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NACC Minimum Data Set (MDS) Data Form

(Version 8, 2006)

Summary of Changes

Changes have been highlighted in red in the Data Element Dictionary and on the MDS Form. This year there are minimal changes.

1. No changes to variable requirements
2. No skip pattern changes.
3. No new variables.
4. Changes to variables—clarifications, new codes, rephrased questions:

4c ABSYEAR	Acceptable Code: 2005 – 2006
5c BIRTHYR	Allowable Codes are: 1875 – 1991.
45 VERSION	Current version is 8.00.

NACC Minimum Data Set Form

Columns	Variable	Form
1-6	MDB001	1. Form Identifier (1-6) <u>MDB001</u> <i>Required</i>
8-9	ADCID	2. Center ID (8-9) ___ ___ <i>Required</i>
11-20	PTID	3. Patient ID (11-20) _____ <i>Required</i>
		4. Date record was abstracted from Center data:
22-23	ABSMO	4a. Month (22-23) ___ ___ <i>Required</i>
25-26	ABSDAY	4b. Day (25-26) ___ ___ <i>Required</i>
28-31	ABSYEAR	4c. Year (28-31) ___ ___ ___ <i>Required</i>
		5. Subject's date of birth:
33-34	BIRTHMO	5a. Month (33-34) ___ ___
36-37	BIRTHDAY	5b. Day (36-37) ___ ___
39-42	BIRTHYR	5c. Year (39-42) ___ ___ ___ <i>Required</i>
44	SEX	6. Subject's sex: (44) <i>Required</i> 1 Male 2 Female
46-47	RACE	7. Subject's race: (46-47) 1 White 2 Black 3 American Indian or Alaskan Native 4 Asian or Pacific Islander 50 Other 99 Missing/Unknown
49	HISPANIC	8. Is the subject Spanish/Hispanic/Latino? (49) 1 Yes 2 No 9 Missing/Unknown
51	PRIMLANG	9. Subject's primary language: (51) 1 English 2 Spanish 3 Other primary language 9 Missing/Unknown
NOTE: For further coding instructions, see Data Element Dictionary		

Columns	Variable	Form
53-54	EDUC	10. Subject's education: Highest grade or number of years of regular school completed. (53-54) ___ __ NOTE: For further coding instructions, see Data Element Dictionary
56	MARISTAT	11. Most recent marital status: (56) 1 Married 2 Widowed 3 Divorced 4 Separated 5 Never married 6 Other; e.g., not married but cohabitating 9 Missing/Unknown NOTE: For further coding instructions, see Data Element Dictionary
58	RESIDENC	12. Type of residence at most recent evaluation: (58) 1 Private residence 2 Retirement community 3 Assisted living/boarded home/adult family home 4 Skilled nursing facility/nursing home 5 Other 9 Missing/Unknown NOTE: For further coding instructions, see Data Element Dictionary
60-61	FEVALMO	13a. Month (60-61) ___ __
63-64	FEVALDAY	13b. Day (63-64) ___ __
66-69	FEVALYR	13c. Year (66-69) ___ __ __ __
71-72	MMSEFRST	14. Mini-Mental State Exam score (0 to 30) at initial NIA-funded evaluation (only if done at or after FEVALYR) (71-72) ___ __ NOTE: For further coding instructions, see Data Element Dictionary
74-75	REVALMO	15a. Month (74-75) ___ __
77-78	REVALDAY	15b. Day (77-78) ___ __
80-83	REVALYR	15c. Year (80-83) ___ __ __ __
85-86	MMSELAST	16. Most recent Mini-Mental State Exam score (0 to 30)

Columns	Variable	Form
88	CLINDEM	<p>(85-86) _ _</p> <p>17. Did the subject meet clinical criteria for dementia (e.g., DSM IV or other) at the most recent evaluation for dementia? (88) <i>Required</i></p> <p>1 Yes 2 No</p> <hr/> <p>SKIP? If 1, skip to item 18. If 2, continue with next item, 17a.</p> <hr/>
90	NOTDEMCI	<p>17a. If the subject did not meet criteria for dementia, what was the diagnosis? (90)</p> <p>1 Not demented control subject, no neurological disorder 2 Not demented, but has other neurological disorder (such as Parkinson's, MS, etc.) 3 Questionable dementia (e.g., CDR = 0.5) or cognitive impairment (MCI, AAMI) 4 Down Syndrome but not demented 5 Other 6 No diagnosis made 9 Missing/Unknown</p> <hr/> <p>SKIP? Skip to item 22a.</p> <hr/>
92-94	AGEDEM	<p>18. At what age did the subject develop dementia symptoms? (92-94) _ _ _</p>
96	CLDEMDX	<p>19. Was the primary clinical dementia diagnosis Alzheimer's at the most recent evaluation for dementia? (96)</p> <p>1 Alzheimer's disease (e.g. NINCDS 'probable Alzheimer's disease' or DSM IV 'dementia of the Alzheimer's type') 2 Alzheimer's disease with other conditions or variations in course (e.g. NINCDS 'possible Alzheimer's disease', DSM IV multiple etiologies where Alzheimer's is the predominate cause) 3 Non-Alzheimer's dementia (primary cause of dementia is not Alzheimer's) 9 Missing/Unknown</p> <hr/> <p>SKIP? If 1 or 2, continue with next item, 20.</p>

Columns	Variable	Form
98	CLDEMLEW	<p>If 3, skip to item 21. If 9, skip to item 22a.</p> <hr/> <p>20. If the primary clinical dementia diagnosis is Alzheimer's Disease (CLDEMDX = 1 or 2), does the subject also meet clinical criteria for dementia with Lewy bodies, Lewy body variant Alzheimer's disease, or diffuse Lewy body disease? (98)</p> <p>1 Yes 2 No 9 Missing/Unknown</p> <hr/> <p>SKIP? Skip to item 22a.</p> <hr/>
100-101	NONADDEM	<p>21. If the primary clinical dementia diagnosis is non-Alzheimer's dementia, what is the suspected etiology? (100-101)</p> <p>1 Frontal lobe dementias (e.g. Pick's, FTD) 2 Parkinson's disease dementia 3 Huntington's disease (HD) 4 Progressive supranuclear palsy (PSP) 5 Alcohol related dementias 6 Corticobasal degeneration 7 Communicating, obstructive, or normal pressure hydrocephalus 8 Vascular dementia (e.g. dementia due to stroke) 9 Dementia with Lewy bodies (not Parkinson's dementia) 10 Prion-associated dementia (e.g. Creutzfeldt-Jakob) 11 Human immunodeficiency virus(HIV) encephalopathy 12 Primary progressive aphasia 13 Posterior cortical dysfunction 14 Down syndrome 16 Dementia due to multiple non-Alzheimer's etiologies 17 Dementia due to other general medical conditions 18 Other (dementia not otherwise specified) 99 Missing/Unknown</p> <p>NOTE: For further coding instructions, see Data Element Dictionary</p>

Columns	Variable	Form
103	STROKE	<p>22. Does the subject have any of the following conditions?</p> <p>22a. Does the subject have a history of stroke? (103)</p> <p>1 Yes 2 No 9 Missing/Unknown</p>
105	PDNODEM	<p>22b. Does the subject have Parkinson's disease? (105)</p> <p>1 Yes 2 No 9 Missing/Unknown</p>
107	DEP	<p>22c. Did the subject have depression at the most recent evaluation? (107)</p> <p>1 Yes 2 No 9 Missing/Unknown</p>
109	DEL	<p>22d. Did the subject have delirium at the most recent evaluation? (109)</p> <p>1 Yes 2 No 9 Missing/Unknown</p>
111	RLDEM	<p>23. Were any first degree relatives (parents, siblings, or children of subject) reported to have had dementia (by symptoms, history or diagnosis)? (111)</p> <p>1 Yes 2 No 8 Not collected at this Center for this type of ID 9 Missing/Unknown</p> <hr/> <p>SKIP? If 1, continue with next item, 23a. If 2, 8 or 9, skip to item 24.</p> <hr/>
113-114	NUMRLDEM	<p>23a. How many first-degree relatives were reported to have had dementia (by symptoms, history or diagnosis)? (113-114) __ __</p>
116	MULTBRTH	<p>24. Is the subject from a multiple birth (twin, triplet, etc.)? (116)</p> <p>1 Yes 2 No 8 Not collected at this Center for this type of ID 9 Missing/Unknown</p>

Columns	Variable	Form
118	VITALST	<p>25. The Subject's last known vital status was: (118) <i>Required</i></p> <p>1 Alive 2 Dead</p> <hr/> <p>SKIP? If 2, continue with next item, 26a. If 1, skip to item 28.</p> <hr/>
120-121	DEATHMO	26. Subject's date of death:
123-124	DEATHDAY	26a. Month (120-121) ___
126-129	DEATHYR	26b. Day (123-124) ___
131	AUTOPSY	<p>26c. Year (126-129) ___</p> <p>27. Has an autopsy been performed that resulted in data or a report that is available or will be available at your Center? (131) <i>Required</i></p> <p>1 Yes 2 No</p> <p>NOTE: For further coding instructions, see Data Element Dictionary</p>
133	BIOPSY	<p>28. Has an antemortem brain biopsy been performed? (133) <i>Required</i></p> <p>1 Yes 2 No</p> <hr/> <p>SKIP? If item 27 (<i>previous</i> item) is 1, continue with next item, 29. Otherwise, skip to item 35. Do not give neuropath diagnoses from biopsy data.</p> <hr/>

Columns	Variable	Form
135-136	NPTHPRIM	<p>29. What is the primary neuropathological diagnostic classification? (135-136)</p> <ol style="list-style-type: none"> 1 Normal brain 2 Alzheimer's disease – Definite (e.g., using CERAD or other neuropathological criteria) 3 Alzheimer's disease – Probable (e.g., using CERAD or other neuropathological criteria) 4 Alzheimer's disease – Possible (e.g., using CERAD or other neuropathological criteria) 5 Idiopathic Parkinson's disease with cortical and/or subcortical Lewy bodies 6 Dementia with Lewy bodies and AD (Lewy body variant of AD) 7 Dementia with Lewy bodies without significant Alzheimer's disease changes (pure diffuse Lewy body disease) 8 Vascular dementia 9 Pick's disease 10 Lobar atrophy without Pick's bodies 11 Hippocampal sclerosis 12 Progressive supranuclear palsy 13 Corticobasal degeneration 14 Prion-associated disease 15 Down syndrome 16 Other 17 Stroke or cerebrovascular disease but not vascular dementia 18 Autopsy report pending 99 Missing/Unknown <p>NOTE: For further coding instructions, see Data Element Dictionary.</p> <hr/> <p>SKIP? If 1, then skip to item 31. Otherwise, continue with next item, 30.</p> <hr/>

Columns	Variable	Form
138-139	NPTHSECN	<p>30. What is the secondary neuropathological diagnostic classification? (138-139)</p> <ol style="list-style-type: none"> 1 No secondary neuropathological diagnostic classification 4 AD pathology present but insufficient for AD diagnosis 5 Idiopathic Parkinson's disease with cortical and/or subcortical Lewy bodies 6 Dementia with Lewy bodies and AD (Lewy body variant of Alzheimer's disease) 7 Dementia with Lewy bodies without significant Alzheimer's disease changes (pure diffuse Lewy body disease) 8 Vascular dementia 9 Pick's disease 10 Lobar atrophy without Pick's bodies 11 Hippocampal sclerosis 12 Progressive supranuclear palsy 13 Corticobasal degeneration 14 Prion-associated disease 15 Down syndrome 16 Other 17 Stroke or cerebrovascular disease but not vascular dementia 18 Autopsy report pending 99 Missing/Unknown <p>NOTE: For further coding instructions, see Data Element Dictionary.</p>
141	BRNFRZN	<p>31. Is banked frozen brain tissue accessible? (141) <i>Required</i></p> <ol style="list-style-type: none"> 1 Yes 2 No
143	BRNFRMLN	<p>32. Is formalin-fixed brain tissue accessible? (143) <i>Required</i></p> <ol style="list-style-type: none"> 1 Yes 2 No
145	BRNPARFN	<p>33. Are paraffin-embedded blocks of brain tissue accessible? (145) <i>Required</i></p> <ol style="list-style-type: none"> 1 Yes 2 No
147	CSFPOSTM	<p>34. Is banked postmortem cerebrospinal fluid (CSF) accessible? (147) <i>Required</i></p> <ol style="list-style-type: none"> 1 Yes 2 No

Columns	Variable	Form	
149	CSFANTEM	35. Is banked antemortem cerebrospinal fluid (CSF) accessible? (149) 1 Yes 2 No	<i>Required</i>
151	DNA	36. Is banked DNA accessible? (151) 1 Yes 2 No	<i>Required</i>
153	SERUM	37. Is banked serum accessible? (153) 1 Yes 2 No	<i>Required</i>
155	APOE	38. Has apolipoprotein-E (APOE) genotyping been performed? (155) 1 Yes 2 No	<i>Required</i>
157	NPSYCH	39. Are data from neuropsychological test results (not Mini-Mental test results) available? (157) 1 Yes 2 No	<i>Required</i>
159		(not used)	
		40. Are data (reports, films or digitized computer-based images) from any of the following neuroimaging studies available?	<i>Required</i>
161	CT	40a. Computed tomography (CT) (161) 1 Yes 2 No	<i>Required</i>
163	PET	40b. Positron emission tomography (PET) (163) 1 Yes 2 No	<i>Required</i>
165	SPECT	40c. Single photon emission computed tomography (SPECT) (165) 1 Yes 2 No	<i>Required</i>
167	MRI	40d. Magnetic resonance imaging (MRI) (167) 1 Yes 2 No	<i>Required</i>
169-175		(not used)	

Columns	Variable	Form
177	SOURCE	41. Source of subject data: (177) 1 Clinical core 2 Satellite 3 Center Affiliated Study 4 Other 9 Missing/Unknown
179-180	MMSEMO	42. Date of last Mini-Mental State Exam: 42a. Month (179-180) __ __
182-183	MMSEDAY	42b. Day (182-183) __ __
185-188	MMSEYR	42c. Year (185-188) __ __ __ __
190-191	CONTMO	43. Date of last contact (telephone or in-person): 43a. Month (190-191) __ __
193-194	CONTDAY	43b. Day (193-194) __ __
196-199	CONTYR	43c. Year (196-199) __ __ __ __
201	ACTIVE	44. Active/Inactive Status of ID (201) <i>Required</i> 1 Active: further in-person visits expected 2 Active: further visits expected (telephone or other) 3 Active: no further visits expected but autopsy expected or have autopsy consent 4 Deceased: autopsy pending 5 Deceased: autopsy complete, NP Form submitted or will be submitted to NACC 6 Deceased: autopsy complete, NP Form will not be submitted to NACC 7 Inactive: deceased, no autopsy 8 Inactive: no further data expected (alive at last contact)
203-207	VERSION	45. Version of MDB001 Form (203-207) <u>8.00</u> <i>Required</i>
209	EOR	46. End of Record (209) <u>X</u> <i>Not Required</i>