



NACC News and Views

ADC Directors Meeting
Washington DC
18 April 2015

Thanks to ADC Clinical Task Force (2002 – 2015)

John Morris, Chair

Charles DeCarli
Norman Foster
Neill Graff-Radford
Elaine Peskind
Sandra Weintraub
Steven Ferris
Jeffrey Cummings
Helena Chui
Douglas Galasko
Dan Mungas

David Salmon
Richard Mayeux
David Knopman (FTLD)
Joe Hesse
Greg Jicha
Steven Arnold
Joseph Quinn
Jeff Burns
Robert Sweet
Cynthia Carlsson

...and Tony Phelps, Nina Silverberg, Neil Buckholtz, and others at NIA

...and all Subcommittee and Work Group members



For the Clinical Task Force...



UDS ver. 3 and FTLD Module

Began 15 March 2015

- Unflagging dedication by CTF members
- Hard work by each ADC
- Blood, sweat and tears by NACC Staff
 - Especially Lilah Besser, Duane Beekly and Elizabeth Robichaud, in constructing the 879 preliminary drafts of UDS 3
- ADCs are already submitting data!
- Small “corrections” are addressed quickly and revisions posted on NACC web
- Larger conceptual and construct issues raised by ADCs will be collected and saved for the *next* CTF !

E-Five for the rest of us...



The NACC database: Are we “Big Data” yet?

Clinical data available	NP data records avail.	Total subjects
Subjects in MDS* only	10,954	66,064
Subjects in UDS**	3,532	31,872
Total	14,486	97,936

Numbers as of the March 1, 2015 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	13,737	3,303	1,930
	Female	18,135	2,836	1,602
Primary race	White	25,415	5,358	3,284
	African American	3,971	504	128
	American Indian or Alaska Native	163	6	2
	Native Hawaiian or other Pacific Islander	17	5	3
	Asian	722	67	28
	Multiracial	1,045	121	58
	Unknown	539	78	29
Ethnicity	Hispanic	2,459 (7.7%)	281 (4.6%)	135 (3.8%)
Total		31,872	6,139	3,532

Numbers as of the March 1, 2015 data freeze

*includes UDS subjects who are also in the MDS

UDS SUBJECTS

Cognitive status AT MOST RECENT VISIT (1-9visits)

Clinical category		UDS*		Deaths	NP data available	
Not impaired		11,109	(35%)	763	379	(11%)
MCI or other impaired	Amnestic	4,135	(13%)	483	223	(6%)
	Non-amnestic	1,144	(4%)	134	74	(2%)
	Not MCI	1,392	(4%)	113	50	(1%)
Demented		14,092	(44%)	4,646	2,806	(80%)
Total		31,872		6,139	3,532	

Numbers as of the March 1, 2015 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**	10,585	3,175	1,861
Vascular dementia**	337	117	60
Dementia with Lewy bodies	724	377	223
Parkinson's disease	187	75	42
FTLD***	1,695	687	477
Other dementia	564	215	143
Total	14,092	4,646	2,806

Numbers as of the March 1, 2015 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 – MRI

	Number	Centers participating
MRI scans, total*	7,195	7 (2 more in process)
T1	2,441	
Flair	1,961	
DTI	1,960	
Unique subjects with MRI files, total	1,567	
Volume data (~20 measures)	589	
Longitudinal MRI files	424	

Numbers as of April 10, 2015 in the current database

* N = 833 MRI scans of other type (e.g., T2, DWI)

Special initiatives – CSF and FTLD Module

	Number	Centers participating
CSF data values		
CSF A β	447	1
CSF P-tau	447	
CSF T-tau	447	
FTLD Module		
In current (freeze) database	749	19
In working database only	233	13

Numbers as of March 1, 2015 data freeze