

# NACC Neuropathology Progress Report

Neuropathology Core Leaders Meeting

Baltimore, MD

10 October 2014

# Announcements

- The Neuropathology Data Form v.10 has been implemented and is working well
- Thank you to the NP Core leaders and committees for the essential effort to create the forms!
- Researchers' Data Element Dictionary
- Many great papers have been published
- NACC funding continues through 06/2019
  - Collaborate, create, compose!

# The Researcher's Data Dictionary — Neuropathology Data Set (RDD-NP)

- **The Researcher's Data Dictionary — Neuropathology Data Set (RDD-NP)** is intended to be the first and primary resource for researchers analyzing NACC neuropathology data.
- The original data-collection instruments (Coding Guidebooks and Forms) for all past and current NP form versions are referenced in the RDD-NP and are available on the NACC website: [www.alz.washington.edu/WEB/forms\\_np.html](http://www.alz.washington.edu/WEB/forms_np.html).
- **The goal of the RDD-NP** is to provide a comprehensive document describing the data elements available to researchers for analysis of the neuropathology data collected using versions 1, 7, 8, 9, and 10 of the NP Form.

# 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
<b>Total</b>	<b>14,148</b>	<b>97,027</b>

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.*

# MDS demographics

Characteristic		DATA SET	
		MDS (only)*	NP
<b>Sex</b>	Male	26,446	5,233
	Female	39,628	5,701
<b>Primary race</b>	Caucasian	54,300	10,326
	African American	6,751	306
	Asian/Pacific Islander	1,005	47
	Other/missing	4,018	255
<b>Ethnicity</b>	Hispanic	3,715 (5.6%)	183 (1.7%)
<b>Total</b>		<b>66,074</b>	<b>10,934</b>

Numbers as of the September 1, 2014 data freeze

\*not included are those MDS subjects who are also in the UDS

# UDS demographics

		Data set	Deaths	Autopsy
Characteristic		UDS*	Milestone Form submitted	NP Form submitted
<b>Sex</b>	Male	13,342	3,074	1,750
	Female	17,611	2,673	1,464
<b>Primary race</b>	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
<b>Ethnicity</b>	Hispanic	2,408 (7.8%)	265 (4.6%)	122 (3.8%)
<b>Total</b>		<b>30,953</b>	<b>5,747</b>	<b>3,214</b>

Numbers as of the September 1, 2014 data freeze

\*includes UDS subjects who are also in the MDS

## 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%)
<b>Total</b>		<b>30,953</b>		<b>5,747</b>	<b>3,214</b>	

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
<b>Total</b>	<b>13,717</b>	<b>4,348</b>	<b>2,567</b>

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





## UDS SUBJECTS

Primary clinical diagnosis for MCI AT MOST  
RECENT VISIT

Clinical diagnosis	UDS*	Deaths	NP data available
Alzheimer's disease**	2,606	246	118
Vascular dementia**	338	46	20
Dementia with Lewy bodies	95	11	6
Parkinson's disease	199	28	10
FTLD***	163	29	16
Other	1,021	88	33
<b>Missing</b>	<b>803</b>	<b>140</b>	<b>63</b>
<b>Total</b>	<b>5,225</b>	<b>588</b>	<b>266</b>

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 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
FTD (behav/exec)	806	310	218
PPA	541	158	98
PSP	107	68	48
CBD	162	88	60
Other FTLD**	16	9	3
<b>Total</b>	<b>1,632</b>	<b>633</b>	<b>427</b>

Numbers as of the September 1, 2014 data freeze

\*includes UDS subjects who are also in the MDS

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

# Motivational sign

