NACC UNIFORM DATA SET

Coding Guidebook

For Telephone Follow-up Packet

UDS v3.0, March 2015
Telephone Follow-up Packet v3.2, June 2020

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Revisions made to this Guidebook since UDS3 implementation (March 15, 2015)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected	Data element(s) affected
2020-07-15	Added revised MCI-LB criteria	D1	12	
2020-07-15	Updated Form C2T to include mode of communication question	C2T	0a	
2020-06-01	Revised to permit telehealth assessments during COVID-19 pandemic			
2019-03-29	Name of CDR® Dementia Staging Instrument changed to comply with trademark	B4, Z1X	N/A	N/A
2018-08-14	Phrase "telephone contact" defined	A2	10b	INCALLS
2017-10-05	Phrase "MCI due to dementia" corrected to "MCI due to AD."	D1	11	ALZDIS, ALZDISIF
2017-09-19	Instructions on completing Form CLS added	A1	N/A	HISPANIC
2017-09-19	LBD diagnostic criteria updated to reflect 2017 guidelines of Dementia With Lewy Bodies Consortium	D1	4e	LBDSYN
2017-03-14	Name of form changed from Functional Assessment Questionnaire (FAQ)	B7	N/A	N/A
2016-08-12	Sample form updated to reflect clarification of instructions — administer NPI-Q to all UDS subjects	B5	N/A	N/A
2015-10-01	Clarification added for subjects with normal cognition and a diagnosis of Parkinson's disease	D1	12, 12a	N/A
2015-10-01	Explanatory text changed to include Parkinson's disease only; Lewy body reference deleted	D1	12b	N/A
2015-07-29	Clarification added for how to answer questions for subjects of normal cognition or whose cognition has not yet been evaluated	B5	All	All
2015-06-17	For Form B5 only, Version 3.1, dated June 2015, supplants Version 3.0	B5	N/A	N/A
2015-06-17	Instructions for Form B5 (NPI-Q) corrected and expanded to match original instrument	B5	All	N/A
2015-06-17	Text of Form Question 3 changed to make it explicit that question applies to visual as well as auditory hallucinations; minor changes made in explanatory text for other questions	B5	Question 3; minor changes to 2, 4, 5	N/A
2015-05-07	Instructions added before Question 1 clarifying form completion for a subject receiving UDS v3 Form A3 for the first time	A3	N/A	N/A
2015-05-05	Clarification added for when version 3 Form A3 is submitted for the first time	A3	1, 5, 6a, 7a	N/A

Form T1: Inclusion Form

INSTRUCTIONS: This form is to be completed by the clinician or clinical interviewer who will participate in the telephone follow-up. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up 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 Follow-up Packet.
When feasible, the optimal modality of assessment would be video-assisted rather than by telephone.

1. Why is the UDS telephone follow-up protocol being used to obtain data about the subject?	**NO**	**YES**
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, and this is the first telephone packet submitted for the subject, then **END FORM HERE**. If No or Unknown but two or more consecutive telephone packets have been submitted for this subject, 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 FOLLOW-UP PACKET NACC UNIFORM DATA SET (UDS)

Form T1: Inclusion 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 follow-up. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up 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 Follow-up Packet.
When feasible, the optimal modality of assessment would be video-assisted rather than by telephone.

1. Why is the UDS telephone follow-up protocol being used to obtain data about the subject?	NO	YES
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, and this is the first telephone packet submitted for the subject, then **END FORM HERE**. If No or Unknown but two or more consecutive telephone packets have been submitted for this subject, 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

Form A1: Subject Demographics

1. Subject's month and year of birth (MM/YYYY): ___ ___ / ___ ___ ___ ___

Based on the best available information from the subject (or co-participant, if necessary), enter the subject's month and year of birth in the specified numerical format (e.g., March 1920 would be entered as "03/1920").

2. Subject's current marital status:

- ☐ 1 Married
- ☐ 2 Widowed
- ☐ 3 Divorced
- ☐ 4 Separated
- ☐ 5 Never married (or marriage was annulled)
- ☐ 6 Living as married/domestic partner
- ☐ 9 Unknown

Select the box for the category that most accurately describes the subject's current marital status.

6=Living as married may be applied to either heterosexual or same-sex relationships.

Select **9=Unknown** only if the subject or co-participant is unable or unwilling to identify the subject's marital status.

3. Subject's sex:

- ☐ 1 Male
- ☐ 2 Female

4. What is the subject's living situation?

- ☐ 1 Lives alone
- ☐ 2 Lives with one other person: a spouse or partner
- ☐ 3 Lives with one other person: a relative, friend, or roommate
- ☐ 4 Lives with caregiver who is not spouse/partner, relative, or friend
- ☐ 5 Lives with a group (related or not related) in a private residence
- ☐ 6 Lives in group home (e.g., assisted living, nursing home, convent)
- ☐ 9 Unknown

Select the box for the category most accurately describes the subject's current living situation.

Select **9=Unknown** only if the subject or co-participant is unable or unwilling to identify the subject's living situation.

5. What is the subject's level of independence?

- ☐ 1 Able to live independently
- ☐ 2 Requires some assistance with complex activities
- ☐ 3 Requires some assistance with basic activities
- ☐ 4 Completely dependent
- ☐ 9 Unknown

Select the box for the category that most accurately describes the level of activity the subject is able to do. If the subject or co-participant indicates that the subject is able to perform complex activities but is not doing the activities because of her/his living situation, the subject is still considered to be able to live independently.

Select **2 = Requires some assistance with complex activities** if subject has deterioration in accustomed complex abilities (e.g., paying bills, shopping, remembering appointments, driving, cooking).

Select **3 = Requires some assistance with basic activities** if subject has deterioration in accustomed basic abilities (e.g., eating, dressing, personal hygiene).

Select **4 = Completely dependent** if subject is unable to perform basic activities of daily living.

Select **9 = Unknown** only if the subject or co-participant is unable or unwilling to identify the subject's living situation.

6. What is the subject's primary type of residence?

- ☐ 1 Single- or multi-family private residence (apartment, condo, house)
- ☐ 2 Retirement community or independent group living
- ☐ 3 Assisted living, adult family home, or boarding home
- ☐ 4 Skilled nursing facility, nursing home, hospital, or hospice
- ☐ 9 Unknown

Select the box for the category that most accurately describes the subject's type of residence.

Select **9 = Unknown** only if the subject or co-participant is unable or unwilling to identify the subject's current type of residence.

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

Provide the first three digits of the subject's ZIP Code. If the ZIP Code is unknown, leave the field blank.

NOTE ON FORM CLS (LINGUISTIC HISTORY FORM)

Please complete the Linguistic History Form (Form CLS) if the subject indicated Hispanic/Latino ethnicity (1=Yes) on their demographics form (Form A1) and has not completed Form CLS at a previous visit.

Form CLS must be completed and submitted to NACC only ONCE. It may be completed along with any UDS Initial or Follow-up visit. Information to complete CLS, may be obtained from the subject or a co-participant.

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

Form A1: Subject Demographics

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

Visit #: ___ Examiner's initials: ___

INSTRUCTIONS: This form is to be completed by the clinician or clinical interviewer based upon co-participant report plus ADC scheduling and medical records. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A1. Check only one box per question.

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

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

Form A2: Co-participant Demographics

1. Co-participant's month and year of birth (MM / YYYY): ___ / ____ *(99/9999 = unknown)*

Enter the co-participant's month and year of birth in the specified numerical format (e.g., March 1920 would be entered as "03/1920"). If the co-participant is unable or unwilling to answer, enter "99/9999".

2. Co-participant's sex:
- ☐ 1 Male
- ☐ 2 Female

3. Is this a new co-participant — i.e., one who was not a co-participant at any past UDS visit?
- ☐ 0 No (If No, **SKIP TO QUESTION 9**)
- ☐ 1 Yes

Select **0=No** if this co-participant has been present at any past UDS visit; if this is the case, ensure that the co-participant's month and year of birth match exactly for all visits in which he/she was a co-participant.

4. Does the co-participant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?
- ☐ 0 No (If No, **SKIP TO QUESTION 4**)
- ☐ 1 Yes
- ☐ 9 Unknown (If Unknown, **SKIP TO QUESTION 4**)

Ask the co-participant whether s/he considers her/his ethnicity to be Hispanic/Latino.

4a. If yes, what are the co-participant's reported origins?
- ☐ 1 Mexican, Chicano, or Mexican-American
- ☐ 2 Puerto Rican
- ☐ 3 Cuban
- ☐ 4 Dominican
- ☐ 5 Central American
- ☐ 6 South American
- ☐ 50 Other (SPECIFY): _____
- ☐ 99 Unknown

Ask the co-participant what s/he considers his/her Hispanic origins to be. Read or show the choices, if required, and allow only one category choice.

Select **1=Mexican, Chicano, or Mexican-American** if the co-participant reports having origins in Mexico.

Select **2=Puerto Rican** if the co-participant reports having origins in Puerto Rico.

Select **3=Cuban** if the co-participant reports having origins in Cuba.

Select **4=Dominican** if the co-participant reports having origins in the Dominican Republic.

Select **5=Central American** if the co-participant reports having origins in Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, or Panama.

Select **6=South American** if the co-participant reports having origins in Argentina, Bolivia, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, or Venezuela.

Select **50=Other (specify)** if the co-participant reports origins other than those listed in options 1 through 6 above, and enter the origin in the space provided.

Select **99=Unknown** only if the co-participant is unable or unwilling to identify his/her origins.

5. What does the co-participant report as his or her race?

- ☐ 1 White
- ☐ 2 Black or African American
- ☐ 3 American Indian or Alaska Native
- ☐ 4 Native Hawaiian or other Pacific Islander
- ☐ 5 Asian
- ☐ 50 Other (SPECIFY): _____
- ☐ 99 Unknown

Ask the co-participant what s/he considers her/his race to be. NIH defines race and Hispanic ethnicity separately; therefore, please do not write in "Hispanic" or the specific Hispanic origins (e.g., Mexico) as the co-participant's race. Instead, be sure to indicate Hispanic ethnicity in Question 4. If the co-participant will not identify a race and identifies only as Hispanic, select **99=Unknown**. Read or show the choices, and allow only one category choice. There will be an opportunity to record other applicable race categories in Questions 6 and 7.

4=Native Hawaiian or Other Pacific Islander: This includes Native Hawaiian, Guamanian or Chamorro, Samoan, or other Pacific Islander.

5=Asian: This includes Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other Asian.

Select **50=Other (specify)** if the co-participant reports a race other than those listed, and enter the race in the space provided. If the co-participant prefers to report her/his race as multiracial, select **50=Other (specify)** and specify "multiracial".

Select **99=Unknown** only if the co-participant is unable or unwilling to identify her/his race.

6. What additional race does the co-participant report?

- ☐ 1 White
- ☐ 2 Black or African American
- ☐ 3 American Indian or Alaska Native
- ☐ 4 Native Hawaiian or other Pacific Islander
- ☐ 5 Asian
- ☐ 50 Other (SPECIFY): _____
- ☐ 88 None reported
- ☐ 99 Unknown

If the co-participant reports an additional race, select the box that corresponds to this additional race. Do not record a race that was already provided in Question 5.

4=Native Hawaiian or Other Pacific Islander and **5=Asian**: See previous inclusion list (Question 5).

Select **50=Other (specify)** if the co-participant reports an additional race other than those listed in options 1 through 5, and enter the race in the space provided.

Select **88=None** reported if the co-participant reports no additional race beyond what was reported in Question 5.

Select **99=Unknown** if the co-participant reports having an additional race but is unable or unwilling to identify it.

7. 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

If the co-participant reports an additional race, select the box that corresponds to this additional race. Do not record a race that was already provided in Questions 5 and 6.

4=Native Hawaiian or Other Pacific Islander and **5=Asian**: See previous inclusion list (Questions 5 and 6).

Select **50=Other (specify)** if the co-participant reports an additional race other than those listed in options 1 through 5, and enter the race in the space provided.

Select **88=None** reported if the co-participant reports no additional race beyond what was recorded in Questions 5 and 6.

Select **99=Unknown** if the co-participant reports an additional race but is unable or unwilling to identify it.

8. Co-participant's years of education — use the codes below to report the level achieved; if an attempted level is not completed, enter the number of years completed: ⌊__⌋⌊__⌋

12 = high school or GED 16 = bachelor's degree 18 = master's degree 20 = doctorate 99 = unknown

This question refers to achieved educational levels, rather than the number of years it took to complete that level. Use the following to describe achieved educational levels: High school or GED=12 years, bachelor's degree=16 years, master's degree=18 years, doctorate=20 years.

If the co-participant hasn't completed a level, enter the total number of years of education completed toward that level.

Examples: If the co-participant attended school for eight years and did not earn a diploma or GED, enter "08". If the co-participant completed 17.5 years of school and earned a bachelor's degree but did not complete an attempted master's degree, enter "17". (However, if the co-participant attended school for 17.5 years to earn a bachelor's degree and that was the intended level of achievement, then enter "16".) If the co-participant attended school for 25 years to earn a doctorate degree, enter "20" to indicate the achieved educational level.

If the co-participant is unable or unwilling to answer the question, enter "99".

9. What is co-participant's relationship to the subject?

- ☐ 1 Spouse, partner, or companion (include ex-spouse, ex-partner, fiancé(e), boyfriend, girlfriend)
- ☐ 2 Child (by blood or through marriage or adoption)
- ☐ 3 Sibling (by blood or through marriage or adoption)
- ☐ 4 Other relative (by blood or through marriage or adoption)
- ☐ 5 Friend, neighbor, or someone known through family, friends, work, or community (e.g., church)
- ☐ 6 Paid caregiver, health care provider, or clinician

9a. How long has the co-participant known the subject? ⌊__⌋⌊__⌋⌊__⌋ years *(999=unknown)*

If the exact number of years is unknown, ask the co-participant to estimate it. If the co-participant is not able to estimate the number of years he/she has known the subject, enter **999=Unknown**.

10. Does the co-participant live with the subject?	☐0 No ☐1 Yes (If Yes, **SKIP TO QUESTION 10**)

Select **1=Yes** if the co-participant currently lives with the subject at least part of the time.

10a. If no, approximate frequency of in-person visits?	☐1 Daily ☐2 At least three times per week ☐3 Weekly ☐4 At least three times per month ☐5 Monthly ☐6 Less than once a month

10b. If no, approximate frequency of telephone contact?	☐1 Daily ☐2 At least three times per week ☐3 Weekly ☐4 At least three times per month ☐5 Monthly ☐6 Less than once a month

"Telephone contact" includes by communcating by phone, video messaging applications, and text/messaging applications.

11. Is there a question about the co-participant's reliability?	☐0 No ☐1 Yes

The co-participant's reliability should be based on a consensus opinion from the staff that interacted with the co-participant. This question would best be filled out after the UDS assessments have been completed, when a better judgment can be made about the co-participant's reliability. If there is any reason to doubt the reliability of the co-participant, select **1=Yes**.

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

Form A2: Co-participant Demographics

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

Visit #: ___ Examiner's initials: ___

INSTRUCTIONS: This form is to be completed by the clinician or clinical interviewer based on co-participant's report. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up 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. Is this a new co-participant — i.e., one who was not a co-participant at any past UDS visit?	☐ 0 No (If No, **SKIP TO QUESTION 9**) ☐ 1 Yes
4. Does the co-participant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	☐ 0 No (If No, **SKIP TO QUESTION 5**) ☐ 1 Yes ☐ 9 Unknown (If Unknown, **SKIP TO QUESTION 5**)
4a. If yes, what are the co-participant's reported origins?	☐ 1 Mexican, Chicano, or Mexican-American ☐ 2 Puerto Rican ☐ 3 Cuban ☐ 4 Dominican ☐ 5 Central American ☐ 6 South American ☐ 50 Other (SPECIFY): _____ ☐ 99 Unknown
5. What does the co-participant report as his or her race?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or other Pacific Islander ☐ 5 Asian ☐ 50 Other (SPECIFY): _____ ☐ 99 Unknown
6. What additional race does the co-participant report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or other Pacific Islander ☐ 5 Asian ☐ 50 Other (SPECIFY): _____ ☐ 88 None reported ☐ 99 Unknown

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

Form A3: Subject Family History

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

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

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

For such subjects, you must fill out this form <u>in its entirety</u>, meaning:

1. You must answer **1=Yes** to Question 1 on genetic mutations and complete 2a – 4b.
2. You must answer **1=Yes** to Question 5 on parents and complete 5a – 5b.

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

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

1. Since the last visit, is new information available concerning genetic mutations addressed by Questions 2a through 4b, below?	☐ 0 No **(Skip to Question 5)** ☐ 1 Yes ☐ 9 Unknown **(Skip to Question 5)**

If for a given subject you are submitting version 3 of Form A3 for the first time, you must enter **1=Yes** to this question and continue to answer Questions 2a, 3a, and 4a. This would apply under the following conditions:

- The A3 data that has been submitted for the subject was collected using UDS version 2; –OR–
- The subject was newly enrolled after UDS version 3 implementation but did not complete Form A3 during his/her IVP evaluation.

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)**

If there is any evidence for an AD mutation in any of the subject's blood relatives, indicate the predominant mutation, otherwise select **0=No**. Although blood relatives might have evidence for more than one genetic mutation, indicate the predominant mutation only. Evidence may be provided via family report, test, or other report or documentation.

Select **9=Unknown whether mutation exists** if it is unknown whether there is an AD mutation.

If an AD mutation is known to exist in the subject's family, but the type of mutation is unknown, select **8=Yes, Other (specify)** and enter "Unknown" on the specify line.

Do not include APOE e4 carrier status.

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)**

If there is any evidence for an FTLD mutation in any of the subject's blood relatives, indicate the predominant mutation, otherwise select **0=No**. Although blood relatives might have evidence for more than one genetic mutation, indicate the predominant mutation only. Evidence may be provided via family report, test or other report or documentation.

Select **9=Unknown whether mutation exists** if it is unknown whether there is an FTLD mutation.

If an FTLD mutation is known to exist in the subject's family, but the type of mutation is unknown, select **8=Yes, other (specify)** and enter "Unknown" in the space provided.

3b. Source of evidence for FTLD mutation (check one):	☐ 1 Family report (no test documentation available) ☐ 2 Commercial test documentation ☐ 3 Research lab test documentation ☐ 8 Other (SPECIFY): _____ ☐ 9 Unknown

4a. In this family, is there evidence for a mutation other than an AD or FTLD mutation? (If No or Unknown, **SKIP TO QUESTION 5**)	☐ 0 No **(SKIP TO QUESTION 5)** ☐ 1 Yes (SPECIFY): _____ ☐ 9 Unknown **(SKIP TO QUESTION 5)**

If there is any evidence for a mutation that has been associated with neurological, cerebrovascular, or psychiatric disorders other than AD or FTLD in any of the subject's blood relatives, select **1=Yes (specify)** and indicate the mutation on the specify line. Otherwise select **0=No**. Evidence may be provided via family report, test or other report or documentation.

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

INSTRUCTIONS FOR SECTIONS 5–7:

For biological parents, full siblings, and biological children with no neurological or psychiatric problem, provide the birth month, birth year, and age at death, enter **8=N/A — no neurological problem or psychiatric condition** in the primary neurological problem column, and leave the rest of the row blank.

For biological parents, full siblings, and biological children with an unknown neurological or psychiatric problem (clinician cannot determine specific neurological or psychiatric problem based on all available information), provide the birth month, birth year, and age at death, enter **9=Unknown** in the primary neurological problem column, and leave the subsequent items in the row blank.

If multiple neurological problems exist for a parent, sibling, or child, enter the code for the neurological condition that corresponds to the primary diagnosis.

When entering a code for the primary diagnosis ("Primary DX"), select the most specific diagnosis that is known.

If the method of evaluation is unknown, select **1=Family report**. If more than one method was used, report the highest level of diagnostic evaluation (see Appendix 2 on page 21 for an explanation of the methods of evaluation and their ranking from the highest [1] to lowest [7]).

"Age of onset" refers to the age at which the first progressive decline in cognition or behavior was noted, not the age at which diagnosis was made. If the subject and/or co-participant is unwilling or unable to answer, enter **999=Unknown**. If the primary diagnosis is a congenital condition, or present since birth, enter an age of onset of "0".

Birth year for parents, siblings, and children should be consistent across forms:

- Uniform Data Set (UDS) Initial Visit Form A3 or UDS Follow-up Visit Form A3 (if applicable),
- FTLD Module Initial Visit Form A3a or FTLD Module Follow-up Visit Form A3a (if applicable), and
- Any previously submitted FTLD Module Initial Visit Form A3F and Follow-up Visit Form A3F (if applicable).

BIOLOGICAL PARENTS

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

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

If for a given subject you are submitting version 3 of Form A3 for the first time, you must enter **1=Yes** to this question and continue to answer the questions in rows 5a and 5b. This would apply under the following conditions:

- The A3 data that has been submitted for the subject was collected using UDS version 2; –OR–
- The subject was newly enrolled after UDS version 3 implementation but did not complete Form A3 during his/her IVP evaluation.

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

	Birth month/year (99/9999=unknown)	Age at death (888=N/A, 999=unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
			See CODES, below			
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

****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: "Unknown" (9999) is not a permissible value for year of birth of full siblings or biological children. If birth year is unknown, please provide an approximate year on UDS Initial Visit Form A3 and UDS Follow-up Visit Form A3 so that the sibling 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 999=Unknown.

FULL SIBLINGS

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

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

☐ 0 No **(SKIP TO QUESTION 7)** ☐ 1 Yes **(COMPLETE QUESTIONS 6AA–6AT, AS APPLICABLE)**

If for a given subject you are submitting version 3 of Form A3 for the first time, you must enter **1=Yes** to this question and continue to answer the questions in rows 6aa through 6at, as appropriate. This would apply under the following conditions:

- The A3 data that has been submitted for the subject was collected using UDS version 2; –OR–
- The subject was newly enrolled after UDS version 3 implementation but did not complete Form A3 during his/her IVP evaluation.

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

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			
6aa. Sibling 1	__/____	___	__	___	__	___
6ab. Sibling 2	__/____	___	__	___	__	___
6ac. Sibling 3	__/____	___	__	___	__	___
6ad. Sibling 4	__/____	___	__	___	__	___
6ae. Sibling 5	__/____	___	__	___	__	___
6af. Sibling 6	__/____	___	__	___	__	___
6ag. Sibling 7	__/____	___	__	___	__	___
6ah. Sibling 8	__/____	___	__	___	__	___
6ai. Sibling 9	__/____	___	__	___	__	___
6aj. Sibling 10	__/____	___	__	___	__	___
6ak. Sibling 11	__/____	___	__	___	__	___
6al. Sibling 12	__/____	___	__	___	__	___
6am. Sibling 13	__/____	___	__	___	__	___
6an. Sibling 14	__/____	___	__	___	__	___
6ao. Sibling 15	__/____	___	__	___	__	___
6ap. Sibling 16	__/____	___	__	___	__	___
6aq. Sibling 17	__/____	___	__	___	__	___
6ar. Sibling 18	__/____	___	__	___	__	___
6as. Sibling 19	__/____	___	__	___	__	___
6at. Sibling 20	__/____	___	__	___	__	___

Only full siblings should be listed.

BIOLOGICAL CHILDREN

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

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

☐ 0 No **(END FORM HERE)** ☐ 1 Yes **(COMPLETE QUESTIONS 7AA–7AO, AS APPLICABLE)**

If for a given subject you are submitting version 3 of Form A3 for the first time, you must enter **1=Yes** to this question and continue to answer the questions in rows 7aa through 7ao, as appropriate. This would apply under the following conditions:

- The A3 data that has been submitted for the subject was collected using UDS version 2; –OR–
- The subject was newly enrolled after UDS version 3 implementation but did not complete Form A3 during his/her IVP evaluation.

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

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

Only biological children should be listed.

***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

****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

Enter **999=Specific diagnosis unknown** for primary diagnosis if the primary diagnosis is unknown and the method of evaluation is by any of following methods:

4=Review of the subject's 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

If an autopsy report is available for a first-degree relative, use the predominant diagnosis indicated by the neuropathologist. In the absence of a neuropathological diagnosis, use your best clinical judgment, based on the reported features, to indicate the predominant neuropathology diagnosis.

Parkinson's disease neuropathology as the primary diagnosis should be coded as **410 = Lewy body disease neuropathology**.

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.

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

Form A3: Subject Family History

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

Visit #: ___ ___ ___ Examiner's initials: ___ ___ ___

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

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

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

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

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

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

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

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

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

BIOLOGICAL PARENTS

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

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

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

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

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

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

****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

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

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

FULL SIBLINGS

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

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

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

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

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

BIOLOGICAL CHILDREN

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

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

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

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

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

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

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

****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

**APPENDIX 1: PRIMARY DIAGNOSIS CODES

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

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

***APPENDIX 2: METHOD OF EVALUATION

1. **Autopsy**

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

2. **Examination**

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

3. **Medical record review from formal dementia evaluation**

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

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

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

5. **Review of general medical records ONLY**

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

6. **Subject and/or co-participant telephone interview**

   See definition No. 4 above.

7. **Family report**

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

A4: Subject Medications

NOTE: The purpose of this form is to record all prescription medications taken by the subject within the two weeks before the current visit. Non-prescription (OTC) medications need not be reported; however, a short list of common OTC medications follows the prescription list. This form lists the 100 drugs most commonly reported by subjects in the UDS for the years 2011– 2013. The drugs are ordered alphabetically by their generic names. If applicable, one or more commercial (brand) names are listed in parentheses.

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

For each medication, find and select the appropriate check box. If a reported drug is not on the list, enter the medication name on one of the lines listed as "Specify" at the end of the form. For all medications specified at the end of the Form, associated drugIDs must also be recorded. The drugIDs may be determined by using the drugID Lookup Tool located on the NACC website at http://www.alz.washington.edu/WEB/adc-home.html.

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 ⌊_⌊_⌊_⌊_⌊_

☐ (SPECIFY:) _____ d ⌊_⌊_⌊_⌊_⌊_

☐ (SPECIFY:) _____ d ⌊_⌊_⌊_⌊_⌊_

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

Form A4: Subject Medications

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

Visit #: ___ ___ ___ Examiner's initials: ___ ___ ___

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

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

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

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

Subject ID: ____ Form date: ____ / ____ / ____ Visit #: ____

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____

☐ (SPECIFY:) _____ d____

☐ (SPECIFY:) _____ d____

☐ (SPECIFY:) _____ d____

☐ (SPECIFY:) _____ d____

☐ (SPECIFY:) _____ d____

☐ (SPECIFY:) _____ d____

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

INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Telephone Follow-up 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 Initial Visit Packet, Form B4.

SECTION 1: CDR® DEMENTIA STAGING INSTRUMENT[1]

The Washington University ADC provides a CDR training website for ADC personnel. This CDR training is required and may be accessed online at http://alzheimer.wustl.edu/cdr/Application/Step1.htm.

Use all information and make the best judgment. Score each category as independently as possible. Select only one box for each category, rating impairment as decline from the person's usual level due to cognitive loss alone, not impairment due to other factors such as physical disability. Occasionally, the evidence is ambiguous and the clinician's best judgment is that a category could be rated in either one of two adjacent boxes, such as **1=Mild** or **2=Moderate** impairment. In that situation, the standard procedure is to select the box of greater impairment.

Aphasia is taken into account by assessing both language and non-language function in each cognitive category. If aphasia is present to a greater degree than the general dementia, the subject is rated according to the general dementia. Supply evidence of non-language cognitive function.

A box score of 0 for Memory **(M=0)** applies to subjects who, in the clinician's judgment, have no memory impairment or have inconsistent slight forgetfulness. The adjective "slight" indicates that there is not even a suggestion that everyday function has been affected by a memory change. In contrast, a box score of 0.5 in Memory indicates a consistent memory change and also suggests that the change may very subtly affect everyday performance (e.g., having to return to the grocery store after forgetting an item on the list).

Before scoring the CDR boxes, the clinician is to synthesize and evaluate all information: the report of the co-participant, the report (and performance) of the subject, and the clinician's own observations. It may be that an inobservant co-participant reports no memory problems, whereas the subject self-reports memory problems; if the clinician's judgment is that the individual is correct, then a box score of 0.5 for Memory can be given **(M=0.5)**. The converse also is true: a 0.5 box score can be given when the co-participant reports a problem but the subject does not. It is also possible for the clinician to rate Memory as 0.5 **(M=0.5)** if he/she believes a problem exists — even though neither the co-participant nor the subject reports a problem.

CDR Sum of Boxes
Calculate the sum of values for all answers and enter the total score in the space provided.

Global CDR
The standard global CDR is derived from the scores in each of the six categories ("box score") as follows:

- Memory (M) is the primary category, and all others are secondary.
- CDR = M if at least three secondary categories are given the same score as memory. Whenever three or more secondary categories are given a score greater or less than the memory score, CDR = score of majority of secondary categories on whichever side of M has the greater number of secondary categories. However, when three secondary categories are scored on one side of M and two secondary categories are scored on the other side of M, then CDR = M.
- When M = 0.5, CDR = 1 if at least three of the other categories are scored 1 or greater. If M = 0.5, then CDR cannot be 0; it can only be 0.5 or 1.
- If M = 0, then CDR = 0 unless there is impairment (0.5 or greater) in two more secondary categories, in which case CDR = 0.5.

Although applicable to most Alzheimer's disease situations, these rules do not cover all possible scoring combinations. Unusual circumstances that occasionally occur in AD, and may be expected in non-Alzheimer's dementia as well, are scored as follows:

1. With ties in the secondary categories on one side of M, choose the tied scores closest to M for CDR (e.g., if M and another secondary category = 3, two secondary categories = 2, and two secondary categories = 1, then CDR = 2).
2. When only one or two secondary categories are given the same score as M, CDR = M as long as no more than two secondary categories are on either side of M.
3. When M = 1 or greater, CDR cannot be 0; in this circumstance, CDR = 0.5 when the majority of secondary categories are 0.

The CDR scoring algorithm can be accessed online at http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html .

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.

SECTION 2: NACC FTLD BEHAVIOR & LANGUAGE DOMAINS

In addition to the factors investigated within the standard CDR, two additional constructs — "Behavior, Comportment, and Personality" and "Language" — have been appended as the **NACC FTLD Behavior & Language Domains**, which will aid in the identification of subjects with frontotemporal dementia and/or primary progressive aphasia, respectively. Because of their specialized nature, instructions for the scoring of each item are outlined below.

Behavior, Comportment, and Personality

This item should be completed by a clinician or other trained health professional who is skilled in the assessment of FTLD, based on informant report and a review of the subject's cognitive, functional, and behavioral status. This domain is intended to assess changes in personality, aberrant behaviors, and changes in interpersonal relationships. The kinds of specific issues that might fall under these rubrics include: loss of insight, disinhibition, apathy, social withdrawal and disengagement, emotional lability, easy distractibility, reduced empathy for the feelings of others, impulsivity, and changes in eating habits and table manners. A key element of each of these is the degree to which these behaviors impact interpersonal relationships.

Language

This item should be completed by a clinician or other trained health professional who is well versed in aphasia and aphasic disorders, based on information derived from the informant and also from clinical assessment of the patient's language functions in the course of the clinical interview and the mental status examination. This domain is intended to assess changes in language. The components of language that are primarily of interest include: spontaneous speech, auditory comprehension, object naming, reading and writing. Using these in combination, the goal is to assess the subject's ability to create and understand various forms of information. The rate at which these are generated or comprehended is also of interest.

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

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

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

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Telephone Follow-up 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 Follow-up 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 Dementia 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.

Form B5 (v3.1): Neuropsychiatric Inventory Questionnaire (NPI-Q[1])

ADC personnel must be certified as an NPI-Q interviewer through the online training system developed by the University of California Los Angeles and NACC. The NPI-Q Interviewer Certification system may be accessed through the NACC website at https://www.alz.washington.edu/npiq/signin.html . The procedures established in the training system must be followed to complete this form.

The Neuropsychiatric Inventory – Questionnaire (NPI-Q) was developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in routine clinical practice settings (Kaufer et al., J Neuropsychiatry Clin Neurosci 2000, 12:233-239). The NPI-Q is adapted from the NPI (Cummings et al., Neurology 1994; 44:2308-2314), a validated informant-based interview that assesses neuropsychiatric symptoms over the previous month. The original NPI included 10 neuropsychiatric domains; two others, Nighttime Behavioral Disturbances and Appetite/Eating Changes, have subsequently been added.

Each of the 12 NPI-Q domains contains a survey question that reflects cardinal symptoms of that domain. Initial responses to each domain question are "Yes" (present), "No" (absent), or "Unknown". If the response to the domain question is "No" or "Unknown", the interviewer goes to the next question. If "Yes", the interviewer then rates the Severity of the symptoms present within the last month on a 3-point scale.

It is recommended that responses to the NPI-Q be reviewed for completeness by the interviewer and for clarifying uncertainties after each administration.

For inquiries regarding the NPI-Q, contact:

Jeffrey L. Cummings, MD (cumminj@ccf.org)
Cleveland Clinic Lou Ruvo Center for Brain Health
Mail Code Las Vegas, 888 W Bonneville
Las Vegas, NV 89106

The NPI-Q can be found at www.NPItest.net

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

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 Follow-up Visit Packet, Form B5. Check only one box for each category of response.

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)

The wording of the original NPI-Q focused on changes that have occurred since the patient first began to experience *memory* problems. However, in order to assess neuropsychiatric symptoms associated with etiologies other than Alzheimer's disease, the NPI-Q instructions have been edited to capture changes that have occurred since the patient first began to experience *cognitive* problems.

For subjects who are cognitively normal or whose cognition has not yet been evaluated — Please report any behaviors or symptoms that were present within the last month, ignoring behaviors and symptoms that are usual for the subject and have been customary throughout his/her life.

If the co-participant does not answer a question, select **9=Unknown**.

		Yes	No	Unknown		SEVERITY: Mild	SEVERITY: Mod	SEVERITY: Severe	SEVERITY: Unknown
NPI CO-PARTICIPANT: ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (SPECIFY): 1. _____									
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
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

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

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

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

INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional based on co-participant interview, as described by the training video. (This is not to be completed by the subject as a paper-and-pencil self-report.) For information on NPI-Q Interviewer Certification, see UDS Coding Guidebook for Telephone Follow-up 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	Mod	Severe	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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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	Mod	Severe	Unknown
6. **Anxiety** — Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	6a.	☐ 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

Form B6: Geriatric Depression Scale (GDS)

ASSESSMENT OF EMOTIONAL FUNCTIONING

While likely an infrequent occurrence, some participants may produce elevated scores on the Geriatric Depression Scale, suggesting the presence of significant emotional distress or suicidal ideation. If not already in place, it is strongly recommended that centers adopt guidelines for handling these situations remotely, including identifying the present location and address of any participant who demonstrates emotional distress. The following set of questions represents one example of how to manage elevated depression scores on the GDS when assessed by phone.

These guidelines are for certified interviewers when they suspect or detect significant emotional distress or suicidal ideation. "Significant emotional distress" is suggested by a score greater than 8 on the Geriatric Depression Scale — Short Form or by any responses during the encounter that suggest significant emotional distress, such as statements regarding suicide, hopelessness, or lasting depressed mood.

Please note that the following questions are intended only as an example. Centers may substitute their own script.

If GDS > 8, or if you suspect the participant is significantly distressed, then say:

1. **"Your response to some of the questions suggests to me that you might be experiencing some significant emotional distress at this time. Is that true?"** ☐ No ☐ Yes

   If "No," then say: **"Thanks. If you do, we recommend you speak with someone you feel comfortable talking to — a family member, your physician, a counselor, or your clergy person."** Continue with administration.

2. If "Yes," then say: ***"I see. I need to ask you a couple more questions."***

   2a. **"In the past month have you thought you would be better off dead or wished you were dead?"** ☐ No ☐ Yes

   2b. **"In the past month have you wanted to harm yourself?** ☐ No ☐ Yes

   2c. **"In the past month have you thought about suicide?"** ☐ No ☐ Yes

   2d. **"In the past month have you had a suicide plan?"** ☐ No ☐ Yes

   2e. **"In the past month have you attempted suicide?"** ☐ No ☐ Yes

If responses to 2b through 2e are "NO," then say: "Thank you. We recommend you speak with a family member, your physician, or another professional like a psychologist, clergy person, or counselor to get help with your distress." Continue with administration.

If any response to 2b – 2e is "YES," then say: "We strongly recommend that you speak with a family member, your physician, or another professional like a psychologist, clergyman, or counselor to get help with your distress. I will let one of our study clinicians and one of the lead investigators at our ADRC know about your distress level so he/she can follow up with you and perhaps assist you in finding help."

Call the on-duty study clinician immediately and inform him/her of the participant's status and review the call with him/her. Study clinician will contact the participant by phone and follow up as per Center protocol.

Save a copy of all emails and other documents related to this event.

SUICIDAL IDEATION		
ADRC CCC PI notified date:	Follow up with participant:	
	Follow-up date:	☐ No follow up required
ADRC staff initials:	Outcome/follow-up comments:	

Complete the form above and attach it to the test administration booklet for data entry in the ADRC website for the study. Update with any follow-up information as it is received. Attach all correspondence to this document and file in participant's file.

The Form is intended for completion by clinician or other trained health professional as a direct subject interview. The form is not to be administered to the co-participant. If your Center prefers to administer the entire 30-item GDS, please first administer this 15-item form and score appropriately; then administer the remaining 15 items on a separate non-UDS form.

The Geriatric Depression Scale was developed by Stanford University as a basic screening measure for depression in older adults. Further information is available online at http://www.stanford.edu/~yesavage/GDS.html .

☐ 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.

Select **9=Did not answer** if the subject is unable or unwilling to answer a question.

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?s	☐ 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)* ⎵⎵

Calculate the sum of values for all checked "Yes" or "No" answers and enter the total score in the space provided. The calculation may include a maximum of three unanswered items, and the final sum must be prorated for the number of unanswered items (see instructions below for prorating scores). If more than three items are unanswered, however, the test must be considered incomplete and the Total GDS Score entered as **88=Did not complete**.

PRORATING SCORES (what to do if the subject does not answer up to three items): If up to three of the 15 items are unanswered (i.e., responses are **9=Did not answer**), add the total score on the completed items plus an estimated score for the unanswered items to get a total score. The estimated score for unanswered items is calculated as:

(Total score of completed items / # of completed items) * (# of unanswered items)

You may get a fractional answer that requires rounding. For example, if the subject got a score of 5 for 12 completed items, then the estimated total score is 5 + [(5/12) * 3] = 6.25. Since the decimal portion of this value is <0.50, the total GDS score is 6.

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

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

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

Visit #: ___ ___ ___ Examiner's initials: ___ ___ ___

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

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

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

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

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

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

Form B7: NACC Functional Assessment Scale (FAS[1])

The Form is intended for completion by clinician or other trained health professional per co-participant interview. The intent of the FAS is to assess change in an individual's functional activities, relative to previously attained abilities, that are caused by cognitive dysfunction. Select the most accurate response, based on the co-participant's assessment.

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

If the co-participant indicates that the subject no longer performs a particular task, it is reasonable to probe further and ask if they think the subject *could* still do the task. This will help tease out the relevant cognitive impairment.

If the co-participant believes the subject did the activity but cannot speak to the subject's potential changes in that activity, then he/she should select **9=Unknown**.

[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.

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

Form B7: FUNCTIONAL ASSESSMENT NACC Functional Assessment Scale (FAS[1])

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

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

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

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

Form B9: Clinician Judgment of Symptoms

It is understood that answering many of these questions may require video-assisted assessments, use of clinical data from the recent medical record, and or participant/co-participant report in cases where the findings may not have previously been documented in a traditional in-person UDS visit or where new signs and symptoms may have emerged since the last evaluation. We recommend that you use the best sources of information available in filling out this form and defer to the "Unknown" answer option in instances where information may be lacking and or considered unreliable by the study clinician.

For evaluations that are conducted by telephone only with participants for whom recent medical records are not available, the informal use of participant and co-participant questionnaires may be useful for collection of such data but are not a required part of the UDS visit packet. The resources below serve as guidance only for cases in which alternate sources of data may be lacking. Potential resources for consideration include the BE-FAST assessment, the SCOPA-MS, and the ALSAQ-5, among many other validated scales:

BE-FAST assessment for stroke-associated signs and symptoms

Aroor S, Singh R, Goldstein LB. BE-FAST (Balance, Eyes, Face, Arm, Speech, Time): Reducing the Proportion of Strokes Missed Using the FAST Mnemonic. Stroke. 2017;48(2):479–481. doi:10.1161/STROKEAHA.116.015169

SCOPA-MS for parkinsonian features

Martínez-Martín P, Benito-León J, Burguera JA, et al. The SCOPA-Motor Scale for assessment of Parkinson's disease is a consistent and valid measure. J Clin Epidemiol. 2005;58(7):674–679. doi:10.1016/j.jclinepi.2004.09.014

ALSAQ-5 for motor neuron disease features

Jenkinson C, Fitzpatrick R. Reduced item set for the amyotrophic lateral sclerosis assessment questionnaire: development and validation of the ALSAQ-5. J Neurol Neurosurg Psychiatry. 2001;70(1):70–73. doi:10.1136/jnnp.70.1.70

The purpose of this Form is to provide clinical determination of the symptoms the subject is currently experiencing and the onset of symptoms. The Form should be completed by the clinician, and conclusions should be based on information obtained through subject, co-participant, medical records, and/or observation. Results from the neuropsychological test battery (except for the MoCA) and imaging should not be used to determine answers for this Form but may be used to make the official clinical diagnosis on Form D1.

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

Decline in memory refers to cognitive changes in the subject's usual or customary memory function. Select **1=Yes** if the subject reports a current (i.e., recent) decline in memory function. This question refers to memory only and not behavior, motor, or other non-memory symptoms. If, based upon the clinician's judgment, the subject is too impaired to provide an answer to this question, then select **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

Decline refers to cognitive changes in the subject's usual or customary memory function. Select **1=Yes** if the co-participant reports a current (i.e., recent) decline in the subject's memory function. This question refers to memory only and not behavior, motor, or other non-memory symptoms. Every effort should be made to have a co-participant present at UDS visits; however, if there is no co-participant, select **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

Cognitive decline refers to changes in the subject's usual or customary memory or non-memory cognitive abilities, reported or observed at the current visit.

If the clinician is certain that there has been no meaningful (i.e., clinically significant) decline in the subject's memory or non-memory cognitive abilities, select **0=No** and skip to Question 8 on behavioral symptoms.

If the clinician is certain that there has been a meaningful decline, select **1=Yes** and complete Questions 4–7.

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?	☐ 0	☐ 1	☐ 9

4g1. If yes, at what age did the fluctuating cognition begin? ___ ___ ___
(777 = Age of onset provided at a previous UDS visit)
(The clinician must use his/her best judgment to estimate an age of onset.)

Enter the age at which the subject first experienced fluctuating cognition. If age of onset of fluctuating cognition was assessed at a previous visit, enter **777=Age of onset provided at a previous UDS visit**.

4h. **Other** (SPECIFY): _____ ☐ 0 ☐ 1

For Questions 4a–4g, select **9=Unknown** only if the answer cannot be determined based upon information gathered from the subject, co-participant, medical records, and/or observation. If the subject exhibits a meaningful decline in any ability (or abilities) other than those listed, select **1=Yes** for Question 4h and briefly describe under "Other (specify)".

5. Indicate the **predominant** symptom that was first recognized as a decline in the subject's cognition:

NOTE: Enter 0 if this information was provided on a previously submitted Form B9.

- ☐ 0 Assessed at a previous UDS visit
- ☐ 1 Memory
- ☐ 2 Orientation
- ☐ 3 Executive function — judgment, planning, problem-solving
- ☐ 4 Language
- ☐ 5 Visuospatial function
- ☐ 6 Attention/concentration
- ☐ 7 Fluctuating cognition
- ☐ 8 Other (SPECIFY): _____
- ☐ 99 Unknown

If the first predominant cognitive symptom was assessed at a previous visit, select **0=Assessed at a previous UDS visit**.

This question refers to the onset of the cognitive change (i.e., when change in cognition was first noticed). If the co-participant or other available information indicates that several symptoms occurred simultaneously, the clinician must ask the co-participant and/or use her/his best clinical judgment to commit to one of the symptoms as the predominant symptom.

If the predominant cognitive symptom first recognized as a decline was other than those listed, select **8=Other** and briefly describe in the space provided.

Select **99=Unknown** only if clinician is unable to ascertain the cognitive symptom predominant at onset, based on available information or observation.

6. Mode of onset of cognitive symptoms	☐ 1 Gradual ☐ 2 Subacute ☐ 3 Abrupt ☐ 4 Other (SPECIFY): _____ ☐ 99 Unknown

This question refers to the onset of the cognitive change (i.e., when change in cognition was first noticed). The clinician should choose the option that most closely resembles the mode of onset of cognitive symptoms for the subject.

If the mode of onset was other than those listed, select **4=Other (specify)** and briefly describe in the space provided.

Select **99=Unknown** only if no information is available to allow the clinician to ascertain the mode of onset.

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

If age of onset of fluctuating cognition was assessed at a previous visit, enter **777=Age of onset provided at a previous UDS visit**.

Cognitive decline refers to changes in the subject's usual or customary memory or non-memory cognitive abilities reported or observed at the current visit. Age of onset of cognitive decline should correspond to the predominant symptom that was first recognized as a change in the subject's cognitive abilities (Question 5 above).

If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that cognitive decline started in the subject's 50s or 60s, estimate age 55 or 60.

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

Decline or changes in behavior refers to meaningful change or decline from the subject's usual or customary behavior reported or observed at the current visit.

If the clinician is certain that there has been no meaningful (i.e., clinically significant) decline or change in the subject's behavior, select **0=No** and skip to Question 13.

If the clinician is certain that there has been a meaningful decline, select **1=Yes** and complete Questions 9–12.

QUESTIONS 9a – 9i: If the symptoms assessed in Questions 9a – 9i are reported or observed to reflect the subject's condition at this clinical evaluation based upon information gathered from the subject, co-participant, medical records, and/or observation, then select **1=Yes**; otherwise, select **0=No**. Select **9=Unknown** only if the answer cannot be determined based upon information gathered from the subject, co-participant, medical records, and/or observation.

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

Select **1=Yes** for Question 9c1a if the hallucinations are well formed and detailed (e.g., people, animals, or objects, not just vague visual images, blurs, lines or colors). Select **0=No** if the hallucinations are not well-formed and detailed.

9c1b. If yes, at what age did the visual hallucinations begin? ___ ___ ___

(777 = Age of onset provided at a previous UDS visit; 888 = N/A, not well-formed)

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

If age of onset of visual hallucinations was assessed at a previous visit, enter **777=Age of onset provided at a previous UDS visit**.

Enter the age at which the subject first experienced well formed, clear-cut visual hallucinations (i.e., they need not be detailed). Exclude hallucinations occurring in the context of a clear-cut delirium or as a clear consequence of an adverse event from a medication. If the subject experiences hallucinations that are not well formed and clear-cut, enter **888=N/A**, not well formed.

If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that hallucinations began in the subject's 50s or 60s, estimate age 55 or 60.

	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
9g.	**Personality change** Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account?	☐ 0 ☐ 1 ☐ 9
9h.	**REM sleep behavior disorder** While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)?	☐ 0 ☐ 1 ☐ 9

9h1. If yes, at what age did the REM sleep behavior disorder begin? ___ ___ ___

(777 = Age of onset provided at a previous UDS visit)

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

If age of onset of RBD was assessed at a previous visit, enter **777=Age of onset provided at a previous UDS visit**.

Enter the age at which the subject first began experiencing REM sleep behavior disorder. If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that REM sleep behavior disorder started in the subject's 50s or 60s, estimate age 55 or 60.

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

If the subject exhibits a meaningful decline in any behavior other than those listed, select **1=Yes** for Question 9j and briefly describe under "Other".

10. Indicate the **predominant** symptom that was first recognized as a decline in the subject's behavior: *NOTE: Enter 0 if this information was provided on a previously submitted Form B9.*	☐ 0 Assessed at a previous UDS visit ☐ 1 Apathy/withdrawal ☐ 2 Depressed mood ☐ 3 Psychosis ☐ 4 Disinhibition ☐ 5 Irritability ☐ 6 Agitation ☐ 7 Personality change ☐ 8 REM sleep behavior disorder ☐ 9 Anxiety ☐ 10 Other (SPECIFY): _____ ☐ 99 Unknown

If the first predominant behavior symptom was assessed at a previous visit, select **0=Assessed at a previous UDS visit**.

This question refers to the subject's symptoms at onset of behavior change. If the co-participant or other available information indicates that several symptoms occurred simultaneously, the clinician must ask the co-participant and/or use her/his best clinical judgment to commit to one of the symptoms as the predominant symptom.

If the predominant behavioral symptom first recognized as a decline was other than those listed, select **10=Other (specify)** and briefly describe in the space provided.

Select **99=Unknown** only if clinician is unable to ascertain the behavioral symptom predominant at onset, based on available information or observation.

11. Mode of onset of behavioral symptoms:	☐ 1 Gradual ☐ 2 Subacute ☐ 3 Abrupt ☐ 4 Other (SPECIFY): _____ ☐ 99 Unknown

The clinician should choose the option that most closely resembles the mode of onset of behavioral symptoms for the subject.

If the mode of onset was other than those listed, select **4=Other** and briefly describe in the space provided.

Select **99=Unknown** only if no information is available to allow the clinician to ascertain the mode of onset.

12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? ___ ___ ___
(777 = Age of onset provided at a previous UDS visit)
(The clinician must use his/her best judgment to estimate an age of onset.)

Age of onset of behavior symptoms should correspond to the predominant symptom that was first recognized as a change in the subject's behavior (Question 10 above). If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that the behavioral symptoms started in the subject's 50s or 60s, estimate age 55 or 60.

If age of onset of behavioral symptoms was assessed at a previous visit, enter **777=Age of onset provided at a previous UDS visit**.

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

Decline or changes in motor/movement refers to meaningful decline from the subject's usual or customary level (for example, as evidenced by gait disorder, falls, tremor, and slowness) reported or observed at the current visit.

If the clinician is certain that there have been no meaningful changes or decline in motor or movement, select **0=No** and skip to Question 20.

If the clinician is certain that there has been a meaningful decline, select **1=Yes** and complete Questions 14 –19.

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

If the symptoms assessed in Questions 14a – 14d are reported or observed to reflect the subject's condition at this clinical evaluation based upon information gathered from the subject, co-participant, medical records, and/or observation, then select **1=Yes**; otherwise, select **0=No**. Select **9=Unknown** only if the answer cannot be determined based upon information gathered from the subject, co-participant, medical records, and/or observation.

15. Indicate the **predominant** symptom that was first recognized as a decline in the subject's motor function: *NOTE: Enter 0 if this information was provided on a previously submitted Form B9.*	☐ 0 Assessed at a previous UDS visit ☐ 1 Gait disorder ☐ 2 Falls ☐ 3 Tremor ☐ 4 Slowness ☐ 99 Unknown

If the first predominant motor symptom was assessed at a previous visit, select **0=Assessed at a previous UDS visit**.

This question refers to the subject's symptoms at onset of decline in motor function. If the co-participant or available information indicates that several symptoms occurred simultaneously, the clinician must ask the co-participant and/or use her/his best clinical judgment to commit to one of the symptoms as the predominant symptom.

Select **99=Unknown** only if clinician is unable to ascertain the motor symptom predominant at onset, based on available information or observation.

16. Mode of onset of motor symptoms:	☐ 1 Gradual ☐ 2 Subacute ☐ 3 Abrupt ☐ 4 Other (SPECIFY): _____ ☐ 99 Unknown

Select the option that most closely resembles the mode of onset of motor symptoms for the subject.

If the mode of onset was other than those listed, select **4=Other (specify)** and briefly describe in the space provided.

Select **99=Unknown** only if no information is available to allow the clinician to ascertain the mode of onset.

17. Were changes in motor function suggestive of parkinsonism? (If No or Unknown, **SKIP TO QUESTION 18**)	☐ 0 No ☐ 1 Yes ☐ 9 Unknown
17a. If Yes, at what age did the motor symptoms suggestive of parkinsonism begin? *(777 = Age of onset provided at a previous UDS visit)* (The clinician must use his/her best judgment to estimate an age of onset.)	⌊__⌋⌊__⌋⌊__⌋

If age of onset of parkinsonism was provided at a previous visit, enter 777=**Age of onset provided at a previous UDS visit**.

Enter the age at which motor function changes suggestive of parkinsonism first were noticed in the subject. If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that motor symptoms started in the subject's 50s or 60s, estimate age 55 or 60. Do not enter the age of diagnosis (if applicable); age of diagnosis should be entered on UDS IVP Form A5.

18. Were changes in motor function suggestive of amyotrophic lateral sclerosis? (If No or Unknown, **SKIP TO QUESTION 19)**	☐ 0 No ☐ 1 Yes ☐ 9 Unknown
18a. If Yes, at what age did the motor symptoms suggestive of ALS begin? *(777 = Age of onset provided at a previous UDS visit)* (The clinician must use his/her best judgment to estimate an age of onset.)	⎽⎽ ⎽⎽ ⎽⎽

Enter the age at which motor function changes suggestive of ALS first were noticed in the subject. If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that motor symptoms started in the subject's 50s or 60s, estimate age 55 or 60. Do not enter the age of diagnosis (if applicable).

If age of onset of ALS symptoms was provided at a previous visit, enter **777=Age of onset provided at a previous UDS visit.**

19. Based on the clinician's assessment, at what age did the motor changes begin? *(777 = Age of onset provided at a previous UDS visit)* (The clinician must use his/her best judgment to estimate an age of onset of motor changes.)	⎽⎽ ⎽⎽ ⎽⎽

Age of onset of motor symptoms should correspond to the predominant symptom that was first recognized as a change in the subject's motor function (Question 15 above). If the exact age is unknown, the clinician should estimate to the nearest decade. For example, if the co-participant says that motor symptoms started in the subject's 50s or 60s, estimate age 55 or 60. Do not enter the age of diagnosis (if applicable).

If age of onset of motor symptoms was provided at a previous visit, enter **777=Age of onset provided at a previous UDS visit.**

Overall course of decline and predominant domain

20. Overall course of decline of cognitive/behavioral/motor syndrome:	☐ 1 Gradually progressive ☐ 2 Stepwise ☐ 3 Static ☐ 4 Fluctuating ☐ 5 Improved ☐ 8 N/A ☐ 9 Unknown

Select the appropriate number to indicate the overall decline in cognitive/behavioral/motor functions during the course of the illness. Fluctuating course does not refer to the short-term fluctuations that are part of DLB.

Select **9=Unknown** only if no information is available to allow the clinician to describe the overall course of the syndrome.

21. Indicate the **predominant** domain that was first recognized as changed in the subject: *NOTE: Enter 0 if this information was provided on a previously submitted Form B9.*	☐ 0 Assessed at a previous UDS visit ☐ 1 Cognition ☐ 2 Behavior ☐ 3 Motor function ☐ 8 N/A ☐ 9 Unknown

If the first predominant symptom was assessed at a previous visit, select **0=Assessed at a previous UDS visit**.

Select the appropriate number to indicate which domain appears to be the first to have changed in the subject. Choose only one domain as predominantly changing first, based on the clinician's best judgment.

Select **9=Unknown** only if no information is available to allow the clinician to describe the predominantly changed domain.

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

This question refers to a potential clinical data module for Lewy body disease. If the participant appears to meet diagnostic criteria for Lewy body disease, select **1=Yes**.

23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration?	☐ 0 No ☐ 1 Yes

This question refers to the participant's potential eligibility for evaluation with the FTLD Module. If the participant appears to meet criteria for any of the FTLD-related diagnoses, select **1=Yes**.

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

Form B9: Clinician Judgment of Symptoms

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

Visit #: ___ ___ ___ Examiner's initials: ___ ___ ___

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

Declines in memory reported by subject and co-participant	
1. Does the subject report a decline in memory (relative to previously attained abilities)?	☐ 0 No ☐ 1 Yes ☐ 8 Could not be assessed/subject is too impaired
2. Does the co-participant report a decline in the subject's memory (relative to previously attained abilities)?	☐ 0 No ☐ 1 Yes ☐ 8 There is no co-participant
Cognitive symptoms	
3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition?	☐ 0 No (If No, **SKIP TO QUESTION 8**) ☐ 1 Yes

4. Indicate whether the subject currently is meaningfully impaired, *relative to previously attained abilities,* in the following cognitive domains, or has fluctuating cognition:

	No	Yes	Unknown
4a. **Memory** For example, does s/he forget conversations and/or dates, repeat questions and/or statements, misplace things more than usual, forget names of people s/he knows well?	☐ 0	☐ 1	☐ 9
4b. **Orientation** For example, does s/he have trouble knowing the day, month, and year, or not recognize familiar locations, or get lost in familiar locations?	☐ 0	☐ 1	☐ 9
4c. **Executive function — judgment, planning, problem-solving** Does s/he have trouble handling money (e.g., tips), paying bills, preparing meals, shopping, using appliances, handling medications, driving?	☐ 0	☐ 1	☐ 9
4d. **Language** Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction?	☐ 0	☐ 1	☐ 9
4e. **Visuospatial function** Does s/he have difficulty interpreting visual stimuli and finding his/her way around?	☐ 0	☐ 1	☐ 9
4f. **Attention, concentration** Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted?	☐ 0	☐ 1	☐ 9
4g. **Fluctuating cognition** Does the subject exhibit pronounced variation in attention and alertness, noticeably over hours or days — for example, long lapses or periods of staring into space, or times when his/her ideas have a disorganized flow? 4g1. If yes, at what age did the fluctuating cognition begin? ___ ___ ___ *(777 = Age of onset provided at a previous UDS visit.)* (The clinician must use his/her best judgment to estimate an age of onset.)	☐ 0	☐ 1	☐ 9
4h. **Other** (SPECIFY): _____	☐ 0	☐ 1	

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

5. Indicate the **predominant** symptom that was first recognized as a decline in the subject's cognition:

   NOTE: Enter 0 if this information was provided on a previously submitted Form B9.

- ☐ 0 Assessed at a previous UDS visit
- ☐ 1 Memory
- ☐ 2 Orientation
- ☐ 3 Executive function — judgment, planning, problem-solving
- ☐ 4 Language
- ☐ 5 Visuospatial function
- ☐ 6 Attention/concentration
- ☐ 7 Fluctuating cognition
- ☐ 8 Other (SPECIFY): _____
- ☐ 99 Unknown

6. Mode of onset of cognitive symptoms

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

7. Based on the clinician's assessment, at what age did the cognitive decline begin? ___ ___ ___

   (777 = Age of cognitive decline entered at a previous UDS visit)

   (The clinician must use her/his best judgment to estimate an age of onset of cognitive decline.)

Behavioral symptoms

8. Based on the clinician's judgment, is the subject currently experiencing any kind of behavioral symptoms?

- ☐ 0 No (If No, **SKIP TO QUESTION 13**)
- ☐ 1 Yes

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

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

Subject ID: ___ Form date: ___/___/___ Visit #: ___

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

9f. **Agitation** Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	☐ 0	☐ 1	☐ 9
9g. **Personality change** Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account?	☐ 0	☐ 1	☐ 9
9h. **REM sleep behavior disorder** While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)?	☐ 0	☐ 1	☐ 9
9h1. If yes, at what age did the REM sleep behavior disorder begin? ___ *(777 = Age of onset provided at a previous UDS visit.)* (The clinician must use his/her best judgment to estimate an age of onset)			
9i. **Anxiety** For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	☐ 0	☐ 1	☐ 9
9j. **Other** (SPECIFY): _____	☐ 0	☐ 1	

10. Indicate the **predominant** symptom that was first recognized as a decline in the subject's behavior:

NOTE: Enter 0 if this information was provided on a previously submitted Form B9.

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

11. Mode of onset of behavioral symptoms:

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

12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? ___
(777 = Age of onset provided at a previous UDS visit.)
(The clinician must use her/his best judgment to estimate age of onset of behavioral symptoms.)

Motor symptoms

13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms?

- ☐ 0 No (If No, **SKIP TO QUESTION 20**)
- ☐ 1 Yes

14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas:

	No	Yes	Unknown
14a. **Gait disorder** Has subject's walking changed, not specifically due to arthritis or an injury? Is s/he unsteady, or does s/he shuffle when walking, have little or no arm-swing, or drag a foot?	☐ 0	☐ 1	☐ 9
14b. **Falls** Does the subject fall more than usual?	☐ 0	☐ 1	☐ 9
14c. **Tremor** Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	☐ 0	☐ 1	☐ 9
14d. **Slowness** Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive?	☐ 0	☐ 1	☐ 9

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

9f. **Agitation** Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	☐ 0	☐ 1	☐ 9
9g. **Personality change** Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account?	☐ 0	☐ 1	☐ 9
9h. **REM sleep behavior disorder** While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)?	☐ 0	☐ 1	☐ 9
9h1. If yes, at what age did the REM sleep behavior disorder begin? ___ ___ ___ *(777 = Age of onset provided at a previous UDS visit.)* (The clinician must use his/her best judgment to estimate an age of onset)			
9i. **Anxiety** For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	☐ 0	☐ 1	☐ 9
9j. **Other** (SPECIFY): _____	☐ 0	☐ 1	

10. Indicate the **predominant** symptom that was first recognized as a decline in the subject's behavior:

NOTE: Enter 0 if this information was provided on a previously submitted Form B9.

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

11. Mode of onset of behavioral symptoms:

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

12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? ___ ___ ___
(777 = Age of onset provided at a previous UDS visit.)
(The clinician must use her/his best judgment to estimate age of onset of behavioral symptoms.)

Motor symptoms

13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms?

- ☐ 0 No (If No, **SKIP TO QUESTION 20**)
- ☐ 1 Yes

14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas:

	No	Yes	Unknown
14a. **Gait disorder** Has subject's walking changed, not specifically due to arthritis or an injury? Is s/he unsteady, or does s/he shuffle when walking, have little or no arm-swing, or drag a foot?	☐ 0	☐ 1	☐ 9
14b. **Falls** Does the subject fall more than usual?	☐ 0	☐ 1	☐ 9
14c. **Tremor** Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	☐ 0	☐ 1	☐ 9
14d. **Slowness** Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive?	☐ 0	☐ 1	☐ 9

Subject ID: ____ ____ ____ ____ ____ ____ ____ ____ ____ ____ Form date: ____ ____ / ____ ____ / ____ ____ ____ ____ Visit #: ____ ____ ____

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

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

Subject ID: _____ Form date: ____ / ____ / _____ Visit #: _____

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

Form C2T: Neuropsychological Battery Scores for T-cog

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 administration

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)
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)

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)

10. 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)

11. 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 unavailable 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)

12. 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 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)

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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)

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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)

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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): _____

Form D1: Clinician Diagnosis

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

It is understood that in some instances it may be difficult to provide an accurate diagnosis where a traditional in-person UDS has not occurred, especially for participants without a previous traditional in-person UDS visit or a recent detailed clinical assessment with documentation, or where new signs and symptoms that alter the diagnosis may have emerged since the last evaluation. We recommend that you use the best sources of information available in filling out this form and defer to an "Other-Unknown" answer option in instances where information may be lacking and or considered unreliable by the study clinician.

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)

Select **2=A formal consensus panel** if the diagnosis was made by a group of clinicians (e.g., neurologists, neuropsychologists, geriatricians) who convene on a regular or semi-regular basis to discuss and decide upon the final diagnosis. In the case of an ad hoc consensus group (e.g., two or more clinicians or other informal group), select **3=Other**.

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)**

Select **1= Yes** if the subject has normal cognition and does not have behavior that is sufficient to diagnose MCI or dementia due to FTD or DLB. Normal cognition is defined as: 1.) No diagnosis of MCI or dementia; and 2.) Either CDR=0 or neuropsychological testing within normal range (or both).

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)**

Review the criteria listed above Question 3 to determine whether the subject meets the criteria for all-cause dementia. These criteria are modified from the McKhann all-cause dementia criteria (2011) to allow a single domain to be affected.

Questions 4a – 4f: Diagnosis of the dementia syndromes listed below should be based exclusively on clinical symptoms, not on biomarkers or imaging.

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

This would include typical AD dementia, as well as non-AD amnestic multidomain dementia.

4b. Posterior cortical atrophy syndrome (or primary visual presentation)	☐ 1

Excerpted from Crutch et al. (2013): "Often considered an atypical or variant form of Alzheimer's disease (AD), PCA typically presents in the mid-50s or early 60s and is characterized by progressive decline in visual processing skills, relatively intact memory and language in the early stages, and atrophy of posterior brain regions. PCA is associated with a variety of unusual symptoms, such as difficulty interpreting, locating, or reaching for objects under visual guidance or difficulty navigating. Understanding numbers and reading and writing or spelling may also be affected and, as the disease progresses, patients often develop a more diffuse pattern of cognitive dysfunction, ultimately leading to dementia."

Table 1: Characteristics of posterior cortical atrophy (Excerpted from Crutch et al. (2013))

Core features of PCA:

- Insidious onset and gradual progression
- Prominent visuoperceptual and visuospatial impairments but no significant impairment of vision itself
- Relative preservation of memory and insight
- Evidence of complex visual disorders (e.g., elements of Balint's syndrome or Gerstmann's syndrome, visual field defects, visual agnosia, environmental disorientation)
- Absence of stroke or tremor

Other supportive features:

- Presenile onset
- Alexia
- Ideootor and dressing apraxia
- Prosopagnosia
- Prolonged color after-images

	4c. Primary progressive aphasia (PPA) syndrome	☐1	

Select **1=Present** if the subject meets the core clinical criteria for PPA.

ROOT DIAGNOSIS OF PRIMARY PROGRESSIVE APHASIA (PPA)[1]

All three core criteria must be present:

1. Most prominent clinical feature is a new and progressive difficulty with language (i.e., retrieving, using, repeating, sequencing, or understanding words).
2. The language disorder (aphasia) should be the most prominent deficit at symptom onset and for the initial phases of the disease.
3. All causes other than neurodegeneration are excluded.

1Mesulam, M.-M., 2003. Primary progressive aphasia: A language-based dementia. New England Journal of Medicine 348, 1535-1542.

Diagnostic features for the nonfluent/agrammatic variant PPA

I. Clinical diagnosis of nonfluent/agrammatic variant PPA

At least one of the following core features must be present:

1. Agrammatism in language production
2. Effortful, halting speech with inconsistent speech sound errors and distortions (apraxia of speech)

At least 2 of 3 of the following other features must be present:

1. Impaired comprehension of syntactically complex sentences
2. Spared single-word comprehension
3. Spared object knowledge

II. Imaging-supported nonfluent/agrammatic variant diagnosis

Both of the following criteria must be present:

1. Clinical diagnosis of nonfluent/agrammatic variant PPA
2. Imaging must show one or more of the following results:
   a. Predominant left posterior fronto-insular atrophy on MRI or
   b. Predominant left posterior fronto-insular hypoperfusion or hypometabolism on SPECT or PET

III. Nonfluent/agrammatic variant PPA with definite pathology

Clinical diagnosis (criterion 1 below) and either criterion 2 or 3 must be present:

1. Clinical diagnosis of nonfluent/agrammatic variant PPA
2. Histopathologic evidence of a specific neurodegenerative pathology (e.g., FTLD-tau, FTLD-TDP, AD, other)
3. Presence of a known pathogenic mutation

Abbreviations: AD = Alzheimer's disease; FTLD = frontotemporal lobar degeneration; PPA = primary progressive aphasia

Diagnostic criteria for the semantic variant PPA

I. Clinical diagnosis of semantic variant PPA

Both of the following core features must be present:

1. Impaired confrontation naming
2. Impaired single-word comprehension

At least 3 of the following other diagnostic features must be present:

1. Impaired object knowledge, particularly for low-frequency or low-familiarity items
2. Surface dyslexia or dysgraphia
3. Spared repetition
4. Spared speech production (grammar and motor speech)

II. Imaging-supported semantic variant PPA diagnosis

Both of the following criteria must be present:

1. Clinical diagnosis of semantic variant PPA
2. Imaging must show one or more of the following results:
   a. Predominant anterior temporal lobe atrophy
   b. Predominant anterior temporal lobe hypoperfusion or hypometabolism on SPECT or PET

III. Semantic variant PPA with definite pathology

Clinical diagnosis (criterion 1 below) and either criterion 2 or 3 must be present:

1. Clinical diagnosis or semantic variant PPA
2. Histopathologic evidence of a specific neurodegenerative pathology (e.g., FTLD-tau, FTLD-TDP, AD, other)
3. Presence of a known pathogenic mutation

Abbreviations: AD = Alzheimer's disease; FTLD = frontotemporal lobar degeneration; PPA = primary progressive aphasia

Diagnostic criteria for logopenic variant PPA

I. Clinical diagnosis of logopenic variant PPA

Both of the following core features must be present:

1. Impaired single-word retrieval in spontaneous speech and naming
2. Impaired repetition of sentences and phrases

At least 3 of the following other features must be present:

1. Speech (phonologic) errors in spontaneous speech and naming
2. Spared single-word comprehension and object knowledge
3. Spared motor speech
4. Absence of frank agrammatism

II. Imaging-supported logopenic variant diagnosis

Both criteria must be present:

1. Clinical diagnosis of logopenic variant PPA
2. Imaging must show at least one of the following results:
   a. Predominant left posterior perisylvian or parietal atrophy on MRI
   b. Predominant left posterior perisylvian or parietal hypoperfusion or hypometabolism on SPECT or PET

Logopenic variant PPA with definite pathology

Clinical diagnosis (criterion 1 below) and either criterion 2 or 3 must be present:

1. Clinical diagnosis of logopenic variant PPA
2. Histopathologic evidence of a specific neurodegenerative pathology (e.g. AD, FTLD-tau, FTLD-TDP, other)
3. Presence of a known pathogenic mutation

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	

Review the criteria above and select the PPA subtype. Select **4=PPA other/not otherwise specified** if the subject meets the core clinical criteria for PPA but cannot be further classified as nonfluent/agrammatic, semantic, or logopenic PPA.

4d.	Behavioral variant FTD (bvFTD) syndrome	☐ 1

Select **1=Present** if the subject meets the core clinical criteria for bvFTD below.

International consensus criteria for behavioural variant FTD (FTDC)

I. Neurodegenerative disease

The following symptom must be present to meet criteria for bvFTD.

A. Shows progressive deterioration of behaviour and/or cognition by observation or history (as provided by a knowledgeable informant).

II. Possible bvFTD

Three of the following behavioural/cognitive symptoms (A–F) must be present to meet criteria. Ascertainment requires that symptoms be persistent or recurrent, rather than single or rare events.

A Early* behavioural disinhibition [one of the following symptoms (A1–A3) must be present]:
- A1. Socially inappropriate behaviour
- A2. Loss of manners or decorum
- A3. Impulsive, rash or careless actions

B. Early apathy or inertia [one of the following symptoms (B1–B2) must be present]:
- B1. Apathy
- B2. Inertia

C. Early loss of sympathy or empathy [one of the following symptoms (C1–C2) must be present]:
- C1. Diminished response to other people's needs and feelings
- C2. Diminished social interest, interrelatedness or personal warmth

D Early perseverative, stereotyped or compulsive/ritualistic behaviour [one of the following symptoms (D1–D3) must be present]:
- D1. Simple repetitive movements
- D2. Complex, compulsive or ritualistic behaviours
- D3. Stereotypy of speech

E. Hyperorality and dietary changes [one of the following symptoms (E1–E3) must be present]:
- E1. Altered food preferences
- E2. Binge eating, increased consumption of alcohol or cigarettes
- E3. Oral exploration or consumption of inedible objects

F. Neuropsychological profile: executive/generation deficits with relative sparing of memory and visuospatial functions [all
of the following symptoms (F1–F3) must be present]:
- F1. Deficits in executive tasks
- F2. Relative sparing of episodic memory
- F3. Relative sparing of visuospatial skills

III. Probable bvFTD

All of the following symptoms (A–C) must be present to meet criteria.

A. Meets criteria for possible bvFTD
B. Exhibits significant functional decline (by caregiver report or as evidenced by Clinical Dementia Rating Scale or Functional Activities Questionnaire scores)
C. Imaging results consistent with bvFTD [one of the following (C1–C2) must be present]:
   C1. Frontal and/or anterior temporal atrophy on MRI or CT
   C2. Frontal and/or anterior temporal hypoperfusion or hypometabolism on PET or SPECT

IV. Behavioural variant FTD with definite FTLD pathology

Criterion A and either criterion B or criterion C must be present to meet criteria.

A. Meets criteria for possible or probable bvFTD
B. Histopathological evidence of FTLD on biopsy or at post-mortem
C. Presence of a known pathogenic mutation

V. Exclusionary criteria for bvFTD

Criteria A and B must be answered negatively for any bvFTD diagnosis. Criterion C can be positive for possible bvFTD but must be negative for probable bvFTD.

A. Pattern of deficits is better accounted for by other non-degenerative nervous system or medical disorders
B. Behavioural disturbance is better accounted for by a psychiatric diagnosis
C. Biomarkers strongly indicative of Alzheimer's disease or other neurodegenerative process

**As a general guideline, "early"refers to symptom presentation within the first 3 years.*
bvFTD = behavioral variant FTD

	4e. Lewy body dementia syndrome	☐ 1	

Select **1=Present** if the subject meets the criteria below for the clinical diagnosis of dementia with Lewy bodies (DLB).

Revised (2017[1]) criteria for the clinical diagnosis of dementia with Lewy Bodies (DLB):

1. Essential for a diagnosis of DLB is dementia, defined as a progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational functions, or with usual daily activities. Prominent or persistent memory impairment may not necessarily occur in the early stages but is usually evident with progression. Deficits on tests of attention, executive function, and visuoperceptual ability may be especially prominent and occur early.
2. Core clinical features (the first 3 typically occur early and may persist throughout the course):
   - Fluctuating cognition with pronounced variations in attention and alertness.
   - Recurrent visual hallucinations that are typically well-formed and detailed.
   - REM sleep behavior disorder, which may precede cognitive decline.
   - One or more spontaneous cardinal features of parkinsonism: these are bradykinesia (defined as slowness of movement and decrement in amplitude or speed), rest tremor, or rigidity.
3. Supportive clinical features:
   - Severe sensitivity to antipsychotic agents; postural instability.
   - Repeated falls.
   - Syncope or other transient episodes of unresponsiveness.
   - Severe autonomic dysfunction, e.g., constipation, orthostatic hypotension, urinary incontinence.
   - Hypersomnia.
   - Hyposmia.
   - Hallucinations in other modalities.
   - Systematized delusions.
   - Apathy.
   - Anxiety.
   - Depression.
4. Indicative biomarkers:
   - Reduced dopamine transporter uptake in basal ganglia demonstrated by SPECT or PET.
   - Abnormal (low-uptake) 123iodine-MIBG myocardial scintigraphy.
   - Polysomnographic confirmation of REM sleep without atonia.
5. Supportive biomarkers:
   - Relative preservation of medial temporal lobe structures on CT/MRI scan.
   - Generalized low uptake on SPECT/PET perfusion/metabolism scan with reduced occipital activity 6 the cingulate island sign on FDG-PET imaging.
   - Prominent posterior slow-wave activity on EEG with periodic fluctuations in the pre-alpha/theta range.
6. Probable DLB can be diagnosed if:
   a. Two or more core clinical features of DLB are present, with or without the presence of indicative biomarkers, or
   b. Only one core clinical feature is present, but with one or more indicative biomarkers. Probable DLB should not be diagnosed on the basis of biomarkers alone.
7. Possible DLB can be diagnosed if:
   a. Only one core clinical feature of DLB is present, with no indicative biomarker evidence, or
   b. One or more indicative biomarkers is present but there are no core clinical features.

8. DLB is less likely:
    - In the presence of any other physical illness or brain disorder including cerebrovascular disease, sufficient to account in part or in total for the clinical picture, although these do not exclude a DLB diagnosis and may serve to indicate mixed or multiple pathologies contributing to the clinical presentation.
    - If parkinsonian features are the only core clinical feature and appear for the first time at a stage of severe dementia.

DLB should be diagnosed when dementia occurs before or concurrently with parkinsonism. The term Parkinson disease dementia (PDD) should be used to describe dementia that occurs in the context of well-established Parkinson disease. In a practice setting the term that is most appropriate to the clinical situation should be used, and generic terms such as Lewy body disease are often helpful. In research studies in which distinction needs to be made between DLB and PDD, the existing 1-year rule between the onset of dementia and parkinsonism continues to be recommended.

(For more information on the criteria above, visit the website of the Lewy Body Dementia Association at https://www.lbda.org/newdlbcriteria.)

[1] Guidebook updated September 19, 2017 to reflect the recommendations for the clinical diagnosis of DLB by the Dementia with Lewy Bodies Consortium.

McKeith IF, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium, Neurology 2017; 89: 88-100.

4f.	Non-amnestic multidomain dementia, not PCA, PPA, bvFTD, or DLB syndrome	☐ 1

This category of dementia syndrome refers to those with a pattern of test results on the neuropsychological battery in which the typical memory-predominant pattern of deficits is not present. This category would be used for subjects who fit none of the other defined syndromes in Questions 4a – 4e (i.e., PPA syndrome, PCA syndrome, the typical pattern of psychomotor slowing and visuospatial cognitive and behavioral deficits associated with DLB [reference Ferman T, Clin Neuropsychol 20:623, 2006], nor the executive deficits seen with bvFTD).

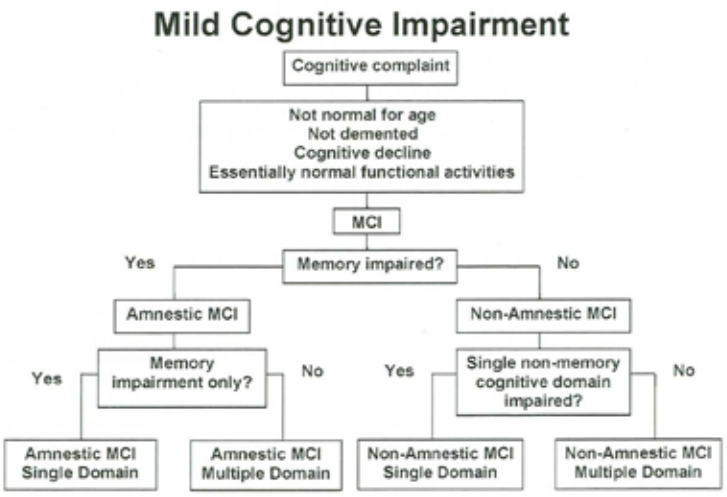
Clin Neuropsychol. 2006 Dec;20(4):623-36. Neuropsychological differentiation of dementia with Lewy bodies from normal aging and Alzheimer's disease. Ferman TJ1, Smith GE, Boeve BF, Graff-Radford NR, Lucas JA, Knopman DS, Petersen RC, Ivnik RJ, Wszolek Z, Uitti R, Dickson DW.

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)?

QUESTIONS 5a – 5d: After having determined that the subject does not have normal cognition (Question 2 above) and does not have dementia (Question 3 above), please use the following chart[1], excerpted from the Alzheimer's Disease Neuroimaging Initiative (ADNI) manual, page 18, to guide your answers to Questions 5a through 5d. First determine whether memory impairment is present, based on your clinical judgment and/or neuropsychological memory test(s) (e.g., the Craft Story immediate and delayed recall tests and/or other memory tests used at your ADC). Then apply the same clinical and/or psychometric approach to determine whether other cognitive domains are also impaired.



[1]Arch Neurol, 2005. 62;1160-63, Figure 1. Reproduced by permission of the publisher. Copyright© 2005. American Medical Association. All rights reserved.

Note: Only one of Questions 5a–5e may be selected as **1=Present**.

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			

If memory is the only cognitive domain impaired, select **1=Present** for Question 5a.

5b. Amnestic MCI, multiple domains (aMCI MD)	☐ 1	**CHECK YES for at least one additional domain (besides memory):**		
		5b1. Language	☐ 0	☐ 1
		5b2. Attention	☐ 0	☐ 1
		5b3. Executive	☐ 0	☐ 1
		5b4. Visuospatial	☐ 0	☐ 1

If one or more cognitive domains are impaired in addition to memory, select **1=Present** for Question 5b, and then select **1=Yes** in Questions 5b1 – 5b4 for the cognitive domain(s) that you judge to be impaired based on your examination and/or neuropsychological test results. **1=Yes** must be selected for at least one domain in Questions 5b1 – 5b4. Select **0=No** for all others.

5c. Non-amnestic MCI, single domain (naMCI SD)	☐ 1	**CHECK YES to indicate the affected domain:**		
		5c1. Language	☐ 0	☐ 1
		5c2. Attention	☐ 0	☐ 1
		5c3. Executive	☐ 0	☐ 1
		5c4. Visuospatial	☐ 0	☐ 1

If memory is not impaired, and only one other cognitive domain is impaired, select **1=Present** for Question 5c, and then select **1=Yes** in Questions 5c1 – 5c4 for the single cognitive domain that you judge to be impaired based on your examination and/or neuropsychological test results. Select **0=No** for all others.

5d. Non-amnestic MCI, multiple domains (naMCI MD)	☐ 1	**CHECK YES for at least two domains:**		
		5d1. Language	☐ 0	☐ 1
		5d2. Attention	☐ 0	☐ 1
		5d3. Executive	☐ 0	☐ 1
		5d4. Visuospatial	☐ 0	☐ 1

If memory is not impaired, but multiple other cognitive domains are impaired, select **1=Present** for Question 5d, and then select **1=Yes** in Questions 5d1 – 5d4 for each of the domains that you judge to be impaired based on your examination and/or neuropsychological test results. Select **1=Yes** for at least two domains in Questions 5d1 – 5d4. Select **0=No** for all others.

5e. Cognitively impaired, not MCI	☐ 1		

If you judge the subject to be cognitively impaired, yet the subject's presentation, test results, symptoms, and clinical evaluation are not consistent with MCI and do not allow you to select **1=Present** for any of the above Questions 5a – 5d, then select **1=Present** for Question 5e.

QUESTIONS 6a – 6j: Use your Center's local standards to determine whether the subject had positive biomarker results for each of the Questions 6a – 6j. If the results were positive for a particular test, according to your local standards, select **1=Yes.** If the results were negative, select **0=No**. If the findings fall within an ambiguous range according to your Center's standard cut-off values (i.e., are "too close to call"), select **0=No**.

If a specific biomarker test or assay (e.g., CSF tau) was repeated over time and the repeated tests/assays were more than a month apart, report the result (+ or -) from the most recent test/assay. If the same test/assay was repeated multiple times (e.g., repeat assays of CSF tau within one month), these are the most recent results available, and the results from these tests/assays are conflicting, select **8=Unknown/not assessed**.

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	

If the subject had additional biomarker testing done within the year preceding this visit, beyond what is captured in Questions 6a–6j, enter the biomarker test in the **Other (specify)** field, and indicate whether the findings were positive (**1=Yes**) or negative (**0=No**) according to your Center's local standards. If the results were ambiguous according to your Center's cut-off values, select **0=No**.

QUESTIONS 7a – 7f: Use your Center's local standards to determine whether the subject had imaging evidence for each of the Questions 7a – 7f. If there is no evidence or ambiguous evidence for each particular CVD listed according to your Center's standards, select **0=No** for the corresponding question.

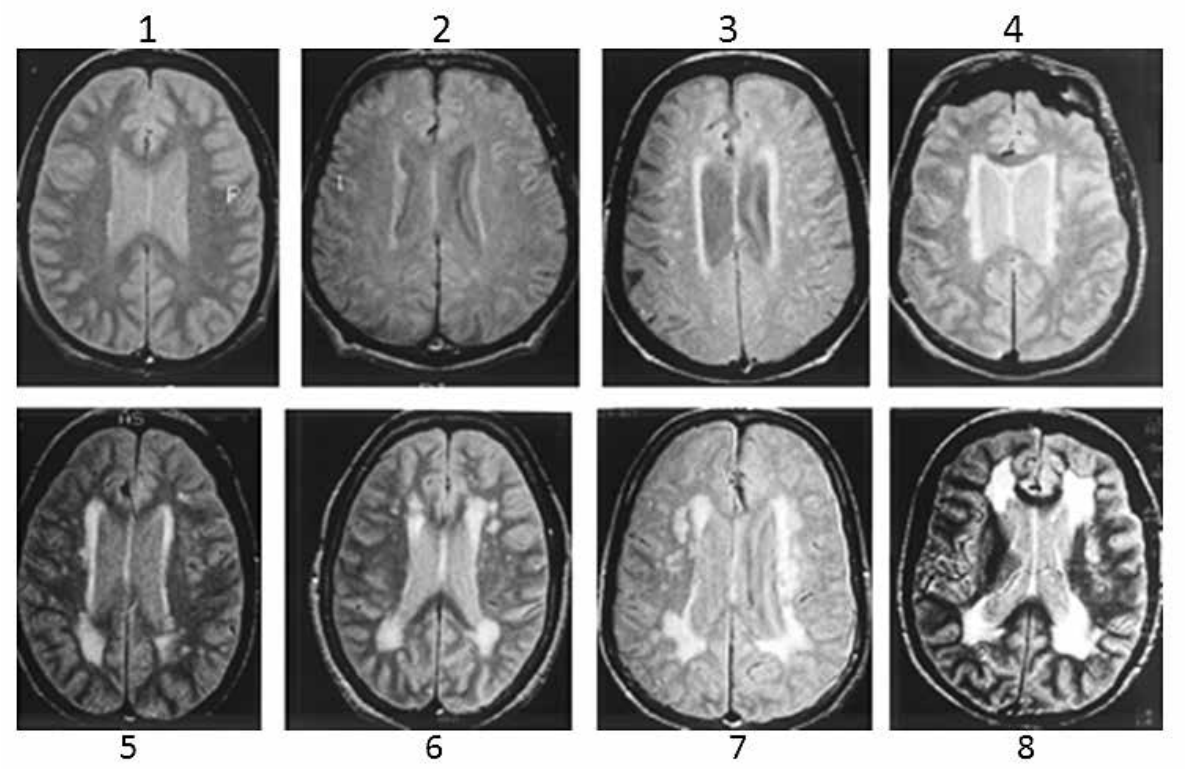
Although each Center's local standards should be used to determine whether the subject has imaging evidence for CVD, clinicians are welcome to refer the following paper:

Wardlaw JM, et al. Neuroimaging standards for research into small vessel disease and its contribution to ageing and neurodegeneration. Lancet Neurol 2013;12:822-38.

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



Examples of single slices from complete scans that were used by the study neuroradiologists to grade white matter. Grade 1 was described as discontinuous periventricular rim with minimal dots of subcortical disease; grade 2,thin, continuous periventricular rim with a few patches of subcortical disease; grade 3, thicker, continuous periventricular rim with scattered patches of subcortical disease; grade 4, thicker, shaggier periventricular rim with mild subcortical disease, may have minimal confluent periventricular lesions; grade 5, mild periventricular confluence surrounding the frontal and occipital horns; grade 6, moderate periventricular confluence surrounding the frontal and occipital horns; grade 7, periventricular confluence with moderate involvement of the centrum semiovale; and grade 8, periventricular confluence involving most of the centrum semiovale. Studies with no white matter findings were graded 0, and those with findings more remarkable than grade 8 were scored 9.

If the subject has a white matter grade of 5 or 6, select **1= Yes**. If the subject has a score of 0, 1, 2, 3, 4, 7, 8, or 9, select **0=No.**

Longstreth WT Jr[1], Manolio TA, Arnold A, Burke GL, Bryan N, Jungreis CA, Enright PL, O'Leary D, Fried L. Clinical correlates of white matter findings on cranial magnetic resonance imaging of 3301 elderly people. The Cardiovascular Health Study. Stroke. Stroke, 27(8):1274-82, 1996.

7f. Extensive white-matter hyperintensity (CHS score 7–8+)	☐ 0	☐ 1	☐ 8

If the subject has a white matter grade of 7, 8, or 9, select **1= Yes**. If the subject has a score of 0, 1, 2, 3, 4, 5, or 6, select **0=No.**

Longstreth WT Jr[1], Manolio TA, Arnold A, Burke GL, Bryan N, Jungreis CA, Enright PL, O'Leary D, Fried L. Clinical correlates of white matter findings on cranial magnetic resonance imaging of 3301 elderly people. The Cardiovascular Health Study.Stroke. Stroke, 27(8):1274-82, 1996.

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

☐ 0 No ☐ 1 Yes ☐ 9 Unknown

If the subject has medical record or lab test evidence of a PSEN1, PSEN2, or APP mutation, select **1=Yes**. If medical record review and/or testing has been done, and the subject does not have a PSEN1, PSEN2, or APP mutation, select **0=No**. If sufficient evidence is not available (e.g., no testing done), select **9=Not assessed/unknown**.

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

☐ 0 No ☐ 1 Yes ☐ 9 Unknown

If the subject has medical record or lab test evidence of an hereditary FTLD mutation, select **1=Yes.** If medical record review and/or testing has been done, and the subject does not have a known hereditary FTLD mutation, select **0=No**. If sufficient evidence is not available (e.g., no testing done), select **9=Not assessed/unknown**.

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

☐ 0 No ☐ 1 Yes (SPECIFY): _____ ☐ 9 Unknown

If the subject has medical record or lab test evidence of an inherited mutation other than an AD or FTLD mutation, select **1=Yes** and enter a brief description of the mutation in the specify field. If medical record review and/or testing has been done and the results were negative for all non-AD and non-FTLD mutations tested, select **0=No**. If sufficient evidence is not available (e.g., no testing done) for other non-AD and non-FTLD mutations, select **9=Not assessed/unknown**.

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 etiologic 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

The AD dementia criteria listed below are excerpted and condensed from the 2011 NIA-AA criteria for AD dementia (McKhann et al., 2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroups. See the original paper for details.

A. Probable AD dementia is diagnosed when the patient:

1. Meets criteria for dementia, and has the following characteristics:
2. Insidious onset. Symptoms have a gradual onset over months to years; and
3. Clear-cut history of worsening of cognition by report or observation; and
4. The initial and most prominent cognitive deficits are evident on history and examination in one of the following categories.
   (1) Amnestic disorder: The most common syndromic presentation of AD dementia.
   (2) Non-amnestic disorders:
   - Language disorder
   - Visuospatial disorder
   - Executive and behavioral disorder
5. Exclusions: The diagnosis of probable AD dementia should not be applied when there is evidence of:
   (a) substantial concomitant cerebrovascular disease or
   (b) core features of dementia with Lewy bodies other than dementia itself; or
   (c) prominent features of behavioral variant frontotemporal dementia; or
   (d) prominent features of semantic variant primary progressive aphasia or non-fluent/agrammatic variant primary progressive aphasia; or
   (e) evidence for another concurrent, active neurological disease, or a non-neurological medical co-morbidity or medication use that could have a substantial impact on cognition.

B. Possible AD dementia is diagnosed when the patient meets one of the two following criteria:

1. Atypical course: Meets the core clinical criteria (1) and (4) (above) for probable AD dementia, but either had a sudden onset of cognitive impairment or demonstrates insufficient historical detail or objective cognitive documentation of progressive decline, or
2. Etiologically mixed presentation: Meets all core clinical criteria (1) through (4) (above) for probable AD dementia but has evidence of:
   (a) concomitant cerebrovascular disease or
   (b) features of dementia with Lewy bodies other than the dementia itself; or
   (c) evidence for another neurological disease or a non-neurological medical co-morbidity or medication use that could have a substantial impact on cognition.

McKhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement. 2011;7(3):263-269.

The following table is excerpted from the 2011 NIA-AA criteria for MCI due to AD (Albert et al., 2011):

Summary of clinical and cognitive evaluation for MCI due to AD

Establish clinical and cognitive criteria
Cognitive concern reflecting a change in cognition reported by patient or informant or clinician (i.e., historical or observed evidence of decline over time)
Objective evidence of impairment in one or more cognitive domains, typically including memory (i.e., formal or bedside testing to establish level of cognitive function in multiple domains)
Largely preserved independence in functional abilities
Not demented
Examine etiology of MCI consistent with AD pathophysiological process
Rule out vascular, traumatic, medical causes of cognitive decline, where possible
Provide evidence of longitudinal decline in cognition, when feasible
Report history consistent with AD genetic factors, where relevant

Abbreviations: AD, Alzheimer's disease; MCI, mild cognitive impairment

"Alzheimer's and Dementia, 7/3, Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox NC, Gamst A, Holtzman DM, Jagust WJ, Petersen RC, Snyder PJ, Carrillo MC, Thies B, Phelps CH, The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease, 270-279, 2011, with permission from Elsevier http://www.sciencedirect.com/science/article/pii/S155252601100104X."

If Alzheimer's disease is not present, leave all boxes for Questions 11 and 11a unchecked.

For subjects with cognitive impairment: If Alzheimer's disease is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** or **2=Contributing** cause of the cognitive impairment. Probable AD can be indicated as **1=Primary** or **2=Contributing**. On the contrary, Possible Alzheimer's disease (atypical course or seemingly mixed etiologies) should not be marked as **1=Primary**; the only exception is when there is an atypical course, positive biomarker evidence for AD, and no compelling clinical or biomarker evidence for another primary etiology.

For subjects with normal cognition: If the subject has normal cognition and either sufficient biomarker evidence for Alzheimer's disease or a known genetic mutation, leave all checkboxes in Questions 11 and 11a blank/unchecked. The biomarker and genetic data from Section 2 are used to determine the presence of preclinical disease.

	12. Lewy body disease	☐ 1	12a ☐ 1	☐ 2	☐ 3	

Refer to the papers McKeith et al., 2017 (see DLB criteria on pages 80 - 81) and Litvan et al., 2003 (see criteria table below) to assess the presence of dementia with Lewy body disease. The following criteria refer to probable and possible MCI with Lewy bodies. Additional details concerning the PD criteria are listed under Question 12b.

Summary of research criteria for the clinical diagnosis of the prodromal phase of dementia with Lewy Bodies (DLB) excerpted from McKeith et al., 2020[1].

RESEARCH CRITERIA for the clinical diagnosis of probable and possible MCI with Lewy bodies (MCI-LB):

1. **Essential for a diagnosis of MCI-LB is MCI defined by the presence of each of the following:**
   - Concern by the patient, informant, or clinician regarding cognitive decline.
   - Objective evidence of impairment in 1 or more cognitive domains. The cognitive impairment may include any domain, but is more likely to be associated with attention-executive and/or visual processing deficits.
   - Preserved or minimally affected performance of previously attained independence in functional abilities, which do not meet the criteria for dementia.

2. **Core clinical features:**
   - Fluctuating cognition with variations in attention and alertness.
   - Recurrent visual hallucinations.
   - REM sleep behavior disorder.
   - One or more spontaneous cardinal features of parkinsonism: these are bradykinesia (defined as slowness of movement and decrement in amplitude or speed), rest tremor, or rigidity.

3. **Supportive clinical features:**

   Severe sensitivity to antipsychotic agents; postural instability; repeated falls; syncope or other transient episodes of unresponsiveness; prolonged or recurrent delirium not due to provoking factors such as surgery, infections, or other systemic illness; autonomic dysfunction, e.g., constipation, orthostatic hypotension, urinary incontinence; hypersomnia; hyposmia; REM sleep without atonia; hallucinations in other modalities including passage, and sense of presence phenomena; systematized delusions including Capgras syndrome; apathy, anxiety, and depression.

4. **Proposed biomarkers:**
   - Reduced dopamine transporter uptake in basal ganglia demonstrated by SPECT or PET.
   - Polysomnographic confirmation of REM sleep without atonia.
   - Reduced meta-iodobenzylguanidine (MIBG) uptake on myocardial scintigraphy.

5. **Potential biomarkers:**
   - Quantitative EEG showing slowing and dominant frequency variability.
   - Relative preservation of medial temporal lobe structures on structural imaging.
   - Insular thinning and gray matter volume loss on MRI.
   - Low occipital uptake on perfusion/metabolism scan.

- MCI plus supportive clinical features or potential biomarkers are insufficient to diagnose MCI-LB but may raise suspicion of it and prompt biomarker investigation and may add weight to an existing MCI-LB diagnosis.
- MCI-LB is less likely in the presence of any other physical illness or brain disease including cerebrovascular disease, sufficient to account in part or in total for the clinical picture, although these do not exclude an MCI-LB diagnosis and may serve to indicate mixed or multiple pathologies contributing to the clinical presentation.

6. Probable MCI-LB can be diagnosed if:

a. Two or more core clinical features of DLB are present, with or without the presence of a proposed biomarker, or
b. Only 1 core clinical feature is present, but with 1 or more proposed biomarkers.

7. Probable MCI-LB should not be diagnosed based on biomarkers alone.

8. Possible MCI-LB can be diagnosed if:

a. Only 1 core clinical feature of DLB is present, with no proposed biomarkers, or
b. One or more of the proposed biomarkers is present, but there are no core clinical features.

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[1] Guidebook updated July 2020 to reflect the recommendations for the clinical diagnosis of prodromal DLB by the Prodromal Dementia With Lewy Bodies Diagnostic Study Group.

McKeith IF, Ferman TJ, Thomas AJ, et al. Research criteria for the dianosis of prodromal dementia with Lewy bodies, Neurology 2020; 94: 1-13

McKeith IF, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium, Neurology 2017; 89: 88-100.

Mov Disord. 2003 May; 18(5):467-86. Movement Disorders Society Scientific Issues Committee report: SIC Task Force appraisal of clinical diagnostic criteria for Parkinsonian disorders. Litvan I[1], Bhatia KP, Burn DJ, Goetz CG, Lang AE, McKeith I, Quinn N, Sethi KD, Shults C, Wenning GK; Movement Disorders Society Scientific Issues Committee.

For subjects with cognitive impairment: If Lewy body disease (DLB or Parkinson's disease) is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** or **2=Contributing** cause of the cognitive impairment. If Lewy body disease is not present, leave all boxes for Questions 12 and 12a unchecked.

For subjects with normal cognition: If the subject has normal cognition but has a clinical diagnosis of Parkinsons's disease, select **1=Present** and leave checkbox 12a blank. If the subject has normal cognition and sufficient biomarker evidence for Lewy body disease, leave all checkboxes in Question 12 and 12a blank/unchecked. The biomarker data from Section 2 are used to determine the presence of preclinical disease.

	12b. ☐ 1 Parkinson's disease					

Select **1=Present** if the subject has Parkinson's disease.

Use the following criteria, excerpted from SIC Task Force Appraisal of Clinical Diagnostic Criteria for Parkinsonian Disorders (Litvan et al., 2003):

UK PARKINSON'S DISEASE SOCIETY BRAIN BANK CLINICAL DIAGNOSTIC CRITERIA

Inclusion criteria	Exclusion criteria	Supportive criteria
Bradykinesia (slowness of initiation of voluntary movement with progressive reduction in speed and amplitude of repetitive actions); And at least one of the following: • Muscular rigidity. • 4- to 6-Hz rest tremor. • Postural instability not caused by primary visual, vertibular, cerebellar, or proprioceptive dysfunction.	History of repeated strokes with stepwise progression of parkinsonian features. History of repeated head injury. History of definite encephalitis. Oculogyric crises. Neuroleptic treatment at onset of symptoms. More than one affected relative. Sustained remission. Strictly unilateral features after 3 years. Supranuclear gaze palsy. Cerebellar signs. Early severe autonomic involvement. Early severe dementia with disturbances of memory, language, and praxis. Babinski sign. Presence of cerebral tumor or communicating hydrocephalus on CT scan. Negative response to large doses of levodopa (if malabsorption excluded). MPTP exposure.	(Three or more required for diagnosis of definite PD): • Unilateral onset. • Rest tremor present. • Progressive disorder. • Persistent asymmetry affecting side of onset most. • Excellent response (70%–100%) to levodopa. • Severe levodopa-induced chorea. • Levodopa response for 5 years or more. • Clinical course of 10 years or more.

UK = United Kingdom; PD = Parkinson's disease; CT = computed tomography.

	13. Multiple system atrophy	☐ 1		13a ☐ 1	☐ 2	☐ 3

Refer to the diagnostic criteria in Gilman et al. (2008) when assessing the presence of multiple system atrophy (MSA).

If MSA is present, select **1=Present** for Question 13, and indicate whether it is **1=Primary**, **2=Contributing**, or **3=Non-contributing** to the observed cognitive impairment, if applicable. If MSA is not present, leave all boxes for Questions 13 and 13a blank/unchecked. If the subject has normal cognition but clinical symptoms sufficient for a diagnosis of MSA, select 1=Present for Question 13 and leave the checkboxes in Question 13a blank/unchecked.

If MSA is not present, leave all checkboxes for Questions 13 and 13a blank/unchecked.

Neurology. 2008 Aug 26;71(9):670-6. doi: 10.1212/01.wnl.0000324625.00404.15. Second consensus statement on the diagnosis of multiple system atrophy. Gilman S1, Wenning GK, Low PA, Brooks DJ, Mathias CJ, Trojanowski JQ, Wood NW, Colosimo C, Dürr A, Fowler CJ, Kaufmann H, Klockgether T, Lees A, Poewe W,Quinn N, Revesz T, Robertson D, Sandroni P, Seppi K, Vidailhet M.

14. Frontotemporal lobar degeneration 14a. Progressive supranuclear palsy (PSP)	☐ 1	14a1 ☐ 1	☐ 2	☐ 3	

Use the following criteria to diagnose PSP (adapted from Bensimon et al., 2009)

Inclusion criteria

ALL OF THE FOLLOWING:

- Age at disease onset ≥30 years;
- Akinetic-rigid syndrome;
- Postural instability or falls (within 3 years from disease onset);
- Supranuclear ophthalmoplegia.

Exclusion criteria

ANY OF THE FOLLOWING:

- Cerebellar ataxia;
- Evidence of any other neurological disease that could explain signs;
- History of repeated strokes with stepwise progression of parkinsonian features;
- Idiopathic Parkinson's disease;
- Oculogyric crises;
- Significant other neurological disease on CT-scan/MRI;
- Signs of corticobasal degeneration;
- Signs of lewy body disease;
- Symptomatic autonomic dysfunction;
- Tremor at rest.

For subjects with cognitive and/or behavioral impairment: If PSP is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

For subjects with normal cognition and behavior: If the subject has normal cognition but clinical symptoms sufficient for a diagnosis of PSP, select **1=Present** and leave the checkboxes about whether it is primary or contributing in Question 14a1 blank/unchecked.

If PSP is not present, leave all boxes for Questions 14a and 14a1 blank/unchecked.

Brain. 2009 Jan;132(Pt 1):156-71. doi: 10.1093/brain/awn291. Epub 2008 Nov 23. Riluzole treatment, survival and diagnostic criteria in Parkinson plus disorders: the NNIPPS study. Bensimon G1, Ludolph A, Agid Y, Vidailhet M, Payan C, Leigh PN; NNIPPS Study Group.

14b.	Corticobasal degeneration (CBD)	☐ 1	14b1 ☐ 1	☐ 2	☐ 3

Refer to diagnostic criteria by Armstrong et al. (2013) when assessing the presence of CBD.

For subjects with cognitive and/or behavioral impairment: If CBD is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

For subjects with normal cognition and behavior: If the subject has normal cognition but clinical symptoms sufficient for a diagnosis of CBD, select CBD as **1=Present** and leave the checkboxes about whether it is primary or contributing in Question 14b1 blank/unchecked.

If CBD is not present, leave all boxes for Questions 14b and 14b1 blank/unchecked.

Proposed clinical phenotypes (syndromes) associated with the pathology of corticobasal degeneration (CBD)

Syndrome	Features
Probable corticobasal syndrome	**Asymmetric presentation of TWO OF:** a) limb rigidity or akinesia, b) limb dystonia, c) limb myoclonus; **PLUS TWO OF:** d) orobuccal or limb apraxia, e) cortical sensory deficit, f) alien limb phenomena (more than simple levitation).
Possible corticobasal syndrome	**May be symmetric; ONE OF:** a) limb rigidity or akinesia, b) limb dystonia, c) limb myoclonus; **PLUS ONE OF:** d) orobuccal or limb apraxia, e) cortical sensory deficit, f) alien limb phenomena (more than simple levitation).

[1] Armstrong, MJ, Litvan I, et al. *Criteria for the diagnosis of corticobasal degeneration.* Neurology 2013;80;496.

14c.	FTLD with motor neuron disease	☐ 1	14c1 ☐ 1	☐ 2	☐ 3

Use the following criteria, adapted from El Escorial revisited: Revised criteria for the diagnosis of amyotrophic lateral sclerosis (Brooks et al., 2000)[1]:

Requirements for the diagnosis of amyotrophic lateral sclerosis

The diagnosis of ALS requires the PRESENCE of:

- Evidence of lower motor neuron (LMN) degeneration by clinical, electrophysiological or neuropathologic examination;
- Evidence of upper motor neuron (UMN) degeneration by clinical examination; **and**
- Progressive spread of symptoms or signs within a region or to other regions, as determined by history or examination, **together with** B1 and B2 in next column.

The diagnosis of ALS requires the ABSENCE of:

- Electrophysiological or pathological evidence of other disease processes that might explain the signs of LMN and/or UMN degeneration; **and**
- Neuroimaging evidence of other disease processes that might explain the observed clinical and electrophysiological signs.

[1] Brooks BR, Miller RG, Swash M, Munsat TL, Diseases WFoNRGoMN. El Escorial revisited: revised criteria for the diagnosis of amyotrophic lateral sclerosis. Amyotroph Lateral Scler Other Motor Neuron Disord. 2000;1(5):293-299.

For subjects with cognitive and/or behavioral impairment: If FTLD with motor neuron disease is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

For subjects with normal cognition and behavior: If the subject has normal cognition but clinical symptoms sufficient for a diagnosis of FTLD with motor neuron disease, select **1=Present** and leave the checkboxes about whether it is primary or contributing in Question 14c1 blank/unchecked.

If FTLD with motor neuron disease is not present, leave the checkboxes in Question 14c1 blank/unchecked.

14d.	FTLD NOS	☐ 1	14d1 ☐ 1	☐ 2	☐ 3

Select **1=Present** if FTLD not otherwise specified (NOS) is present. This diagnosis should not be selected if PSP, CBD, or FTLD with motor neuron disease is present. If FTLD NOS is present, indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

If FTLD NOS is not present, leave all checkboxes for Questions 14d and 14d1 blank/unchecked.

14e. If FTLD (Questions 14a – 14d) is Present, specify FTLD subtype:

☐ 1 Tauopathy

☐ 2 TDP-43 proteinopathy

☐ 3 Other (SPECIFY): _____

☐ 9 Unknown

Select **1=Tauopathy**, **2=TDP-43 proteinopathy**, or **3=Other (specify)** if specific evidence (e.g., genetics) beyond the clinical syndrome is available to indicate the FTLD subtype. If a subtype other than Tauopathy or TDP-43 proteinopathy is present, select **3=Other** and specify the subtype. Select **9=Unknown** if there is no evidence beyond the clinical syndrome to specify the FTLD subtype.

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.**	☐ 1	15a ☐ 1	☐ 2	☐ 3

If there is evidence of significant vascular brain injury confirmed by clinical or neuroimaging studies, select **1=Present** for Question 15. Significant vascular brain injury includes either:

- CLINICAL EVIDENCE of symptomatic stroke (i.e., abrupt onset of focal neurological signs)

– OR –

- NEUROIMAGING EVIDENCE of one or more of the following:
  - cystic infarcts (large or small)
  - significant white matter changes (Grade 7–8+ on Cardiovascular Health Study Scale)
  - intraparenchymal hemorrhage
  - multiple microbleeds

If the subject has no clinical evidence of symptomatic stroke and neuroimaging studies do not indicate evidence of significant vascular brain injury, skip to Question 16.

For subjects with cognitive impairment: Indicate whether vascular brain injury is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

Select **1=Primary** if the subject has one or more of the following:

- a temporal relationship between a symptomatic stroke (confirmed by neuroimaging) and cognitive decline;
- imaging evidence of cystic infarction(s) in a cognitive network
- cystic infarct (anywhere in the brain), and imaging evidence of extensive confluent white matter changes (WMH Grade 7–8+), and impairment in executive function.

If there is clinical evidence of a symptomatic stroke with temporal relationship to cognitive decline but no available supporting neuroimaging, select **1=Primary** or **2=Contributing** based on clinical judgment.

If there is significant vascular brain injury but no clear temporal or anatomical relationship with cognitive impairment, select **2=Contributing** or **3=Non-contributing** based on clinical judgment.

If there is a history of gradually progressive cognitive decline preceding a symptomatic stroke in the absence of extensive confluent white matter changes (thereby suggesting an underlying neurodegenerative etiology), select **2=Contributing** or **3=Non-contributing** based on clinical judgment.

For subjects with normal cognition: If the subject has normal cognition but has evidence of significant vascular brain injury, select **1=Present** for Question 15 and leave the primary and contributing boxes in Question 15a blank/unchecked.

Questions 15b – 15d:

Questions 15b, 15c, and 15d represent three possible, non-mutually exclusive scenarios that support a causal relationship between vascular brain injury and cognitive impairment based on temporal or anatomical relationships.

15b. Previous symptomatic stroke?

☐ 0 No **(SKIP TO QUESTION 15c)**

☐ 1 Yes

Select **1=Yes** if the subject has clinical evidence of at least one previous symptomatic stroke. Select **0=No** if the subject has never had a symptomatic stroke.

15b1. Temporal relationship between stroke and cognitive decline?

☐ 0 No

☐ 1 Yes

Temporal relationship is defined in two ways: either 1) when the stroke occurred, there was a stepwise decline in cognition; or 2) the symptomatic stroke was followed by cognitive decline noted within three to six months. Select **1=Yes** if either of these two conditions is present (for any previous symptomatic stroke). Select **0=No** if there is a no history of cognitive decline within six months of a symptomatic stroke.

15b2. Confirmation of stroke by neuroimaging?

☐ 0 No

☐ 1 Yes

☐ 9 Unknown; no imaging data available

Select **0=No** if neuroimaging does not support stroke as the etiology for a history of abrupt onset of focal neurological signs. Select **1=Yes** if neuroimaging data/report confirm stroke as the etiology for a history of abrupt onset of neurological signs (if subject has had more than one previous symptomatic stroke, select **1=Yes** if at least one instance of symptomatic stroke was confirmed by neuroimaging). Select **9=Unknown** if there are no relevant imaging data available to make this determination.

15c. Is there imaging evidence of cystic infarction in cognitive network(s)?

☐ 0 No

☐ 1 Yes

☐ 9 Unknown; no imaging data available

Select **1=Yes** if there is imaging evidence of cystic infarction(s) in cognitive network(s) (e.g., involving prefrontal-subcortical loops, medial temporal diencephalic memory system, language, or visual-spatial systems). Select **0=No** if imaging evidence does not show cystic infarction in a cognitive network.

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 imaging data available

Select **1=Yes** if the subject has imaging evidence of cystic infarct (not necessarily in a cognitive network) and imaging evidence of extensive confluent WMH (CHS grade 7–8+) and impairment in executive function (which could be slowly progressive in course). Select **0=No** if there is evidence that at least one of these is absent.

16.	Essential tremor	☐ 1	16a ☐ 1	☐ 2	☐ 3

Refer to the consensus criteria (Deuschl et al., 1998) for essential tremor. If essential tremor is not present, leave all checkboxes in Questions 16 and 16a blank/unchecked.

For subjects with cognitive impairment: If essential tremor is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

For subjects with normal cognition: If the subject has normal cognition but has essential tremor features, select **1=Present** and leave the boxes for Question 16a blank/unchecked.

Deuschl G, Bain P, Brin M. Mov Disord. 1998; 12 Suppl 3:2–23. Consensus statement of the Movement Disorder Society on Tremor. Ad Hoc Scientific Committee.

17.	Down syndrome	☐ 1	17a ☐ 1	☐ 2	☐ 3

If Down syndrome is present, select **1=Present** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment, if applicable.

If Down syndrome is not present, leave all boxes for Questions 17 and 17a blank/unchecked. If the subject has normal cognition but has Down syndrome, select **1=Present** for Question 17 and leave the primary and contributing boxes in Question 17a blank/unchecked.

18.	Huntington's disease	☐ 1	18a ☐ 1	☐ 2	☐ 3

If Huntington's disease is present, select **1=Present** for Question 18a, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment in Question 18a, if applicable. If Huntington's disease is not present, leave all boxes for Questions 18 and 18a blank/unchecked. If the subject has normal cognition but has Huntington's disease features or a known mutation, select **1=Present** and leave the primary and contributing boxes in Question 18a blank/unchecked.

19.	Prion disease (CJD, other)	☐ 1	19a ☐ 1	☐ 2	☐ 3

Refer to the paper by Puoti et al. (2012)[1] regarding the clinical diagnosis of prion disease.

If prion disease is not present, leave all checkboxes in Questions 19 and 19a blank/unchecked.

Select **1=Present** if prion disease (Creutzfeldt-Jakob disease or other type) is present, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment in Question 19a. If the subject has normal cognition but has tested positive for prion disease, select **1=Present** for Question 19 and leave the primary, contributing, and non-contributing boxes in Question 19a blank/unchecked.

[1] Lancet Neurol. 2012 Jul;11(7):618-28. doi: 10.1016/S1474-4422(12)70063-7. Sporadic human prion diseases: molecular insights and diagnosis. Puoti G1, Bizzi A, Forloni G, Safar JG, Tagliavini F, Gambetti P.

	20. Traumatic brain injury	☐ 1	20a ☐ 1	☐ 2	☐ 3	

The definition of TBI below has been condensed from Menon et al. (2010):

TBI is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force.

A. Alteration in brain function is defined as 1 of the following clinical signs:
   - Any period of loss of or a decreased LOC
   - Any loss of memory for events immediately before (retrograde amnesia) or after the injury (PTA)
   - Neurologic deficits (weakness, loss of balance, change in vision, dyspraxia paresis/plegia [paralysis], sensory loss, aphasia, etc.)
   - Any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc.)"

B. or other evidence of brain pathology: Such evidence may include visual, neuroradiologic, or laboratory confirmation of damage to the brain.

C. caused by an external force may include any of the following events:
   - The head being struck by an object
   - The head striking an object
   - The brain undergoing an acceleration/deceleration movement without direct external trauma to the head
   - A foreign body penetrating the brain
   - Forces generated from events such as a blast or explosion
   - Or other force yet to be defined

For subjects with cognitive impairment: If the subject has had one or more TBIs as defined above, select **1=Present** for Question 20 and indicate whether the TBI is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment in Question 20a.

For subjects with normal cognition: If the subject has normal cognition but has had one or more TBIs as defined above, select **1=Present** for Question 20 and leave the primary, contributing, and non-contributing boxes for Question 20a blank/unchecked.

If the subject has had no previous TBI, leave all boxes in Questions 20 and 20a blank and unchecked.

MENON, D. K., SCHWAB, K., WRIGHT, D. W. & MAAS, A. I. 2010. Position statement: definition of traumatic brain injury. Arch Phys Med Rehabil, 91, 1637-40.

	20b. If Present, does the subject have symptoms consistent with chronic traumatic encephalopathy? ☐ 0 No ☐ 1 Yes ☐ 9 Unknown					

Refer to the published papers by McKee et al. (2009) and Stern et al. (2013) for additional details on clinical CTE symptoms.

Select **1=Yes** if the subject has symptoms consistent with chronic traumatic encephalopathy. If the subject does not have symptoms consistent with CTE, select **0=No**. If it is unknown whether the subject has symptoms consistent with CTE, select **9=Unknown**.

J Neuropathol Exp Neurol. 2009 Jul;68(7):709-35. doi: 10.1097/NEN.0b013e3181a9d503. Chronic traumatic encephalopathy in athletes: progressive tauopathy after repetitive head injury. McKee AC1, Cantu RC, Nowinski CJ, Hedley-Whyte ET, Gavett BE, Budson AE, Santini VE, Lee HS, Kubilus CA, Stern RA.

Neurology. 2013 Sep 24;81(13):1122-9. Clinical presentation of chronic traumatic encephalopathy. Stern RA, Daneshvar DH, Baugh CM, Seichepine DR, Montenigro PH, Riley DO, Fritts NG, Stamm JM, Robbins CA, McHale L, Simkin I, Stein TD, Alvarez VE, Goldstein LE, Budson AE, Kowall NW, Nowinski CJ, Cantu RC, McKee AC.

21.	Normal-pressure hydrocephalus	☐ 1	21a ☐ 1	☐ 2	☐ 3

If normal-pressure hydrocephalus is not present, leave all boxes in Questions 21 and 21a blank/unchecked. If normal-pressure hydrocephalus is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment. If the subject has normal cognition, but has other non-cognitive features of normal-pressure hydrocephalus, select **1=Present** for Question 21 and leave the primary, contributing, and non-contributing boxes for Question 21a blank/unchecked.

22.	Epilepsy	☐ 1	22a ☐ 1	☐ 2	☐ 3

Refer to the paper by Fisher et al. (2014)[1] for clinical symptoms consistent with epilepsy.

If epilepsy is not present, leave all boxes in Questions 22 and 22a blank/unchecked. If epilepsy is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment. If the subject has normal cognition but has other non-cognitive features of epilepsy, select **1=Present** for Question 22 and leave the primary, contributing, and non-contributing boxes for Question 22a blank/unchecked.

[1] Epilepsia. 2014 Apr;55(4):475-82. doi: 10.1111/epi.12550. Epub 2014 Apr 14. ILAE official report: a practical clinical definition of epilepsy. Fisher RS1, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, Engel J Jr, Forsgren L, French JA, Glynn M, Hesdorffer DC, Lee BI, Mathern GW, Moshé SL, Perucca E, Scheffer IE, Tomson T, Watanabe M, Wiebe S.

23.	CNS neoplasm 23b. ☐ 1 Benign ☐ 2 Malignant	☐ 1	23a ☐ 1	☐ 2	☐ 3

If CNS neoplasm (benign or malignant) is not present, leave all boxes for Questions 23, 23a, and 23b blank/unchecked. If CNS neoplasm is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment. If the subject has normal cognition and has CNS neoplasm, select **1=Present** for Question 23 and leave the primary, contributing, and non-contributing boxes for Question 23a blank/unchecked.

24.	Human immunodeficiency virus (HIV)	☐ 1	24a ☐ 1	☐ 2	☐ 3

Recent publications outline updated research criteria for determining the presence of an HIV-associated neurocognitive disorder — for instance, the paper by Antinori et al. (2007).

For subjects with cognitive impairment: If HIV is present, select, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment.

For subjects with normal cognition: If the subject has normal cognition and has HIV, select **1=Present** for Question 24 and leave the primary, contributing, and non-contributing boxes for Question 24a blank/unchecked.

If HIV is not present, leave all boxes for Questions 24 and 24a blank/unchecked.

Antinori A, Arendt G, Becker JT, et al. Updated research nosology for HIV-associated neurocognitive disorders. Neurology. 2007;69(18):1789-1799.

25.	Cognitive impairment due to other neurologic, genetic, or infectious conditions not listed above	☐ 1	25a ☐ 1	☐ 2	☐ 3

	25b. If Present, specify: _____					

If the subject has cognitive impairment due to a neurological, genetic, or infectious condition other than those described in Questions 11 – 24, select **1=Present**, specify the etiologic cause in the **Specify** field, and indicate whether the etiology is the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the observed cognitive impairment.

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 etiologic diagnoses marked 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

Consult the Diagnostic and Statistical Manual of Mental Disorders regarding the diagnosis of depression. If depression is not present, leave all boxes for Questions 26 and 26a blank/unchecked. If active depression (regardless of whether it is active but successfully treated with medication or counseling) is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment in Question 26a. If the subject has normal cognition but has active depression, select **1=Present** for Question 26 and leave the boxes for Question 26a blank/unchecked.

QUESTIONS 27 – 31: Consult the Diagnostic and Statistical Manual of Mental Disorders regarding the diagnosis of the psychiatric conditions listed in Questions 27 – 31. If the psychiatric disorder is not present, leave all questions related to the particular psychiatric disorder blank/unchecked. If the psychiatric condition (regardless of whether it is active but successfully treated with medication or counseling) is present, select **1=Present,** and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment. If the subject has normal cognition but has the psychiatric disorder, select **1=Present** and leave the primary, contributing, and non-contributing boxes for that respective question blank/unchecked.

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

If the subject has cognitive impairment due to a psychiatric condition other than those described in Questions 26 – 31, select **1=Present** for Question 32, specify the etiologic cause in the specify field, and indicate whether the etiology is the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the observed cognitive impairment.

Questions 33 – 36: Consult the Diagnostic and Statistical Manual of Mental Disorders regarding the diagnosis of the psychiatric conditions listed in Questions 33 – 36. If the psychiatric disorder is not present, leave all questions related to the particular psychiatric disorder blank/unchecked. If the psychiatric condition (regardless of whether it is active but successfully treated with medication or counseling) is present, select **1=Present**, and indicate whether it is thought to be the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the cognitive impairment. If the subject has normal cognition but has the psychiatric disorder, select **1=Present** and leave the primary, contributing, and non-contributing boxes for the respective question blank/unchecked.

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

Questions 37 – 39: If the subject has cognitive impairment due to a condition other than those described in Questions 11 – 36, select **1=Present**, enter the etiologic cause in the **Specify** field, and indicate whether the etiology is the **1=Primary** cause, a **2=Contributing** cause, or a **3=Non-contributing** cause of the observed cognitive impairment.

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

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

Form D1: Clinician Diagnosis

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

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

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up 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)**

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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	☐ 0	☐ 1
		5b2. Attention	☐ 0	☐ 1
		5b3. Executive	☐ 0	☐ 1
		5b4. Visuospatial	☐ 0	☐ 1

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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	☐ 0	☐ 1
		5c2. Attention	☐ 0	☐ 1
		5c3. Executive	☐ 0	☐ 1
		5c4. Visuospatial	☐ 0	☐ 1
5d. Non-amnestic MCI, multiple domains (naMCI MD)	☐ 1	**CHECK YES for at least two domains:**		
		5d1. Language	☐ 0	☐ 1
		5d2. Attention	☐ 0	☐ 1
		5d3. Executive	☐ 0	☐ 1
		5d4. Visuospatial	☐ 0	☐ 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	

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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				

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

Subject ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___ Form date: ___ ___ / ___ ___ / ___ ___ ___ ___ Visit #: ___ ___ ___

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

Form D2: Clinician-assessed Medical Conditions

When to answer No: When the clinician has sufficient evidence to conclude that the subject does not have the condition. Example 1: If the subject is not currently taking hypertension medications, does not report having hypertension, and did not have high blood pressure at his/her UDS visit, select **0=No** for hypertension. Example 2: If the subject and/or co-participant reports that the subject has hypercholesterolemia and is not taking cholesterol lowing drugs, but the subject's cholesterol levels were examined recently and were normal, the clinician may decide to select **0=No** for hypercholesterolemia.

When to answer Yes: When the clinician believes there is sufficient evidence to conclude that the subject currently has the condition (even if present but successfully treated), or — for specific conditions or procedures — that the subject has experienced it in the last 12 months. For some conditions, subject and co-participant report may be sufficient to warrant concluding that a condition is present, based on the clinician's best judgment.

When to answer Not assessed: If the only information for assessing the presence of these conditions is self-report by the subject or the co-participant, and the clinician believes the self-reported information is not sufficient enough to warrant concluding that a condition is present, mark **8=Not assessed** or **9=Not assessed or unknown**.

Definition of "Active"condition: Unless otherwise indicated, active means the subject is currently experiencing and/or being treated for the condition at this visit (e.g., within the last two weeks).

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 the clinician has sufficient evidence of the subject having recent/active cancer in the last 12 months, select 1=**Yes, primary/non-metastatic** or **2=Yes, metastatic** and specify the primary site where the cancer started in Question 1a. If results are pending to determine whether the cancer is metastatic, select **1=Yes, primary/non-metastatic** and revise to **2=Yes, metastatic** at a later date if it is found to be metastatic around the time of this UDS visit.

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

Select **1=Yes, Type I; 2=Yes, Type II;** or **3=Yes, other type** if the clinician has sufficient evidence of active diabetes, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **9=Not assessed or unknown**.

	No	Yes	Not assessed
3. Myocardial infarct	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of a myocardial infarct within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

4. Congestive heart failure	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active congestive heart failure. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

5. Atrial fibrillation	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active atrial fibrillation, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

6. Hypertension	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active hypertension, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

7. Angina	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active angina, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

8. Hypercholesterolemia	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active hypercholesterolemia, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

9. B12 deficiency	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active B12 deficiency, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

10. Thyroid disease	☐0	☐1	☐8

Select **1=Yes** if the clinician has sufficient evidence of active thyroid disease, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

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**	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of active arthritis, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

11a. If yes, what type?

☐ 1 Rheumatoid

☐ 2 Osteoarthritis

☐ 3 Other (SPECIFY): _____

☐ 9 Unknown

If the subject has both rheumatoid arthritis and osteoarthritis, select **1=Rheumatoid**. See instructions at top of page 111 to determine when to select **0=No** or **9=Unknown**.

11b. If yes, regions affected (check all that apply):

11b1. ☐ 1 Upper extremity

11b2. ☐ 1 Lower extremity

11b3. ☐ 1 Spine

11b4. ☐ 1 Unknown

Indicate all regions that are affected by arthritis.

12. Incontinence — urinary	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of active urinary incontinence, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

13. Incontinence — bowel	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of active bowel incontinence, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

14. Sleep apnea	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of sleep apnea, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

15. REM sleep behavior disorder (RBD)	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of REM sleep behavior disorder, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

16. Hyposomnia/insomnia	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence hyposomnia/insomnia, even if successfully treated. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

17. Other sleep disorder (SPECIFY): _____	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of an active sleep disorder not already listed in Questions 14–16, even if that sleep disorder is successfully treated. Write the sleep disorder in the space provided. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

18. Carotid procedure: angioplasty, endarterectomy, or stent	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of carotid procedure — angioplasty, endarterectomy, or stent, within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

19. Percutaneous coronary intervention: angioplasty and/or stent	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of percutaneous coronary intervention — angioplasty and/or stent — within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

20. Procedure: pacemaker and/or defibrillator	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of a pacemaker implant within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

21. Procedure: heart valve replacement or repair	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of a heart valve replacement or repair surgery within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

22. Antibody-mediated encephalopathy 22a. Specify antibody: _____	☐ 0	☐ 1	☐ 8

Select **1=Yes** if the clinician has sufficient evidence of antibody-mediated encephalopathy within the past 12 months. See instructions at top of page 111 to determine when to select **0=No** or **8=Not assessed**.

23. Other medical conditions or procedures not listed above (IF YES, SPECIFY): _____	☐ 0	☐ 1	

Select **1=Yes** if the clinician has sufficient evidence of another major medical condition that is active or a major surgical procedure that occurred in the past 12 months. See instructions at top of page 111 to determine when to select **0=No**.

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

Form D2: Clinician-assessed Medical Conditions

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

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

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

Subject ID: _____ Form date: ____ / ____ / _____ Visit #: _____

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 (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 (IF YES, SPECIFY): _____	☐ 0	☐ 1	