



# *The semi-annual* NACC update

The ADC Directors Meeting

(sunny) Philadelphia, PA

26 April 2014

# The NACC database: total subjects

Clinical data available	NP data records avail.	Total subjects
Subjects in MDS* only	10,909	66,094
Subjects in UDS**	3,036	29,913
<b>Total</b>	<b>13,945</b>	<b>96,007</b>

Numbers as of the March 1, 2014 data archive

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

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

*Note: Subjects in the MDS were brought into the UDS if they were active and met the ADC's inclusion criteria. As a result, some subjects are in both the MDS and the UDS.*

# UDS demographics

		Data set	Deaths	Autopsy
Characteristic		UDS*	Milestone Form submitted	NP Form submitted
<b>Sex</b>	Male	12,885	2,894	1,657
	Female	17,028	2,498	1,379
<b>Primary race</b>	Caucasian	23,904	4,693	2,823
	African American	3,696	450	110
	American Indian or Alaska Native	137	6	2
	Native Hawaiian or other Pacific Islander	15	5	3
	Asian	663	62	26
	Multiracial	982	104	46
	Unknown	516	72	26
	Hispanic	2,339 (7.8%)	240 (4.5%)	114 (3.8%)
<b>Total</b>		<b>29,913</b>	<b>5,392</b>	<b>3,036</b>

Numbers as of the March 1, 2014 data archive

\*includes UDS subjects who are also in the MDS

## UDS SUBJECTS

# Gross Cognitive status AT MOST RECENT VISIT

Clinical category		UDS*		Deaths	NP data available	
Not impaired		10,305	(35%)	662	322	(11%)
MCI or other impaired	Amnestic	3,993	(13%)	442	193	(6%)
	Non-amnestic	1,096	(4%)	119	64	(2%)
	Not MCI	1,298	(4%)	99	43	(1%)
Demented		13,221	(44%)	4,070	2,414	(80%)
<b>Total</b>		<b>29,913</b>		<b>5,392</b>	<b>3,036</b>	

Numbers as of the March 1, 2014 data archive

\*includes some UDS subjects who were initially reported in the MDS

## UDS SUBJECTS

# Primary clinical diagnosis for dementia

AT MOST RECENT VISIT

Clinical diagnosis	UDS*	Deaths	NP data available
Alzheimer's disease**	9,977	2,780	1,600
Vascular dementia**	314	104	51
Dementia with Lewy bodies	689	345	206
Parkinson's disease	185	73	40
FTLD***	1,534	578	397
Other dementia	522	190	120
<b>Total</b>	<b>13,221</b>	<b>4,070</b>	<b>2,414</b>

Numbers as of the March 1, 2014 data archive

\*\*includes Probable and Possible

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

## UDS SUBJECTS

Primary clinical diagnosis for MCI AT MOST  
RECENT VISIT

Clinical diagnosis	UDS*	Deaths	NP data available
Alzheimer's disease**	2,540	235	113
Vascular dementia**	324	39	18
Dementia with Lewy bodies	88	10	6
Parkinson's disease	193	27	10
FTLD***	147	29	16
Other	994	82	31
<b>Missing</b>	<b>803</b>	<b>139</b>	<b>63</b>
<b>Total</b>	<b>5,089</b>	<b>561</b>	<b>257</b>

Numbers as of the March 1, 2014 data archive

\*\*includes Probable and Possible

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

## UDS SUBJECTS

# Primary clinical diagnosis of FTLD for dementia AT MOST RECENT VISIT

Clinical diagnosis	UDS*	Deaths	NP data available
bvFTD	754	289	206
PPA	505	134	88
PSP	101	62	43
CBD	159	84	57
Other FTLD**	15	9	3
<b>Total</b>	<b>1,534</b>	<b>578</b>	<b>397</b>

Numbers as of the March 1, 2014 data archive

\*includes UDS subjects who are also in the MDS

\*\*includes write-ins of ALS, MND and others

## UDS SUBJECTS

### ADC performance on enrollment and follow-up

UDS visit	Eligible subjects	Completed	Percent of eligible subjects
Initial visit	n/a	26,679	n/a
Follow-up: #1	18,545	15,218	82%
#2	14,119	11,497	81%
#3	10,856	8,742	81%
#4	8,236	6,619	80%
#5	6,303	5,065	80%
#6	4,430	3,446	78%
#7	2,559	1,814	71%
#8	262	252	96%

Numbers as of the March 1, 2014 data archive

**Note: Report uses active Centers only.**





# Special initiatives:

Note: Dr. Moulder will present LP results at Clinical Core Leaders meeting and Dr. Knopman will discuss FTLD module enrollment

Study	Number of subjects completed	Number of participating Centers
<b>LP survey: Patient experience</b>		
Initial	592	18
Follow-up	437	
<b>FTLD Module*</b>		
In current (freeze) database	442	17
In working database only	52	9

Numbers as of the March 1, 2014 data archive

\*In addition to these packets from the ADCs, the current database has 44 FTLD packets from the University of Pennsylvania FTLD Center. The UPenn FTLD Center also has 8 packets in the working database only.

# “Crosswalk” Study:

Sandy Weintraub and Sarah Monsell will present detailed discussion at Clinical Core Leaders meeting.

- Excellent correlations were achieved for all tests.
- 879 subjects from 24 Centers
- 100 initial visit subjects from 16 Centers
- 136 African American subjects, 24 Asian, 1 American Native, 27 mixed race
- Thanks to all participating ADCs, CTF and the Neuropsychology work group!

## RESEARCH STRUCTURAL MRI

# Scans by number and type

Dr. DeCarli will discuss at Clinical Core mtg

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Scans per subject	Subjects with each scan type (n)			
	T1	T2	Flair	DTI
1	762	321	731	626
2	206	0	211	168
3+	140	0	151	152
<b>Total</b>	<b>1,108</b>	<b>321</b>	<b>1,123</b>	<b>946</b>

**1136 unique subjects as of March 1, 2014 from 5 ADC's**

(more have been received very recently not included here)

**Eight additional ADC are preparing to send images**

**We are requesting UDS Subjects only. C'mon join the fun!**

# UDS 3 is coming!

Dr Morris will provide details later...



**H. Clinton dodging thrown shoes after announcing UDS 3.**

Photo courtesy of Dr. Galasko

I just can't help it, I love UDS 3...  
Please, hold your shoes!

