



NACC UNIFORM DATA SET

Follow-up Visit Packet

Version 3.0, March 2015

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This publication was funded by the National Institutes of Health through the National Institute on Aging (Cooperative Agreement U01 AG016976).

Revisions made to the follow-up visit packet since UDS3 implementation (March 15, 2015)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected	Data element(s) affected
2018-04-02	Form Z1 replaced with Form Z1X	Z1	All	N/A
2017-10-20	Form A5 removed from Form Z1X	Z1X	A5	N/A
2017-10-02	Form Z1X added	Z1X	N/A	N/A
2017-03-07	Name of the form was changed from Functional Assessment Questionnaire (FAQ). Only the name was affected; all items and scoring remain unchanged.	B7	N/A	N/A
2016-08-12	Clarification added to Form B5, v3.1, instructions: NPI-Q to be given to all UDS subjects.	B5	N/A	N/A
2015-12-14	Question numbers added for two specify blanks	D2	17a, 23a	SLEEPOTX, OTHCONDX
2015-08-12	Fixed broken link to UDS DrugID Lookup	A4	N/A	DRUGID
2015-06-17	Version 3.0 of Form B5 is now supplanted by Version 3.1 of Form B5, dated June 2015 . The version change applies to Form B5 only; all other current UDS forms remain Version 3.0, dated March 2015.	B5	N/A	N/A
2015-06-17	Instructions corrected for consistency with original instrument	B5	All	N/A
2015-06-17	Text of Question 3 changed to make it explicit that question applies to both visual and auditory hallucinations; minor wording changes made in explanatory text of other questions.	B5	Question 3; minor changes in 2, 4, 5	N/A
2015-05-07	Instructions added before Question 1 on how to complete form for subject receiving UDS v3 Form A3 for the first time	A3	1, 5, 6a, 7a	N/A

Form Z1X: Form Checklist

ADC name: _____ Subject ID: _____ Form date: ____/____/____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by clinic personnel.

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no co-participant, or for other reasons. An explanation is required below for forms that are not submitted.

UDS

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY):
	English	Spanish		Yes	No	
A1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Demographics	Required		
A2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Co-participant Demographics	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A3	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Family History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Medications	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Physical	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Global Staging — CDR: Standard and Supplemental	Required		
B5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT NPI-Q	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B6	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT GDS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	FUNCTIONAL ASSESSMENT NACC FAS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B8	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Neurological Examination Findings	Required		
B9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Judgment of Symptoms	Required		
C1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	Either C1 or C2 is required		
C2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Scores			
D1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Diagnosis	Required		
D2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician-assessed Medical Conditions	Required		

FTLD MODULE

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY*):
	English	Spanish		Yes	No	
A3a	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Supplemental UPDRS	Required		
B9F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinical PPA and bvFTD Features	Required		
C1F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	Required		
C2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Norms Questionnaire	Required		
C3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Behavior Observer Checklist	Required		
C4F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Behavioral Inhibition Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C5F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Interpersonal Reactivity Index	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C6F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Revised Self-monitoring Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
E2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging Available	Required		
E3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging in Diagnosis	Required		

CLS FORM

Form	Language:		Description	Submitted:		
	English	Spanish		Yes	No	
CLS	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject's Language History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	Submit only once

KEY: If the specified form was not completed, please enter one of the following codes: 95=Physical problem 96=Cognitive or behavioral problem 97=Other problem 98=Verbal refusal
 *KEY FOR FTLD MODULE ONLY: Allowable codes are 95 – 98 as above, as well as 99=Unknown or inadequate information.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A1: Subject Demographics

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by intake interviewer based on ADC scheduling records, subject interview, medical records, and co-participant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A1. Check only one box per question.

To print a copy of data collected for this form at a previous UDS visit, go to <https://www.alz.washington.edu/MEMBER/siteprint.html>.

1. Subject's month and year of birth (MM/YYYY):	_____ / _____
2. Subject's <u>current</u> marital status:	<input type="checkbox"/> 1 Married <input type="checkbox"/> 2 Widowed <input type="checkbox"/> 3 Divorced <input type="checkbox"/> 4 Separated <input type="checkbox"/> 5 Never married (or marriage was annulled) <input type="checkbox"/> 6 Living as married/domestic partner <input type="checkbox"/> 9 Unknown
3. Subject's sex:	<input type="checkbox"/> 1 Male <input type="checkbox"/> 2 Female
4. What is the subject's living situation?	<input type="checkbox"/> 1 Lives alone <input type="checkbox"/> 2 Lives with one other person: a spouse or partner <input type="checkbox"/> 3 Lives with one other person: a relative, friend, or roommate <input type="checkbox"/> 4 Lives with caregiver who is not spouse/partner, relative, or friend <input type="checkbox"/> 5 Lives with a group (related or not related) in a private residence <input type="checkbox"/> 6 Lives in a group home (e.g., assisted living, nursing home, or convent) <input type="checkbox"/> 9 Unknown
5. What is the subject's level of independence?	<input type="checkbox"/> 1 Able to live independently <input type="checkbox"/> 2 Requires some assistance with complex activities <input type="checkbox"/> 3 Requires some assistance with basic activities <input type="checkbox"/> 4 Completely dependent <input type="checkbox"/> 9 Unknown
6. What is the subject's primary type of residence?	<input type="checkbox"/> 1 Single- or multi-family private residence (apartment, condo, house) <input type="checkbox"/> 2 Retirement community or independent group living <input type="checkbox"/> 3 Assisted living, adult family home, or boarding home <input type="checkbox"/> 4 Skilled nursing facility, nursing home, hospital, or hospice <input type="checkbox"/> 9 Unknown
7. ZIP Code (first three digits) of subject's primary residence:	_____ (If unknown, leave blank)

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A2: Co-participant Demographics

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by intake interviewer based on co-participant's report. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A2. Check only one box per question.

To print a copy of data collected for this form at a previous UDS visit, go to <https://www.alz.washington.edu/MEMBER/siteprint.html>

1. Co-participant's month and year of birth (MM / YYYY):	____ / _____ (99/9999 = unknown)
2. Co-participant's sex:	<input type="checkbox"/> 1 Male <input type="checkbox"/> 2 Female
3. Is this a new co-participant — i.e., one who was not a co-participant at any past UDS visit?	<input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 9) <input type="checkbox"/> 1 Yes
4. Does the co-participant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	<input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 5) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown (If Unknown, SKIP TO QUESTION 5)
4a. If yes, what are the co-participant's reported origins?	<input type="checkbox"/> 1 Mexican, Chicano, or Mexican-American <input type="checkbox"/> 2 Puerto Rican <input type="checkbox"/> 3 Cuban <input type="checkbox"/> 4 Dominican <input type="checkbox"/> 5 Central American <input type="checkbox"/> 6 South American <input type="checkbox"/> 50 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown
5. What does the co-participant report as his or her race?	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown
6. What additional race does the co-participant report?	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): _____ <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown

7. What additional race, beyond those reported in Questions 5 and 6, does the co-participant report?	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): _____ <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown
8. Co-participant's years of education — use the codes below to report the level achieved; if an attempted level is not completed, enter the number of years completed: _____ 12 = high school or GED 16 = bachelor's degree 18 = master's degree 20 = doctorate 99 = unknown	
9. What is co-participant's relationship to the subject?	<input type="checkbox"/> 1 Spouse, partner, or companion (include ex-spouse, ex-partner, fiancé(e), boyfriend, girlfriend) <input type="checkbox"/> 2 Child (by blood or through marriage or adoption) <input type="checkbox"/> 3 Sibling (by blood or through marriage or adoption) <input type="checkbox"/> 4 Other relative (by blood or through marriage or adoption) <input type="checkbox"/> 5 Friend, neighbor, or someone known through family, friends, work, or community (e.g., church) <input type="checkbox"/> 6 Paid caregiver, health care provider, or clinician
9a. How long has the co-participant known the subject?	_____ years (999=unknown)
10. Does the co-participant live with the subject?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (If Yes, SKIP TO QUESTION 11)
10a. If no, approximate frequency of in-person visits?	<input type="checkbox"/> 1 Daily <input type="checkbox"/> 2 At least three times per week <input type="checkbox"/> 3 Weekly <input type="checkbox"/> 4 At least three times per month <input type="checkbox"/> 5 Monthly <input type="checkbox"/> 6 Less than once a month
10b. If no, approximate frequency of telephone contact?	<input type="checkbox"/> 1 Daily <input type="checkbox"/> 2 At least three times per week <input type="checkbox"/> 3 Weekly <input type="checkbox"/> 4 At least three times per month <input type="checkbox"/> 5 Monthly <input type="checkbox"/> 6 Less than once a month
11. Is there a question about the co-participant's reliability?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A3: Subject Family History

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by a clinician with experience in evaluating patients with neurological problems and psychiatric conditions. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A3.

SPECIAL INSTRUCTIONS for subjects who are receiving UDS Version 3 of Form A3 for the first time:

NOTE: A subject is receiving UDS v3 Form A3 for the first time if:

- No A3 data has been submitted yet for this subject –OR–
- A3 data has been submitted for this subject, but it was collected using UDS v2

For such subjects, you must fill out this form in its entirety, meaning:

1. You must answer **1=Yes** to Question 1 on genetic mutations and complete 2a – 4b.
2. You must answer **1=Yes** to Question 5 on parents and complete 5a – 5b.
3. You must answer **1=Yes** to Question 6a on siblings and complete 6aa – 6at, as appropriate.
4. You must answer **1=Yes** to Question 7a on children and complete 7aa – 7ao, as appropriate.

Corrections or new information on previously submitted family members — For family members who were denoted as being “affected” with a neurological or psychiatric condition or who were not affected at a previous UDS visit, any corrections to their data should be made to that previous A3 Form. Any newly obtained information (e.g., new mutation information, new diagnoses, new method of evaluation), including for family members previously reported as being affected at a past UDS visit, should be indicated on this form and should not be submitted as a correction to a previously submitted Form A3.

A summary of all previously submitted family history data can be found at: <https://www.alz.washington.edu/MEMBER/siteprint.html>.

1. Since the last visit, is new information available concerning genetic mutations addressed by Questions 2a through 4b, below?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 5) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 5)
2a. In this family, is there evidence for an AD mutation? If Yes, select predominant mutation. NOTE: APOE should not be reported here.	<input type="checkbox"/> 0 No (SKIP TO QUESTION 3a) <input type="checkbox"/> 1 Yes, APP <input type="checkbox"/> 2 Yes, PS-1 (PSEN 1) <input type="checkbox"/> 3 Yes, PS-2 (PSEN 2) <input type="checkbox"/> 8 Yes, other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown whether mutation exists (SKIP TO QUESTION 3a)
2b. Source of evidence for AD mutation (check one):	<input type="checkbox"/> 1 Family report (no test documentation available) <input type="checkbox"/> 2 Commercial test documentation <input type="checkbox"/> 3 Research lab test documentation <input type="checkbox"/> 8 Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown

<p>3a. In this family, is there evidence for an FTLN mutation? If Yes, select predominant mutation.</p>	<p><input type="checkbox"/> 0 No (SKIP TO QUESTION 4a)</p> <p><input type="checkbox"/> 1 Yes, MAPT</p> <p><input type="checkbox"/> 2 Yes, PGRN</p> <p><input type="checkbox"/> 3 Yes, C9orf72</p> <p><input type="checkbox"/> 4 Yes, FUS</p> <p><input type="checkbox"/> 8 Yes, other (SPECIFY): _____</p> <p><input type="checkbox"/> 9 Unknown whether mutation exists (SKIP TO QUESTION 4a)</p>
<p>3b. Source of evidence for FTLN mutation (check one):</p>	<p><input type="checkbox"/> 1 Family report (no test documentation available)</p> <p><input type="checkbox"/> 2 Commercial test documentation</p> <p><input type="checkbox"/> 3 Research lab test documentation</p> <p><input type="checkbox"/> 8 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 9 Unknown</p>
<p>4a. In this family, is there evidence for a mutation other than an AD or FTLN mutation? (If No or Unknown, SKIP TO QUESTION 5)</p>	<p><input type="checkbox"/> 0 No (SKIP TO QUESTION 5)</p> <p><input type="checkbox"/> 1 Yes (SPECIFY): _____</p> <p><input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 5)</p>
<p>4b. Source of evidence for other mutation (check one):</p>	<p><input type="checkbox"/> 1 Family report (no test documentation available)</p> <p><input type="checkbox"/> 2 Commercial test documentation</p> <p><input type="checkbox"/> 3 Research lab test documentation</p> <p><input type="checkbox"/> 8 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 9 Unknown</p>

BIOLOGICAL PARENTS

5. Since the last UDS visit, is new information available concerning the status of the subject’s biological mother or father?

- 0 No (**SKIP TO QUESTION 6**) 1 Yes (**COMPLETE QUESTIONS 5A–5B, AS APPLICABLE**)

If birth year is unknown, please provide an approximate year on the Initial Visit Form A3 and ensure that it is consistently reported on all Forms A3 submitted (Initial Visit and Follow-up). If it is impossible for the subject and co-participant to estimate year of birth, enter 9999=*Unknown*. For any biological parent with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter 9=*Unknown* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the parent has no neurological or psychiatric problem, enter 8=*N/A — no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
			See CODES below this table			
5a. Mother	__ / ____	__	__	__	__	__
5b. Father	__ / ____	__	__	__	__	__

***CODES for neurological problems and psychiatric conditions**

- 1 Cognitive impairment/behavior change
- 2 Parkinsonism
- 3 ALS
- 4 Other neurologic condition such as multiple sclerosis or stroke
- 5 Psychiatric condition such as schizophrenia, bipolar disorder, alcoholism, or depression
- 8 N/A — no neurological problem or psychiatric condition
- 9 Unknown

****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

*****CODES for method of evaluation**

- 1 Autopsy
- 2 Examination
- 3 Medical record review from formal dementia evaluation
- 4 Review of general medical records AND co-participant and/or subject telephone interview
- 5 Review of general medical records only
- 6 Subject and/or co-participant telephone interview
- 7 Family report

Year of birth for full siblings and biological children: If birth year is unknown, please provide an approximate year on UDS Initial Visit Form A3 and UDS Follow-up Visit Form A3 so that the sibling/child with unknown birth year ends up in correct birth order relative to the other siblings/children.

Example: A subject is the oldest of three children. The subject was born in 1940 and the middle sibling in 1943; the youngest sibling's birth year is unknown. An approximate birth year of 1944 or later should be assigned to the youngest sibling.

Use that same birth year on FTLD Module Form A3a, if applicable, and across all UDS visits so that any new information on a particular sibling or child can be linked to previously submitted information. If it is impossible for the subject and co-participant to estimate year of birth, enter 9999=Unknown.

FULL SIBLINGS

6. How many full siblings does the subject have? ____ If subject has no full siblings, **SKIP TO QUESTION 7.**

6a. Since the last UDS visit, is new information available concerning the status of the subject's siblings?

0 No (**SKIP TO QUESTION 7**) 1 Yes (**COMPLETE QUESTIONS 6aa–6at, AS APPLICABLE**)

For any full sibling with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter 9=Unknown in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the sibling has no neurological or psychiatric problem, enter 8=N/A — *no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888 = N/A, 999 = unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999 = unknown)
See CODES on page 4						
6aa. Sibling 1	___/_____	____	__	____	__	____
6ab. Sibling 2	___/_____	____	__	____	__	____
6ac. Sibling 3	___/_____	____	__	____	__	____
6ad. Sibling 4	___/_____	____	__	____	__	____
6ae. Sibling 5	___/_____	____	__	____	__	____
6af. Sibling 6	___/_____	____	__	____	__	____
6ag. Sibling 7	___/_____	____	__	____	__	____
6ah. Sibling 8	___/_____	____	__	____	__	____
6ai. Sibling 9	___/_____	____	__	____	__	____
6aj. Sibling 10	___/_____	____	__	____	__	____
6ak. Sibling 11	___/_____	____	__	____	__	____
6al. Sibling 12	___/_____	____	__	____	__	____
6am. Sibling 13	___/_____	____	__	____	__	____
6an. Sibling 14	___/_____	____	__	____	__	____
6ao. Sibling 15	___/_____	____	__	____	__	____
6ap. Sibling 16	___/_____	____	__	____	__	____
6aq. Sibling 17	___/_____	____	__	____	__	____
6ar. Sibling 18	___/_____	____	__	____	__	____
6as. Sibling 19	___/_____	____	__	____	__	____
6at. Sibling 20	___/_____	____	__	____	__	____

BIOLOGICAL CHILDREN

7. How many biological children does the subject have? ____ If subject has no biological children, **END FORM HERE.**

7a. Since the last UDS visit, is new information available concerning the status of the subject's biological children?

0 No (**END FORM HERE**) 1 Yes (**COMPLETE QUESTIONS 7aa–7ao, AS APPLICABLE**)

For any biological child with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter 9=Unknown in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the child has no neurological or psychiatric problem, enter 8=N/A — *no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888 = N/A, 999 = unknown)	Primary neurological problem/ psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999 = unknown)
See CODES below this table						
7aa. Child 1	__/____	____	__	____	__	____
7ab. Child 2	__/____	____	__	____	__	____
7ac. Child 3	__/____	____	__	____	__	____
7ad. Child 4	__/____	____	__	____	__	____
7ae. Child 5	__/____	____	__	____	__	____
7af. Child 6	__/____	____	__	____	__	____
7ag. Child 7	__/____	____	__	____	__	____
7ah. Child 8	__/____	____	__	____	__	____
7ai. Child 9	__/____	____	__	____	__	____
7aj. Child 10	__/____	____	__	____	__	____
7ak. Child 11	__/____	____	__	____	__	____
7al. Child 12	__/____	____	__	____	__	____
7am. Child 13	__/____	____	__	____	__	____
7an. Child 14	__/____	____	__	____	__	____
7ao. Child 15	__/____	____	__	____	__	____

***CODES for neurological problems and psychiatric conditions**

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- 2 Parkinsonism
- 3 ALS
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****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

*****CODES for method of evaluation**

- 1 Autopsy
- 2 Examination
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- 6 Subject and/or co-participant telephone interview
- 7 Family report

****APPENDIX 1: PRIMARY DIAGNOSIS CODES**

040	Mild cognitive impairment (MCI), not otherwise specified
041	MCI — single domain amnesic
042	MCI — multiple domain with amnesia
043	MCI — single domain nonamnesic
044	MCI — multiple domain nonamnesic
045	Impaired, but not MCI
050	Alzheimer's disease dementia
070	Dementia with Lewy bodies
080	Vascular cognitive impairment or dementia
100	Impairment due to alcohol abuse
110	Dementia of undetermined etiology
120	Behavioral variant frontotemporal dementia
130	Primary progressive aphasia, semantic variant
131	Primary progressive aphasia, nonfluent/agrammatic variant
132	Primary progressive aphasia, logopenic variant
133	Primary progressive aphasia, not otherwise specified
140	Clinical progressive supranuclear palsy
150	Clinical corticobasal syndrome/corticobasal degeneration
160	Huntington's disease
170	Clinical prion disease
180	Cognitive dysfunction from medications
190	Cognitive dysfunction from medical illness
200	Depression
210	Other major psychiatric illness
220	Down syndrome
230	Parkinson's disease
240	Stroke
250	Hydrocephalus
260	Traumatic brain injury
270	CNS neoplasm
280	Other
310	Amyotrophic lateral sclerosis
320	Multiple sclerosis
999	Specific diagnosis unknown (<i>acceptable if method of evaluation is not by autopsy, examination, or dementia evaluation</i>)

Neuropathology diagnosis from autopsy

400	Alzheimer's disease neuropathology
410	Lewy body disease — neuropathology
420	Gross infarct(s) neuropathology
421	Hemorrhage(s) neuropathology
422	Other cerebrovascular disease neuropathology
430	ALS/MND
431	FTLD with Tau pathology — Pick's disease
432	FTLD with Tau pathology — CBD
433	FTLD with Tau pathology — PSP
434	FTLD with Tau pathology — argyrophillic grains
435	FTLD with Tau pathology — other
436	FTLD with TDP-43
439	FTLD other (FTLD-FUS, FTLD-UPS, FTLD NOS)
440	Hippocampal sclerosis
450	Prion disease neuropathology
490	Other neuropathologic diagnosis not listed above

*****APPENDIX 2: METHOD OF EVALUATION****1. Autopsy**

If the autopsy was performed at an outside institution, **you must have the report** to code as diagnosis by autopsy.

2. Examination

The subject must have been examined in person at your ADC/ institution or by genetic studies staff associated with your ADC/ institution to code as diagnosis by examination. Medical records may or may not have been used when assigning diagnosis.

3. Medical record review from formal dementia evaluation

Medical records should be from an examination that focused specifically on dementia; that was performed by a neurologist, geriatrician, or psychiatrist; and that includes a neurologic examination, an imaging study, and cognitive testing (e.g., MMSE, Blessed, or more formal tests). A telephone interview may also be used to collect additional information.

4. Review of general medical records AND co-participant and/or subject telephone interview

General medical records can be of various types, including those from a primary-care physician's office, hospitalization records, nursing home records, etc. They may include a neurologic exam and a cognitive test such as the MMSE along with a medical history. **The telephone interview** with the subject and/or the co-participant should include a medical history to capture the nature and presentation of cognitive deficits, if present, and age of onset if symptomatic. If the subject is normal or is in the early stages of cognitive impairment, brief formal cognitive testing should be included in the interview.

5. Review of general medical records ONLY

See definition No. 4 above. If general medical records are used to diagnose a subject as demented or not demented, they should include a medical history, neurologic exam, and a cognitive test such as an MMSE. In most cases, general medical records alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTL spectrum subtypes, or of parkinsonian disorders other than Parkinson's disease.

6. Subject and/or co-participant telephone interview

See definition No. 4 above.

7. Family report

Family report should be coded when the co-participant for the family reports a subject as having been diagnosed with a particular disorder. In most cases, family report alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTL spectrum subtypes, or of parkinsonian disorders other than Parkinson's disease.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A4: Subject Medications

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / ____
 Visit #: _____ Examiner's initials: _____

*INSTRUCTIONS: This form is to be completed by the clinician or ADC staff. The purpose of this form is to record all prescription medications taken by the subject **within the two weeks before the current visit**. For prescription medications not listed here, please follow the instructions at the end of this form. OTC (non-prescription) medications need not be reported; however, a short list of medications that could be either prescription or OTC follows the prescription list.*

Is the subject currently taking any medications? 0 No **(END FORM HERE)** 1 Yes

MEDICATION NAME	DrugID
<input type="checkbox"/> acetaminophen-HYDROcodone (Vicodin)	d03428
<input type="checkbox"/> albuterol (Proventil, Ventolin, Volmax)	d00749
<input type="checkbox"/> alendronate (Fosamax)	d03849
<input type="checkbox"/> allopurinol (Aloprim, Lopurin, Zyloprim)	d00023
<input type="checkbox"/> alprazolam (Niravam, Xanax)	d00168
<input type="checkbox"/> amlodipine (Norvasc)	d00689
<input type="checkbox"/> atenolol (Senormin, Tenormin)	d00004
<input type="checkbox"/> atorvastatin (Lipitor)	d04105
<input type="checkbox"/> benazepril (Lotensin)	d00730
<input type="checkbox"/> bupropion (Budeprion, Wellbutrin, Zyban)	d00181
<input type="checkbox"/> calcium acetate (Calphron, PhosLo)	d03689
<input type="checkbox"/> carbidopa-levodopa (Atamet, Sinemet)	d03473
<input type="checkbox"/> carvedilol (Coreg, Carvedilol)	d03847
<input type="checkbox"/> celecoxib (Celebrex)	d04380
<input type="checkbox"/> cetirizine (Zyrtec)	d03827
<input type="checkbox"/> citalopram (Celexa)	d04332
<input type="checkbox"/> clonazepam (Klonopin)	d00197
<input type="checkbox"/> clopidogrel (Plavix)	d04258
<input type="checkbox"/> conjugate estrogens (Cenestin, Premarin)	d00541
<input type="checkbox"/> cyanocobalamin (Neuroforte-R, Vitamin B12)	d00413
<input type="checkbox"/> digoxin (Digitek, Lanoxin)	d00210
<input type="checkbox"/> diltiazem (Cardizem, Tiazac)	d00045
<input type="checkbox"/> donepezil (Aricept)	d04099
<input type="checkbox"/> duloxetine (Cymbalta)	d05355
<input type="checkbox"/> enalapril (Vasotec)	d00013
<input type="checkbox"/> ergocalciferol (Calciferol, Disdol, Vitamin D)	d03128
<input type="checkbox"/> escitalopram (Lexapro)	d04812
<input type="checkbox"/> esomeprazole (Nexium)	d04749

MEDICATION NAME	DrugID
<input type="checkbox"/> estradiol (Estrace, Estrogel, Fempatch)	d00537
<input type="checkbox"/> ezetimibe (Zetia)	d04824
<input type="checkbox"/> ferrous sulfate (FeroSul, Iron Supplement)	d03824
<input type="checkbox"/> fexofenadine (Allegra)	d04040
<input type="checkbox"/> finasteride (Propecia, Proscar)	d00563
<input type="checkbox"/> fluoxetine (Prozac)	d00236
<input type="checkbox"/> fluticasone (Flovent)	d01296
<input type="checkbox"/> fluticasone nasal (Flonase, Veramyst)	d04283
<input type="checkbox"/> fluticasone-salmeterol (Advair)	d04611
<input type="checkbox"/> furosemide (Lasix)	d00070
<input type="checkbox"/> gabapentin (Neurontin)	d03182
<input type="checkbox"/> galantamine (Razadyne, Reminyl)	d04750
<input type="checkbox"/> glipizide (Glucotrol)	d00246
<input type="checkbox"/> hydrochlorothiazide (Esidrix, Hydrodiuril)	d00253
<input type="checkbox"/> hydrochlorothiazide-triamterene (Dyazide)	d03052
<input type="checkbox"/> latanoprost ophthalmic (Xalatan)	d04017
<input type="checkbox"/> levothyroxine (Levothroid, Levoxyl, Synthroid)	d00278
<input type="checkbox"/> lisinopril (Prinivil, Zestril)	d00732
<input type="checkbox"/> lorazepam (Ativan)	d00149
<input type="checkbox"/> losartan (Cozaar)	d03821
<input type="checkbox"/> lovastatin (Altacor, Mevacor)	d00280
<input type="checkbox"/> meloxicam (Meloxicam, Mobic)	d04532
<input type="checkbox"/> memantine (Namenda)	d04899
<input type="checkbox"/> metformin (Glucophage, Riomet)	d03807
<input type="checkbox"/> metoprolol (Lopressor, Toprol-XL)	d00134
<input type="checkbox"/> mirtazapine (Remeron)	d04025
<input type="checkbox"/> montelukast (Singulair)	d04289
<input type="checkbox"/> naproxen (Aleve, Anaprox, Naprosyn)	d00019

MEDICATION NAME	DrugID
<input type="checkbox"/> niacin (Niacor, Nico-400, Nicotinic Acid)	d00314
<input type="checkbox"/> nifedipine (Adalat, Procardia)	d00051
<input type="checkbox"/> nitroglycerin (Nitro-Bid, Nitro-Dur, Nitrostat)	d00321
<input type="checkbox"/> omega-3 polyunsaturated fatty acids (Omacor, Lovaza)	d00497
<input type="checkbox"/> omeprazole (Prilosec)	d00325
<input type="checkbox"/> oxybutynin (Ditropan, Urotrol)	d00328
<input type="checkbox"/> pantoprazole (Protonix)	d04514
<input type="checkbox"/> paroxetine (Paxil, Paxil CR, Pexeva)	d03157
<input type="checkbox"/> potassium chloride (K-Dur 10, K-Lor, Slow-K)	d00345
<input type="checkbox"/> pravastatin (Pravachol)	d00348
<input type="checkbox"/> quetiapine (Seroquel)	d04220
<input type="checkbox"/> ranitidine (Zantac)	d00021

MEDICATION NAME	DrugID
<input type="checkbox"/> rivastigmine (Exelon)	d04537
<input type="checkbox"/> rosuvastatin (Crestor)	d04851
<input type="checkbox"/> sertraline (Zoloft)	d00880
<input type="checkbox"/> simvastatin (Zocor)	d00746
<input type="checkbox"/> tamsulosin (Flomax)	d04121
<input type="checkbox"/> terazosin (Hytrin)	d00386
<input type="checkbox"/> tramadol (Ryzolt, Ultram)	d03826
<input type="checkbox"/> trazodone (Desyrel)	d00395
<input type="checkbox"/> valsartan (Diovan)	d04113
<input type="checkbox"/> venlafaxine (Effexor)	d03181
<input type="checkbox"/> warfarin (Coumadin, Jantoven)	d00022
<input type="checkbox"/> zolpidem (Ambien)	d00910

Commonly reported medications that may be purchased over the counter (but that may also be prescription):

Medication name	DrugID
<input type="checkbox"/> acetaminophen (Anacin, Tempra, Tylenol)	d00049
<input type="checkbox"/> ascorbic acid (C Complex, Vitamin C)	d00426
<input type="checkbox"/> aspirin	d00170
<input type="checkbox"/> calcium carbonate (Rolaids, Tums)	d00425
<input type="checkbox"/> calcium-vitamin D (Dical-D, O-Cal-D)	d03137
<input type="checkbox"/> cholecalciferol (Vitamin D3, Replesta)	d03129
<input type="checkbox"/> chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)	d04420
<input type="checkbox"/> docusate (Calcium Stool Softener, Dioctyl SS)	d01021
<input type="checkbox"/> folic acid (Folic Acid)	d00241
<input type="checkbox"/> glucosamine (Hydrochloride)	d04418

Medication name	DrugID
<input type="checkbox"/> ibuprofen (Advil, Motrin, Nuprin)	d00015
<input type="checkbox"/> loratadine (Alavert, Claritin, Dimetapp, Tavist)	d03050
<input type="checkbox"/> melatonin (Melatonin, Melatonin Time Release)	d04058
<input type="checkbox"/> multivitamin	d03140
<input type="checkbox"/> multivitamin with minerals	d03145
<input type="checkbox"/> polyethylene glycol 3350 (Miralax)	d05350
<input type="checkbox"/> psyllium (Fiberall, Metamucil)	d01018
<input type="checkbox"/> pyridoxine (Vitamin B6)	d00412
<input type="checkbox"/> ubiquinone (Co Q-10)	d04523
<input type="checkbox"/> vitamin E (Aquavite-E, Centrum Singles)	d00405

If a medication is not listed above, specify the drug or brand name and determine its drugID by using the Lookup Tool on the NACC website at <https://www.alz.washington.edu/MEMBER/DrugCodeLookup.html>

- (SPECIFY:) _____ d _____
- (SPECIFY:) _____ d _____
- (SPECIFY:) _____ d _____
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FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B1: EVALUATION FORM Physical

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B1. Check only one box per question.

Subject physical measurements				
1. Subject height (inches)	_____	<i>(88.8=not assessed)</i>		
2. Subject weight (lbs.)	_____	<i>(888=not assessed)</i>		
3. Subject blood pressure at initial reading (sitting)	_____ / _____	<i>(888/888=not assessed)</i>		
4. Subject resting heart rate (pulse)	_____	<i>(888=not assessed)</i>		
Additional physical observations		No	Yes	Unknown
5. Without corrective lenses, is the subject's vision functionally normal?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
6. Does the subject usually wear corrective lenses? <i>(If no or unknown, SKIP TO QUESTION 7)</i>		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
6a. If yes, is the subject's vision functionally normal <u>with</u> corrective lenses?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
7. Without a hearing aid(s), is the subject's hearing functionally normal?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
8. Does the subject usually wear a hearing aid(s)? <i>(If no or unknown, END FORM HERE)</i>		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
8a. If yes, is the subject's hearing functionally normal <u>with</u> a hearing aid(s)?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

Form B4: Global Staging — Clinical Dementia Rating (CDR) STANDARD AND SUPPLEMENTAL

ADC name: _____ Subject ID: _____ Form date: ____/____/____ Visit #: ____ Examiner's initials: ____

INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4.

SECTION 1: STANDARD CDR¹

Please enter score below:	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
1. Memory ____	No memory loss, or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; “benign” forgetfulness	Moderate memory loss, more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
2. Orientation ____	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only
3. Judgment and problem solving ____	Solves everyday problems, handles business and financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
4. Community affairs ____	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities, although may still be engaged in some; appears normal to casual inspection	No pretense of independent function outside the home; appears well enough to be taken to functions outside the family home	No pretense of independent function outside the home; appears too ill to be taken to functions outside the family home
5. Home and hobbies ____	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in the home
6. Personal care ____.0	Fully capable of self-care (= 0).		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence
7. _____	STANDARD CDR SUM OF BOXES				
8. _____	STANDARD GLOBAL CDR				

¹Morris JC. The Clinical Dementia Rating (CDR): Current version and scoring rules. Neurology 43(11):2412-4, 1993. Copyright© Lippincott, Williams & Wilkins. Reproduced by permission.

INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4.

SECTION 2: SUPPLEMENTAL CDR

	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
Please enter score below: 9. Behavior, comporment, and personality² _____	Socially appropriate behavior	Questionable changes in comportment, empathy, appropriateness of actions	Mild but definite changes in behavior	Moderate behavioral changes, affecting interpersonal relationships and interactions in a significant manner	Severe behavioral changes, making interpersonal interactions all unidirectional
10. Language³ _____	No language difficulty, or occasional mild tip-of-the-tongue	Consistent mild word-finding difficulties; simplification of word choice; circumlocution; decreased phrase length; and/or mild comprehension difficulties	Moderate word-finding difficulty in speech; cannot name objects in environment; reduced phrase length and/or agrammatical speech and/or reduced comprehension in conversation and reading	Moderate to severe impairments in either speech or comprehension; has difficulty communicating thoughts; writing may be slightly more effective	Severe comprehension deficits; no intelligible speech

²Excerpted from the Frontotemporal Demential Multicenter Instrument & MR Study (Mayo Clinic, UCSF, UCLA, UW).

³Excerpted from the PPA-CDR: A modification of the CDR for assessing dementia severity in patients with primary progressive aphasia (Johnson N, Weintraub S, Mesulam MM), 2002.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B5: BEHAVIORAL ASSESSMENT Neuropsychiatric Inventory Questionnaire (NPI-Q¹)

ADC name: _____ Subject ID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional based on co-participant interview, as described by the training video. (This is not to be completed by the subject as a paper-and-pencil self-report.) For information on NPI-Q Interviewer Certification, see UDS Coding Guidebook for Follow-up Visit Packet, Form B5. Check only one box for each category of response.

CORRECTED INSTRUCTIONS: Please answer the following questions based on changes that have occurred since the patient first began to experience memory (i.e., cognitive) problems. **Select 1=Yes only if the symptom(s) has been present in the last month. Otherwise, select 0=No.** (NOTE: for the UDS, please administer the NPI-Q to all subjects.)

For each item marked **1=Yes**, rate the SEVERITY of the symptom (how it affects the patient):
 1=**Mild** (noticeable, but not a significant change) 2=**Moderate** (significant, but not a dramatic change) 3=**Severe** (very marked or prominent; a dramatic change)

1. NPI CO-PARTICIPANT: <input type="checkbox"/> 1 Spouse <input type="checkbox"/> 2 Child <input type="checkbox"/> 3 Other (SPECIFY): _____	Yes	No	Unknown	SEVERITY			Unknown
				Mild	Mod	Severe	
2. Delusions — Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?	2a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	2b. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
3. Hallucinations — Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?	3a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	3b. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
4. Agitation/aggression — Is the patient resistive to help from others at times, or hard to handle?	4a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	4b. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
5. Depression/dysphoria — Does the patient seem sad or say that he/she is depressed?	5a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	5b. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9

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CORRECTED INSTRUCTIONS: Please answer the following questions based on changes that have occurred since the patient first began to experience memory (i.e., cognitive) problems. **Select 1=Yes only if the symptom(s) has been present in the last month. Otherwise, select 0=No.** (NOTE: for the UDS, please administer the NPI-Q to all subjects.)

For each item marked **1=Yes**, rate the SEVERITY of the symptom (how it affects the patient):

1=**Mild** (noticeable, but not a significant change) 2=**Moderate** (significant, but not a dramatic change) 3=**Severe** (very marked or prominent; a dramatic change)

					SEVERITY				
		Yes	No	Unknown	Mild	Mod	Severe	Unknown	
6. Anxiety — Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	6a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	6b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
7. Elation/euphoria — Does the patient appear to feel too good or act excessively happy?	7a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	7b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
8. Apathy/indifference — Does the patient seem less interested in his/her usual activities or in the activities and plans of others?	8a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	8b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
9. Disinhibition — Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?	9a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	9b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
10. Irritability/lability — Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?	10a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	10b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
11. Motor disturbance — Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	11a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	11b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
12. Nighttime behaviors — Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	12a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	12b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
13. Appetite/eating — Has the patient lost or gained weight, or had a change in the type of food he/she likes?	13a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	13b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B6: BEHAVIORAL ASSESSMENT — Geriatric Depression Scale (GDS)¹

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional, based on subject response. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B6. Check only one answer per question.

Check this box and enter "88" below for the Total GDS Score **if and only if** the subject: 1.) does not attempt the GDS, or 2.) answers fewer than 12 questions.

Instruct the subject: "In the next part of this interview, I will ask you questions about your feelings. Some of the questions I will ask you may not apply, and some may make you feel uncomfortable. For each question, please answer "yes" or "no," depending on how you have been feeling **in the past week, including today.**"

	Yes	No	Did not answer
1. Are you basically satisfied with your life?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2. Have you dropped many of your activities and interests?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
3. Do you feel that your life is empty?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
4. Do you often get bored?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
5. Are you in good spirits most of the time?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
6. Are you afraid that something bad is going to happen to you?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
7. Do you feel happy most of the time?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
8. Do you often feel helpless?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
9. Do you prefer to stay at home, rather than going out and doing new things?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
10. Do you feel you have more problems with memory than most?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
11. Do you think it is wonderful to be alive now?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
12. Do you feel pretty worthless the way you are now?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
13. Do you feel full of energy?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14. Do you feel that your situation is hopeless?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
15. Do you think that most people are better off than you are?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9

16. **Sum all checked answers for a Total GDS Score** (max score=15; did not complete=88) _____

¹Sheikh JI, Yesavage JA. Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontology: A Guide to Assessment and Intervention* 165-173, NY: The Haworth Press, 1986. Reproduced by permission of the publisher.

Form B7: FUNCTIONAL ASSESSMENT NACC Functional Assessment Scale (FAS¹)

ADC name: _____ Subject ID: _____ Form date: ____/____/____ Visit #: ____ Examiner's initials: ____

INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional, based on information provided by the co-participant. For further information, see UDS Coding Guidebook for Follow-up Visit Packet, Form B7. Indicate the level of performance for each activity by checking the one appropriate response.

<i>In the past four weeks, did the subject have difficulty or need help with:</i>	Not applicable (e.g., never did)	Normal	Has difficulty, but does by self	Requires assistance	Dependent	Unknown
1. Writing checks, paying bills, or balancing a checkbook	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
2. Assembling tax records, business affairs, or other papers	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
3. Shopping alone for clothes, household necessities, or groceries	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
4. Playing a game of skill such as bridge or chess, working on a hobby	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
5. Heating water, making a cup of coffee, turning off the stove	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
6. Preparing a balanced meal	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
7. Keeping track of current events	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
8. Paying attention to and understanding a TV program, book, or magazine	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
9. Remembering appointments, family occasions, holidays, medications	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
10. Traveling out of the neighborhood, driving, or arranging to take public transportation	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9

¹Adapted from table 4 of Pfeffer RI, Kurosaki TT, Harrah CH, et al. Measurement of functional activities of older adults in the community. J Gerontol 37:323-9, 1982. Copyright© 1982. The Gerontological Society of America. Reproduced by permission of the publisher.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B8: EVALUATION FORM Neurological Examination Findings

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form must be completed by a clinician with experience in assessing the neurological signs listed below and in attributing the observed findings to a particular syndrome. Please use your best clinical judgment in assigning the syndrome. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B8.

1. Were there abnormal neurological exam findings?

- 0 No abnormal findings (**END FORM HERE**)
- 1 Yes — abnormal findings were consistent with syndromes listed in Questions 2–8
- 2 Yes — abnormal findings were consistent with age-associated changes or irrelevant to dementing disorders (e.g., Bell's palsy) (**SKIP TO QUESTION 8**)

INSTRUCTIONS FOR QUESTIONS 2 – 8

Please complete the appropriate sections below, using your best clinical judgment in selecting findings that indicate the likely syndrome(s) that is/are present.

CHECK ALL OF THE GROUPS OF FINDINGS / SYNDROMES THAT WERE PRESENT:

2. Parkinsonian signs

- 0 No (**SKIP TO QUESTION 3**)
- 1 Yes

Findings not marked Yes or Not assessed will default to No in the NACC database.

Parkinsonian signs	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
2a. Resting tremor — arm	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
2b. Slowing of fine motor movements	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
2c. Rigidity — arm	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	Yes	Not assessed
2d. Bradykinesia	<input type="checkbox"/> 1	<input type="checkbox"/> 8
2e. Parkinsonian gait disorder	<input type="checkbox"/> 1	<input type="checkbox"/> 8
2f. Postural instability	<input type="checkbox"/> 1	<input type="checkbox"/> 8

Please complete the appropriate sections below, using your best clinical judgment in selecting findings that indicate the likely syndrome(s) that is/are present.

3. Neurological signs considered by examiner to be most likely consistent with cerebrovascular disease

0 No (SKIP TO QUESTION 4) 1 Yes

Findings not marked Yes or Not assessed will default to No in the NACC database.

Findings consistent with stroke/cerebrovascular disease	PRESENT	
	Yes	Not assessed
3a. Cortical cognitive deficit (e.g., aphasia, apraxia, neglect)	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3b. Focal or other neurological findings consistent with SIVD (subcortical ischemic vascular dementia)	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
3c. Motor (may include weakness of combinations of face, arm, and leg; reflex changes; etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3d. Cortical visual field loss	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3e. Somatosensory loss	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8

4. Higher cortical visual problem suggesting posterior cortical atrophy (e.g., prosopagnosia, simultagnosia, Balint's syndrome) or apraxia of gaze

0 No 1 Yes

5. Findings suggestive of progressive supranuclear palsy (PSP), corticobasal syndrome, or other related disorders

0 No (SKIP TO QUESTION 6) 1 Yes

Findings not marked Yes or Not assessed will default to No in the NACC database.

Findings	PRESENT	
	Yes	Not assessed
5a. Eye movement changes consistent with PSP	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5b. Dysarthria consistent with PSP	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5c. Axial rigidity consistent with PSP	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5d. Gait disorder consistent with PSP	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5e. Apraxia of speech	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
5f. Apraxia consistent with CBS	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5g. Cortical sensory deficits consistent with CBS	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5h. Ataxia consistent with CBS	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5i. Alien limb consistent with CBS	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5j. Dystonia consistent with CBS, PSP, or related disorder	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5k. Myoclonus consistent with CBS	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8

Please complete the appropriate sections below, using your best clinical judgment in selecting findings that indicate the likely syndrome(s) that is/are present.

6. Findings suggesting ALS (e.g., muscle wasting, fasciculations, upper motor neuron and/or lower motor neuron signs) 0 No 1 Yes**7. Normal-pressure hydrocephalus: gait apraxia** 0 No 1 Yes**8. Other findings (e.g., cerebellar ataxia, chorea, myoclonus)**

(NOTE: For this question, do not specify symptoms that have already been checked above)

 0 No 1 Yes (SPECIFY): _____

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B9: Clinician Judgment of Symptoms

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B9. Check only one box per question.

Declines in memory reported by subject and co-participant			
1. Does the subject report a decline in memory (relative to previously attained abilities)?	<input type="checkbox"/> 0 No		
	<input type="checkbox"/> 1 Yes		
	<input type="checkbox"/> 8 Could not be assessed/subject is too impaired		
2. Does the co-participant report a decline in the subject's memory (relative to previously attained abilities)?	<input type="checkbox"/> 0 No		
	<input type="checkbox"/> 1 Yes		
	<input type="checkbox"/> 8 There is no co-participant		
Cognitive symptoms			
3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition?	<input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 8)		
	<input type="checkbox"/> 1 Yes		
4. Indicate whether the subject currently is meaningfully impaired, <i>relative to previously attained abilities</i> , in the following cognitive domains, or has fluctuating cognition:		No	Yes
			Unknown
4a. Memory For example, does s/he forget conversations and/or dates, repeat questions and/or statements, misplace things more than usual, forget names of people s/he knows well?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4b. Orientation For example, does s/he have trouble knowing the day, month, and year, or not recognize familiar locations, or get lost in familiar locations?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4c. Executive function — judgment, planning, problem-solving Does s/he have trouble handling money (e.g., tips), paying bills, preparing meals, shopping, using appliances, handling medications, driving?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4d. Language Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4e. Visuospatial function Does s/he have difficulty interpreting visual stimuli and finding his/her way around?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4f. Attention, concentration Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4g. Fluctuating cognition Does the subject exhibit pronounced variation in attention and alertness, noticeably over hours or days — for example, long lapses or periods of staring into space, or times when his/her ideas have a disorganized flow?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4g1. If yes, at what age did the fluctuating cognition begin? _____ (777 = Age of onset provided at a previous UDS visit.) (The clinician must use his/her best judgment to estimate an age of onset.)			
4h. Other (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B9. Check only one box per question.

<p>5. Indicate the predominant symptom that was first recognized as a decline in the subject's cognition: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p>	<p><input type="checkbox"/> 0 Assessed at a previous UDS visit</p> <p><input type="checkbox"/> 1 Memory</p> <p><input type="checkbox"/> 2 Orientation</p> <p><input type="checkbox"/> 3 Executive function — judgment, planning, problem-solving</p> <p><input type="checkbox"/> 4 Language</p> <p><input type="checkbox"/> 5 Visuospatial function</p> <p><input type="checkbox"/> 6 Attention/concentration</p> <p><input type="checkbox"/> 7 Fluctuating cognition</p> <p><input type="checkbox"/> 8 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 99 Unknown</p>
<p>6. Mode of onset of cognitive symptoms</p>	<p><input type="checkbox"/> 1 Gradual</p> <p><input type="checkbox"/> 2 Subacute</p> <p><input type="checkbox"/> 3 Abrupt</p> <p><input type="checkbox"/> 4 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 99 Unknown</p>

7. Based on the clinician's assessment, at what age did the cognitive decline begin? _____
(777 = Age of cognitive decline entered at a previous UDS visit)
 (The clinician must use her/his best judgment to estimate an age of onset of cognitive decline.)

Behavioral symptoms

8. Based on the clinician's judgment, is the subject currently experiencing any kind of behavioral symptoms? 0 No (If No, **SKIP TO QUESTION 13**)
 1 Yes

9. Indicate whether the subject currently manifests meaningful change in behavior in any of the following ways:

	No	Yes	Unknown
9a. Apathy, withdrawal Has the subject lost interest in or displayed a reduced ability to initiate usual activities and social interaction, such as conversing with family and/or friends?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9b. Depressed mood Has the subject seemed depressed for more than two weeks at a time, e.g., shown loss of interest or pleasure in nearly all activities, sadness, hopelessness, loss of appetite, fatigue?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c. Psychosis			
9c1. Visual hallucinations	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c1a. If yes, are the hallucinations well formed and detailed?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c1b. If well formed and clear-cut, at what age did these visual hallucinations begin? _____ <i>(777 = Age of onset provided at a previous UDS visit; 888 = N/A, not well-formed)</i> (The clinician must use his/her best judgment to estimate age of onset)			
9c2. Auditory hallucinations	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c3. Abnormal, false, or delusional beliefs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9d. Disinhibition Does the subject use inappropriate coarse language or exhibit inappropriate speech or behaviors in public or in the home? Does s/he talk personally to strangers or have disregard for personal hygiene?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9e. Irritability Does the subject overreact, e.g., by shouting at family members or others?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B9. Check only one box per question.

9f. Agitation Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9g. Personality change Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9h. REM sleep behavior disorder While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)? 9h1. If yes, at what age did the REM sleep behavior disorder begin? _____ (777 = Age of onset provided at a previous UDS visit.) (The clinician must use his/her best judgment to estimate an age of onset)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9i. Anxiety For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9j. Other (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
10. Indicate the predominant symptom that was first recognized as a decline in the subject's behavior: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i>	<input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Apathy/withdrawal <input type="checkbox"/> 2 Depressed mood <input type="checkbox"/> 3 Psychosis <input type="checkbox"/> 4 Disinhibition <input type="checkbox"/> 5 Irritability <input type="checkbox"/> 6 Agitation <input type="checkbox"/> 7 Personality change <input type="checkbox"/> 8 REM sleep behavior disorder <input type="checkbox"/> 9 Anxiety <input type="checkbox"/> 10 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown		
11. Mode of onset of behavioral symptoms:	<input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <input type="checkbox"/> 4 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown		
12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? (777 = Age of onset provided at a previous UDS visit.) (The clinician must use her/his best judgment to estimate age of onset of behavioral symptoms.)	_____		
Motor symptoms			
13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms?	<input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 20) <input type="checkbox"/> 1 Yes		
14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas:	No	Yes	Unknown
14a. Gait disorder Has subject's walking changed, not specifically due to arthritis or an injury? Is s/he unsteady, or does s/he shuffle when walking, have little or no arm-swing, or drag a foot?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14b. Falls Does the subject fall more than usual?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14c. Tremor Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14d. Slowness Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B9. Check only one box per question.

<p>15. Indicate the predominant symptom that was first recognized as a decline in the subject's motor function: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p>	<p><input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Gait disorder <input type="checkbox"/> 2 Falls <input type="checkbox"/> 3 Tremor <input type="checkbox"/> 4 Slowness <input type="checkbox"/> 99 Unknown</p>
<p>16. Mode of onset of motor symptoms:</p>	<p><input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <input type="checkbox"/> 4 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown</p>
<p>17. Were changes in motor function suggestive of parkinsonism?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown If No or Unknown, SKIP TO QUESTION 18</p>
<p>17a. If yes, at what age did the motor changes suggestive of parkinsonism begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p>	
<p>18. Were changes in motor function suggestive of amyotrophic lateral sclerosis?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown If No or Unknown, SKIP TO QUESTION 19</p>
<p>18a. If yes, at what age did the motor changes suggestive of ALS begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p>	
<p>19. Based on the clinician's assessment, at what age did the motor changes begin? (The clinician must use her/his best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p>	
<p>Overall course of decline and predominant domain</p>	
<p>20. Overall course of decline of cognitive/behavioral/ motor syndrome:</p>	<p><input type="checkbox"/> 1 Gradually progressive <input type="checkbox"/> 2 Stepwise <input type="checkbox"/> 3 Static <input type="checkbox"/> 4 Fluctuating <input type="checkbox"/> 5 Improved <input type="checkbox"/> 8 N/A <input type="checkbox"/> 9 Unknown</p>
<p>21. Indicate the predominant domain that was first recognized as changed in the subject: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p>	<p><input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Cognition <input type="checkbox"/> 2 Behavior <input type="checkbox"/> 3 Motor function <input type="checkbox"/> 8 N/A <input type="checkbox"/> 9 Unknown</p>

Candidate for further evaluation for Lewy body disease or frontotemporal lobar degeneration

22. Is the subject a potential candidate for further evaluation for Lewy body disease?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form C1: Neuropsychological Battery Summary Scores

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by ADC or clinic staff. For test administration and scoring, see Instructions for Neuropsychological Battery Form C1.

PROTOCOL FOR ADMINISTERING the neuropsychological battery for UDS Version 3 FVP (using either Form C1 or Form C2): **For subjects who had already been seen for one or more UDS visits before the implementation of Version 3, you may:**

- a.) continue to follow those subjects with the old neuropsychological battery (Form C1);
- OR-**
- b.) switch those subjects to the new neuropsychological battery (Form C2).

A given subject may be switched to the new battery at any time after Version 3 implementation, at the Center's discretion.

KEY: If the subject cannot complete any of the following tests, please give the reason by entering one of the following codes: **95 / 995 = Physical problem** **96 / 996 = Cognitive/behavior problem** **97 / 997 = Other problem** **98 / 998 = Verbal refusal**

1. Mini-Mental State Examination	
1. Was any part of the MMSE completed?	<input type="checkbox"/> 0 No (<i>Enter reason code, 95–98, and SKIP TO QUESTION 2a</i>): _____ <input type="checkbox"/> 1 Yes (CONTINUE TO QUESTION 1a)
1a. Administration of the MMSE was:	<input type="checkbox"/> 1 In ADC/clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other
1a1. Language of MMSE administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____
1b. Subject was unable to complete one or more sections due to visual impairment	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1c. Subject was unable to complete one or more sections due to hearing impairment	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

KEY: 95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

1d. Orientation subscale score		
1d1. Time:	_____	(0–5, 95–98)
1d2. Place:	_____	(0–5, 95–98)
1e. Intersecting pentagon subscale score:	_____	(0–1, 95–98)
1f. Total MMSE score (using D-L-R-O-W) <i>(If any of the MMSE items are 95–98, enter 88):</i>	_____	(0–30, 88)
2. Administration of the remainder of the battery		
2a. The remainder of the battery (i.e., the tests summarized below) was administered:	<input type="checkbox"/> 1 In ADC/clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other	
2b. Language of test administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____	
3. Logical Memory IA — Immediate		
3a. If this test has been administered to the subject within the past three months, specify the date previously administered:	_____ / _____ / _____	(88/88/8888=N/A)
3a1. Total score from the previous test administration:	_____	(0–25; 88=N/A)
3b. Total number of story units recalled from this current test administration:	_____	(0–25, 95–98)
4. Benson Complex Figure Copy		
4a. Total score for copy of Benson figure:	_____	(0–17, 95–98)
5. Digit Span Forward		
5a. Total number of trials correct before two consecutive errors at same digit length: <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 6a)</i>	_____	(0–12, 95–98)
5b. Digit span forward length:	_____	(0–8)
6. Digit Span Backward		
6a. Total number of trials correct before two consecutive errors at same digit length: <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 7a)</i>	_____	(0–12, 95–98)
6b. Digit span backward length:	_____	(0–7)
7. Category Fluency		
7a. Animals: Total number of animals named in 60 seconds:	_____	(0–77, 95–98)
7b. Vegetables: Total number of vegetables named in 60 seconds:	_____	(0–77, 95–98)

KEY: 95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

8. Trail Making Test		
8a. PART A: Total number of seconds to complete (if not finished by 150 seconds, enter 150): <i>(If test not completed, enter reason code, 995–998, and SKIP TO QUESTION 8b)</i>	_____	(0–150, 995–998)
8a1. Number of commission errors:	_____	(0–40)
8a2. Number of correct lines:	_____	(0–24)
8b. PART B: Total number of seconds to complete (if not finished by 300 seconds, enter 300): <i>(If test not completed, enter reason code, 995–998, and SKIP TO QUESTION 9a)</i>	_____	(0–300, 995–998)
8b1. Number of commission errors:	_____	(0–40)
8b2. Number of correct lines:	_____	(0–24)
9. Logical Memory IIA — Delayed		
9a. Total number of story units recalled: <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 10a)</i>	_____	(0–25, 95–98)
9b. Time elapsed since Logical Memory IA — Immediate:	_____	(0–85 minutes) (99=Unknown)
10. Benson Complex Figure Recall		
10a. Total score for 10- to 15-minute delayed drawing of Benson figure: <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 11a)</i>	_____	(0–17, 95–98)
10b. Recognized original stimulus from among four options?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
11. Boston Naming Test (30 odd-numbered items)		
11a. Total score:	_____	(0–30, 95–98)
12. Verbal Fluency: Phonemic Test		
12a. Number of correct F-words generated in 1 minute <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 12d)</i>	_____	(0–40, 95–98)
12b. Number of F-words repeated in 1 minute	_____	(0–15)
12c. Number of non-F-words and rule violation errors in 1 minute	_____	(0–15)
12d. Number of correct L-words generated in 1 minute <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 13a)</i>	_____	(0–40, 95–98)
12e. Number of L-words repeated in one minute	_____	(0–15)
12f. Number of non-L-words and rule violation errors in 1 minute	_____	(0–15)
12g. TOTAL number of correct F-words and L-words	_____	(0–80)
12h. TOTAL number of F-word and L-word repetition errors	_____	(0–30)
12i. TOTAL number of non-F/L words and rule violation errors	_____	(0–30)

13. Overall appraisal

13a. Per the clinician (e.g., neuropsychologist, behavioral neurologist, or other suitably qualified clinician), based on the UDS neuropsychological examination, the subject's cognitive status is deemed:

- 1 Better than normal for age
- 2 Normal for age
- 3 One or two test scores are abnormal
- 4 Three or more scores are abnormal or lower than expected
- 0 Clinician unable to render opinion

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form C2: Neuropsychological Battery Scores

ADC name: _____ Subject ID: _____ Form date: ____/____/____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by ADC or clinic staff. For test administration and scoring, see Instructions for Neuropsychological Battery Form C2. Any new subjects who enroll in the UDS after the implementation of UDS3 must be assessed with the new neuropsychological test battery (Form C2).

KEY: If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:

95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

1. Montreal Cognitive Assessment (MoCA)	
1a. Was any part of the MoCA administered?	
<input type="checkbox"/> 0 No (If No, enter reason code, 95 – 98): ____ (SKIP TO QUESTION 2a)	
<input type="checkbox"/> 1 Yes (CONTINUE WITH QUESTION 1b)	
1b. MoCA was administered:	<input type="checkbox"/> 1 In ADC or clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other
1c. Language of MoCA administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____
1d. Subject was unable to complete one or more sections due to visual impairment:	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1e. Subject was unable to complete one or more sections due to hearing impairment:	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1f. TOTAL RAW SCORE — UNCORRECTED (Not corrected for education or visual/hearing impairment)	
<i>Enter 88 if any of the following MoCA items were not administered: 1g–1l, 1n–1t, 1w–1bb</i>	____ (0–30, 88)
1g. Visuospatial/executive — Trails	____ (0–1, 95–98)
1h. Visuospatial/executive — Cube	____ (0–1, 95–98)
1i. Visuospatial/executive — Clock contour	____ (0–1, 95–98)
1j. Visuospatial/executive — Clock numbers	____ (0–1, 95–98)
1k. Visuospatial/executive — Clock hands	____ (0–1, 95–98)
1l. Language — Naming	____ (0–3, 95–98)
1m. Memory — Registration (two trials)	____ (0–10, 95–98)
1n. Attention — Digits	____ (0–2, 95–98)
1o. Attention — Letter A	____ (0–1, 95–98)

KEY: 95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

1p. Attention — Serial 7s	__ __ (0-3, 95-98)
1q. Language — Repetition	__ __ (0-2, 95-98)
1r. Language — Fluency	__ __ (0-1, 95-98)
1s. Abstraction	__ __ (0-2, 95-98)
1t. Delayed recall — No cue	__ __ (0-5, 95-98)
1u. Delayed recall — Category cue	__ __ (0-5; 88=Not applicable)
1v. Delayed recall — Recognition	__ __ (0-5; 88=Not applicable)
1w. Orientation — Date	__ __ (0-1, 95-98)
1x. Orientation — Month	__ __ (0-1, 95-98)
1y. Orientation — Year	__ __ (0-1, 95-98)
1z. Orientation — Day	__ __ (0-1, 95-98)
1aa. Orientation — Place	__ __ (0-1, 95-98)
1bb. Orientation — City	__ __ (0-1, 95-98)
2. ADMINISTRATION OF THE REMAINDER OF THE BATTERY	
2a. The tests following the MoCA were administered: <input type="checkbox"/> 1 In ADC or clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other	
2b. Language of test administration: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____	
3. Craft Story 21 Recall (Immediate)	
3a. Total story units recalled, verbatim scoring (If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 4a.)	__ __ (0-44, 95-98)
3b. Total story units recalled, paraphrase scoring	__ __ (0-25)
4. Benson Complex Figure Copy	
4a. Total score for copy of Benson figure (If test not completed, enter reason code, 95-98)	__ __ (0-17, 95-98)
5. Number Span Test: Forward	
5a. Number of correct trials (If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 6a.)	__ __ (0-14, 95-98)
5b. Longest span forward	__ __ (0, 3-9)

KEY: 95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

6. Number Span Test: Backward	
6a. Number of correct trials <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 7a.)</i>	__ __ (0–14, 95–98)
6b. Longest span backward	__ __ (0, 2–8)
7. Category Fluency	
7a. Animals: Total number of animals named in 60 seconds <i>(If test not completed, enter reason code, 95–98)</i>	__ __ (0–77, 95–98)
7b. Vegetables: Total number of vegetables named in 60 seconds <i>(If test not completed, enter reason code, 95–98)</i>	__ __ (0–77, 95–98)
8. Trail Making Test	
8a. PART A: Total number of seconds to complete (if not finished by 150 seconds, enter 150) <i>(If test not completed, enter reason code, 995–998, and SKIP TO QUESTION 8b.)</i>	__ __ __ (0–150, 995–998)
8a1. Number of commission errors	__ __ (0–40)
8a2. Number of correct lines	__ __ (0–24)
8b. PART B: Total number of seconds to complete (if not finished by 300 seconds, enter 300) <i>(If test not completed, enter reason code, 995–998, and SKIP TO QUESTION 9a.)</i>	__ __ __ (0–300, 995–998)
8b1. Number of commission errors	__ __ (0–40)
8b2. Number of correct lines	__ __ (0–24)
9. Craft Story 21 Recall (Delayed)	
9a. Total story units recalled, verbatim scoring <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 10a.)</i>	__ __ (0–44, 95–98)
9b. Total story units recalled, paraphrase scoring	__ __ (0–25)
9c. Delay time (minutes) <i>(99=Unknown)</i>	__ __ (0 – 85 minutes)
9d. Cue (“boy”) needed	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
10. Benson Complex Figure Recall	
10a. Total score for drawing of Benson figure following 10- to 15-minute delay <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 11a.)</i>	__ __ (0–17, 95–98)
10b. Recognized original stimulus from among four options?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

KEY: 95 / 995 = Physical problem 96 / 996 = Cognitive/behavior problem 97 / 997 = Other problem 98 / 998 = Verbal refusal

11. Multilingual Naming Test (MINT)

11a. Total score
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 12a**) _____ (0–32, 95–98)

11b. Total correct without semantic cue _____ (0–32)

11c. Semantic cues: Number given _____ (0–32)

11d. Semantic cues: Number correct with cue (88 = Not applicable) _____ (0–32, 88)

11e. Phonemic cues: Number given _____ (0–32)

11f. Phonemic cues: Number correct with cue (88 = Not applicable) _____ (0–32, 88)

12. Verbal Fluency: Phonemic Test

12a. Number of correct **F-words** generated in 1 minute
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 12d.**) _____ (0–40, 95–98)

12b. Number of **F-words** repeated in 1 minute _____ (0–15)

12c. Number of **non-F-words** and rule violation errors in 1 minute _____ (0–15)

12d. Number of correct **L-words** generated in 1 minute
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 13a.**) _____ (0–40, 95–98)

12e. Number of **L-words** repeated in one minute _____ (0–15)

12f. Number of **non-L-words** and rule violation errors in 1 minute _____ (0–15)

12g. TOTAL number of correct **F-words and L-words** _____ (0–80)

12h. TOTAL number of **F-word and L-word** repetition errors _____ (0–30)

12i. TOTAL number of **non-F/L words** and rule violation errors _____ (0–30)

13. Overall appraisal

- 13a. Per the clinician (e.g., neuropsychologist, behavioral neurologist, or other suitably qualified clinician), based on the UDS neuropsychological examination, the subject's cognitive status is deemed:
- 1 Better than normal for age
- 2 Normal for age
- 3 One or two test scores are abnormal
- 4 Three or more scores are abnormal or lower than expected
- 0 Clinician unable to render opinion

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form D1: Clinician Diagnosis

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form D1. Check only one box per question.

This form is divided into three main sections:

- Section 1 **Cognitive and behavioral status:** Normal cognition / MCI / dementia and dementia syndrome
- Section 2 **Biomarkers, imaging, and genetics:** Neurodegenerative imaging and CSF biomarkers, imaging evidence for CVD, and known genetic mutations for AD and FTLD
- Section 3 **Etiological diagnoses:** presumed etiological diagnoses for the cognitive disorder

1. Diagnosis method — responses in this form are based on diagnosis by:

- 1 A single clinician 2 A formal consensus panel 3 Other (e.g., two or more clinicians or other informal group)

SECTION 1: Cognitive and behavioral status

2. Does the subject have normal cognition (global CDR=0 and/or neuropsychological testing within normal range) and normal behavior (i.e., the subject does not exhibit behavior sufficient to diagnose MCI or dementia due to FTLD or LBD)?

- 0 No (**CONTINUE TO QUESTION 3**)
 1 Yes (**SKIP TO QUESTION 6**)

ALL-CAUSE DEMENTIA

The subject has cognitive or behavioral (neuropsychiatric) symptoms that meet all of the following criteria:

- Interfere with ability to function as before at work or at usual activities?
- Represent a decline from previous levels of functioning?
- Are not explained by delirium or major psychiatric disorder?
- Include cognitive impairment detected and diagnosed through a combination of 1) history-taking and 2) objective cognitive assessment (bedside or neuropsychological testing)?

AND

Impairment in one* or more of the following domains.

- Impaired ability to acquire and remember new information
- Impaired reasoning and handling of complex tasks, poor judgment
- Impaired visuospatial abilities
- Impaired language functions
- Changes in personality, behavior, or comporment

** In the event of single-domain impairment (e.g., language in PPA, behavior in bvFTD, posterior cortical atrophy), the subject must not fulfill criteria for MCI.*

3. Does the subject meet the criteria for dementia?

- 0 No (**SKIP TO QUESTION 5**)
 1 Yes (**CONTINUE TO QUESTION 4**)

4. If the subject meets criteria for dementia, answer Questions 4a–4f below and then SKIP TO QUESTION 6.

Based entirely on the history and examination (including neuropsychological testing), what is the cognitive/behavioral syndrome? **Select one or more as Present; all others will default to Absent in the NACC database.**

Dementia syndrome	Present
4a. Amnestic multidomain dementia syndrome	<input type="checkbox"/> 1
4b. Posterior cortical atrophy syndrome (or primary visual presentation)	<input type="checkbox"/> 1
4c. Primary progressive aphasia (PPA) syndrome	<input type="checkbox"/> 1
4c1. <input type="checkbox"/> 1 Meets criteria for semantic PPA <input type="checkbox"/> 2 Meets criteria for logopenic PPA <input type="checkbox"/> 3 Meets criteria for nonfluent/agrammatic PPA <input type="checkbox"/> 4 PPA other/not otherwise specified	
4d. Behavioral variant FTD (bvFTD) syndrome	<input type="checkbox"/> 1
4e. Lewy body dementia syndrome	<input type="checkbox"/> 1
4f. Non-amnestic multidomain dementia, not PCA, PPA, bvFTD, or DLB syndrome	<input type="checkbox"/> 1

5. If the subject does not have normal cognition or behavior and is not clinically demented, indicate the type of cognitive impairment below.

MCI CORE CLINICAL CRITERIA

- Is the subject, the co-participant, or a clinician concerned about a change in cognition compared to the subject's previous level?
- Is there impairment in one or more cognitive domains (memory, language, executive function, attention, and visuospatial skills)?
- Is there largely preserved independence in functional abilities (no change from prior manner of functioning or uses minimal aids or assistance)?

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5a. Amnestic MCI, single domain (aMCI SD)	<input type="checkbox"/> 1			
5b. Amnestic MCI, multiple domains (aMCI MD)	<input type="checkbox"/> 1	CHECK YES for at least one additional domain (besides memory): 5b1. Language 5b2. Attention 5b3. Executive 5b4. Visuospatial	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5c. Non-amnesic MCI, single domain (naMCI SD)	<input type="checkbox"/> 1	CHECK YES to indicate the affected domain: 5c1. Language 5c2. Attention 5c3. Executive 5c4. Visuospatial	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1
5d. Non-amnesic MCI, multiple domains (naMCI MD)	<input type="checkbox"/> 1	CHECK YES for at least two domains: 5d1. Language 5d2. Attention 5d3. Executive 5d4. Visuospatial	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1
5e. Cognitively impaired, not MCI	<input type="checkbox"/> 1			

SECTION 2: Biomarkers, imaging, and genetics

Section 2 must be completed for all subjects.

6. Indicate neurodegenerative biomarker status, using local standards for positivity.

Biomarker findings	No	Yes	Unknown/ not assessed
6a. Abnormally elevated amyloid on PET	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6b. Abnormally low amyloid in CSF	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6c. FDG-PET pattern of AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6d. Hippocampal atrophy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6e. Tau PET evidence for AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6f. Abnormally elevated CSF tau or ptau	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6g. FDG-PET evidence for frontal or anterior temporal hypometabolism for FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6h. Tau PET evidence for FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6i. Structural MR evidence for frontal or anterior temporal atrophy for FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6j. Dopamine transporter scan (DATscan) evidence for Lewy body disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6k. Other (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

7. Is there evidence for cerebrovascular disease (CVD) on imaging?

Imaging findings	No	Yes	Unknown/ not assessed
7a. Large vessel infarct(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7b. Lacunar infarct(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7c. Macrohemorrhage(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7d. Microhemorrhage(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7e. Moderate white-matter hyperintensity (CHS score 5–6)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7f. Extensive white-matter hyperintensity (CHS score 7–8+)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

8. Does the subject have a dominantly inherited AD mutation (PSEN1, PSEN2, APP)?

0 No 1 Yes 9 Unknown/not assessed

9. Does the subject have a hereditary FTLN mutation (e.g., GRN, VCP, TARBP, FUS, C9orf72, CHMP2B, MAPT)?

0 No 1 Yes 9 Unknown/not assessed

10. Does the subject have a hereditary mutation other than an AD or FTLN mutation?

0 No 1 Yes (SPECIFY): _____ 9 Unknown/not assessed

SECTION 3: Etiologic diagnoses

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician’s best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as 1=Primary.

For subjects with normal cognition: Indicate the presence of any diagnoses by marking Present, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer’s disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses marked as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses	Present	Primary	Contributing	Non-contributing
11. Alzheimer’s disease	<input type="checkbox"/> 1	11a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
12. Lewy body disease 12b. <input type="checkbox"/> 1 Parkinson’s disease	<input type="checkbox"/> 1	12a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
13. Multiple system atrophy	<input type="checkbox"/> 1	13a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14. Frontotemporal lobar degeneration				
14a. Progressive supranuclear palsy (PSP)	<input type="checkbox"/> 1	14a1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14b. Corticobasal degeneration (CBD)	<input type="checkbox"/> 1	14b1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14c. FTLN with motor neuron disease	<input type="checkbox"/> 1	14c1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14d. FTLN NOS	<input type="checkbox"/> 1	14d1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14e. If FTLN (Questions 14a – 14d) is Present, specify FTLN subtype: <input type="checkbox"/> 1 Tauopathy <input type="checkbox"/> 2 TDP-43 proteinopathy <input type="checkbox"/> 3 Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown				

SECTION 3: Etiologic diagnoses (cont.)

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1=Primary**.

For subjects with normal cognition: Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
15.	Vascular brain injury (based on clinical or imaging evidence) <i>If significant vascular brain injury is absent, SKIP TO QUESTION 16.</i>	<input type="checkbox"/> 1	15a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
15b.	Previous symptomatic stroke? <input type="checkbox"/> 0 No (SKIP TO QUESTION 15c) <input type="checkbox"/> 1 Yes				
15b1.	Temporal relationship between stroke and cognitive decline? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes				
15b2.	Confirmation of stroke by neuroimaging? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available				
15c.	Is there imaging evidence of cystic infarction in cognitive network(s)? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available				
15d.	Is there imaging evidence of cystic infarction, imaging evidence of extensive white matter hyperintensity (CHS grade 7–8+), <u>and</u> impairment in executive function? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available				
16.	Essential tremor	<input type="checkbox"/> 1	16a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
17.	Down syndrome	<input type="checkbox"/> 1	17a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
18.	Huntington's disease	<input type="checkbox"/> 1	18a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
19.	Prion disease (CJD, other)	<input type="checkbox"/> 1	19a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
20.	Traumatic brain injury 20b. If Present, does the subject have symptoms consistent with chronic traumatic encephalopathy? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<input type="checkbox"/> 1	20a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
21.	Normal-pressure hydrocephalus	<input type="checkbox"/> 1	21a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
22.	Epilepsy	<input type="checkbox"/> 1	22a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
23.	CNS neoplasm 23b. <input type="checkbox"/> 1 Benign <input type="checkbox"/> 2 Malignant	<input type="checkbox"/> 1	23a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
24.	Human immunodeficiency virus (HIV)	<input type="checkbox"/> 1	24a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
25.	Cognitive impairment due to other neurologic, genetic, or infectious conditions not listed above 25b. If Present, specify: _____	<input type="checkbox"/> 1	25a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1= Primary**.

For subjects with normal cognition: Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Condition	Present	Primary	Contributing	Non-contributing
26. Active depression 26b. If Present, select one: <input type="checkbox"/> 0 Untreated <input type="checkbox"/> 1 Treated with medication and/or counseling	<input type="checkbox"/> 1	26a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
27. Bipolar disorder	<input type="checkbox"/> 1	27a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
28. Schizophrenia or other psychosis	<input type="checkbox"/> 1	28a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
29. Anxiety disorder	<input type="checkbox"/> 1	29a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
30. Delirium	<input type="checkbox"/> 1	30a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
31. Post-traumatic stress disorder (PTSD)	<input type="checkbox"/> 1	31a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
32. Other psychiatric disease 32b. If Present, specify: _____	<input type="checkbox"/> 1	32a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

33. Cognitive impairment due to alcohol abuse 33b. Current alcohol abuse: <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<input type="checkbox"/> 1	33a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
34. Cognitive impairment due to other substance abuse	<input type="checkbox"/> 1	34a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
35. Cognitive impairment due to systemic disease/ medical illness (as indicated on Form D2)	<input type="checkbox"/> 1	35a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
36. Cognitive impairment due to medications	<input type="checkbox"/> 1	36a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
37. Cognitive impairment NOS 37b. If Present, specify: _____	<input type="checkbox"/> 1	37a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
38. Cognitive impairment NOS 38b. If Present, specify: _____	<input type="checkbox"/> 1	38a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
39. Cognitive impairment NOS 39b. If Present, specify: _____	<input type="checkbox"/> 1	39a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form D2: Clinician-assessed Medical Conditions

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by a physician, physician's assistant, nurse practitioner, or other qualified practitioner. For additional clarifications and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form D2.

Medical conditions and procedures

The following questions should be answered based on review of all available information, including new diagnoses made during the current visit, previous medical records, procedures, laboratory tests, and the clinical exam.

1. Cancer (excluding non-melanoma skin cancer), primary or metastatic

- 0 No **(SKIP TO QUESTION 2)**
- 1 Yes, primary/non-metastatic
- 2 Yes, metastatic
- 8 Not assessed **(SKIP TO QUESTION 2)**

1a. If yes, specify primary site: _____

If any of the conditions below are present (even if successfully treated), please check Yes.

2. Diabetes
- 0 No
 - 1 Yes, Type I
 - 2 Yes, Type II
 - 3 Yes, other type (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes)
 - 9 Not assessed or unknown

	No	Yes	Not assessed
3. Myocardial infarct	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4. Congestive heart failure	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5. Atrial fibrillation	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6. Hypertension	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7. Angina	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
8. Hypercholesterolemia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
9. B12 deficiency	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
10. Thyroid disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

<i>If any of the conditions below are present (even if successfully treated), please check Yes.</i>			
	No	Yes	Not assessed
11. Arthritis <i>If No or Not assessed, SKIP TO QUESTION 12</i> 11a. If yes, what type? <input type="checkbox"/> 1 Rheumatoid <input type="checkbox"/> 2 Osteoarthritis <input type="checkbox"/> 3 Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown 11b. If yes, regions affected (check at least one): 11b1. <input type="checkbox"/> 1 Upper extremity 11b2. <input type="checkbox"/> 1 Lower extremity 11b3. <input type="checkbox"/> 1 Spine 11b4. <input type="checkbox"/> 1 Unknown	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
12. Incontinence — urinary	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
13. Incontinence — bowel	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
14. Sleep apnea	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
15. REM sleep behavior disorder (RBD)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
16. Hyposomnia/insomnia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
17. Other sleep disorder 17a. (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
18. Carotid procedure: angioplasty, endarterectomy, or stent	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
19. Percutaneous coronary intervention: angioplasty and/or stent	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
20. Procedure: pacemaker and/or defibrillator	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
21. Procedure: heart valve replacement or repair	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
22. Antibody-mediated encephalopathy 22a. Specify antibody: _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
23. Other medical conditions or procedures not listed above 23a. (IF YES, SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	