia with Lewy bodies	78	9	5
Parkinson's disease	185	21	6
FTLD**	132	22	11
Other	881	71	26
Missing	847	139	61
Total	4,825	485	207

Numbers as of the March 1, 2013 data archive

*includes probable and possible Alzheimer's

** FTLD includes bvFTD, SD, PPA, CBD, PSP, Picks, and other write-ins indicating FTLD as suspected cause of MCI

Primary clinical diagnosis of FTLD for dementia

Clinical diagnosis	UDS (any)	Deaths	NP
FTD (behav/exec)	694	243	164
PPA	436	99	62
PSP	93	49	28
CBD	143	70	46
Other FTLD*	16	8	3
Total	1,382	469	303

Numbers as of the March 1, 2013 data archive

* Other FTLD includes write-ins of ALS, MSTD, and MND

Performance on UDS enrollment and follow-up

UDS visit	Eligible	Completed	Percent of eligible
Initial visit	n/a	24,550	n/a
Follow-up: #1	16,662	13,585	82%
#2	12,646	10,237	81%
#3	9,532	7,686	81%
#4	7,230	5,823	81%
#5	5,153	4,095	79%
#6	2,919	2,171	74%

Numbers as of the March 1, 2013 data archive

Note: Report uses active Centers only.

The answers we seek may be in more detailed comparison of biomarker positive and negative preclinical cases, not extensive effort on late progression cases

