NACC UNIFORM DATA SET

Telephone Initial Visit Packet

UDS v3.0, March 2015
Telephone Initial Visit Packet, v3.0, July 2020

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CLEAR ALL FORMS

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form Z1X: Form Checklist

CLEAR FORM

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):
T1	☐ 1	☐ 2	Inclusion Form	Required		
A1	☐ 1	☐ 2	Subject Demographics	Required		
A2	☐ 1	☐ 2	Co-participant Demographics	Required		
A3	☐ 1	☐ 2	Subject Family History	☐ 1	☐ 0	_ _
A4	☐ 1	☐ 2	Subject Medications	☐ 1	☐ 0	_ _
A5	☐ 1	☐ 2	Subject Health History	Required		
B1	☐ 1	☐ 2	EVALUATION FORM Physical	Required		
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	☐ 1	☐ 0	_ _
B9	☐ 1	☐ 2	Clinician Judgment of Symptoms	Required		
C2T	☐ 1	☐ 2	Neuropsychological Battery Scores	Required		
D1	☐ 1	☐ 2	Clinician Diagnosis	Required		
D2	☐ 1	☐ 2	Clinician-assessed Medical Conditions	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

TELEPHONE INITIAL VISITPACKET NACC UNIFORM DATA SET (UDS)

Form T1: Inclusion Form

CLEAR FORM

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

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

INSTRUCTIONS: This form is to be completed by the clinician or clinical interviewer who will participate in the telephone initial visit. For additional clarification and examples, see UDS Coding Guidebook for Telephone Initial Visit Packet, Form T1.

To print a copy of data previously collected for this form, go to https://www.alz.washington.edu/MEMBER/siteprint.html.

Please complete the following before continuing with the Telephone Initial Visit Packet.
When feasible, the optimal modality of assessment would be video-assisted rather than by telephone.

	NO	YES
1. Why is the UDS telephone initial visit protocol being used to obtain data about the subject?		
a. Subject is too cognitively impaired for an in-person UDS visit	☐ 0	☐ 1
b. Subject is too physically impaired (medical illness or injury) to attend an in-person UDS visit.	☐ 0	☐ 1
c. Subject is homebound or in a nursing home and cannot travel.	☐ 0	☐ 1
d. Subject or co-participant refused an in-person UDS visit.	☐ 0	☐ 1
e. COVID pandemic precludes traditional in-person UDS visit.	☐ 0	☐ 1
f. Other (SPECIFY): _____ (ADC staff convenience is not an acceptable reason.)	☐ 0	☐ 1

2. What modality of communication was used to collect this remote UDS packet?	☐ 1 Telephone ☐ 2 Video-assisted conference ☐ 3 Some combination of the two

	NO	YES	UNKNOWN
3. Is the subject likely to resume in-person UDS follow-up evaluation? If Yes or Unknown, **END FORM HERE**. If No, then **CONTINUE TO QUESTION 4**.	☐ 0	☐ 1	☐ 9
4. Has a Milestones Form documenting the change to telephone follow-up been completed? (If no, complete a Milestones Form now.)	☐ 0	☐ 1	☐ 9

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A1: Subject Demographics CLEAR FORM

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 proxy co-participant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Telephone Initial Visit Packet, Form A1. Check only one box per question.

1. Primary reason for coming to ADC:	☐ 1 To participate in a research study ☐ 2 To have a clinical evaluation ☐ 4 Both (to participate in a research study and to have a clinical evaluation) ☐ 9 Unknown
2a. Principal referral source: (If answer is 1 or 2, **CONTINUE TO QUESTION 2B**; otherwise, **SKIP TO QUESTION 3**.)	☐ 1 Self-referral ☐ 2 Non-professional contact (spouse/partner, relative, friend, coworker, etc.) ☐ 3 ADC participant referral ☐ 4 ADC clinician, staff, or investigator referral ☐ 5 Nurse, doctor, or other health care provider ☐ 6 Other research study clinician/staff/investigator (non-ADC; e.g., ADNI, Women's Health Initiative) ☐ 8 Other ☐ 9 Unknown
2b. If the referral source was self-referral or a non-professional contact, how did the referral source learn of the ADC?	☐ 1 ADC advertisement (e.g., website, mailing, newspaper ad, community presentation) ☐ 2 News article or TV program mentioning the ADC study ☐ 3 Conference or community event (e.g., community memory walk) ☐ 4 Another organization's media appeal or website (e.g., Alzheimer's Association, clinicaltrials.gov) ☐ 8 Other ☐ 9 Unknown
3. Presumed disease status at enrollment:	☐ 1 Case, patient, or proband ☐ 2 Control or normal ☐ 3 No presumed disease status
4. Presumed participation:	☐ 1 Initial evaluation only ☐ 2 Longitudinal follow-up planned
5. ADC enrollment type:	☐ 1 Primarily ADC-funded (Clinical Core, Satellite Core, or other ADC Core or project) ☐ 2 Subject is supported primarily by a non-ADC study (e.g., R01, including non-ADC grants supporting FTLD Module participation)

6. Subject's month and year of birth (MM/YYYY):	___ ___ / ___ ___ ___ ___
7. Subject's sex:	☐ 1 Male ☐ 2 Female
8. Does the subject 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 9**) ☐ 1 Yes ☐ 9 Unknown (If Unknown, **SKIP TO QUESTION 9**)
8a. If yes, what are the subject'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
9. What does the subject 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
10. What additional race does the subject 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
11. What additional race, beyond those reported in Questions 9 and 10, does the subject 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

12. Subject's primary language:

- ☐ 1 English
- ☐ 2 Spanish
- ☐ 3 Mandarin
- ☐ 4 Cantonese
- ☐ 5 Russian
- ☐ 6 Japanese
- ☐ 8 Other primary language (SPECIFY): _____
- ☐ 9 Unknown

13. Subject'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

14. 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

15. 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 group home (e.g., assisted living, nursing home, convent)
- ☐ 9 Unknown

16. 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

17. 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

18. ZIP Code (first three digits) of subject's primary residence: ___ ___ ___ *(If unknown, leave blank)*

19. Is the subject left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)?

- ☐ 1 Left-handed
- ☐ 2 Right-handed
- ☐ 3 Ambidextrous
- ☐ 9 Unknown

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A2: Co-participant Demographics

CLEAR FORM

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 Telephone Initial Visit Packet, Form A2. Check only one box per question.

1. Co-participant's month and year of birth (MM / YYYY):	_ _ / _ _ _ _ *(99/9999 = unknown)*
2. Co-participant's sex:	☐ 1 Male ☐ 2 Female
3. 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 4**) ☐ 1 Yes ☐ 9 Unknown (If Unknown, **SKIP TO QUESTION 4**)
3a. 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
4. 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
5. 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

6. What additional race, beyond those reported in Questions 4 and 5, 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. 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

8. 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

8a. How long has the co-participant known the subject? ___ ___ ___ years *(999=unknown)*

9. Does the co-participant live with the subject?

- ☐ 0 No
- ☐ 1 Yes (If Yes, **SKIP TO QUESTION 10**)

9a. 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

9b. 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

10. Is there a question about the co-participant's reliability?

- ☐ 0 No
- ☐ 1 Yes

Form A3: Subject Family History

CLEAR FORM

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 Telephone Initial Visit Packet, Form A3.

1. Are there affected first-degree relatives (biological parents, full siblings, or biological children)? *"Affected" = having dementia or one of the non-normal diagnoses listed in Appendix 1 on page 5*	☐ 0 No ☐ 1 Yes ☐ 9 Unknown
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 5a**)	☐ 0 No **(SKIP TO QUESTION 5a)** ☐ 1 Yes (SPECIFY): _____ ☐ 9 Unknown **(SKIP TO QUESTION 5a)**
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

Provide information on biological parents below. If birth year is unknown, please provide an approximate year on the Telephone Initial Visit Form A3 and ensure that it is consistently reported on any Follow-up Visit Form A3, as applicable. If it is impossible for the subject and co-participant to estimate the birth year, enter *9999=Unknown.*

For any biological parent with a neurological or psychiatric condition, 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. For a biological parent with 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			
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 Telephone Initial Visit Form A3 and UDS Follow-up Visit Form A3 so that the sibling or 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 the birth year, enter *9999=Unknown.*

FULL SIBLINGS

6. How many full siblings does the subject have? ___ ___

If subject has no full siblings, **SKIP TO QUESTION 7**; otherwise, provide information on all full siblings below.

For any full sibling with a neurological or psychiatric condition, 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. For a sibling with 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.

See next page of form for list of codes	**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			
6a. Sibling 1	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6b. Sibling 2	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6c. Sibling 3	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6d. Sibling 4	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6e. Sibling 5	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6f. Sibling 6	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6g. Sibling 7	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6h. Sibling 8	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6i. Sibling 9	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6j. Sibling 10	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6k. Sibling 11	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6l. Sibling 12	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6m. Sibling 13	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6n. Sibling 14	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6o. Sibling 15	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6p. Sibling 16	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6q. Sibling 17	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6r. Sibling 18	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6s. Sibling 19	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
6t. Sibling 20	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___

BIOLOGICAL CHILDREN

7. How many biological children does the subject have? ___ ___

If subject has no biological children, **END FORM HERE**; otherwise, provide information on all biological children below.

For any biological child with a neurological or psychiatric condition, 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. For a biological child with 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			
7a. Child 1	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7b. Child 2	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7c. Child 3	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7d. Child 4	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7e. Child 5	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7f. Child 6	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7g. Child 7	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7h. Child 8	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7i. Child 9	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7j. Child 10	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7k. Child 11	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7l. Child 12	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7m. Child 13	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7n. Child 14	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
7o. 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
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****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

1 Autopsy
2 Examination
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 — amnestic, single domain
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.

Form A4: Subject Medications

CLEAR FORM

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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☐ (SPECIFY:) ______________________ d __ __ __ __ __

☐ (SPECIFY:) ______________________ d __ __ __ __ __

Form A5: Subject Health History

CLEAR FORM

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

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

INSTRUCTIONS: This form is to be completed by the clinician or ADC staff. For additional clarification and examples, see UDS Coding Guidebook for Telephone Initial Visit Packet, Form A5. Check only one box per question.

1. History of cigarette smoking and alcohol use

CIGARETTE SMOKING

1a. Has subject smoked within the last 30 days? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown

1b. Has subject smoked more than 100 cigarettes in her/his life? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown
(If No or Unknown, **SKIP TO QUESTION 1F**)

1c. Total years smoked *(99 = unknown)*: _ _

1d. Average number of packs smoked per day:
- ☐ 1 1 cigarette to less than ½ pack
- ☐ 2 ½ pack to less than 1 pack
- ☐ 3 1 pack to less than 1½ packs
- ☐ 4 1½ packs to less than 2 packs
- ☐ 5 2 packs or more
- ☐ 9 Unknown

1e. If the subject quit smoking, specify the age at which he/she last smoked (i.e., quit) *(888=N/A, 999 = unknown)*: _ _ _

ALCOHOL USE

1f. In the past three months, has the subject consumed any alcohol?
- ☐ 0 No **(SKIP TO QUESTION 2a)**
- ☐ 1 Yes
- ☐ 9 Unknown **(SKIP TO QUESTION 2a)**

1g. During the past three months, how often did the subject have at least one drink of any alcoholic beverage such as wine, beer, malt liquor, or spirits?
- ☐ 0 Less than once a month
- ☐ 1 About once a month
- ☐ 2 About once a week
- ☐ 3 A few times a week
- ☐ 4 Daily or almost daily
- ☐ 9 Unknown

FOR SECTIONS 2–7, BELOW, record the presence or absence of a **history** of these conditions **at this visit**, as determined by the clinician's best judgment following the medical history interview with the subject and co-participant.

A CONDITION SHOULD BE CONSIDERED ...

- **Absent** IF ... it is not indicated by information obtained from the subject and co-partipant interview.
- **Recent/Active** IF ... it happened within the last year or still requires active management and is consistent with information obtained from the subject and co-partipant interview.
- **Remote/Inactive** IF ... it existed or occurred in the past (more than one year ago) but was resolved or there is no treatment currently under way.
- **Unknown** IF ... there is insufficient information available from the subject and co-partipant interview.

2. Cardiovascular disease	**Absent**	**Recent/ active**	**Remote/ inactive**	**Unknown**
2a. Heart attack / cardiac arrest (If absent or unknown, **SKIP TO QUESTION 2b**)	☐ 0	☐ 1	☐ 2	☐ 9
2a1. More than one heart attack? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown				
2a2. Year of most recent heart attack *(9999 = unknown)*: ___ ___ ___ ___				
2b. Atrial fibrillation	☐ 0	☐ 1	☐ 2	☐ 9
2c. Angioplasty / endarterectomy / stent	☐ 0	☐ 1	☐ 2	☐ 9
2d. Cardiac bypass procedure	☐ 0	☐ 1	☐ 2	☐ 9
2e. Pacemaker and/or defibrillator	☐ 0	☐ 1	☐ 2	☐ 9
2f. Congestive heart failure	☐ 0	☐ 1	☐ 2	☐ 9
2g. Angina	☐ 0	☐ 1	☐ 2	☐ 9
2h. Heart valve replacement or repair	☐ 0	☐ 1	☐ 2	☐ 9
2i. Other cardiovascular disease (SPECIFY): _____	☐ 0	☐ 1	☐ 2	☐ 9

3. Cerebrovascular disease	**Absent**	**Recent/ active**	**Remote/ inactive**	**Unknown**
3a. Stroke — by history, not exam (imaging is not required) *(If absent or unknown,* **SKIP TO QUESTION 3b***)*	☐ 0	☐ 1	☐ 2	☐ 9
3a1. More than one stroke? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown				
3a2. Year of most recent stroke *(9999 = unknown)*: ___ ___ ___ ___				
3b. Transient ischemic attack (TIA) (If absent or unknown, **SKIP TO QUESTION 4a**)	☐ 0	☐ 1	☐ 2	☐ 9
3b1. More than one TIA? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown				
3b2. Year of most recent TIA *(9999 = unknown)*: ___ ___ ___ ___				

4. Neurologic conditions	Absent	Recent/ active	Remote/ inactive	Unknown
4a. Parkinson's disease (PD) (If Absent or Unknown, **SKIP TO QUESTION 4b**)	☐ 0	☐ 1		☐ 9
4a1. Year of PD diagnosis *(9999 = unknown)*: ___ ___ ___ ___				
4b. Other parkinsonism disorder (e.g., PSP, CBD) (If absent or unknown, **SKIP TO QUESTION 4c**)	☐ 0	☐ 1		☐ 9
4b1. Year of parkinsonism disorder diagnosis *(9999 = unknown)*: ___ ___ ___ ___				
4c. Seizures	☐ 0	☐ 1	☐ 2	☐ 9
4d. Traumatic brain injury (TBI) (If Absent or Unknown, **SKIP TO QUESTION 5a**)	☐ 0	☐ 1	☐ 2	☐ 9

4d1. TBI with brief loss of consciousness (< 5 minutes)
☐ 0 No ☐ 1 Single ☐ 2 Repeated/multiple ☐ 9 Unknown

4d2. TBI with extended loss of consciousness (≥ 5 minutes)
☐ 0 No ☐ 1 Single ☐ 2 Repeated/multiple ☐ 9 Unknown

4d3. TBI without loss of consciousness (as might result from military detonations or sports injuries)?
☐ 0 No ☐ 1 Single ☐ 2 Repeated/multiple ☐ 9 Unknown

4d4. Year of most recent TBI *(9999 = unknown)*: ___ ___ ___ ___

5. Medical conditions	Absent	Recent/ active	Remote/ inactive	Unknown
If any of the conditions still require active management and/or medications, please select "Recent/active."				
5a. Diabetes (If absent or unknown, **SKIP TO QUESTION 5b**)	☐ 0	☐ 1	☐ 2	☐ 9
5b. Hypertension	☐ 0	☐ 1	☐ 2	☐ 9
5c. Hypercholesterolemia	☐ 0	☐ 1	☐ 2	☐ 9
5d. B12 deficiency	☐ 0	☐ 1	☐ 2	☐ 9
5e. Thyroid disease	☐ 0	☐ 1	☐ 2	☐ 9
5f. Arthritis (If absent or unknown, **SKIP TO QUESTION 5g**)	☐ 0	☐ 1	☐ 2	☐ 9

5a1. If Recent/active or Remote/inactive, which type?
☐ 1 Type 1
☐ 2 Type 2
☐ 3 Other type (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes)
☐ 9 Unknown

5f1. Type of arthritis:
☐ 1 Rheumatoid ☐ 2 Osteoarthritis ☐ 3 Other (SPECIFY): _____ ☐ 9 Unknown

5f2. Region(s) affected (check all that apply):
5f2a. ☐ 1 Upper extremity 5f2b. ☐ 1 Lower extremity 5f2c. ☐ 1 Spine 5f2d. ☐ 1 Unknown

5. Medical conditions (cont.)	Absent	Recent/ active	Remote/ inactive	Unknown
5g. Incontinence — urinary	☐ 0	☐ 1	☐ 2	☐ 9
5h. Incontinence — bowel	☐ 0	☐ 1	☐ 2	☐ 9
5i. Sleep apnea	☐ 0	☐ 1	☐ 2	☐ 9
5j. REM sleep behavior disorder (RBD)	☐ 0	☐ 1	☐ 2	☐ 9
5k. Hyposomnia/insomnia	☐ 0	☐ 1	☐ 2	☐ 9
5l. Other sleep disorder (SPECIFY): _____	☐ 0	☐ 1	☐ 2	☐ 9

6. Substance abuse	Absent	Recent/ active	Remote/ inactive	Unknown
6a. Alcohol abuse: clinically significant impairment occurring over a 12-month period manifested in one of the following areas: work, driving, legal, or social.	☐ 0	☐ 1	☐ 2	☐ 9
6b. Other abused substances: clinically significant impairment occuring over a 12-month period manifested in one of the following areas: work, driving, legal, or social. (If absent or unknown, **SKIP TO QUESTION 7a**)	☐ 0	☐ 1	☐ 2	☐ 9
6b1. If recent/active or remote/inactive, specify abused substance: _____				

7. Psychiatric conditions, diagnosed or treated by a physician	Absent	Recent/ active	Remote/ inactive	Unknown
7a. Post-traumatic stress disorder (PTSD)	☐ 0	☐ 1	☐ 2	☐ 9
7b. Bipolar disorder	☐ 0	☐ 1	☐ 2	☐ 9
7c. Schizophrenia	☐ 0	☐ 1	☐ 2	☐ 9
7d. Depression				
7d1. Active depression in the last two years ☐ 0 No ☐ 1 Yes ☐ 9 Unknown				
7d2. Depression episodes more than two years ago ☐ 0 No ☐ 1 Yes ☐ 9 Unknown				
7e. Anxiety	☐ 0	☐ 1	☐ 2	☐ 9
7f. Obsessive-compulsive disorder (OCD)	☐ 0	☐ 1	☐ 2	☐ 9
7g. Developmental neuropsychiatric disorders (e.g., autism spectrum disorder [ASD], attention-deficit hyperactivity disorder [ADHD], dyslexia)	☐ 0	☐ 1	☐ 2	☐ 9
7h. Other psychiatric disorders (If absent or unknown, **END FORM HERE.**)	☐ 0	☐ 1	☐ 2	☐ 9
7h1. If recent/active or remote/inactive, specify disorder: _____				

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B1: EVALUATION FORM Physical

CLEAR FORM

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 Telephone Initial Visit Packet, Form B1. Check only one box per question.

Physical observations	No	Yes	Unknown
1. Without corrective lenses, is the subject's vision functionally normal?	☐ 0	☐ 1	☐ 9
2. Does the subject usually wear corrective lenses? *(If no or unknown,* **SKIP TO QUESTION 3***)*	☐ 0	☐ 1	☐ 9
2a. If yes, is the subject's vision functionally normal with corrective lenses?	☐ 0	☐ 1	☐ 9
3. Without a hearing aid(s), is the subject's hearing functionally normal?	☐ 0	☐ 1	☐ 9
4. Does the subject usually wear a hearing aid(s)? *(If no or unknown,* **END FORM HERE***)*	☐ 0	☐ 1	☐ 9
4a. If yes, is the subject's hearing functionally normal with a hearing aid(s)?	☐ 0	☐ 1	☐ 9

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

CLEAR FORM

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

INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Telephone Initial 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 Telephone Initial 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 Telephone Initial 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 Telephone Initial 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.

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form B5: BEHAVIORAL ASSESSMENT Neuropsychiatric Inventory Questionnaire (NPI-Q[1])

CLEAR FORM

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 Telephone Initial Visit Packet, Form B5. Check only one box for each category of response.

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

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

CLEAR FORM

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 Telephone Initial 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])

CLEAR FORM

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 Telephone Initial Visit v3.0 Packet, Form B7. Indicate the level of performance for each activity by checking the one appropriate

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

CLEAR FORM

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 Telephone Initial Visit Packet, Form B8.

1. Were there abnormal neurological exam findings?

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

INSTRUCTIONS FOR QUESTIONS 2 – 8

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

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

2. Parkinsonian signs

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

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

Parkinsonian signs	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
2a. Resting tremor — arm	☐ 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):** _____

Form B9: Clinician Judgment of Symptoms

CLEAR FORM

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 Telephone Initial 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? _ _ _ (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 Telephone Initial 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:	☐ 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? (The clinician must use his/her best judgment to estimate an age of onset.)	___ ___ ___

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, clear-cut visual hallucinations, at what age did these visual hallucinations begin? ___ ___ ___ *(888 = N/A, not well-formed)* (The clinician must use his/her best judgment to estimate an 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
9f. **Agitation** Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	☐ 0	☐ 1	☐ 9

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

	No	Yes	Unknown
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)? 9h1. If yes, at what age did the REM sleep behavior disorder begin? ___ ___ ___ (The clinician must use his/her best judgment to estimate an age of onset.)	☐ 0	☐ 1	☐ 9
9i. **Anxiety** For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	☐ 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:

- ☐ 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? ___ ___ ___
(The clinician must use his/her best judgment to estimate an age of onset.)

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 the 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 Telephone Initial 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:	☐ 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 symptoms suggestive of parkinsonism begin? (The clinician must use his/her best judgment to estimate an age of onset.)	___ ___ ___
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 symptoms suggestive of ALS begin? (The clinician must use his/her best judgment to estimate an age of onset.)	___ ___ ___
19. Based on the clinician's assessment, at what age did the motor changes begin? (The clinician must use his/her best judgment to estimate an age of onset of motor changes.)	___ ___ ___
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:	☐ 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

CLEAR FORM

NACC National Alzheimer's Coordinating Center

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

Form C2T: Neuropsychological Battery Scores for T-cog

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 C2T.

KEY: 88/888 = Optional item 95/995 = Physical problem 96/996 = Cognitive/behavior problem 97/997 = Other problem 98/998 = Verbal refusal

NOTE: Based on clinical judgment, if factors are present that significantly affect the validity of the test, select 97/997 = Other problem.

0. Mode of communication

0a. What modality of communication was used to administer this neuropsychological battery?

- ☐ 1 Telephone
- ☐ 2 Video-assisted conference
- ☐ 3 Some combination of the two

1. Montreal Cognitive Assessment (MoCA) Blind

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

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

1d.	TOTAL RAW SCORE — UNCORRECTED (Not corrected for education or visual/hearing impairment) *Enter 88 if any of the following MoCA items were not administered: 1e–1k, 1n–1s*	_ _ (0–22, 88)
1e.	Attention — Digits	_ _ (0–2, 95-98)
1f.	Attention — Letter A	_ _ (0–1, 95-98)
1g.	Attention — Serial 7s	_ _ (0–3, 95-98)
1h.	Language — Repetition	_ _ (0–2, 95-98)
1i.	Language — Fluency	_ _ (0–1, 95-98)
1j.	Abstraction	_ _ (0–2, 95-98)
1k.	Delayed recall — No cue	_ _ (0–5, 95-98)
1l.	Delayed recall — Category cue	_ _ (0–5; 88=Not applicable)

KEY: 88/888 = Optional item 95/995 = Physical problem 96/996 = Cognitive/behavior problem 97/997 = Other problem 98/998 = Verbal refusal

1m.	Delayed recall — Recognition	___ ___ (0–5; 88=Not applicable)
1n.	Orientation — Date	___ ___ (0–1, 95-98)
1o.	Orientation — Month	___ ___ (0–1, 95-98)
1p.	Orientation — Year	___ ___ (0–1, 95-98)
1q.	Orientation — Day	___ ___ (0–1, 95-98)
1r.	Orientation — Place	___ ___ (0–1, 95-98)
1s.	Orientation — City	___ ___ (0–1, 95-98)

2. ADMINISTRATION OF THE REMAINDER OF THE BATTERY

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

3. Craft Story 21 Recall — Immediate

3a.	Total story units recalled, verbatim scoring *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 4a.***)*	___ ___ (0–44, 95-98)
3b.	Total story units recalled, paraphrase scoring	___ ___ (0–25)

4. Rey Auditory Verbal Learning — Immediate (Optional)

Special instructions: The Rey Auditory Verbal Learning test should not be administered to participants being assessed in Spanish.

4a.	Trial 1 — Total recall *(If test was not completed, enter reason code, 95-98. If test was skipped because optional or not available in Spanish translation, enter 88, and* **SKIP TO QUESTION 5a**.*)*	___ ___ (0–15, 88, 95-98)
4b.	Intrusions	___ ___ (No limit)
4c.	Trial 2 — Total recall	___ ___ (0–15)
4d.	Intrusions	___ ___ (No limit)
4e.	Trial 3 — Total recall	___ ___ (0–15)
4f.	Intrusions	___ ___ (No limit)
4g.	Trial 4 — Total recall	___ ___ (0–15)
4h.	Intrusions	___ ___ (No limit)
4i.	Trial 5 — Total recall	___ ___ (0–15)
4j.	Intrusions	___ ___ (No limit)
4k.	Trial 6 — Total recall	___ ___ (0–15)
4l.	Intrusions	___ ___ (No limit)

KEY: 88/888 = Optional item 95/995 = Physical problem 96/996 = Cognitive/behavior problem 97/997 = Other problem 98/998 = Verbal refusal

5. Number Span Test: Forward

5a. Number of correct trials *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 6a.***)*	___ ___	(0–14, 95-98)
5b. Longest span forward	___ ___	(0, 3–9)

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. Oral Trail Making Test (Optional)

7a. PART A: Total number of seconds to complete (if not finished by 100 seconds, enter 100) *(If test was not completed, enter reason code, 995-998. If test was skipped because optional, enter 888, and* **SKIP TO QUESTION 7b.***)*	___ ___ ___	(0–100, 888, 995–998)
7a1. Number of commission errors	___ ___	(No limit)
7a2. Total number correct	___ ___	(0–25)
7b. PART B: Total number of seconds to complete (if not finished by 300 seconds, enter 300) *(If test was not completed, enter reason code, 995-998. If test was skipped because optional, enter 888, and* **SKIP TO QUESTION 8a.***)*	___ ___ ___	(0–300,888, 995–998)
7b1. Number of commission errors	___ ___	(No limit)
7b2. Total number correct	___ ___	(0–25)

8. Craft Story 21 Recall (Delayed)

8a. Total story units recalled, verbatim scoring *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 9a.***)*	___ ___	(0–44, 95–98)
8b. Total story units recalled, paraphrase scoring	___ ___	(0–25)
8c. Delay time (minutes) *(99 = Unknown)*	___ ___	*(0 – 85 minutes)*
8d. Cue ("boy") needed	☐ 0 No ☐ 1 Yes	

9. Category Fluency

9a. Animals: Total number of animals named in 60 seconds *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 9b.***)*	___ ___	(0–77, 95-98)
9b. Vegetables: Total number of vegetables named in 60 seconds *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 10a.***)*	___ ___	(0–77, 95-98)

KEY: 88/888 = Optional item 95/995 = Physical problem 96/996 = Cognitive/behavior problem 97/997 = Other problem 98/998 = Verbal refusal

Verbal Fluency: Phonemic Test

10a.	Number of correct **F-words** generated in 1 minute *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 10d.***)*	___ ___ (0–40, 95–98)
10b.	Number of **F-words** repeated in 1 minute	___ ___ (0–15)
10c.	Number of **non-F-words** and rule violation errors in 1 minute	___ ___ (0–15)
10d.	Number of correct **L-words** generated in 1 minute *(If test not completed, enter reason code, 95–98, and* **SKIP TO QUESTION 11a.***)*	___ ___ (0–40, 95–98)
10e.	Number of **L-words** repeated in one minute	___ ___ (0–15)
10f.	Number of **non-L-words** and rule violation errors in 1 minute	___ ___ (0–15)
10g.	TOTAL number of correct **F-words and L-words**	___ ___ (0–80)
10h.	TOTAL number of **F-word and L-word** repetition errors	___ ___ (0–30)
10i.	TOTAL number of **non-F/L words** and rule violation errors	___ ___ (0–30)

Rey Auditory Verbal Learning — Delayed recall and recognition (Optional)

11a.	Total delayed recall *(If test not completed, enter reason code, 95-98. If test was skipped because optional or not available in Spanish translation, enter 88, and* **SKIP TO QUESTION 12a.***)*	___ ___ (0–15, 88, 95-98)
11b.	Intrusions	___ ___ (No limit)
11c.	Recognition — Total correct	___ ___ (0–15)
11d.	Recognition — Total false positive	___ ___ (0–15)

Verbal Naming Test (Optional)

12a.	Total correct without a cue *(If test was not completed, enter reason code, 95-98. If test was skipped because optional, enter 88, and* **SKIP TO QUESTION 12b.***)*	___ ___ (0–50, 88, 95-98)
12b.	Total correct with phonemic cue *(If test was not completed, enter reason code, 95-98. If test was skipped because optional or if no cues were given, enter 88, and* **SKIP TO QUESTION 13a.***)*	___ ___ (0–50, 88, 95-98)

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

14. Validity of participant's responses

Please record your impression of whether hearing or other factors significantly influenced test results. It can be difficult to judge, but it is helpful in adjudication and data analysis to know that such an influence may have been present.

14a. How valid do you think the participant's responses are?

- ☐ 1 Very valid, probably accurate indication of participant's cognitive abilities **(END FORM HERE)**
- ☐ 2 Questionably valid, possibly inaccurate indication of participant's cognitive abilities **(CONTINUE)**
- ☐ 3 Invalid, probably inaccurate indication of participant's cognitive abilities **(CONTINUE)**

14b. What makes this participant's responses less valid? (Select all that apply)

- ☐ 14b1 Hearing impairment
- ☐ 14b2 Distractions
- ☐ 14b3 Interruptions
- ☐ 14b4 Lack of effort or disinterest
- ☐ 14b5 Fatigue
- ☐ 14b6 Emotional issues
- ☐ 14b7 Unapproved assistance
- ☐ 14b8 Other (SPECIFY): _____

TELEPHONE INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form D1: Clinician Diagnosis

CLEAR FORM

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 Telephone Initial 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

Form D2: Clinician-assessed Medical Conditions

CLEAR FORM

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 Telephone Initial 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	