

The Abbreviated NACC update

The ADC Directors Meeting

Baltimore, MD

11 October 2014

Announcements

- UDS 3: Thank you all for your comments.
 - Dr Morris reports the details
 - February 1, 2015: begin clinical use for all subjects
 - Info at NACC meeting this afternoon
- MRI's are available
 - It's easy to submit and lots of fun!
 - See query system at NACC meeting
- NACC lives on! Rejoice!
 - FOA (from NACC) for Collaborative and Jr Investigator projects in your meeting folder

Attention ADC Statisticians and methodologists

- There will be a brief meeting to discuss reviving “Alzheimer Centers statistical methods conference”
 - immediately following the Data Core meeting this afternoon (~5:00pm)
- Conference last held in about 2002 in Lexington, KY

The NACC database: total subjects

Clinical data available	NP data records avail.	Total subjects
Subjects in MDS* only	10,934	66,074
Subjects in UDS**	3,214	30,953
Total	14,148	97,027

Numbers as of the September 1, 2014 data freeze

***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
Sex	Male	13,342	3,074	1,750
	Female	17,611	2,673	1,464
Primary race	White	24,708	5,010	2,988
	African American	3,835	471	116
	American Indian or Alaska Native	146	6	2
	Native Hawaiian or other Pacific Islander	16	5	3
	Asian	701	64	28
	Multiracial	1,017	114	50
	Unknown	530	77	27
Ethnicity	Hispanic	2,408 (7.8%)	265 (4.6%)	122 (3.8%)
Total		30,953	5,747	3,214

Numbers as of the September 1, 2014 data freeze

UDS SUBJECTS

Cognitive status AT MOST RECENT VISIT

Clinical category		UDS*		Deaths	NP data available	
Not impaired		10,668	(35%)	707	336	(11%)
MCI or other impaired	Amnestic	4,097	(13%)	463	200	(6%)
	Non-amnestic	1,128	(4%)	125	66	(2%)
	Not MCI	1,343	(4%)	104	45	(1%)
Demented		13,717	(44%)	4,348	2,567	(80%)
Total		30,953		5,747	3,214	

Numbers as of the September 1, 2014 data freeze

*includes UDS subjects who are also in the MDS

UDS SUBJECTS

Primary clinical diagnosis for dementia

AT MOST RECENT VISIT

Clinical diagnosis	UDS*	Deaths	NP data available
Alzheimer's disease**	10,322	2,962	1,697
Vascular dementia**	327	111	57
Dementia with Lewy bodies	706	357	210
Parkinson's disease	184	75	42
FTLD***	1,632	633	427
Other dementia	546	210	134
Total	13,717	4,348	2,567

Numbers as of the September 1, 2014 data freeze

* includes UDS subjects who are also in the MDS

**includes probable and possible

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



Special initiatives

Study	Number of subjects completed	Number of participating Centers
LP survey: Patient experience		
Initial	606	18
Follow-up	445	
FTLD Module*		
In current (freeze) database	640	17
In working database only	175	10

Numbers as of the September 1, 2014 data freeze

*Totals include 61 FTLD packets in the current (freeze) database and 5 FTLD packets working database from non-ADCs.