NACC update

ADC Directors Meeting.
April 2017

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The NACC database: total subjects

Clinical data available	NP data records avail.	Total subjects
Subjects in MDS* only	11,057	66,036
Subjects in UDS**	4,563	35,183
Total	**15,620**	**101,219**

Numbers as of the March 1, 2017 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.

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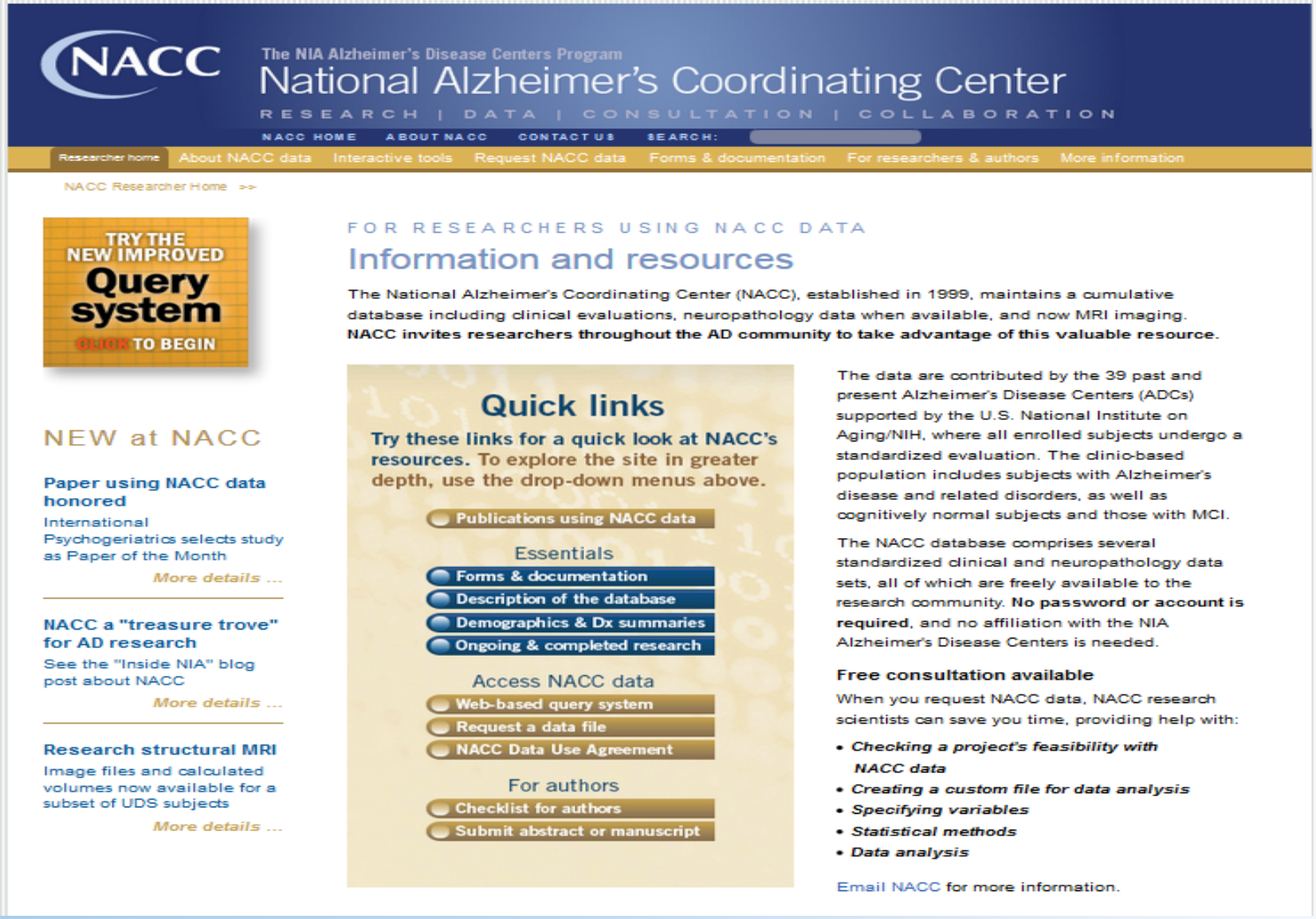

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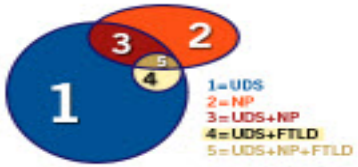
WEB-BASED

Query system



This diagram illustrates the relationships among the Uniform Data Set (UDS), NP Data Set, and FTLD Module, as well as the relative numbers of subjects. Not shown: the Minimum Data Set (MDS).

With NACC's query system, you can determine quickly whether NACC is likely to have subjects you're looking for in numbers sufficient to address your research question. (Also, some research questions about available data can be answered quickly by NACC's data summary tables.) Please note that query results should be used only as rough, preliminary numbers. **For publication purposes, please make a** custom data request.

Many data elements used in NACC's direct query system are derived or calculated variables that describe a combination of data elements taken directly from the UDS forms (e.g., "Age at initial visit" is derived from the subject's birth year and month and the date of the initial UDS visit). The guide to the query system describes the sources for those data elements.

PLEASE MAKE YOUR SELECTIONS from the table below. Note that some variables are available only as a row option or only as row and column. After making your selections, click "SUBMIT" to continue.

SUBMIT RESET

+ Subject's follow-up characteristics			
+ Subject demographics			
Available as:	ROW	COLUMN	PAGE
Age, initial visit	○	○	
Age, most recent visit	○	○	
Sex	○	○	○
Race	○	○	
Hispanic ethnicity	○	○	○
Primary language	○	○	
Years of Education	○	○	○
+ Clinical Dementia Rating (CDR)			
Available as:	ROW	COLUMN	PAGE
Global CDR, initial visit	○	○	
Global CDR, most recent visit	○	○	
CDR – Behavior, comportment, and personality, initial visit	○	○	
CDR – Behavior, comportment, and personality, most recent visit	○	○	
CDR – Language, initial visit	○	○	
CDR – Language, most recent visit	○	○	
+ Cognitive status			
Available as:	ROW	COLUMN	PAGE
Cognitive status, initial visit	○	○	○

At least one MRI available for download - by scan type (ROW) by Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD) (COLUMN)

	Genotype data available at ADGC	Genotype data available at NIAGADS	Exome sequencing data available from dbGaP / ADSP	DNA sample available at NCRAD	Total UDS subjects
No MRI available for download	9539	2945	1627	18709	31473
At least one MRI available for download, any type	1518	340	240	2801	3710
At least one T1 available for download	1358	332	230	2443	3167
At least one T2 available for download	587	45	78	1158	1512
At least one FLAIR available for download	1231	307	210	2110	2678
At least one DTI available for download	689	182	108	1194	1621
Total UDS subjects	11057	3285	1867	21510	35183

Primary clinical diagnosis,	Genotype data available at ADGC	Genotype data available at NIAGADS	Exome sequencing data available from dbGaP / ADSP	DNA sample available at NCRAD	Total UDS subjects
Alzheimers disease (AD)	5031	1569	1168	8960	14905
Lewy body disease (LBD)	152	53	37	722	1371
Multiple system atrophy (MSA)	0	0	0	0	2
Progressive supranuclear palsy (PSP)	8	2	0	122	185
Corticobasal degeneration (CBD)	23	8	9	159	223
FTLD with motor neuron disease (e.g., ALS)	1	0	0	13	18
FTLD, other (including bvFTD and PPA)	83	33	15	1098	1733
Vascular brain injury or vascular dementia inc stroke	194	64	33	522	92
Normal cognition	5166	1477	571	8157	12260
All	11057	3285	1867	21510	35183

Lewy body disease pathology - by region (ROW) by Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD) (COLUMN)

	Genotype data available at ADGC	Genotype data available at NIAGADS	Exome sequencing data available from dbGaP / ADSP	DNA sample available at NCRAD	Total UDS subjects
No Lewy body pathology	1314	511	390	2111	3063
Brainstem-predominant	75	33	23	122	176
Limbic (transitional) or amygdala-predominant	222	97	62	343	513
Neocortical (diffuse)	221	97	78	396	566
Lewy bodies present, but region unspecified or found in the olfactory bulb	105	55	27	153	214
Not assessed/ missing/ unknown	15	7	7	21	31
Deceased, no autopsy data	929	341	283	1681	3264
Subjects not deceased	8176	2144	997	16683	27356
All	11057	3285	1867	21510	35183

MRI Selection Preview System

With NACC's MRI selection preview system, you can download a sample of up to 10 image files from UDS participants that meet the criteria you define — criteria based on MRI image type, or UDS clinical characteristics of the participants, or both. Along with the sample images, you will also be given a rough estimate of the number of MRIs that meet your criteria.

Please note that the sample images and estimated totals supplied by the MRI selection preview system are **not suitable for data analysis or publication.** When you are ready to download images for analysis and publication purposes — or if your inquiry requires more detailed information — please submit a custom data request.

PLEASE MAKE YOUR SELECTIONS from the table below. You may specify any of the eight criteria. If no selection is made for a given criterion, the system defaults to include ANY of the options listed for it.

SCAN TYPE	◉ Any ○ T1 ○ T2 ○ DTI ○ Flair ○ DWI
MAGNETIC FIELD STRENGTH	◉ Any ○ 1.5 ○ 3
SEX	◉ Any ○ Male ○ Female
AGE AT MRI SCAN	◉ Any ○ <65 ○ 65 – 89 ○ ≥90
RACE	◉ Any ○ White ○ Black or African American ○ American Indian or Alaska Native ○ Native Hawaiian or Pacific Islander ○ Asian ○ Multiracial
NUMBER OF APOE e4 ALLELES	◉ Any ○ 0 ○ 1 ○ 2
COGNITIVE STATUS*	◉ Any ○ Normal ○ Impaired, not MCI ○ MCI ○ Dementia

RESEARCH ARTICLE

Genetic assessment of age-associated Alzheimer disease risk: Development and validation of a polygenic hazard score

Rahul S. Desikan[1☯]*, Chun Chieh Fan[2☯], Yunpeng Wang[3,4,5], Andrew J. Schork[2], Howard J. Cabral[6], L. Adrienne Cupples[6], Wesley K. Thompson[7], Lilah Besser[8], Walter A. Kukull[8], Dominic Holland[3], Chi-Hua Chen[9], James B. Brewer[3,9,10], David S. Karow[9], Karolina Kauppi[9], Aree Witoelar[4,5], Celeste M. Karch[11], Luke W. Bonham[12], Jennifer S. Yokoyama[12], Howard J. Rosen[12], Bruce L. Miller[12], William P. Dillon[1], David M. Wilson[1], Christopher P. Hess[1], Margaret Pericak-Vance[13], Jonathan L. Haines[14,15], Lindsay A. Farrer[16,17,18,19,20], Richard Mayeux[21,22,23], John Hardy[24], Alison M. Goate[25,26], Bradley T. Hyman[27], Gerard D. Schellenberg[28], Linda K. McEvoy[9], Ole A. Andreassen[4,5]*, Anders

PLOS Medicine | DOI:10.1371/journal.pmed.1002258 March 21, 2017

APOE-related risk of mild cognitive impairment and dementia for prevention trials: An analysis of four cohorts

Jing Qian[1], Frank J. Wolters[2], Alexa Beiser[3,4], Mary Haan[5], M. Arfan Ikram[2], Jason Karlawish[6], Jessica B. Langbaum[7], John M. Neuhaus[5], Eric M. Reiman[7,8,9,10], J. Scott Roberts[11], Sudha Seshadri[3], Pierre N. Tariot[7,8], Beth McCarty Woods[6], Rebecca A. Betensky[12], Deborah Blacker[13,14]*

PLOS Medicine | DOI:10.1371/journal.pmed.1002254 March 21, 2017

Gene-based association study of genes linked to hippocampal sclerosis of aging neuropathology: *GRN*, *TMEM106B*, *ABCC9*, and *KCNMB2*

Yuriko Katsumata [a], Peter T. Nelson [b,c], Sally R. Ellingson [d], David W. Fardo [a,b,*]

Neurobiology of Aging 53 (2017) 193.e17–193.e25

Neuropathological and genetic correlates of survival and dementia onset in synucleinopathies: a retrospective analysis

David J Irwin, Murray Grossman, Daniel Weintraub, Howard I Hurtig, John E Duda, Sharon X Xie, Edward B Lee, Vivianna M Van Deerlin, Oscar L Lopez, Julia K Kofler, Peter T Nelson, Gregory A Jicha, Randy Woltjer, Joseph F Quinn, Jeffery Kaye, James B Leverenz, Debby Tsuang, Katelan Longfellow, Dora Yearout, Walter Kukull, C Dirk Keene, Thomas J Montine, Cyrus P Zabetian, John Q Trojanowski

Lancet Neurol 2017; 16: 55–65

Featured Article

Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample

Willa D. Brenowitz[a,*], Rebecca A. Hubbard[b], C. Dirk Keene[c], Stephen E. Hawes[d], W. T. Longstreth, Jr.,[a,e], Randy L. Woltjer[f], Walter A. Kukull[a]

Alzheimer's & Dementia ■ (2016) 1-9

Genomics and CSF analyses implicate thyroid hormone in hippocampal sclerosis of aging

Peter T. Nelson[1] · Yuriko Katsumata[1] · Kwangsik Nho[2] · Sergey C. Artiushin[1] · Gregory A. Jicha[1] · Wang-Xia Wang[1] · Erin L. Abner[1] · Andrew J. Saykin[2] · Walter A. Kukull[3] · Alzheimer's Disease Neuroimaging Initiative (ADNI) · David W. Fardo[1]

Acta Neuropathol (2016) 132:841–858

Cognitive decline associated with pathological burden in primary age-related tauopathy

Kyra S. Jefferson-George[a], David A. Wolk[a], Edward B. Lee[b], Corey T. McMillan[a,*]

Alzheimer's & Dementia ■ (2017) 1-6

Mental speed is associated with the shape irregularity of white matter MRI hyperintensity load

Catharina Lange, Per Suppa, Anja Mäurer, Kerstin Ritter, Uwe Pietrzyk, Elisabeth Steinhagen-Thiessen, Jochen B. Fiebach, Lothar Spies, Ralph Buchert

Brain Imaging and Behavior (2016). doi:10.1007/s11682-016-9647-x

Neuropsychological Testing in Pathologically Verified Alzheimer Disease and Frontotemporal Dementia

How Well Do the Uniform Data Set Measures Differentiate Between Diseases?

Aaron R. Ritter, MD, Gabriel C. Leger, MD, Justin B. Miller, PhD, and Sarah J. Banks, PhD

(*Alzheimer Dis Assoc Disord* 2016;00:000–000)

Executive Dysfunction and Behavioral Symptoms Are Associated with Deficits in Instrumental Activities of Daily Living in Frontotemporal Dementia

Moheb N.[a] · Mendez M.F.[a-c] · Kremen S.A.[a] · Teng E.[a, c]

Dement Geriatr Cogn Disord 2017;43:89-99

Genetic Comparison of Symptomatic and Asymptomatic Persons With Alzheimer Disease Neuropathology

Sarah E. Monsell, MS, Charles Mock, MD, PhD,† David W. Fardo, PhD,‡ Sarah Bertelsen, MA, JD,§ Nigel J. Cairns, PhD, FRCPath,‖ Catherine M. Roe, PhD,‖ Sally R. Ellingson, PhD,‡ John C. Morris, MD,‖ Alison M. Goate, D.Phil,§ and Walter A. Kukull, PhD†*

(*Alzheimer Dis Assoc Disord* 2016;00:000–000)

NACC family photo

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