NACC UNIFORM DATA SET

Follow-up Visit Packet

Version 3.0, March 2015

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
2020-11-10	Added new allowable code 777=BP Addendum submitted	B1	Q3	
2020-11-10	Added optional Form B1a, Blood Pressure Addendum	B1, B1a		
2019-03-29	Name of CDR® Dementia Staging Instrument revised to comply with trademark	B4, Z1X	N/A	N/Q
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

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

Form Z1X: Form Checklist

NACC National Alzheimer's Coordinating Center

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: English	Language: Spanish	Description	Submitted: Yes	Submitted: No	If not submitted, specify reason (see KEY):
A1	☐ 1	☐ 2	Subject Demographics	Required		
A2	☐ 1	☐ 2	Co-participant Demographics	☐ 1	☐ 0	_ _
A3	☐ 1	☐ 2	Subject Family History	☐ 1	☐ 0	_ _
A4	☐ 1	☐ 2	Subject Medications	☐ 1	☐ 0	_ _
B1	☐ 1	☐ 2	EVALUATION FORM Physical	☐ 1	☐ 0	_ _
B4	☐ 1	☐ 2	CDR® Plus NACC FTLD	Required		
B5	☐ 1	☐ 2	BEHAVIORAL ASSESSMENT NPI-Q	☐ 1	☐ 0	_ _
B6	☐ 1	☐ 2	BEHAVIORAL ASSESSMENT GDS	☐ 1	☐ 0	_ _
B7	☐ 1	☐ 2	FUNCTIONAL ASSESSMENT NACC FAS	☐ 1	☐ 0	_ _
B8	☐ 1	☐ 2	EVALUATION FORM Neurological Examination Findings	Required		
B9	☐ 1	☐ 2	Clinician Judgment of Symptoms	Required		
C1	☐ 1	☐ 2	Neuropsychological Battery Summary Scores	Either C1 or C2 is required		
C2	☐ 1	☐ 2	Neuropsychological Battery Scores			
D1	☐ 1	☐ 2	Clinician Diagnosis	Required		
D2	☐ 1	☐ 2	Clinician-assessed Medical Conditions	Required		

FTLD MODULE

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

CLS FORM

Form	Language: English	Language: Spanish	Description	Submitted: Yes	Submitted: No	
CLS	☐ 1	☐ 2	Subject's Language History	☐ 1	☐ 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.**

LBD MODULE V3.0 — ORIGINAL VERSION

Form	Description	Submitted: Yes No
B1L	Clinical Symptoms and Exam	Required
B2L	UPDRS II: Activities of Daily Living	Required
B3L	UPDRS III: Motor Examination	Required
B4L	Neuropsychiatric Inventory (NPI)	Required
B5L	Mayo Fluctuations Scale	Required
B6L	Mayo Sleep Questionnaire — Participant	Required
B7L	Mayo Sleep Questionnaire — Co-participant	Required
B8L	Scopa Sleep — Participant	Required
B9L	Scopa Sleep — Co-participant	Required
C1L	Neuropsychological Battery Summary Scores	Required
E1L	Genetics	Required
E2L	Neuroimaging Available and Findings	Required
E3L	Other Labs and Findings	Required
D1L	Clinical DLB and PD Features	Required

LBD MODULE V3.1 — SHORT VERSION

Form	Description	Submitted: Yes No	If not submitted, specify reason (see KEY)*:
B1L	Clinical Symptoms and Exam	Required	
B2L	UPDRS II: Activities of Daily Living	☐1 ☐0	— —
B3L	UPDRS III: Motor Examination	Required	
B4L	Neuropsychiatric Inventory (NPI)	Required	
B5L	Mayo Fluctuations Scale	Required	
B6L	Mayo Sleep Questionnaire — Participant	☐1 ☐0	— —
B7L	Mayo Sleep Questionnaire — Co-participant	Required	
B9L	Scopa Sleep — Co-participant	Required	
C1L	Neuropsychological Battery Summary Scores	Required	
E1L	Genetics	Required	
E2L	Neuroimaging Available and Findings	Required	
E3L	Other Labs and Findings	Required	
D1L	Clinical DLB and PD Features	Required	

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 current marital status:	☐1 Married ☐2 Widowed ☐3 Divorced ☐4 Separated ☐5 Never married (or marriage was annulled) ☐6 Living as married/domestic partner ☐9 Unknown
3. Subject's sex:	☐1 Male ☐2 Female
4. What is the subject's living situation?	☐1 Lives alone ☐2 Lives with one other person: a spouse or partner ☐3 Lives with one other person: a relative, friend, or roommate ☐4 Lives with caregiver who is not spouse/partner, relative, or friend ☐5 Lives with a group (related or not related) in a private residence ☐6 Lives in a group home (e.g., assisted living, nursing home, or convent) ☐9 Unknown
5. What is the subject's level of independence?	☐1 Able to live independently ☐2 Requires some assistance with complex activities ☐3 Requires some assistance with basic activities ☐4 Completely dependent ☐9 Unknown
6. What is the subject's primary type of residence?	☐1 Single- or multi-family private residence (apartment, condo, house) ☐2 Retirement community or independent group living ☐3 Assisted living, adult family home, or boarding home ☐4 Skilled nursing facility, nursing home, hospital, or hospice ☐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:	☐ 1 Male ☐ 2 Female
3. Is this a new co-participant — i.e., one who was not a co-participant at any past UDS visit?	☐ 0 No (If No, **SKIP TO QUESTION 9**) ☐ 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?	☐ 0 No (If No, **SKIP TO QUESTION 5**) ☐ 1 Yes ☐ 9 Unknown (If Unknown, **SKIP TO QUESTION 5**)
4a. If yes, what are the co-participant's reported origins?	☐ 1 Mexican, Chicano, or Mexican-American ☐ 2 Puerto Rican ☐ 3 Cuban ☐ 4 Dominican ☐ 5 Central American ☐ 6 South American ☐ 50 Other (SPECIFY): _____ ☐ 99 Unknown
5. What does the co-participant report as his or her race?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or other Pacific Islander ☐ 5 Asian ☐ 50 Other (SPECIFY): _____ ☐ 99 Unknown
6. What additional race does the co-participant report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or other Pacific Islander ☐ 5 Asian ☐ 50 Other (SPECIFY): _____ ☐ 88 None reported ☐ 99 Unknown

7. What additional race, beyond those reported in Questions 5 and 6, does the co-participant report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or other Pacific Islander ☐ 5 Asian ☐ 50 Other (SPECIFY): _____ ☐ 88 None reported ☐ 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?	☐ 1 Spouse, partner, or companion (include ex-spouse, ex-partner, fiancé(e), boyfriend, girlfriend) ☐ 2 Child (by blood or through marriage or adoption) ☐ 3 Sibling (by blood or through marriage or adoption) ☐ 4 Other relative (by blood or through marriage or adoption) ☐ 5 Friend, neighbor, or someone known through family, friends, work, or community (e.g., church) ☐ 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?	☐ 0 No ☐ 1 Yes (If Yes, **SKIP TO QUESTION 11**)
10a. If no, approximate frequency of in-person visits?	☐ 1 Daily ☐ 2 At least three times per week ☐ 3 Weekly ☐ 4 At least three times per month ☐ 5 Monthly ☐ 6 Less than once a month
10b. If no, approximate frequency of telephone contact?	☐ 1 Daily ☐ 2 At least three times per week ☐ 3 Weekly ☐ 4 At least three times per month ☐ 5 Monthly ☐ 6 Less than once a month
11. Is there a question about the co-participant's reliability?	☐ 0 No ☐ 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?	☐ 0 No **(SKIP TO QUESTION 5)** ☐ 1 Yes ☐ 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.	☐ 0 No (**SKIP TO QUESTION 3a**) ☐ 1 Yes, APP ☐ 2 Yes, PS-1 (PSEN 1) ☐ 3 Yes, PS-2 (PSEN 2) ☐ 8 Yes, other (SPECIFY): _____ ☐ 9 Unknown whether mutation exists (**SKIP TO QUESTION 3a**)
2b. Source of evidence for AD mutation (check one):	☐ 1 Family report (no test documentation available) ☐ 2 Commercial test documentation ☐ 3 Research lab test documentation ☐ 8 Other (SPECIFY): _____ ☐ 9 Unknown

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

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**

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

**APPENDIX 1: PRIMARY DIAGNOSIS CODES

040	Mild cognitive impairment (MCI), not otherwise specified
041	MCI — single domain amnestic
042	MCI — multiple domain with amnesia
043	MCI — single domain nonamnestic
044	MCI — multiple domain nonamnestic
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 *(acceptable if method of evaluation is not by autopsy, examination, or dementia evaluation)*

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

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

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

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

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

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

	Medication name	DrugID
☐	ibuprofen (Advil, Motrin, Nuprin)	d00015
☐	loratadine (Alavert, Claritin, Dimetapp, Tavist)	d03050
☐	melatonin (Melatonin, Melatonin Time Release)	d04058
☐	multivitamin	d03140
☐	multivitamin with minerals	d03145
☐	polyethylene glycol 3350 (Miralax)	d05350
☐	psyllium (Fiberall, Metamucil)	d01018
☐	pyroxidine (Vitamin B6)	d00412
☐	ubiquinone (Co Q-10)	d04523
☐	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 __ __ __ __ __

☐ (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)	_ _ . _ *(88.8=not assessed)*			
2. Subject weight (lbs.)	_ _ _ *(888=not assessed)*			
3. Subject blood pressure at initial reading (sitting)	_ _ _ / _ _ _ *(888/888=not assessed, 777/777=BP Addendum submitted)*			
4. Subject resting heart rate (pulse)	_ _ _ *(888=not assessed)*			
Additional physical observations		**No**	**Yes**	**Unknown**
5. Without corrective lenses, is the subject's vision functionally normal?		☐ 0	☐ 1	☐ 9
6. Does the subject usually wear corrective lenses? *(If no or unknown,* **SKIP TO QUESTION 7***)*		☐ 0	☐ 1	☐ 9
6a. If yes, is the subject's vision functionally normal with corrective lenses?		☐ 0	☐ 1	☐ 9
7. Without a hearing aid(s), is the subject's hearing functionally normal?		☐ 0	☐ 1	☐ 9
8. Does the subject usually wear a hearing aid(s)? *(If no or unknown,* **END FORM HERE***)*		☐ 0	☐ 1	☐ 9
8a. If yes, is the subject's hearing functionally normal with a hearing aid(s)?		☐ 0	☐ 1	☐ 9

NACC UNIFORM DATA SET (UDS)

Form B1a: EVALUATION FORM Blood Pressure Addendum

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

Visit #: _ _ _ Examiner's initials: _ _ _

INSTRUCTIONS: This form is an addendum to UDS Form B1 Physical. It provides guidance and captures data from standardized measurement of blood pressure. This form is to be completed by the clinician.

1. Enter the average (mean) of two readings spaced at least 1 minute apart for each arm.
   *For detailed instructions, see **Steps for Proper BP Measurement**, next page*

   1a. Participant blood pressure — left arm: ___ ___ ___ / ___ ___ ___ *(888/888=not assessed)*

   1b. Participant blood pressure — right arm: ___ ___ ___ / ___ ___ ___ *(888/888=not assessed)*

2. Was the blood pressure taken using an approved device or cuff?

   For a list of approved devices, please visit
   http://www.dableducational.org/sphygmomanometers/p_devices_1_clinical.html

   ☐ 0 No
   ☐ 1 Yes
   ☐ 9 Unknown

SOURCE: Checklist for accurate measurement of BP adapted from AHA Guidelines: Whelton PK et al., Hypertension. 2018;71:e13-e11

Steps for Proper BP Measurement	Instructions
Step 1: Properly prepare the patient	1. Have the patient relax, sitting in a chair (feet on floor, back supported) for >5 min. 2. The patient should avoid caffeine, exercise, and smoking for at least 30 minutes before measurement. 3. Ensure that patient has emptied his/her bladder. 4. Neither the patient nor the observer should talk during the rest period or during the measurement. 5. Remove all clothing covering the location of cuff placement. 6. Measurements made while the patient is sitting or lying on an examining table do not fulfill these criteria.
Step 2: Use proper technique for BP measurements	1. Use a BP measurement device that has been validated, and ensure that the device is calibrated periodically. 2. Support the patient's arm (e.g., have it resting on a desk). 3. Position the middle of the cuff on the patient's upper arm at the level of the right atrium (the midpoint of the sternum). 4. Use the correct cuff size, such that the bladder encircles 80% of the arm, and note if a larger- or smaller-than-normal cuff size is used. 5. Either the stethoscope diaphragm or bell may be used for auscultatory readings
Step 3: Take the proper measurements needed for diagnosis and treatment of elevated BP/ hypertension	1. Take two BP readings in both arms. 2. Separate the second set of measurements from the first by 1 minute. 3. For auscultatory determinations, use a palpated estimate of radial pulse obliteration pressure to estimate SBP. Inflate the cuff 20–30 mm Hg above this level for an auscultatory determination of the BP level. 4. For auscultatory readings, deflate the cuff pressure 2 mm Hg per second, and listen for Korotkoff sounds.
Step 4: Properly document accurate BP readings	1. Record SBP and DBP. If using the auscultatory technique, record SBP and DBP as onset of the first Korotkoff sound and disappearance of all Korotkoff sounds, respectively, using the nearest even number. 2. It is recommended to note the time of most recent BP medication taken before measurements (this would be noted locally and not submitted to NACC).
Step 5: Average the readings	Record the average of the two readings of SBP and DBP in the left arm, and the two readings of SBP and DBP in the right arm. Enter the averages in 1a and 1b, respectively.
Step 6: Give BP readings to patient	It is recommended to provide patients with the SBP/DBP readings both orally and in writing.

Interpretation of values: Categories of BP in Adults *

BP Category		SBP		DBP
Normal		<120 mm Hg	and	<80 mm Hg
Elevated		120–129 mm Hg	and	<80 mm Hg
Hypertension:	Stage 1	130–139 mm Hg	or	80–89 mm Hg
	Stage 2	≥140 mm Hg	or	≥90 mm Hg

**Individuals with SBP and DBP in 2 categories should be designated to the higher BP category. BP indicates blood pressure (based on an average of ≥2 careful readings obtained on ≥2 occasions); DBP, diastolic blood pressure; and SBP, systolic blood pressure*

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

Form B4: CDR® Dementia Staging Instrument
PLUS NACC FTLD Behavior & Language Domains (CDR® Plus NACC FTLD)

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: CDR® DEMENTIA STAGING INSTRUMENT[1]

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. _ _ . _ **CDR SUM OF BOXES**					
8. _ . _ **GLOBAL CDR**					

[1]Morris 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: NACC FTLD BEHAVIOR & LANGUAGE DOMAINS

Please enter score below:	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
9. Behavior, comportment, and personality[2] ⌊_.⌊_	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. Language[3] ⌊_.⌊_	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

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

[3]Excerpted 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.

This is Version 3.1 of Form B5. The instructions in the box below have changed significantly over Version 3.0.

NACC National Alzheimer's Coordinating Center

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

Form B5: BEHAVIORAL ASSESSMENT Neuropsychiatric Inventory Questionnaire (NPI-Q[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 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:** ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (SPECIFY): _____

		Yes	No	Unknown		SEVERITY Mild	SEVERITY Mod	SEVERITY Severe	SEVERITY Unknown
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.**	☐ 1	☐ 0	☐ 9	**2b.**	☐ 1	☐ 2	☐ 3	☐ 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.**	☐ 1	☐ 0	☐ 9	**3b.**	☐ 1	☐ 2	☐ 3	☐ 9
4. **Agitation/aggression** — Is the patient resistive to help from others at times, or hard to handle?	**4a.**	☐ 1	☐ 0	☐ 9	**4b.**	☐ 1	☐ 2	☐ 3	☐ 9
5. **Depression/dysphoria** — Does the patient seem sad or say that he/she is depressed?	**5a.**	☐ 1	☐ 0	☐ 9	**5b.**	☐ 1	☐ 2	☐ 3	☐ 9

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)

		Yes	No	Unknown		SEVERITY Mild	SEVERITY Mod	SEVERITY Severe	SEVERITY 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.**	☐ 1	☐ 0	☐ 9	**6b.**	☐ 1	☐ 2	☐ 3	☐ 9
7. **Elation/euphoria** — Does the patient appear to feel too good or act excessively happy?	**7a.**	☐ 1	☐ 0	☐ 9	**7b.**	☐ 1	☐ 2	☐ 3	☐ 9
8. **Apathy/indifference** — Does the patient seem less interested in his/her usual activities or in the activities and plans of others?	**8a.**	☐ 1	☐ 0	☐ 9	**8b.**	☐ 1	☐ 2	☐ 3	☐ 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.**	☐ 1	☐ 0	☐ 9	**9b.**	☐ 1	☐ 2	☐ 3	☐ 9
10. **Irritability/lability** — Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?	**10a.**	☐ 1	☐ 0	☐ 9	**10b.**	☐ 1	☐ 2	☐ 3	☐ 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.**	☐ 1	☐ 0	☐ 9	**11b.**	☐ 1	☐ 2	☐ 3	☐ 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.**	☐ 1	☐ 0	☐ 9	**12b.**	☐ 1	☐ 2	☐ 3	☐ 9
13. **Appetite/eating** — Has the patient lost or gained weight, or had a change in the type of food he/she likes?	**13a.**	☐ 1	☐ 0	☐ 9	**13b.**	☐ 1	☐ 2	☐ 3	☐ 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?	☐ 0	☐ 1	☐ 9
2. Have you dropped many of your activities and interests?	☐ 1	☐ 0	☐ 9
3. Do you feel that your life is empty?	☐ 1	☐ 0	☐ 9
4. Do you often get bored?	☐ 1	☐ 0	☐ 9
5. Are you in good spirits most of the time?	☐ 0	☐ 1	☐ 9
6. Are you afraid that something bad is going to happen to you?	☐ 1	☐ 0	☐ 9
7. Do you feel happy most of the time?	☐ 0	☐ 1	☐ 9
8. Do you often feel helpless?	☐ 1	☐ 0	☐ 9
9. Do you prefer to stay at home, rather than going out and doing new things?	☐ 1	☐ 0	☐ 9
10. Do you feel you have more problems with memory than most?	☐ 1	☐ 0	☐ 9
11. Do you think it is wonderful to be alive now?	☐ 0	☐ 1	☐ 9
12. Do you feel pretty worthless the way you are now?	☐ 1	☐ 0	☐ 9
13. Do you feel full of energy?	☐ 0	☐ 1	☐ 9
14. Do you feel that your situation is hopeless?	☐ 1	☐ 0	☐ 9
15. Do you think that most people are better off than you are?	☐ 1	☐ 0	☐ 9

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

[1]Sheikh 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 (FAS[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 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.

In the past four weeks, did the subject have difficulty or need help with:	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	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
2. Assembling tax records, business affairs, or other papers	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
3. Shopping alone for clothes, household necessities, or groceries	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
4. Playing a game of skill such as bridge or chess, working on a hobby	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
5. Heating water, making a cup of coffee, turning off the stove	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
6. Preparing a balanced meal	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
7. Keeping track of current events	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
8. Paying attention to and understanding a TV program, book, or magazine	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
9. Remembering appointments, family occasions, holidays, medications	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9
10. Traveling out of the neighborhood, driving, or arranging to take public transportation	☐ 8	☐ 0	☐ 1	☐ 2	☐ 3	☐ 9

[1]Adapted 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.

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.

	LEFT		RIGHT	
Parkinsonian signs	**Yes**	**Not assessed**	**Yes**	**Not assessed**
2a. Resting tremor — arm	☐ 1	☐ 8	☐ 1	☐ 8
2b. Slowing of fine motor movements	☐ 1	☐ 8	☐ 1	☐ 8
2c. Rigidity — arm	☐ 1	☐ 8	☐ 1	☐ 8

	Yes	Not assessed
2d. Bradykinesia	☐ 1	☐ 8
2e. Parkinsonian gait disorder	☐ 1	☐ 8
2f. Postural instability	☐ 1	☐ 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)	☐ 1	☐ 8
3b. Focal or other neurological findings consistent with SIVD (subcortical ischemic vascular dementia)	☐ 1	☐ 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
3c. Motor (may include weakness of combinations of face, arm, and leg; reflex changes; etc.)	☐ 1	☐ 8	☐ 1	☐ 8
3d. Cortical visual field loss	☐ 1	☐ 8	☐ 1	☐ 8
3e. Somatosensory loss	☐ 1	☐ 8	☐ 1	☐ 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	☐ 1	☐ 8
5b. Dysarthria consistent with PSP	☐ 1	☐ 8
5c. Axial rigidity consistent with PSP	☐ 1	☐ 8
5d. Gait disorder consistent with PSP	☐ 1	☐ 8
5e. Apraxia of speech	☐ 1	☐ 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
5f. Apraxia consistent with CBS	☐ 1	☐ 8	☐ 1	☐ 8
5g. Cortical sensory deficits consistent with CBS	☐ 1	☐ 8	☐ 1	☐ 8
5h. Ataxia consistent with CBS	☐ 1	☐ 8	☐ 1	☐ 8
5i. Alien limb consistent with CBS	☐ 1	☐ 8	☐ 1	☐ 8
5j. Dystonia consistent with CBS, PSP, or related disorder	☐ 1	☐ 8	☐ 1	☐ 8
5k. Myoclonus consistent with CBS	☐ 1	☐ 8	☐ 1	☐ 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)?	☐ 0 No ☐ 1 Yes ☐ 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)?	☐ 0 No ☐ 1 Yes ☐ 8 There is no co-participant
Cognitive symptoms	
3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition?	☐ 0 No (If No, **SKIP TO QUESTION 8**) ☐ 1 Yes

4. Indicate whether the subject currently is meaningfully impaired, *relative to previously attained abilities,* 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?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 9
4d. **Language** Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction?	☐ 0	☐ 1	☐ 9
4e. **Visuospatial function** Does s/he have difficulty interpreting visual stimuli and finding his/her way around?	☐ 0	☐ 1	☐ 9
4f. **Attention, concentration** Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted?	☐ 0	☐ 1	☐ 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? 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.)	☐ 0	☐ 1	☐ 9
4h. **Other** (SPECIFY): _____	☐ 0	☐ 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.

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

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?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 9
9c. **Psychosis**			
9c1. Visual hallucinations	☐ 0	☐ 1	☐ 9
9c1a. If yes, are the hallucinations well formed and detailed?	☐ 0	☐ 1	☐ 9
9c1b. If well formed and clear-cut, at what age did these visual hallucinations begin? ___ ___ ___ *(777 = Age of onset provided at a previous UDS visit; 888 = N/A, not well-formed)* (The clinician must use his/her best judgment to estimate age of onset)			
9c2. Auditory hallucinations	☐ 0	☐ 1	☐ 9
9c3. Abnormal, false, or delusional beliefs	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 9
9e. **Irritability** Does the subject overreact, e.g., by shouting at family members or others?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 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)?	☐ 0	☐ 1	☐ 9
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)			
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?	☐ 0	☐ 1	☐ 9
9j.	**Other** (SPECIFY): _____	☐ 0	☐ 1	

10. Indicate the **predominant** symptom that was first recognized as a decline in the subject's behavior:
NOTE: Enter 0 if this information was provided on a previously submitted Form B9.

- ☐ 0 Assessed at a previous UDS visit
- ☐ 1 Apathy/withdrawal
- ☐ 2 Depressed mood
- ☐ 3 Psychosis
- ☐ 4 Disinhibition
- ☐ 5 Irritability
- ☐ 6 Agitation
- ☐ 7 Personality change
- ☐ 8 REM sleep behavior disorder
- ☐ 9 Anxiety
- ☐ 10 Other (SPECIFY): _____
- ☐ 99 Unknown

11. Mode of onset of behavioral symptoms:

- ☐ 1 Gradual
- ☐ 2 Subacute
- ☐ 3 Abrupt
- ☐ 4 Other (SPECIFY): _____
- ☐ 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?

- ☐ 0 No (If No, **SKIP TO QUESTION 20**)
- ☐ 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?	☐ 0	☐ 1	☐ 9
14b.	**Falls** Does the subject fall more than usual?	☐ 0	☐ 1	☐ 9
14c.	**Tremor** Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	☐ 0	☐ 1	☐ 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?	☐ 0	☐ 1	☐ 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.

15. Indicate the predominant symptom that was first recognized as a decline in the subject's motor function: *NOTE: Enter 0 if this information was provided on a previously submitted Form B9.*	☐ 0 Assessed at a previous UDS visit ☐ 1 Gait disorder ☐ 2 Falls ☐ 3 Tremor ☐ 4 Slowness ☐ 99 Unknown
16. Mode of onset of motor symptoms:	☐ 1 Gradual ☐ 2 Subacute ☐ 3 Abrupt ☐ 4 Other (SPECIFY): _____ ☐ 99 Unknown
17. Were changes in motor function suggestive of parkinsonism?	☐ 0 No ☐ 1 Yes ☐ 9 Unknown If No or Unknown, **SKIP TO QUESTION 18**
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.)	___ ___ ___ *(777 = Provided at a previous UDS visit)*
18. Were changes in motor function suggestive of amyotrophic lateral sclerosis?	☐ 0 No ☐ 1 Yes ☐ 9 Unknown If No or Unknown, **SKIP TO QUESTION 19**
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.)	___ ___ ___ *(777 = Provided at a previous UDS visit)*
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.)	___ ___ ___ *(777 = Provided at a previous UDS visit)*
Overall course of decline and predominant domain	
20. Overall course of decline of cognitive/behavorial/motor syndrome:	☐ 1 Gradually progressive ☐ 2 Stepwise ☐ 3 Static ☐ 4 Fluctuating ☐ 5 Improved ☐ 8 N/A ☐ 9 Unknown
21. Indicate the **predominant** domain that was first recognized as changed in the subject: *NOTE: Enter 0 if this information was provided on a previously submitted Form B9.*	☐ 0 Assessed at a previous UDS visit ☐ 1 Cognition ☐ 2 Behavior ☐ 3 Motor function ☐ 8 N/A ☐ 9 Unknown

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?	☐ 0 No ☐ 1 Yes
23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration?	☐ 0 No ☐ 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?	☐ 0 No *(Enter reason code, 95–98, and* **SKIP TO QUESTION 2a):** ____ ____ ☐ 1 Yes **(CONTINUE TO QUESTION 1a)**
1a. Administration of the MMSE was:	☐ 1 In ADC/clinic ☐ 2 In home ☐ 3 In person — other
1a1. Language of MMSE administration:	☐ 1 English ☐ 2 Spanish ☐ 3 Other (SPECIFY): _____
1b. Subject was unable to complete one or more sections due to visual impairment	☐ 0 No ☐ 1 Yes
1c. Subject was unable to complete one or more sections due to hearing impairment	☐ 0 No ☐ 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) *(If any of the MMSE items are 95–98, enter 88):*	___ ___ (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:

- ☐ 1 In ADC/clinic
- ☐ 2 In home
- ☐ 3 In person — other

2b. Language of test administration:

- ☐ 1 English
- ☐ 2 Spanish
- ☐ 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: *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 6a***)*	___ ___ (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: *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 7a***)*	___ ___ (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): *(If test not completed, enter reason code, 995–998, and* **SKIP TO QUESTION 8b***)*	____ ____ ____ (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): *(If test not completed, enter reason code, 995–998, and* **SKIP TO QUESTION 9a***)*	____ ____ ____ (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: *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 10a***)*	____ ____ (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: *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 11a***)*	____ ____ (0–17, 95–98)
10b.	Recognized original stimulus from among four options?	☐ 0 No ☐ 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 *(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 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?

☐ 0 No *(If No, enter reason code, 95 – 98):* _ _ **(SKIP TO QUESTION 2a)**

☐ 1 Yes **(CONTINUE WITH QUESTION 1b)**

1b. MoCA was administered: ☐ 1 In ADC or clinic ☐ 2 In home ☐ 3 In person — other

1c. Language of MoCA administration: ☐ 1 English ☐ 2 Spanish ☐ 3 Other (SPECIFY): _____

1d. Subject was unable to complete one or more sections due to visual impairment: ☐ 0 No ☐ 1 Yes

1e. Subject was unable to complete one or more sections due to hearing impairment: ☐ 0 No ☐ 1 Yes

1f. TOTAL RAW SCORE — UNCORRECTED (Not corrected for education or visual/hearing impairment)

Enter 88 if any of the following MoCA items were not administered: 1g –1l, 1n–1t, 1w–1bb _ _ (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: ☐ 1 In ADC or clinic ☐ 2 In home ☐ 3 In person — other

2b. Language of test administration: ☐ 1 English ☐ 2 Spanish ☐ 3 Other (SPECIFY): _____

3. Craft Story 21 Recall (Immediate)

3a. Total story units recalled, verbatim scoring ___ ___ (0–44, 95-98)
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 4a.***)*

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 ___ ___ (0–14, 95-98)
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 6a.***)*

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
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 7a.***)* ___ ___ (0–14, 95-98)

6b. Longest span backward ___ ___ (0, 2–8)

7. Category Fluency

7a. Animals: Total number of animals named in 60 seconds
(If test not completed, enter reason code, 95–98) ___ ___ (0–77, 95-98)

7b. Vegetables: Total number of vegetables named in 60 seconds
(If test not completed, enter reason code, 95–98) ___ ___ (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)
(If test not completed, enter reason code, 995–998, and **SKIP TO QUESTION 8b.***)* ___ ___ ___ (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)
(If test not completed, enter reason code, 995–998, and **SKIP TO QUESTION 9a.***)* ___ ___ ___ (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
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 10a.***)* ___ ___ (0–44, 95–98)

9b. Total story units recalled, paraphrase scoring ___ ___ (0–25)

9c. Delay time (minutes) *(99=Unknown)* ___ ___ *(0 – 85 minutes)*

9d. Cue ("boy") needed ☐ 0 No ☐ 1 Yes

10. Benson Complex Figure Recall

10a. Total score for drawing of Benson figure following 10- to 15-minute delay
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 11a.***)* ___ ___ (0–17, 95–98)

10b. Recognized original stimulus from among four options? ☐ 0 No ☐ 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 comportment

** 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	☐ 1
4b. Posterior cortical atrophy syndrome (or primary visual presentation)	☐ 1
4c. Primary progressive aphasia (PPA) syndrome 4c1. ☐ 1 Meets criteria for semantic PPA ☐ 2 Meets criteria for logopenic PPA ☐ 3 Meets criteria for nonfluent/agrammatic PPA ☐ 4 PPA other/not otherwise specified	☐ 1
4d. Behavioral variant FTD (bvFTD) syndrome	☐ 1
4e. Lewy body dementia syndrome	☐ 1
4f. Non-amnestic multidomain dementia, not PCA, PPA, bvFTD, or DLB syndrome	☐ 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)	☐ 1			
5b. Amnestic MCI, multiple domains (aMCI MD)	☐ 1	**CHECK YES for at least one additional domain (besides memory):** 5b1. Language 5b2. Attention 5b3. Executive 5b4. Visuospatial	 ☐ 0 ☐ 0 ☐ 0 ☐ 0	 ☐ 1 ☐ 1 ☐ 1 ☐ 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-amnestic MCI, single domain (naMCI SD)	☐ 1	**CHECK YES to indicate the affected domain:** 5c1. Language 5c2. Attention 5c3. Executive 5c4. Visuospatial	 ☐ 0 ☐ 0 ☐ 0 ☐ 0	 ☐ 1 ☐ 1 ☐ 1 ☐ 1
5d. Non-amnestic MCI, multiple domains (naMCI MD)	☐ 1	**CHECK YES for at least two domains:** 5d1. Language 5d2. Attention 5d3. Executive 5d4. Visuospatial	 ☐ 0 ☐ 0 ☐ 0 ☐ 0	 ☐ 1 ☐ 1 ☐ 1 ☐ 1
5e. Cognitively impaired, not MCI	☐ 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	☐ 0	☐ 1	☐ 8
6b. Abnormally low amyloid in CSF	☐ 0	☐ 1	☐ 8
6c. FDG-PET pattern of AD	☐ 0	☐ 1	☐ 8
6d. Hippocampal atrophy	☐ 0	☐ 1	☐ 8
6e. Tau PET evidence for AD	☐ 0	☐ 1	☐ 8
6f. Abnormally elevated CSF tau or ptau	☐ 0	☐ 1	☐ 8
6g. FDG-PET evidence for frontal or anterior temporal hypometabolism for FTLD	☐ 0	☐ 1	☐ 8
6h. Tau PET evidence for FTLD	☐ 0	☐ 1	☐ 8
6i. Structural MR evidence for frontal or anterior temporal atrophy for FTLD	☐ 0	☐ 1	☐ 8
6j. Dopamine transporter scan (DATscan) evidence for Lewy body disease	☐ 0	☐ 1	☐ 8
6k. Other (SPECIFY): _____	☐ 0	☐ 1	

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

Imaging findings	No	Yes	Unknown/ not assessed
7a. Large vessel infarct(s)	☐ 0	☐ 1	☐ 8
7b. Lacunar infarct(s)	☐ 0	☐ 1	☐ 8
7c. Macrohemorrhage(s)	☐ 0	☐ 1	☐ 8
7d. Microhemorrhage(s)	☐ 0	☐ 1	☐ 8
7e. Moderate white-matter hyperintensity (CHS score 5–6)	☐ 0	☐ 1	☐ 8
7f. Extensive white-matter hyperintensity (CHS score 7–8+)	☐ 0	☐ 1	☐ 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 FTLD 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 FTLD 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	☐ 1	11a ☐ 1	☐ 2	☐ 3
12. Lewy body disease 12b. ☐ 1 Parkinson's disease	☐ 1	12a ☐ 1	☐ 2	☐ 3
13. Multiple system atrophy	☐ 1	13a ☐ 1	☐ 2	☐ 3
14. Frontotemporal lobar degeneration				
14a. Progressive supranuclear palsy (PSP)	☐ 1	14a1 ☐ 1	☐ 2	☐ 3
14b. Corticobasal degeneration (CBD)	☐ 1	14b1 ☐ 1	☐ 2	☐ 3
14c. FTLD with motor neuron disease	☐ 1	14c1 ☐ 1	☐ 2	☐ 3
14d. FTLD NOS	☐ 1	14d1 ☐ 1	☐ 2	☐ 3
14e. If FTLD (Questions 14a – 14d) is Present, specify FTLD subtype: ☐ 1 Tauopathy ☐ 2 TDP-43 proteinopathy ☐ 3 Other (SPECIFY): _____ ☐ 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) *If significant vascular brain injury is absent,* **SKIP TO QUESTION 16.** 15b. Previous symptomatic stroke? ☐ 0 No **(SKIP TO QUESTION 15c)** ☐ 1 Yes 15b1. Temporal relationship between stroke and cognitive decline? ☐ 0 No ☐ 1 Yes 15b2. Confirmation of stroke by neuroimaging? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown; no relevant imaging data available 15c. Is there imaging evidence of cystic infarction in cognitive network(s)? ☐ 0 No ☐ 1 Yes ☐ 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+), and impairment in executive function? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown; no relevant imaging data available	☐ 1	15a ☐ 1	☐ 2	☐ 3
16. Essential tremor	☐ 1	16a ☐ 1	☐ 2	☐ 3
17. Down syndrome	☐ 1	17a ☐ 1	☐ 2	☐ 3
18. Huntington's disease	☐ 1	18a ☐ 1	☐ 2	☐ 3
19. Prion disease (CJD, other)	☐ 1	19a ☐ 1	☐ 2	☐ 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? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown	☐ 1	20a ☐ 1	☐ 2	☐ 3
21. Normal-pressure hydrocephalus	☐ 1	21a ☐ 1	☐ 2	☐ 3
22. Epilepsy	☐ 1	22a ☐ 1	☐ 2	☐ 3
23. CNS neoplasm 23b. ☐ 1 Benign ☐ 2 Malignant	☐ 1	23a ☐ 1	☐ 2	☐ 3
24. Human immunodeficiency virus (HIV)	☐ 1	24a ☐ 1	☐ 2	☐ 3
25. Cognitive impairment due to other neurologic, genetic, or infectious conditions not listed above 25b. If Present, specify: _____	☐ 1	25a ☐ 1	☐ 2	☐ 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: ☐ 0 Untreated ☐ 1 Treated with medication and/or counseling	☐ 1	26a ☐ 1	☐ 2	☐ 3
27. Bipolar disorder	☐ 1	27a ☐ 1	☐ 2	☐ 3
28. Schizophrenia or other psychosis	☐ 1	28a ☐ 1	☐ 2	☐ 3
29. Anxiety disorder	☐ 1	29a ☐ 1	☐ 2	☐ 3
30. Delirium	☐ 1	30a ☐ 1	☐ 2	☐ 3
31. Post-traumatic stress disorder (PTSD)	☐ 1	31a ☐ 1	☐ 2	☐ 3
32. Other psychiatric disease 32b. If Present, specify: _____	☐ 1	32a ☐ 1	☐ 2	☐ 3

33. Cognitive impairment due to alcohol abuse 33b. Current alcohol abuse: ☐0 No ☐1 Yes ☐9 Unknown	☐1	33a ☐1	☐2	☐3
34. Cognitive impairment due to other substance abuse	☐1	34a ☐1	☐2	☐3
35. Cognitive impairment due to systemic disease/ medical illness (as indicated on Form D2)	☐1	35a ☐1	☐2	☐3
36. Cognitive impairment due to medications	☐1	36a ☐1	☐2	☐3
37. Cognitive impairment NOS 37b. If Present, specify: _____	☐1	37a ☐1	☐2	☐3
38. Cognitive impairment NOS 38b. If Present, specify: _____	☐1	38a ☐1	☐2	☐3
39. Cognitive impairment NOS 39b. If Present, specify: _____	☐1	39a ☐1	☐2	☐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	☐ 0	☐ 1	☐ 8
4. Congestive heart failure	☐ 0	☐ 1	☐ 8
5. Atrial fibrillation	☐ 0	☐ 1	☐ 8
6. Hypertension	☐ 0	☐ 1	☐ 8
7. Angina	☐ 0	☐ 1	☐ 8
8. Hypercholesterolemia	☐ 0	☐ 1	☐ 8
9. B12 deficiency	☐ 0	☐ 1	☐ 8
10. Thyroid disease	☐ 0	☐ 1	☐ 8

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

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