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NACC Uniform Data Set (UDS)
FORMS – Telephone Follow-up Packet

(Version 2.0, February 2008)

NOTE: Version 2 is NOT the most current version of the UDS forms and is no longer used for data submission. For the most current version, please visit http://www.alz.washington.edu.

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The National Alzheimer's Coordinating Center (NACC)
Uniform Data Set (UDS) Forms for Telephone Follow-up Packet (TFP)

The Telephone Follow-up Packet (TFP) aims to obtain information from the informant when the subject is unable to attend an in-person UDS evaluation:

- When, in unusual instances, the patient or control may be unable to return to the clinic for the annual UDS follow-up assessment (e.g., temporarily or permanently too ill, because of medical problems, to be assessed).
- When more than minimal contact (e.g., to determine vital status in terminal patients) is feasible.

The UDS Milestones Form must be completed along with the Telephone Follow-up Packet:

- When a subject is first moved to the UDS telephone follow-up protocol.
- When a subject is moved back from the UDS telephone protocol to an in-person UDS follow-up.

> In-person UDS visits provide the principal UDS research value. Annual, direct patient examination and neuropsychological testing will enable the observation and analysis of patterns of change over time, and detailed diagnostic information can be gathered and examined. When in-person UDS visits are no longer possible, data provided by informant interview only may be useful to monitor some features.
>
> Informants may be able to detect meaningful cognitive and functional decline before there are clear deficits on neuropsychological measures. For the UDS, therefore, it is critical to obtain informant observations at each annual assessment for all participants, including nondemented controls. When the subject is able to attend in-person UDS evaluation, informant information can be obtained directly with those UDS forms, collected in-person or occasionally supplemented by telephone interaction with the informant.

The ADC Clinical Task Force requires that the UDS be administered as a standard protocol, separate from protocols that have been developed for administration at individual ADCs. The ADCs may continue to separately administer their site specific protocols to maintain fidelity with data collected prior to the implementation of the UDS and to address research questions that are not addressed by the UDS.

Typographical Conventions

Instructions will appear as a sans serif font against a shaded background... sample text.

General Instructions for All Forms

1. Complete the following required information in all form headers:

   Center:..........................Enter the name of the ADC.

   ADC Subject ID:..........Enter the subject ID used at the ADC. This is the same as the Minimum Data Set (MDS) Patient ID (PTID), if the subject was enrolled in the NACC MDS.

   Form Date:..................Enter the date that each form was completed at the ADC (mm/dd/yyyy). The Form Date on Form A1 should correspond to the first day of the subject's visit. If the visit takes several days to complete, the Form Date for each form should reflect the date it was completed. For example, if a subject was first seen on January 1, 2006 and forms A1 through B9 were completed, but forms D1 and E1 weren't completed until January 5, 2006, then the Form Date should be entered as "01/01/2006" for forms A1 through B9, and the Form Date for D1 and E1 should be "01/05/2006".

   ADC Visit #:................Enter the visit number assigned at the ADC.

   Examiner's initials: .....Enter the initials for the examiner specified in the form instructions. ("Clinician" includes physicians, PAs, RNs, psychologists, psychometrists and other health professionals specifically trained/certified for patient evaluation or treatment. "ADC staff" refers to any non-clinician at the ADC, typically with some experience conducting research interviews with the specific data collection instrument.)

2. Provide only one answer per question, unless instructed otherwise.
3. Many items include “unknown” as a response category. Use this code only if the respondent is unable or unwilling to provide information that would allow a more specific response.
4. NOTE: The Telephone Follow-up Packet is a sub-set of the Follow-up Visit Packet, with the exception of Form T1, which is required.

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Telephone Follow-Up Form Z1: Form Checklist

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by clinic staff. ADC Visit #:__ __ __

Examiner's initials: __ __ __

The Telephone Follow-up Packet (TFP) aims to obtain information from the informant when the subject is unable to attend an in-person UDS evaluation. NACC requires that Forms Z1, T1, A1, A2, A5, B4, B9, D1, and E1 be submitted with a telephone packet. This data must be obtained from an informant.

For forms not designated as required, if it is not feasible to collect all or almost all of the data elements for a subject and the ADC therefore decides not to attempt collection of those data, an explanation must be provided. Please indicate this decision below by including the appropriate explanatory code and any additional comments.

KEY: If the specified form was not completed, please enter one of the following codes:

95 = Physical problem
96 = Cognitive/behavior problem
97 = Other problem
98 = Verbal refusal

Form	Description	Submitted: Yes	Submitted: No	If not submitted, specify reason (see Key)	Comments (provide if needed)
T1	Inclusion Form	**REQUIRED**		n/a	n/a
A1	Subject Demographics	**REQUIRED**		n/a	n/a
A2	Informant Demographics	**REQUIRED**		n/a	n/a
A3	Subject Family History	☐ 1	☐ 0	__ __	
A4	Subject Medications	☐ 1	☐ 0	__ __	
A5	Subject Health History	**REQUIRED**		n/a	n/a
B4	Global Staging – CDR: Standard and Supplemental	**REQUIRED**		n/a	n/a
B5 or B5S	Behavioral Assessment – NPI-Q	☐ 1	☐ 0	__ __	
B7 or B7S	Functional Assessment – FAQ	☐ 1	☐ 0	__ __	
B9	Clinician Judgment of Symptoms	**REQUIRED**		n/a	n/a
D1	Clinician Diagnosis – Cognitive Status and Dementia	**REQUIRED**		n/a	n/a
E1	Imaging/Labs	**REQUIRED**		n/a	n/a

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Telephone Follow-up Form T1: Inclusion Form

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: 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.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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.

1. Why is the UDS telephone follow-up protocol being used to obtain data about the subject?	Yes	No
a. Too cognitively impaired for in-person UDS visit.	☐ 1	☐ 0
b. Too physically impaired (medical illness or injury) to attend in-person UDS visit.	☐ 1	☐ 0
c. Homebound or in nursing home and cannot travel.	☐ 1	☐ 0
d. Subject or informant refused in-person UDS visit.	☐ 1	☐ 0
e. Other (*specify*): ___________________________________ (ADC staff convenience is not an acceptable reason.)	☐ 1	☐ 0

	Yes	No
2. Has a UDS Milestones Form documenting the change to telephone follow-up been completed? *(If no, complete a Milestones Form now.)*	☐ 1	☐ 0

	Yes	No	Unknown
3. Is the subject likely to resume in-person UDS follow-up evaluations?	☐ 1	☐ 0	☐ 9

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Telephone Follow-up Form A1: Subject Demographics

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by ADC clinician or interviewer with the informant plus ADC records 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.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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

1.	Subject's month/year of birth:	__ __/__ __ __ __	
2.	Subject's sex:	☐ 1 Male	☐ 2 Female
3.	What is the subject's living situation?	☐ 1 Lives alone ☐ 2 Lives with spouse or partner ☐ 3 Lives with relative or friend	☐ 4 Lives with group ☐ 5 Other (*specify*): ____________ ☐ 9 Unknown
4.	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
5.	What is the subject's primary type of residence?	☐ 1 Single family residence ☐ 2 Retirement community ☐ 3 Assisted living/ boarding home/adult family home	☐ 4 Skilled nursing facility/ nursing home ☐ 5 Other (*specify*): ____________ ☐ 9 Unknown
6.	Subject's primary residence zip code (first 3 digits):	__ __ __ (*leave blank if unknown*)	
7.	Subject's current marital status:	☐ 1 Married ☐ 2 Widowed ☐ 3 Divorced ☐ 4 Separated	☐ 5 Never married ☐ 6 Living as married ☐ 8 Other (*specify*): ____________ ☐ 9 Unknown

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Telephone Follow-up Form A2: Informant Demographics

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form must be completed with the informant by the clinician/interviewer for a telephone follow-up. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A2. Check only <u>one</u> box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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

Question		
1. Informant's month/year of birth:	__ __/__ __ __ __ (*99/9999 = Unknown*)	
2. Informant's sex:	☐ 1 Male	☐ 2 Female
3. Is this a new informant? (If no, skip to item #9)	☐ 1 Yes	☐ 0 No
4. Does the informant report being of Hispanic/Latino <u>ethnicity</u> (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	☐ 1 Yes	☐ 0 No ☐ 9 Unknown
4a. If yes, what are the informant's reported origins?	☐ 1 Mexican/Chicano/ Mexican-American ☐ 2 Puerto Rican ☐ 3 Cuban ☐ 4 Dominican	☐ 5 Central American ☐ 6 South American ☐ 50 Other (*specify*): ______________ ☐ 99 Unknown
5. What does informant report as his/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 informant 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

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form must be completed with the informant by the clinician/interviewer for a telephone follow-up. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A2. Check only one box per question.

ADC Visit #:__ __ __

Question	Options	Options
7. What additional race, beyond what was indicated above in questions 5 and 6, does informant 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. Informant's years of education (report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended). High school/GED = 12; Bachelors degree = 16; Master's degree = 18; Doctorate = 20 years:		__ __ (*99 = Unknown*)
9. What is informant's relationship to subject?	☐ 1 Spouse/partner ☐ 2 Child ☐ 3 Sibling ☐ 4 Other relative	☐ 5 Friend/neighbor ☐ 6 Paid caregiver/provider ☐ 7 Other (*specify*): ____________
10. Does the informant live with the subject?	☐ 1 Yes (*if yes, skip to #11*)	☐ 0 No
10a. If no, approximate frequency of in-person visits:	☐ 1 Daily ☐ 2 At least 3x/week ☐ 3 Weekly	☐ 4 At least 3x/month ☐ 5 Monthly ☐ 6 Less than once a month
10b. If no, approximate frequency of telephone contact:	☐ 1 Daily ☐ 2 At least 3x/week ☐ 3 Weekly	☐ 4 At least 3x/month ☐ 5 Monthly ☐ 6 Less than once a month
11. Is there a question about the informant's reliability?	☐ 1 Yes	☐ 0 No

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Telephone Follow-up Form A3: Subject Family History

Center: ________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician/interviewer with the informant. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A3.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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

For the following questions:

Dementia refers to progressive loss of memory and cognition, and is often described as senility, dementia, Alzheimer's Disease, hardening of the arteries, or other causes that compromised the subject's social or occupational functioning and from which they did not recover.

Age at onset refers to the age at which dementia symptoms began, not the age at which the diagnosis was made.

☐ Review with the subject/informant the data collected for this form at the previous UDS visit. If a version 2.0 Form A3 has been submitted previously and if there have been no changes, check this box and end form here.

Please consider blood relatives only.

PARENTS:

☐ Provide all information below if it has not been previously submitted. If there has been any change, enter all data in the row for the appropriate parent. Otherwise, check this box and proceed to the next section.

	a. Year of birth	b. Is the parent still living?			c. If deceased, indicate year of death	d. Does/did this parent have dementia (defined above), as indicated by symptoms, history or diagnosis?			e. If yes, indicate age at onset
	(9999=unknown)	Yes	No	Unknown	*(9999=unknown)*	Yes	No	Unknown	*(999=unknown)*
1. Mother	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
2. Father	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __

SIBLINGS:

☐ Provide all information below if it has not been previously submitted. If there has been any change, enter all data in the row for the appropriate sibling. Otherwise, check this box and proceed to the next section.

3. How many full siblings did the subject have? *(99 = Unknown)* __ __

4. For full siblings, indicate the following:

	4a. Year of birth	4b. Is the sibling still living?			4c. If deceased, indicate year of death	4d. Does/did this sibling have dementia (defined above), as indicated by symptoms, history or diagnosis?			4e. If yes, indicate age at onset
	(9999=unknown)	Yes	No	Unknown	*(9999=unknown)*	Yes	No	Unknown	*(999=unknown)*
Sibling 1	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __

Center: __________________ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician/interviewer with the informant. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A3. ADC Visit #:__ __ __

SIBLINGS: *(continued)*	4a. **Year of birth**	4b. **Is the sibling still living?**			4c. **If deceased, indicate year of death**	4d. **Does/did this sibling have dementia (defined above), as indicated by symptoms, history or diagnosis?**			4e. **If yes, indicate age at onset**
	(9999=unknown)	**Yes**	**No**	**Unknown**	*(9999=unknown)*	**Yes**	**No**	**Unknown**	*(999=unknown)*
Sibling 2	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 3	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 4	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 5	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 6	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 7	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 8	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 10	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 11	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 12	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 13	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 14	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 15	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 16	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 17	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 18	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 19	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 20	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __

Center: ________________ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician/interviewer with the informant. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A3. ADC Visit #:__ __ __

CHILDREN:

☐ Provide all information below if it has not been previously submitted. If there has been any change, enter all data in the row for the appropriate child. Otherwise, check this box and proceed to the next section.

5. How many biological children did the subject have? *(99 = Unknown)* __ __

6. For biological children, indicate the following:

	6a. **Year of birth**	6b. **Is the child still living?**			6c. **If deceased, indicate year of death**	6d. **Does/did this child have dementia (defined above), as indicated by symptoms, history or diagnosis?**			6e. **If yes, indicate age at onset**
	(9999=unknown)	**Yes**	**No**	**Unknown**	*(9999=unknown)*	**Yes**	**No**	**Unknown**	*(999=unknown)*
Child 1	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 2	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 3	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 4	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 5	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 6	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 7	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 8	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 10	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 11	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 12	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 13	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 14	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Child 15	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __

Center: ________________ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician/interviewer with the informant. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A3.

ADC Visit #:__ __ __

OTHER DEMENTED RELATIVES:

☐ Provide all information below if it has not been previously submitted. If there has been any change, enter all data in the row for the appropriate relative. Otherwise, check this box and end form here.

7. Number of "other demented relatives" (cousins, aunts, uncles, grandparents, half siblings), as indicated by symptoms, history or diagnosis. *(99 = Unknown)* __ __

8. For "other demented relatives" (cousins, aunts, uncles, grandparents, half siblings), indicate the following:

	8a. **Year of birth** *(9999=unknown)*	8b. **Is the relative still living?** Yes	No	Unknown	8c. **If deceased, indicate year of death** *(9999=unknown)*	8d. **Indicate age at onset** *(999=unknown)*
Relative 1	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 2	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 3	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 4	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 5	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 6	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 7	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 8	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 10	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 11	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 12	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 13	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 14	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __
Relative 15	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	__ __ __

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Telephone Follow-up Form A4: Subject Medications

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: The purpose of this form is to record all prescription medications taken by the subject within the two weeks prior to the current visit. OTC/non-prescription medications and vitamins/supplements need not be recorded.

ADC Visit #:__ __ __

If a medication is not one of the 100 drugs listed below, 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.

Examiner's initials:__ __ __

Is the subject currently taking any medications? ☐ Yes ☐ No

Medication Name	drugID
☐ acetaminophen (Anacin, Tempra, Tylenol)	d00049
☐ acetaminophen-hydrocodone (Vicodin)	d03428
☐ albuterol (Proventil, Ventolin, Volmax)	d00749
☐ alendronate (Fosamax)	d03849
☐ allopurinol (Aloprim, Lopurin, Zyloprim)	d00023
☐ alprazolam (Niravam, Xanax)	d00168
☐ amitriptyline (Elavil, Endep, Vanatrip)	d00146
☐ amlodipine (Norvasc)	d00689
☐ ascorbic acid (C Complex, Vitamin C)	d00426
☐ aspirin	d00170
☐ atenolol (Senormin, Tenormin)	d00004
☐ atorvastatin (Lipitor)	d04105
☐ benazepril (Lotensin)	d00730
☐ bupropion (Budeprion, Wellbutrin, Zyban)	d00181
☐ calcium acetate (Calphron, PhosLo)	d03689
☐ calcium carbonate (Rolaids, Tums)	d00425
☐ calcium-vitamin D (Dical-D, O-Cal-D)	d03137
☐ carbidopa-levodopa (Atamet, Sinemet)	d03473
☐ celecoxib (Celebrex)	d04380
☐ citalopram (Celexa)	d04332
☐ clonazepam (Klonopin)	d00197
☐ clopidogrel (Plavix)	d04258
☐ conjugated estrogens (Cenestin, Premarin)	d00541
☐ conj. estrog.-medroxyprogesterone (Prempro)	d03819

Medication Name	drugID
☐ cyanocobalamin (Neuroforte-R, Vitamin B12)	d00413
☐ digoxin (Digitek, Lanoxin)	d00210
☐ diltiazem (Cardizem, Tiazac)	d00045
☐ divalproex sodium (Depakote)	d03833
☐ docusate (Calcium Stool Softener, Dioctyl SS)	d01021
☐ donepezil (Aricept)	d04099
☐ enalapril (Vasotec)	d00013
☐ ergocalciferol (Calciferol, Drisdol, Vitamin D)	d03128
☐ escitalopram (Lexapro)	d04812
☐ estradiol (Estrace, Estrogel, Fempatch)	d00537
☐ famotidine (Mylanta AR, Pepcid)	d00141
☐ ferrous sulfate (FeroSul, Iron Supplement)	d03824
☐ fexofenadine (Allegra)	d04040
☐ finasteride (Propecia, Proscar)	d00563
☐ fluoxetine (Prozac)	d00236
☐ folic acid (Folic Acid)	d00241
☐ furosemide (Lasix)	d00070
☐ gabapentin (Neurontin)	d03182
☐ galantamine (Razadyne, Reminyl)	d04750
☐ glipizide (Glucotrol)	d00246
☐ glucosamine (Hydrochloride)	d04418
☐ glyburide (DiaBeta, Glycron, Micronase)	d00248
☐ hydrochlorothiazide (Esidrix, Hydrodiuril)	d00253
☐ hydrochlorothiazide-triamterene (Dyazide)	d03052

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: The purpose of this form is to record all prescription medications taken by the subject within the two weeks prior to the current visit. OTC/non-prescription medications and vitamins/supplements need not be recorded.

ADC Visit #:__ __ __

If a medication is not one of the 100 drugs listed below, 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.

Medication Name	drugID	Medication Name	drugID
☐ ibuprofen (Advil, Motrin, Nuprin)	d00015	☐ pyridoxine (Vitamin B6)	d00412
☐ lansoprazole (Prevacid)	d03828	☐ quetiapine (Seroquel)	d04220
☐ latanoprost ophthalmic (Xalatan)	d04017	☐ rabeprazole (Aciphex)	d04448
☐ levothyroxine (Levothroid, Levoxyl, Synthroid)	d00278	☐ raloxifene (Evista)	d04261
☐ lisinopril (Prinivil, Zestril)	d00732	☐ ranitidine (Zantac)	d00021
☐ loratadine (Alavert, Claritin, Dimetapp, Tavist)	d03050	☐ risperidone (Risperdal)	d03180
☐ lorazepam (Ativan)	d00149	☐ rivastigmine (Exelon)	d04537
☐ losartan (Cozaar)	d03821	☐ sertraline (Zoloft)	d00880
☐ lovastatin (Altocor, Mevacor)	d00280	☐ simvastatin (Zocor)	d00746
☐ medroxyprogesterone (Depo-Provera)	d00284	☐ tamsulosin (Flomax)	d04121
☐ memantine (Namenda)	d04899	☐ temazepam (Restoril)	d00384
☐ metformin (Glucophage, Riomet)	d03807	☐ terazosin (Hytrin)	d00386
☐ metoprolol (Lopressor, Toprol-XL)	d00134	☐ tolterodine (Detrol)	d04294
☐ mirtazapine (Remeron)	d04025	☐ trazodone (Desyrel)	d00395
☐ multivitamin	d03140	☐ trolamine salicylate topical (Analgesia Creme)	d03884
☐ multivitamin with minerals	d03145	☐ valsartan (Diovan)	d04113
☐ naproxen (Aleve, Anaprox, Naprosyn)	d00019	☐ venlafaxine (Effexor)	d03181
☐ niacin (Niacor, Nico-400, Nicotinic Acid)	d00314	☐ verapamil (Calan, Isoptin, Verelan)	d00048
☐ nifedipine (Adalat, Procardia)	d00051	☐ vitamin E (Aquavite-E, Centrum Singles)	d00405
☐ nitroglycerin (Nitro-Bid, Nitro-Dur, Nitrostat)	d00321	☐ warfarin (Coumadin, Jantoven)	d00022
☐ olanzapine (Zyprexa)	d04050	☐ zolpidem (Ambien)	d00910
☐ omega-3 polyunsaturated fatty acids (Omacor)	d00497	☐ *Specify:*	d _ _ _ _ _
☐ omeprazole (Prilosec)	d00325	☐ *Specify:*	d _ _ _ _ _
☐ oxybutynin (Ditropan, Urotrol)	d00328	☐ *Specify:*	d _ _ _ _ _
☐ pantoprazole (Protonix)	d04514	☐ *Specify:*	d _ _ _ _ _
☐ paroxetine (Paxil, Paxil CR, Pexeva)	d03157	☐ *Specify:*	d _ _ _ _ _
☐ phenytoin (Dilantin)	d00143	☐ *Specify:*	d _ _ _ _ _
☐ potassium chloride (K-Dur 10, K-Lor, Slow-K)	d00345	☐ *Specify:*	d _ _ _ _ _
☐ pravastatin (Pravachol)	d00348	☐ *Specify:*	d _ _ _ _ _
☐ prednisone (Deltasone, Orasone)	d00350	☐ *Specify:*	d _ _ _ _ _
☐ psyllium (Fiberall, Metamucil)	d01018	☐ *Specify:*	d _ _ _ _ _

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Telephone Follow-up Form A5: Subject Health History

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A5. Check only one box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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

Record the presence or absence of a history of these conditions at this visit as determined by the clinician's best judgment, based on informant report, medical records, and/or observation.

1. Cardiovascular disease	Absent	Active	Inactive	Unknown
a. Heart attack/cardiac arrest	☐ 0	☐ 1	☐ 2	☐ 9
b. Atrial fibrillation	☐ 0	☐ 1	☐ 2	☐ 9
c. Angioplasty/endarterectomy/stent	☐ 0	☐ 1	☐ 2	☐ 9
d. Cardiac bypass procedure	☐ 0	☐ 1	☐ 2	☐ 9
e. Pacemaker	☐ 0	☐ 1	☐ 2	☐ 9
f. Congestive heart failure	☐ 0	☐ 1	☐ 2	☐ 9
g. Other (*specify*): ______________________________	☐ 0	☐ 1	☐ 2	☐ 9

2. Cerebrovascular disease	Absent	Active	Inactive	Unknown
a. Stroke If active, indicate year(s) in which this occurred: (*9999 = Year unknown*)	☐ 0	☐ 1	☐ 2	☐ 9
	1) __ __ __ __	2) __ __ __ __	3) __ __ __ __	
	4) __ __ __ __	5) __ __ __ __	6) __ __ __ __	
b. Transient ischemic attack If active, indicate year(s) in which this occurred: (*9999 = Year unknown*)	☐ 0	☐ 1	☐ 2	☐ 9
	1) __ __ __ __	2) __ __ __ __	3) __ __ __ __	
	4) __ __ __ __	5) __ __ __ __	6) __ __ __ __	
c. Other (*specify*): ______________________________	☐ 0	☐ 1	☐ 2	☐ 9

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A5. Check only one box per question.

ADC Visit #:__ __ __

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

3. Parkinsonian features	Absent	Active	Unknown
a. Parkinson's disease	☐ 0	☐ 1	☐ 9
If active, indicate year of diagnosis: (*9999 = Year unknown*) __ __ __ __			
b. Other Parkinsonism disorder	☐ 0	☐ 1	☐ 9
If active, indicate year of diagnosis: (*9999 = Year unknown*) __ __ __ __			

4. Other neurologic conditions	Absent	Active	Inactive	Unknown
a. Seizures	☐ 0	☐ 1	☐ 2	☐ 9
b. Traumatic brain injury				
1) with brief loss of consciousness (< 5 minutes)	☐ 0	☐ 1	☐ 2	☐ 9
2) with extended loss of consciousness (≥ 5 minutes)	☐ 0	☐ 1	☐ 2	☐ 9
3) with chronic deficit or dysfunction	☐ 0	☐ 1	☐ 2	☐ 9
c. Other (*specify*): ______________________	☐ 0	☐ 1	☐ 2	☐ 9

5. Medical/metabolic conditions	Absent	Active	Inactive	Unknown
a. Hypertension	☐ 0	☐ 1	☐ 2	☐ 9
b. Hypercholesterolemia	☐ 0	☐ 1	☐ 2	☐ 9
c. Diabetes	☐ 0	☐ 1	☐ 2	☐ 9
d. B12 deficiency	☐ 0	☐ 1	☐ 2	☐ 9
e. Thyroid disease	☐ 0	☐ 1	☐ 2	☐ 9
f. Incontinence – urinary	☐ 0	☐ 1	☐ 2	☐ 9
g. Incontinence – bowel	☐ 0	☐ 1	☐ 2	☐ 9

NOTE: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form A5. Check only <u>one</u> box per question.

ADC Visit #:__ __ __

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

6. Depression	No	Yes	Unknown
a. Active within past 2 years	☐ 0	☐ 1	☐ 9
b. Other episodes (prior to 2 years)	☐ 0	☐ 1	☐ 9

7. Substance abuse and psychiatric disorders

a. Substance abuse – alcohol	Absent	Active	Inactive	Unknown
1) Clinically significant impairment occurring over a 12-month period manifested in one of the following: work, driving, legal or social.	☐ 0	☐ 1	☐ 2	☐ 9

b. Cigarette smoking history	No	Yes	Unknown
1) Has subject smoked within last 30 days?	☐ 0	☐ 1	☐ 9
2) Has subject smoked more than 100 cigarettes in his/her life?	☐ 0	☐ 1	☐ 9

3) Total years smoked: (*88 = N/A; 99 = Unknown*) __ __

4) Average number of packs/day smoked:

☐ 1 1 cigarette – < ½ pack ☐ 4 1½ – < 2 packs ☐ 9 Unknown

☐ 2 ½ – < 1 pack ☐ 5 ≥ 2 packs

☐ 3 1 – < 1½ pack ☐ 8 N/A

5) If subject quit smoking, specify age when last smoked (i.e., quit): (*888 = N/A; 999 = Unknown*) __ __ __

c. Other abused substances	Absent	Active	Inactive	Unknown
1) Clinically significant impairment occurring over a 12-month period manifested in one of the following: work, driving, legal or social.	☐ 0	☐ 1	☐ 2	☐ 9

If active or inactive, specify abused substance(s): ______________________________

d. Psychiatric disorders	☐ 0	☐ 1	☐ 2	☐ 9

If active or inactive, specify disorder(s): ______________________________

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Telephone Follow-up Form B4: Global Staging – Clinical Dementia Rating (CDR): Standard and Supplemental

Center: ______________ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Form Date: __ __/__ __/__ __ __ __ ADC Visit #:__ __ __

Examiner's initials:__ __ __

NOTE: This form is to be completed by the clinician or other trained health professional, based on informant report and previous records of neurological exam of the subject. In the extremely rare instances when no informant is available, the clinician or other trained health professional must complete this form utilizing 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. For further information, see UDS Coding Guidebook for Telephone Follow-up Packet, Form B4.

SECTION 1: STANDARD CDR [1]

	IMPAIRMENT				
Please enter scores below	**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 & PROBLEM SOLVING __ . __	Solves everyday problems, handles business & 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 & HOBBIES __ . __	Life at home, hobbies, and intellectual interests well maintained.	Life at home, hobbies, and intellectual interests slightly impaired.	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned.	Only simple chores preserved; very restricted interests, poorly maintained.	No significant function in the home.
6. PERSONAL CARE __ . 0	Fully capable of self-care (= 0).		Needs prompting.	Requires assistance in dressing, hygiene, keeping of personal effects.	Requires much help with personal care; frequent incontinence.
7. __ __ . __	**STANDARD CDR SUM OF BOXES**				
8. __ . __	**STANDARD GLOBAL CDR**				

[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.

NOTE: This form is to be completed by the clinician or other trained health professional, based on informant report and previous records of neurological exam of the subject. In the extremely rare instances when no informant is available, the clinician or other trained health professional must complete this form utilizing 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. For further information, see UDS Coding Guidebook for Telephone Follow-up Packet, Form B4.

SECTION 2: SUPPLEMENTAL CDR

	IMPAIRMENT				
Please enter scores below	**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-CRD: A modification of the CDR for assessing dementia severity in patients with Primary Progressive Aphasia (Johnson N, Weintraub S, Mesulam MM), 2002.

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Telephone Follow-up Form B5: Behavioral Assessment – Neuropsychiatric Inventory Questionnaire (NPI-Q[1])

Center: __________ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Form Date: __ __/__ __/__ __ __ __ ADC Visit #:__ __ __

NOTE: This form is to be completed by the clinician or other trained health professional per informant 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 regarding NPI-Q Interviewer Certification, see UDS Coding Guidebook for Telephone Follow-up Packet, Form B5. Check only one box for each category of response.

Examiner's initials:__ __ __

Please ask the following questions based upon changes. Indicate "yes" only if the symptom has been present in the past month; otherwise, indicate "no".

For each item marked "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 informant: ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (*specify*): __________

Item		Yes	No		Severity		
2. DELUSIONS: Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?	2a.	☐ 1	☐ 0	2b.	☐ 1	☐ 2	☐ 3
3. HALLUCINATIONS: Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?	3a.	☐ 1	☐ 0	3b.	☐ 1	☐ 2	☐ 3
4. AGITATION OR AGGRESSION: Is the patient stubborn and resistive to help from others?	4a.	☐ 1	☐ 0	4b.	☐ 1	☐ 2	☐ 3
5. DEPRESSION OR DYSPHORIA: Does the patient act as if he or she is sad or in low spirits? Does he or she cry?	5a.	☐ 1	☐ 0	5b.	☐ 1	☐ 2	☐ 3
6. ANXIETY: Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	6a.	☐ 1	☐ 0	6b.	☐ 1	☐ 2	☐ 3

[1] Copyright© Jeffrey L. Cummings, MD. Reproduced by permission.

Center: __________________ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Form Date: __ __/__ __/__ __ __ __ ADC Visit #:__ __ __

NOTE: This form is to be completed by the clinician or other trained health professional per informant 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 regarding NPI-Q Interviewer Certification, see UDS Coding Guidebook for Telephone Follow-up Packet, Form B5. Check only one box for each category of response.

Please ask the following questions based upon changes. Indicate "yes" only if the symptom has been present in the past month; otherwise, indicate "no".

For each item marked "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	Severity
7. ELATION OR EUPHORIA: Does the patient appear to feel too good or act excessively happy?	7a. ☐ 1 ☐ 0	7b. ☐ 1 ☐ 2 ☐ 3
8. APATHY OR INDIFFERENCE: Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	8a. ☐ 1 ☐ 0	8b. ☐ 1 ☐ 2 ☐ 3
9. DISINHIBITION: Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?	9a. ☐ 1 ☐ 0	9b. ☐ 1 ☐ 2 ☐ 3
10. IRRITABILITY OR LABILITY: Is the patient impatient or cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	10a. ☐ 1 ☐ 0	10b. ☐ 1 ☐ 2 ☐ 3
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	11b. ☐ 1 ☐ 2 ☐ 3
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	12b. ☐ 1 ☐ 2 ☐ 3
13. APPETITE AND EATING: Has the patient lost or gained weight, or had a change in the food he or she likes?	13a. ☐ 1 ☐ 0	13b. ☐ 1 ☐ 2 ☐ 3

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Telephone Follow-up Form B7: Functional Assessment – Functional Assessment Questionnaire (FAQ[1])

Center: ______________________ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Form Date: __ __/__ __/__ __ __ __ ADC Visit #:__ __ __

NOTE: This form is to be completed by the clinician or other trained health professional, based on information provided by informant. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form B7. Indicate the level of performance for each activity by circling the one appropriate response.

Examiner's initials:__ __ __

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

[1] 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.

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Telephone Follow-up Form B9: Clinician Judgment of Symptoms

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

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

ADC Visit #:__ __ __

Examiner's initials:__ __ __

MEMORY COMPLAINT/AGE OF ONSET:	**Yes**	**No**
Relative to previously attained abilities:		
1. Does the subject report a decline in memory?	☐ 1	☐ 0
2. Does the informant report a decline in subject's memory?	☐ 1	☐ 0
3a. Does the clinician believe there has been a current meaningful decline in the subject's memory, non-memory cognitive abilities, behavior, or ability to manage his/her affairs, or have there been motor/movement changes?	☐ 1	☐ 0 (*If no, end form here*)
3b. At what age did the cognitive decline begin (based upon the clinician's assessment)?	__ __ __	(*999 = Unknown*) (*888 = N/A*)

COGNITIVE SYMPTOMS:	**Yes**	**No**	**Unknown**
4. Indicate whether the subject currently is impaired meaningfully, relative to previously attained abilities in the following cognitive domains, or has fluctuating cognition:			
a. **Memory** (For example, does s/he forget conversations and/or dates; repeat questions and/or statements; misplace more than usual; forget names of people s/he knows well?)	☐ 1	☐ 0	☐ 9
b. **Judgment and problem-solving** (For example, does s/he have trouble handling money (tips); paying bills; shopping; preparing meals; handling appliances; handling medications; driving?)	☐ 1	☐ 0	☐ 9
c. **Language** (For example, does s/he have hesitant speech; have trouble finding words; use inappropriate words without self-correction?)	☐ 1	☐ 0	☐ 9
d. **Visuospatial function** (Difficulty interpreting visual stimuli and finding his/her way around.)	☐ 1	☐ 0	☐ 9
e. **Attention/concentration** (For example, does the subject have a short attention span or ability to concentrate? Is s/he easily distracted?)	☐ 1	☐ 0	☐ 9
f. **Fluctuating cognition** (Does s/he have pronounced variation in attention and alertness, noticeably over hours or days? For example, long periods of staring into space or lapses, or times when his/her ideas have a disorganized flow.)	☐ 1	☐ 0	☐ 9
g. **Other** (*If yes, then specify*): ______________________________	☐ 1	☐ 0	☐ 9

(*continued on next page*)

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

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

ADC Visit #:__ __ __

5. Indicate the predominant symptom which was first recognized as a decline in the subject's cognition:	☐ 1 Memory ☐ 2 Judgment and problem solving ☐ 3 Language ☐ 4 Visuospatial function ☐ 5 Attention/concentration	☐ 6 Other (*specify*): ______________ ☐ 7 Fluctuating cognition ☐ 88 N/A ☐ 99 Unknown
6. Mode of onset of cognitive symptoms:	☐ 1 Gradual (> *6 months*) ☐ 2 Subacute (≤ *6 months*) ☐ 3 Abrupt (*within days*)	☐ 4 Other (*specify*): ______________ ☐ 88 N/A ☐ 99 Unknown

BEHAVIOR SYMPTOMS:	**Yes**	**No**	**Unknown**
7. Indicate whether the subject currently manifests the following behavioral symptoms:			
a. **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?)	☐ 1	☐ 0	☐ 9
b. **Depression** (Has the subject seemed depressed for more than two weeks at a time; e.g., loss of interest or pleasure in nearly all activities; sadness, hopelessness, loss of appetite, fatigue?)	☐ 1	☐ 0	☐ 9
c. **Psychosis**			
1) Visual hallucinations	☐ 1	☐ 0	☐ 9
a) If yes, are the hallucinations well-formed and detailed?	☐ 1	☐ 0	☐ 9
2) Auditory hallucinations	☐ 1	☐ 0	☐ 9
3) Abnormal/false/delusional beliefs	☐ 1	☐ 0	☐ 9
d. **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?)	☐ 1	☐ 0	☐ 9
e. **Irritability** (Does the subject overreact, such as shouting at family members or others?)	☐ 1	☐ 0	☐ 9
f. **Agitation** (Does the subject have trouble sitting still; does s/he shout, hit, and/or kick?)	☐ 1	☐ 0	☐ 9
g. **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 other's feelings into account?)	☐ 1	☐ 0	☐ 9
h. **REM sleep behavior disorder** (Does the subject appear to act out his/her dreams while sleeping (e.g., punch or flail their arms, shout or scream?)	☐ 1	☐ 0	☐ 9
i. **Other** (*If yes, then specify*): ________________________________	☐ 1	☐ 0	☐ 9

(continued on next page)

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

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

ADC Visit #:__ __ __

8. Indicate the predominant symptom which was first recognized as a decline in the subject's behavioral symptoms:
   - ☐ 1 Apathy/withdrawal
   - ☐ 2 Depression
   - ☐ 3 Psychosis
   - ☐ 4 Disinhibition
   - ☐ 5 Irritability
   - ☐ 6 Agitation
   - ☐ 7 Personality change
   - ☐ 8 Other (*specify*): ___________________
   - ☐ 9 REM sleep behavior disorder
   - ☐ 88 N/A
   - ☐ 99 Unknown

9. Mode of onset of behavioral symptoms:
   - ☐ 1 Gradual (> *6 months*)
   - ☐ 2 Subacute (≤ *6 months*)
   - ☐ 3 Abrupt (*within days*)
   - ☐ 4 Other (*specify*): ___________________
   - ☐ 88 N/A
   - ☐ 99 Unknown

MOTOR SYMPTOMS:

10. Indicate whether the subject currently has the following motor symptoms:

	Yes	No	Unknown
a. **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?)	☐ 1	☐ 0	☐ 9
b. **Falls** (Does the subject fall more than usual?)	☐ 1	☐ 0	☐ 9
c. **Tremor** (Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?)	☐ 1	☐ 0	☐ 9
d. **Slowness** (Has the subject noticeably slowed down in walking or moving or handwriting, other than due to an injury or illness? Has his/her facial expression changed, or become more "wooden" or masked and unexpressive?)	☐ 1	☐ 0	☐ 9

11. Indicate the predominant symptom which was first recognized as a decline in the subject's motor symptoms:
    - ☐ 1 Gait disorder
    - ☐ 2 Falls
    - ☐ 3 Tremor
    - ☐ 4 Slowness
    - ☐ 88 N/A
    - ☐ 99 Unknown

12. Mode of onset of motor symptoms:
    - ☐ 1 Gradual (> *6 months*)
    - ☐ 2 Subacute (≤ *6 months*)
    - ☐ 3 Abrupt (*within days*)
    - ☐ 4 Other (*specify*): ___________________
    - ☐ 88 N/A
    - ☐ 99 Unknown

    a. If there were changes in motor function, were these suggestive of parkinsonism?
    - ☐ 1 Yes
    - ☐ 0 No
    - ☐ 88 N/A

OVERALL SUMMARY OF SYMPTOMS ONSET:

13. Course of overall cognitive/behavioral/ motor syndrome:
    - ☐ 1 Gradually progressive
    - ☐ 2 Stepwise
    - ☐ 3 Static
    - ☐ 4 Fluctuating
    - ☐ 5 Improved
    - ☐ 9 Unknown

14. Indicate the predominant domain which was first recognized as changed in the subject:
    - ☐ 1 Cognition
    - ☐ 2 Behavior
    - ☐ 3 Motor function
    - ☐ 9 Unknown

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Telephone Follow-up Form D1: Clinician Diagnosis – Cognitive Status and Dementia

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician. For diagnostic criteria, see UDS Coding Guidebook for Telephone Follow-up Packet, Form D1. Check only one box per response category.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

1. Responses are based on:	☐ 1 Diagnosis from single clinician	☐ 2 Consensus diagnosis

2. Does the subject have normal cognition (no MCI, dementia, or other neurological condition resulting in cognitive impairment)?	☐ 1 Yes (*If yes, skip to #14*)	☐ 0 No (*If no, continue to #3*)
3. Does the subject meet criteria for dementia (in accordance with standard criteria for dementia of the Alzheimer's type or for other non-Alzheimer's dementing disorders)?	☐ 1 Yes (*If yes, skip to #5*)	☐ 0 No (*If no, continue to #4*)

4. If the subject does not have normal cognition and is not clinically demented, indicate the type of cognitive impairment (*choose only one impairment from items 4a thru 4e as being "present"; mark all others "absent"*) **and then designate the suspected underlying cause(s) of the impairment by indicating "present" for applicable items 5–30**:

	Present	Absent	Domains	Yes	No
4a. Amnestic MCI – memory impairment only	☐ 1	☐ 0			
4b. Amnestic MCI – memory impairment plus one or more other domains (*if present, check one or more domain boxes "yes" and check all other domain boxes "no"*)	☐ 1	☐ 0	1) Language	☐ 1	☐ 0
			2) Attention	☐ 1	☐ 0
			3) Executive function	☐ 1	☐ 0
			4) Visuospatial	☐ 1	☐ 0
4c. Non-amnestic MCI – single domain (*if present, check only one domain box "yes"; check all other domain boxes "no"*)	☐ 1	☐ 0	1) Language	☐ 1	☐ 0
			2) Attention	☐ 1	☐ 0
			3) Executive function	☐ 1	☐ 0
			4) Visuospatial	☐ 1	☐ 0
4d. Non-amnestic MCI – multiple domains (*if present, check two or more domain boxes "yes" and check all other domain boxes "no"*)	☐ 1	☐ 0	1) Language	☐ 1	☐ 0
			2) Attention	☐ 1	☐ 0
			3) Executive function	☐ 1	☐ 0
			4) Visuospatial	☐ 1	☐ 0
4e. Impaired, not MCI	☐ 1	☐ 0			

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician. For diagnostic criteria, see UDS Coding Guidebook for Telephone Follow-up Packet, Form D1.
Check only <u>one</u> box per response category.

ADC Visit #:__ __ __

Please indicate if the following conditions are present or absent. If present, also indicate if the condition is primary or contributing to the observed cognitive impairment (reported in items 3 or 4), based on the clinician's best judgment. Mark only <u>one</u> condition as primary.

		Present	Absent		If Present: Primary	Contributing
5.	Probable AD (NINCDS/ADRDA) (*if present, skip to item #7*)	☐ 1	☐ 0	5a.	☐ 1	☐ 2
6.	Possible AD (NINCDS/ADRDA) (*if #5 is present, leave this blank*)	☐ 1	☐ 0	6a.	☐ 1	☐ 2
7.	Dementia with Lewy bodies	☐ 1	☐ 0	7a.	☐ 1	☐ 2
8.	Vascular dementia (NINDS/AIREN Probable) (*if present, skip to item #10*)	☐ 1	☐ 0	8a.	☐ 1	☐ 2
9.	Vascular dementia (NINDS/AIREN Possible) (*if #8 is present, leave this blank*)	☐ 1	☐ 0	9a.	☐ 1	☐ 2
10.	Alcohol-related dementia	☐ 1	☐ 0	10a.	☐ 1	☐ 2
11.	Dementia of undetermined etiology	☐ 1	☐ 0	11a.	☐ 1	☐ 2
12.	Frontotemporal dementia (behavioral/executive dementia)	☐ 1	☐ 0	12a.	☐ 1	☐ 2
13.	Primary progressive aphasia (aphasic dementia)	☐ 1	☐ 0	13a.	☐ 1	☐ 2
	(*If PPA is present, specify type by checking <u>one</u> box below "present" and <u>all others</u> "absent"*):					
	1) Progressive nonfluent aphasia	☐ 1	☐ 0			
	2) Semantic dementia – anomia plus word comprehension	☐ 1	☐ 0			
	3) Semantic dementia – agnosic variant	☐ 1	☐ 0			
	4) Other (e.g., logopenic, anomic, transcortical, word deafness, syntactic comprehension, motor speech disorder)	☐ 1	☐ 0			

Center: __________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by the clinician. For diagnostic criteria, see UDS Coding Guidebook for Telephone Follow-up Packet, Form D1. Check only one box per response category.

ADC Visit #:__ __ __

If the subject has normal cognition, indicate only if the following conditions are present or absent. If the subject is cognitively impaired, indicate if the condition is present and also whether the condition is primary, contributing or non-contributing to the observed cognitive impairment, based on your best judgment. Mark only one condition as primary.

		Present	Absent		If Present: Primary	Contributing	Non-contrib.
14.	Progressive supranuclear palsy	☐ 1	☐ 0	14a.	☐ 1	☐ 2	☐ 3
15.	Corticobasal degeneration	☐ 1	☐ 0	15a.	☐ 1	☐ 2	☐ 3
16.	Huntington's disease	☐ 1	☐ 0	16a.	☐ 1	☐ 2	☐ 3
17.	Prion disease	☐ 1	☐ 0	17a.	☐ 1	☐ 2	☐ 3
18.	Cognitive dysfunction from medications	☐ 1	☐ 0	18a.	☐ 1	☐ 2	☐ 3
19.	Cognitive dysfunction from medical illnesses	☐ 1	☐ 0	19a.	☐ 1	☐ 2	☐ 3
20.	Depression	☐ 1	☐ 0	20a.	☐ 1	☐ 2	☐ 3
21.	Other major psychiatric illness	☐ 1	☐ 0	21a.	☐ 1	☐ 2	☐ 3
22.	Down's syndrome	☐ 1	☐ 0	22a.	☐ 1	☐ 2	☐ 3
23.	Parkinson's disease	☐ 1	☐ 0	23a.	☐ 1	☐ 2	☐ 3
24.	Stroke	☐ 1	☐ 0	24a.	☐ 1	☐ 2	☐ 3
25.	Hydrocephalus	☐ 1	☐ 0	25a.	☐ 1	☐ 2	☐ 3
26.	Traumatic brain injury	☐ 1	☐ 0	26a.	☐ 1	☐ 2	☐ 3
27.	CNS neoplasm	☐ 1	☐ 0	27a.	☐ 1	☐ 2	☐ 3
28.	Other (*specify*): ______________________________	☐ 1	☐ 0	28a.	☐ 1	☐ 2	☐ 3
29.	Other (*specify*): ______________________________	☐ 1	☐ 0	29a.	☐ 1	☐ 2	☐ 3
30.	Other (*specify*): ______________________________	☐ 1	☐ 0	30a.	☐ 1	☐ 2	☐ 3

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Telephone Follow-up Form E1: Imaging/Labs

Center: ___________________ ADC Subject ID:__ __ __ __ __ __ __ __ __ __ Form Date:__ __/__ __/__ __ __ __

NOTE: This form is to be completed by ADC or clinic staff. For additional clarification and examples, see UDS Coding Guidebook for Telephone Follow-up Packet, Form E1.Check only one box per response category.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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

Since the last visit, has neuroimaging been completed and available at your ADC?		**Film** Yes	**Film** No		**Digital image** Yes	**Digital image** No
1. Computed tomography	1a.	☐ 1	☐ 0	1b.	☐ 1	☐ 0
2. Magnetic resonance imaging – Clinical study	2a.	☐ 1	☐ 0	2b.	☐ 1	☐ 0
3. Magnetic resonance imaging – Research study/structural	3a.	☐ 1	☐ 0	3b.	☐ 1	☐ 0
4. Magnetic resonance imaging – Research study/functional	4a.	☐ 1	☐ 0	4b.	☐ 1	☐ 0
5. Magnetic resonance spectroscopy	5a.	☐ 1	☐ 0	5b.	☐ 1	☐ 0
6. SPECT	6a.	☐ 1	☐ 0	6b.	☐ 1	☐ 0
7. PET	7a.	☐ 1	☐ 0	7b.	☐ 1	☐ 0

Are specimens of the following available at your ADC?	**Yes**	**No**
8. DNA	☐ 1	☐ 0
9. Cerebrospinal fluid – ante-mortem	☐ 1	☐ 0
10. Serum/plasma	☐ 1	☐ 0

Is genotype data available at your ADC?	**Yes**	**No**
11. APOE	☐ 1	☐ 0