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NACC Uniform Data Set (UDS)

FORMS for Initial Visit Packet

(Version 2.0, February 2008)

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The National Alzheimer's Coordinating Center (NACC)
Uniform Data Set (UDS) Forms for Initial Visit Packet (IVP)

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 C1 and D1 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 C1 and D1 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 <u>one answer per question</u>, 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.

Informants are expected for all case and control subjects enrolled in the UDS. Please <u>do your best</u> to identify a reliable informant for the subject. If a local informant is not available, you can contact a long-distance informant. The informant must be <u>one</u> individual (not a group of friends or family members) who is considered the "best" source of information available on the subject. However, in very exceptional instances (e.g., if the subject refuses to supply an informant or there is no information available), the subject can still be enrolled.

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no informant, or for other reasons. NACC <u>requires</u> that Forms Z1, A1, A5, B4, B9, C1, D1, and E1 be submitted for a subject to be included in the UDS database, even though these forms may include some missing data.

For forms <u>not</u> 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 to collect those data, an explanation must be provided. Please indicate this decision on Form Z1 by including the appropriate explanatory code and any additional comments.

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NACC Uniform Data Set (UDS) – Initial Visit Packet

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: __ __ __

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no informant, or for other reasons. NACC requires that Forms Z1, A1, A5, B4, B9, C1, D1, and E1 be submitted for a subject to be included in the UDS database, even though these forms may include some missing data.

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 No	If not submitted, specify reason (see Key)	Comments (provide if needed)
A1	Subject Demographics	**REQUIRED**	n/a	n/a
A2	Informant Demographics	☐ 1 ☐ 0	__ __	
A3	Subject Family History	☐ 1 ☐ 0	__ __	
A4	Subject Medications	☐ 1 ☐ 0	__ __	
A5	Subject Health History	**REQUIRED**	n/a	n/a
B1	Evaluation Form – Physical	☐ 1 ☐ 0	__ __	
B2	Evaluation Form – HIS and CVD	☐ 1 ☐ 0	__ __	
B3	Evaluation Form – UPDRS	☐ 1 ☐ 0	__ __	
B4	Global Staging – CDR: Standard and Supplemental	**REQUIRED**	n/a	n/a
B5 or B5S	Behavioral Assessment – NPI-Q	☐ 1 ☐ 0	__ __	
B6 or B6S	Behavioral Assessment – GDS	☐ 1 ☐ 0	__ __	
B7 or B7S	Functional Assessment – FAQ	☐ 1 ☐ 0	__ __	

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

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

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)
B8	Evaluation – Physical/Neurological Exam Findings	☐ 1	☐ 0	__ __	
B9	Clinician Judgment of Symptoms	**REQUIRED**		n/a	n/a
C1 or C1S	MMSE and Neuropsychological Battery	**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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Form A1: Subject Demographics

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

NOTE: This form is to be completed by intake interviewer per ADC scheduling records, subject interview, medical records, and proxy informant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A1. Check only one box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

Source of Referral:

1.	Subject enrolled in NACC MDS:	☐ 1 Yes	☐ 0 No
2.	Primary reason for coming to ADC:	☐ 1 Participate in research study ☐ 2 Clinical evaluation	☐ 3 Other (*specify*): _____ ☐ 9 Unknown
3.	Principal referral source:	☐ 1 Self/relative/friend ☐ 2 Clinician ☐ 3 ADC solicitation ☐ 4 Non-ADC study ☐ 5 Clinic sample	☐ 6 Population sample ☐ 7 Non-ADC media appeal (e.g., Alzheimer's Association) ☐ 8 Other (*specify*): _____ ☐ 9 Unknown
4.	Presumed disease status at enrollment:	☐ 1 Case/patient/proband ☐ 2 Control/normal	☐ 3 No presumed disease status
5.	Presumed participation:	☐ 1 Initial evaluation only	☐ 2 Longitudinal follow-up planned

6.	ADC enrollment type:	☐ 1 Clinical Core ☐ 2 Satellite Core	☐ 3 Other ADC Core/project ☐ 4 Center-affiliated/non-ADC

7.	Subject's month/year of birth:	__ __/__ __ __ __

8.	Subject's sex:	☐ 1 Male	☐ 2 Female

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

NOTE: This form is to be completed by intake interviewer per ADC scheduling records, subject interview, medical records, and proxy informant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A1. Check only one box per question.

ADC Visit #:__ __ __

9. Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	☐ 1 Yes ☐ 0 No	☐ 9 Unknown
9a. If yes, what are the subject'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
10. What does subject 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
11. What additional race does subject report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or Other Pacific Islander	☐ 5 Asian ☐ 50 Other (*specify*): _____ ☐ 88 None reported ☐ 99 Unknown
12. What additional race, beyond what was indicated above in questions 10 and 11, does subject report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or Other Pacific Islander	☐ 5 Asian ☐ 50 Other (*specify*): _____ ☐ 88 None reported ☐ 99 Unknown

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

NOTE: This form is to be completed by intake interviewer per ADC scheduling records, subject interview, medical records, and proxy informant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A1. Check only one box per question.

ADC Visit #:__ __ __

13. Subject's primary language:	☐ 1 English ☐ 2 Spanish ☐ 3 Mandarin ☐ 4 Cantonese ☐ 5 Russian	☐ 6 Japanese ☐ 8 Other primary language (*specify*): _____ ☐ 9 Unknown
14. Subject'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*)	
15. 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
16. What is the subject's level of independence?	☐ 1 Able to live independently ☐ 2 Requires some assistance with complex activities	☐ 3 Requires some assistance with basic activities ☐ 4 Completely dependent ☐ 9 Unknown
17. What is the subject's primary type of residence?	☐ 1 Single family residence ☐ 2 Retirement community ☐ 3 Assisted living/ boarding home/adult family home	☐ 4 Skilled nursing facility/ nursing home ☐ 5 Other (*specify*): _____ ☐ 9 Unknown
18. Subject's primary residence zip code (first 3 digits):	__ __ __ (*leave blank if unknown*)	
19. 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
20. Is the subject left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)?	☐ 1 Left-handed ☐ 2 Right-handed	☐ 3 Ambidextrous ☐ 9 Unknown

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Form A2: Informant Demographics

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

NOTE: This form is to be completed by intake interviewer per informant's report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A2. Check only one box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

1. Informant's month/year of birth:	__ __/__ __ __ __ (*99/9999 = Unknown*)	
2. Informant's sex:	☐ 1 Male	☐ 2 Female

3. Does the informant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	☐ 1 Yes	☐ 0 No ☐ 9 Unknown
3a. 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

4. 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
5. 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 is to be completed by intake interviewer per informant's report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A2. Check only one box per question.

ADC Visit #:__ __ __

6. What additional race, beyond what was indicated above in questions 4 and 5, 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
7. 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*)	
8. 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*): _____
9. Does the informant live with the subject?	☐ 1 Yes (*if yes, skip to #10*)	☐ 0 No
9a. 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
9b. 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
10. Is there a question about the informant's reliability?	☐ 1 Yes	☐ 0 No

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Form A3: Subject Family History

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

NOTE: This form is to be completed by intake interviewer per subject/informant report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A3.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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.

Please consider blood relatives only.

PARENTS:

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

SIBLINGS:

3. Is the subject a twin? ☐ 1 Yes ☐ 0 No ☐ 9 Unknown

3a. If yes, indicate type: ☐ 1 Monozygotic (i.e., identical) ☐ 2 Dizygotic (i.e., fraternal) ☐ 9 Unknown

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

5. For all full siblings, indicate the following:

	5a. Year of birth (9999=unknown)	5b. Is the sibling still living? Yes	No	Unknown	5c. If deceased, indicate year of death (9999=unknown)	5d. Does/did this sibling have dementia (defined above), as indicated by symptoms, history or diagnosis? Yes	No	Unknown	5e. If yes, indicate age at onset (999=unknown)
Sibling 1	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 2	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __
Sibling 3	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __ __	☐ 1	☐ 0	☐ 9	__ __ __

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

NOTE: This form is to be completed by intake interviewer per subject/informant report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A3..

ADC Visit #:__ __ __

SIBLINGS: *(continued)*	5a. **Year of birth** *(9999=unknown)*	5b. **Is the sibling still living?** Yes	No	Unknown	5c. **If deceased, indicate year of death** *(9999=unknown)*	5d. **Does/did this sibling have dementia (defined above), as indicated by symptoms, history or diagnosis?** Yes	No	Unknown	5e. **If yes, indicate age at onset** *(999=unknown)*
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 intake interviewer per subject/informant report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A3..

ADC Visit #:__ __ __

CHILDREN:

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

7. For all biological children, indicate the following:

	7a. **Year of birth** *(9999=unknown)*	7b. **Is the child still living?** Yes	No	Unknown	7c. **If deceased, indicate year of death** *(9999=unknown)*	7d. **Does/did this child have dementia (defined above), as indicated by symptoms, history or diagnosis?** Yes	No	Unknown	7e. **If yes, indicate age at onset** *(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 intake interviewer per subject/informant report. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A3..

ADC Visit #:__ __ __

OTHER DEMENTED RELATIVES:

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

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

	9a. **Year of birth** *(9999=unknown)*	9b. **Is the relative still living?** Yes	No	Unknown	9c. **If deceased, indicate year of death** *(9999=unknown)*	9d. **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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Form A4: Subject Medications

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

NOTE: This form is to be completed by the clinician or ADC staff. Record ALL medications (prescription, non-prescription, and vitamin/supplements) taken by the subject within the past two weeks.

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/NONMEMBER/UDS/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: This form is to be completed by the clinician or ADC staff. Record ALL medications (prescription, non-prescription, and vitamin/supplements) taken by the subject within the past two weeks.

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/NONMEMBER/UDS/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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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit Packet, Form A5. Check only one box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

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	Recent/Active	Remote/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	Recent/Active	Remote/Inactive	Unknown
a. Stroke	☐ 0	☐ 1	☐ 2	☐ 9
If recent/active or remote/inactive, indicate year(s) in which this occurred: (*9999 = Year unknown*)		1) __ __ __ __	2) __ __ __ __	3) __ __ __ __
		4) __ __ __ __	5) __ __ __ __	6) __ __ __ __
b. Transient ischemic attack	☐ 0	☐ 1	☐ 2	☐ 9
If recent/active or remote/inactive, indicate year(s) in which this occurred: (*9999 = Year unknown*)		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 Initial Visit Packet, Form A5. Check only one box per question.

ADC Visit #:__ __ __

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

4. Other neurologic conditions	Absent	Recent/Active	Remote/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	Recent/Active	Remote/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 Initial Visit Packet, Form A5. Check only one box per question.

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	Recent/Active	Remote/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	Recent/Active	Remote/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 recent/active or remote/inactive, specify abused substance(s): _____

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

If recent/active or remote/inactive, specify disorder(s): _____

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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B1: Evaluation Form – Physical

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 Initial Visit Packet, Form B1.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

SUBJECT PHYSICAL MEASUREMENTS		
1. Subject height (inches):	(*99.9 = unknown*)	__ __ . __
2. Subject weight (lbs.):	(*999 = unknown*)	__ __ __
3. Subject blood pressure (sitting)	(*999/999 = unknown*)	__ __ __ /__ __ __
4. Subject resting heart rate (pulse)	(*999 = unknown*)	__ __ __

ADDITIONAL PHYSICAL OBSERVATIONS	Yes	No	Unknown
5. Without corrective lenses, is the subject's vision functionally normal?	☐ 1	☐ 0	☐ 9
6. Does the subject usually wear corrective lenses?	☐ 1	☐ 0	☐ 9
6a. If yes, is the subject's vision functionally normal <u>with</u> corrective lenses?	☐ 1	☐ 0	☐ 9
7. Without a hearing aid(s), is the subject's hearing functionally normal?	☐ 1	☐ 0	☐ 9
8. Does the subject usually wear a hearing aid(s)?	☐ 1	☐ 0	☐ 9
8a. If yes, is the subject's hearing functionally normal <u>with</u> a hearing aid(s)?	☐ 1	☐ 0	☐ 9

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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B2: Evaluation Form – HIS and CVD

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

NOTE: This form is to be completed by the clinician or other trained health professional. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B2.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

HACHINSKI ISCHEMIC SCORE [1]

Please complete the following scale using information obtained from history/physical/neurological exam and/or medical records. Circle the appropriate value to indicate if a specific item is present (characteristic of the patient) or absent.

	Present	Absent
1. Abrupt onset (re: cognitive status)	2	0
2. Stepwise deterioration (re: cognitive status)	1	0
3. Somatic complaints	1	0
4. Emotional incontinence	1	0
5. History or presence of hypertension	1	0
6. History of stroke	2	0
7. Focal neurological symptoms	2	0
8. Focal neurological signs	2	0
9. **Sum all circled answers for a Total Score:**	__ __	

[1] Rosen Modification of Hachinski Ischemic Score (*Ann Neurol* 7:486-488, 1980). Copyright© John Wiley & Sons, Inc. Reproduced by permission.

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

NOTE: This form is to be completed by the clinician or other trained health professional. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B2.

ADC Visit #:__ __ __

CEREBROVASCULAR DISEASE	**Yes**	**No**	**N/A**
10. Using your best judgment, do you believe that cerebrovascular disease (CVD) is contributing to the cognitive impairment?	☐ 1	☐ 0	☐ 8
11. If there is a stroke, is there a temporal relationship between stroke and onset of cognitive impairment?	☐ 1	☐ 0	☐ 8
12. Is there imaging evidence which supports that CVD is contributing to the cognitive impairment?	☐ 1	☐ 0	☐ 8
12a. If yes, indicate which imaging evidence was found:			
1) Single strategic infarct	☐ 1	☐ 0	
2) Multiple infarcts	☐ 1	☐ 0	
3) Extensive white matter hyperintensity	☐ 1	☐ 0	
4) Other (*specify*): _____	☐ 1	☐ 0	

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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B3: Evaluation Form – Unified Parkinson's Disease Rating Scale (UPDRS[1]) – Motor Exam

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

NOTE: This form is to be completed by the clinician or other trained health professional. ADC Visit #: __ __ __
For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B3.Check only one box per question. Examiner's initials: __ __ __

☐ [Optional] If the clinician completes the UPDRS examination and determines all items are normal, check this box and end form here.

1. Speech	☐ 0 Normal. ☐ 1 Slight loss of expression, diction and/or volume. ☐ 2 Monotone, slurred but understandable; moderately impaired.	☐ 3 Marked impairment, difficult to understand. ☐ 4 Unintelligible. ☐ 8 Untestable (*specify reason*): _____	
2. Facial expression	☐ 0 Normal. ☐ 1 Minimal hypomimia, could be normal "poker face". ☐ 2 Slight but definitely abnormal diminution of facial expression.	☐ 3 Moderate hypomimia; lips parted some of the time. ☐ 4 Masked or fixed facies with severe or complete loss of facial expression; lips parted ¼ inches or more. ☐ 8 Untestable (*specify reason*): _____	

3. Tremor at rest			
3a. Face, lips, chin	☐ 0 Absent. ☐ 1 Slight and infrequently present. ☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present.	☐ 3 Moderate in amplitude and present most of the time. ☐ 4 Marked in amplitude and present most of the time. ☐ 8 Untestable (*specify reason*): _____	
3b. Right hand	☐ 0 Absent. ☐ 1 Slight and infrequently present. ☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present.	☐ 3 Moderate in amplitude and present most of the time. ☐ 4 Marked in amplitude and present most of the time. ☐ 8 Untestable (*specify reason*): _____	

[1] Fahn S, Elton RL, UPDRS Development Committee. The Unified Parkinson's Disease Rating Scale. In Fahn S, Marsden CD, Calne DB, Goldstein M, eds. Recent developments in Parkinson's disease, Vol. 2. Florham Park, NJ: Macmillan Healthcare Information, 1987:153-163, 293-304. Reproduced by permission of the author.

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

NOTE: This form is to be completed by the clinician or other trained health professional. ADC Visit #: __ __ __
For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B3.Check only one box per question.

3c. Left hand	☐ 0 Absent. ☐ 1 Slight and infrequently present. ☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present.	☐ 3 Moderate in amplitude and present most of the time. ☐ 4 Marked in amplitude and present most of the time. ☐ 8 Untestable (*specify reason*): _____
3d. Right foot	☐ 0 Absent. ☐ 1 Slight and infrequently present. ☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present.	☐ 3 Moderate in amplitude and present most of the time. ☐ 4 Marked in amplitude and present most of the time. ☐ 8 Untestable (*specify reason*): _____
3e. Left foot	☐ 0 Absent. ☐ 1 Slight and infrequently present. ☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present.	☐ 3 Moderate in amplitude and present most of the time. ☐ 4 Marked in amplitude and present most of the time. ☐ 8 Untestable (*specify reason*): _____

4. Action or postural tremor of hands		
4a. Right hand	☐ 0 Absent. ☐ 1 Slight; present with action. ☐ 2 Moderate in amplitude, present with action.	☐ 3 Moderate in amplitude with posture holding as well as action. ☐ 4 Marked in amplitude; interferes with feeding. ☐ 8 Untestable (*specify reason*): _____
4b. Left hand	☐ 0 Absent. ☐ 1 Slight; present with action. ☐ 2 Moderate in amplitude, present with action.	☐ 3 Moderate in amplitude with posture holding as well as action. ☐ 4 Marked in amplitude; interferes with feeding. ☐ 8 Untestable (*specify reason*): _____

5. Rigidity (judged on passive movement of major joints with patient relaxed in sitting position; cogwheeling to be ignored)		
5a. Neck	☐ 0 Absent. ☐ 1 Slight or detectable only when activated by mirror or other movements. ☐ 2 Mild to moderate.	☐ 3 Marked, but full range of motion easily achieved. ☐ 4 Severe; range of motion achieved with difficulty. ☐ 8 Untestable (*specify reason*): _____

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

NOTE: This form is to be completed by the clinician or other trained health professional. ADC Visit #: __ __ __
For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B3.Check only <u>one</u> box per question.

5b. Right upper extremity	☐ 0 Absent. ☐ 1 Slight or detectable only when activated by mirror or other movements. ☐ 2 Mild to moderate.	☐ 3 Marked, but full range of motion easily achieved. ☐ 4 Severe; range of motion achieved with difficulty. ☐ 8 Untestable (*specify reason*): _____
5c. Left upper extremity	☐ 0 Absent. ☐ 1 Slight or detectable only when activated by mirror or other movements. ☐ 2 Mild to moderate.	☐ 3 Marked, but full range of motion easily achieved. ☐ 4 Severe; range of motion achieved with difficulty. ☐ 8 Untestable (*specify reason*): _____
5d. Right lower extremity	☐ 0 Absent. ☐ 1 Slight or detectable only when activated by mirror or other movements. ☐ 2 Mild to moderate.	☐ 3 Marked, but full range of motion easily achieved. ☐ 4 Severe; range of motion achieved with difficulty. ☐ 8 Untestable (*specify reason*): _____
5e. Left lower extremity	☐ 0 Absent. ☐ 1 Slight or detectable only when activated by mirror or other movements. ☐ 2 Mild to moderate.	☐ 3 Marked, but full range of motion easily achieved. ☐ 4 Severe; range of motion achieved with difficulty. ☐ 8 Untestable (*specify reason*): _____

6. Finger taps (patient taps thumb with index finger in rapid succession)		
6a. Right hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____
6b. Left hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____

7. Hand movements (patient opens and closes hands in rapid succession)		
7a. Right hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____

NOTE: This form is to be completed by the clinician or other trained health professional. ADC Visit #: __ __ __
For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B3.Check only one box per question.

7b. Left hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____

8. Rapid alternating movements of hands (pronation-supination movements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously)		
8a. Right hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____
8b. Left hand	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____

9. Leg agility (patient taps heel on the ground in rapid succession, picking up entire leg; amplitude should be at least 3 inches)		
9a. Right leg	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____
9b. Left leg	☐ 0 Normal. ☐ 1 Mild slowing and/or reduction in amplitude. ☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement.	☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement. ☐ 4 Can barely perform the task. ☐ 8 Untestable (*specify reason*): _____

NOTE: This form is to be completed by the clinician or other trained health professional. ADC Visit #: __ __ __
For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B3.Check only one box per question.

10. Arising from chair (patient attempts to rise from a straight-backed chair, with arms folded across chest)	☐ 0 Normal. ☐ 1 Slow; or may need more than one attempt. ☐ 2 Pushes self up from arms of seat.	☐ 3 Tends to fall back and may have to try more than one time, but can get up without help. ☐ 4 Unable to arise without help. ☐ 8 Untestable (*specify reason*): _____
11. Posture	☐ 0 Normal. ☐ 1 Not quite erect, slightly stooped posture; could be normal for older person. ☐ 2 Moderately stooped posture, definitely abnormal; can be slightly leaning to one side.	☐ 3 Severely stooped posture with kyphosis; can be moderately leaning to one side. ☐ 4 Marked flexion with extreme abnormality of posture. ☐ 8 Untestable (*specify reason*): _____
12. Gait	☐ 0 Normal. ☐ 1 Walks slowly; may shuffle with short steps, but no festination (hastening steps) or propulsion. ☐ 2 Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion.	☐ 3 Severe disturbance of gait requiring assistance. ☐ 4 Cannot walk at all, even with assistance. ☐ 8 Untestable (*specify reason*): _____
13. Posture stability (response to sudden, strong posterior displacement produced by pull on shoulders while patient erect with eyes open and feet slightly apart; patient is prepared)	☐ 0 Normal erect. ☐ 1 Retropulsion, but recovers unaided. ☐ 2 Absence of postural response; would fall if not caught by examiner.	☐ 3 Very unstable, tends to lose balance spontaneously. ☐ 4 Unable to stand without assistance. ☐ 8 Untestable (*specify reason*): _____
14. Body bradykinesia and hypokinesia (combining slowness, hesitancy, decreased arm swing, small amplitude, and poverty of movement in general)	☐ 0 None. ☐ 1 Minimal slowness, giving movement a deliberate character; could be normal for some persons; possibly reduced amplitude. ☐ 2 Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.	☐ 3 Moderate slowness, poverty or small amplitude of movement. ☐ 4 Marked slowness, poverty or small amplitude of movement. ☐ 8 Untestable (*specify reason*): _____

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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B4: Global Staging – Clinical Dementia Rating (CDR): Standard and Supplemental

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 informant report and 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 Initial Visit Packet, Form B4.

Examiner's initials:__ __ __

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.

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 informant report and 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 Initial Visit 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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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit 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*): _____

	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

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 <u>not</u> 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 Initial Visit Packet, Form B5. Check only <u>one</u> box for each category of response.

Please ask the following questions based upon <u>changes</u>. Indicate "yes" only if the symptom has been present in the <u>past month</u>; 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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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B6: Behavioral Assessment – Geriatric Depression Scale (GDS[1])

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

NOTE: 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 Initial Visit Packet, Form B6. Circle only one number per question. ADC Visit #:__ __ __

Examiner's initials:__ __ __

☐ 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 twelve 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
1. Are you basically satisfied with your life?	0	1
2. Have you dropped many of your activities and interests?	1	0
3. Do you feel that your life is empty?	1	0
4. Do you often get bored?	1	0
5. Are you in good spirits most of the time?	0	1
6. Are you afraid that something bad is going to happen to you?	1	0
7. Do you feel happy most of the time?	0	1
8. Do you often feel helpless?	1	0
9. Do you prefer to stay at home, rather than going out and doing new things?	1	0
10. Do you feel you have more problems with memory than most?	1	0
11. Do you think it is wonderful to be alive now?	0	1
12. Do you feel pretty worthless the way you are now?	1	0
13. Do you feel full of energy?	0	1
14. Do you feel that your situation is hopeless?	1	0
15. Do you think that most people are better off than you are?	1	0

16. **Sum all circled answers for a Total GDS Score** (maximum 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.

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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit 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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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form B8: Evaluation – Physical/Neurological Exam Findings

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 Initial Visit Packet, Form B8. Check only one box per question.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

PHYSICAL/NEUROLOGICAL EXAM FINDINGS	Yes	No	Unknown
1. Are all findings unremarkable (normal or normal for age)?	☐ 1	☐ 0	☐ 9
2. Are focal deficits present indicative of central nervous system disorder?	☐ 1	☐ 0	☐ 9
3. Is gait disorder present indicative of central nervous system disorder?	☐ 1	☐ 0	☐ 9
4. Are there eye movement abnormalities present indicative of central nervous system disorder?	☐ 1	☐ 0	☐ 9

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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit 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 Initial Visit 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 Initial Visit 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:	**Yes**	**No**	**Unknown**
10. Indicate whether the subject currently has the following motor symptoms:			
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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NACC Uniform Data Set (UDS) – Initial Visit Packet

Form C1: MMSE and Neuropsychological Battery

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

NOTE: This form is to be completed by ADC or clinic staff. For test administration and scoring, see UDS Coding Guidebook for Initial Visit Packet, Form C1.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

KEY: If the subject cannot complete any of the following exams, please use the following codes for test scores (except for the Trail Making Test):

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

1. Mini-Mental State Examination

1a. The administration of the MMSE was: ☐ 1 In ADC/ clinic ☐ 2 In home ☐ 3 In person–other

1) Language of MMSE administration: ☐ 1 English ☐ 2 Spanish ☐ 3 Other (*specify*): _____

1b. Orientation subscale score

1) Time: __ __ (0–5) *see Key*

2) Place: __ __ (0–5) *see Key*

1c. Intersecting pentagon subscale score: __ __ (0–1) *see Key*

1d. Total MMSE score (using D-L-R-O-W) __ __ (0–30) *see Key*

2. The remainder of the battery (below) was administered: ☐ 1 In ADC/ clinic ☐ 2 In home ☐ 3 In person–other

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

3. Logical Memory IA – Immediate

3a. If this test has been administered to the subject within the past 3 months, specify the date previously administered: __ __/__ __/__ __ __ __ (88/88/8888 = N/A)

1) Total score from the previous test administration: __ __ (0–25; *88 = N/A*)

3b. Total number of story units recalled from this current test administration: __ __ (0–25) *see Key*

4. Digit Span Forward

4a. Total number of trials correct prior to two consecutive errors at the same digit length: __ __ (0–12) *see Key*

4b. Digit span forward length: __ __ (0–8) *see Key*

NOTE: This form is to be completed by ADC or clinic staff. For test administration and scoring, see UDS Coding Guidebook for Initial Visit Packet, Form C1.

ADC Visit #:__ __ __

5.	**Digit Span Backward**		
	5a. Total number of trials correct prior to two consecutive errors at the same digit length:	__ __	(0–12) *see Key*
	5b. Digit span backward length:	__ __	(0–7) *see Key*
6.	**Category Fluency**		
	6a. Animals – Total number of animals named in 60 seconds:	__ __	(0–77) *see Key*
	6b. Vegetables – Total number of vegetables named in 60 seconds:	__ __	(0–77) *see Key*

KEY 2: If necessary, use the following codes for the Trail Making Test only:
995 = Physical problem
996 = Cognitive/behavior problem
997 = Other problem
998 = Verbal refusal

7.	**Trail Making Test**		
	7a. Part A–Total number of seconds to complete (if not finished by 150 seconds, enter 150):	__ __ __	(0–150) *see Key 2*
	1) Number of commission errors	__ __	(0–40; *88 = N/A*)
	2) Number of correct lines	__ __	(0–24; *88 = N/A*)
	7b. Part B–Total number of seconds to complete (if not finished by 300 seconds, enter 300):	__ __ __	(0–300) *see Key 2*
	1) Number of commission errors	__ __	(0–40; *88 = N/A*)
	2) Number of correct lines	__ __	(0–24; *88 = N/A*)
8.	**WAIS-R Digit Symbol**		
	8a. Total number of items correctly completed in 90 seconds:	__ __	(0–93) *see Key*
9.	**Logical Memory IIA – Delayed**		
	9a. Total number of story units recalled:	__ __	(0–25) *see Key*
	9b. Time elapsed since Logical Memory IA – Immediate:	__ __	(0–85 minutes) (*88 = N/A*) (*99 = Unknown*)
10.	**Boston Naming Test (30 Odd-numbered items)**		
	10a. Total score:	__ __	(0–30) *see Key*

Check only <u>one</u> box below:

11.	**Overall Appraisal**		
	11a. 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 abnormal	☐ 4 Three or more scores are abnormal or lower than expected ☐ 0 Clinician unable to render opinion

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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit Packet, Form D1. Check only <u>one</u> 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 <u>one</u> impairment from items 4a thru 4e as being "present"; mark <u>all others</u> "absent"*) **and then designate the suspected underlying cause(s) of the impairment by completing 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 <u>one</u> domain box "yes"; check <u>all other</u> 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 <u>two</u> 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 Initial Visit Packet, Form D1. Check only one 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 one condition as primary.

		Present	Absent		If Present: Primary	If Present: 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 one box below "present" and all others "absent"*):					
	1) Progressive nonfluent aphasia	☐ 1	☐ 0			
	2) Semantic dementia – anomia plus word comprehension	☐ 1	☐ 0			
	3) Semantic dementia – agnostic 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 Initial Visit Packet, Form D1. Check only one box per response category.

ADC Visit #:__ __ __

For subjects with normal cognition, indicate whether the following conditions are present or absent. If the subject is cognitively impaired, indicate 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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NACC Uniform Data Set (UDS) – Initial Visit Packet

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 Initial Visit Packet, Form E1.Check only one box per response category.

ADC Visit #:__ __ __

Examiner's initials:__ __ __

Neuroimaging 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

Specimens available at your ADC:	Yes	No
8. DNA	☐ 1	☐ 0
9. Cerebrospinal fluid – ante-mortem	☐ 1	☐ 0
10. Serum/plasma	☐ 1	☐ 0

Genotyping results:	Yes	No
11. APOE genotype collected	☐ 1	☐ 0