

## Changes to ISP

### **2015 Changes**

- No longer collecting B2 HIS and CVD and B3 UDPRS (3/15/2015)
- A5 Subject Health History is only collected at the initial visit (3/15/2015)
- Major changes to B8 (3/15/2015)
- Added D2 Clinician-assessed Medical Conditions (3/15/2015)
- No longer collecting the Physical Performance Test (September 2015)
- Collateral Source Interview (9/21/2015)
  - Removed the following fields because they are asked on the A2 form:
    - (1) How long has the CS known the Participant?
    - (2) How often does the CS see the subject?
    - (3) Talk with the Participant (e.g. phone)?

### **2016 Changes**

- No longer collecting the ACS Physical Activity Questionnaire and CS GDS (April 2016)
- N Health History (June 2016)
  - Removed: (1) major and minor fall questions, (2) Sleep Questionnaire
  - Removed/Added illnesses from health history table and are now asked if ever occurred during lifetime
  - Added: Information about participation in memory and thinking studies

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NACC UNIFORM DATA SET

# Initial Visit Packet

**Version 3.0, March 2015**

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February 18 Final

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WASHINGTON UNIVERSITY  
MEMORY AND AGING PROJECT  
INITIAL SUBJECT PROTOCOL (ISP) ©

Variable names are in red  
font in blue boxes

Participant Information

Date: \_\_\_\_\_

Phone: (    ) \_\_\_\_\_ - \_\_\_\_\_

\*Sex: M \_\_\_\_ F \_\_\_\_

\*Date of Birth        /        /         
                    DAY        MO        YEAR

Age \_\_\_\_\_

SS# \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Personal Physician as of (            )

Personal Physician as of (            )

Address: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone: (    ) \_\_\_\_\_ - \_\_\_\_\_

Phone: (    ) \_\_\_\_\_ - \_\_\_\_\_

Additional Remarks: \_\_\_\_\_

**HOLLINGSHEAD INDEX OF SOCIAL POSITION****1. SCORING**occup\_scoreOCCUPATION SCALE SCORE X 7 = occup\_scale\_scoreeduc\_scoreEDUCATION SCALE SCORE X 4 = educ\_scale\_score**SOCIAL CLASS**SUM sum

I 11-17

II 18-27

III 28-43

IV 44-60

V 61-77

\*SOCIAL CLASS social\_class**OCCUPATIONAL SCALE** (Head of Household) **EDUCATIONAL SCALE** (Participant)

1. Higher executives, proprietors of large concerns, major professionals

1. Graduate professional training

2. Business managers; proprietors of medium sized business, lesser professionals

2. Standard college/university graduate

3. Administrative personnel; small independent business, minor professionals

3. Partial college

4. Clerical and sales workers; owners of little business

4. High school graduate (12)

5. Skilled manual employees

5. Partial high school (10,11)

6. Machine operators; semi-skilled employees

6. Junior high school (7,8,9)

7. Unskilled employees

7. Less than 7 years of school

	<b><u>Participant</u></b>	<b><u>Spouse</u></b>
Occupation	<u>occupuation_p</u>	<u>occupation_s</u>
*Years of education	<u>education_yrs_p</u>	<u>education_yrs_s</u>
College degree(s)	<u>college_degree_p</u>	<u>college_degree_s</u>
Major subject	<u>college_major_p</u>	<u>college_major_s</u>

(If P has a GED and no college education, years of education =  $\frac{12 + \text{last grade}}{2}$ )

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form A1: Subject Demographics

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

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

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

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

6. Subject's month and year of birth (MM/YYYY):	<input type="text" value="birthmo"/>	<input type="text" value="birthyr"/>
7. Subject's sex:	<input type="text" value="sex"/>	<input type="checkbox"/> 1 Male <input type="checkbox"/> 2 Female
8. Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	<input type="text" value="hispanic"/>	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 9</b> ) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown (If Unknown, <b>SKIP TO QUESTION 9</b> )
8a. If yes, what are the subject's reported origins?	<input type="text" value="hispor"/>	<input type="checkbox"/> 1 Mexican, Chicano, or Mexican-American <input type="checkbox"/> 2 Puerto Rican <input type="checkbox"/> 3 Cuban <input type="checkbox"/> 4 Dominican <input type="checkbox"/> 5 Central American <input type="checkbox"/> 6 South American <input type="checkbox"/> 50 Other (SPECIFY): <input type="text" value="hisporx"/> <input type="checkbox"/> 99 Unknown
9. What does the subject report as his or her race?	<input type="text" value="race"/>	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): <input type="text" value="racex"/> <input type="checkbox"/> 99 Unknown
10. What additional race does the subject report?	<input type="text" value="racesec"/>	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): <input type="text" value="racesecx"/> <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown
11. What additional race, beyond those reported in Questions 9 and 10, does the subject report?	<input type="text" value="raceter"/>	<input type="checkbox"/> 1 White <input type="checkbox"/> 2 Black or African American <input type="checkbox"/> 3 American Indian or Alaska Native <input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander <input type="checkbox"/> 5 Asian <input type="checkbox"/> 50 Other (SPECIFY): <input type="text" value="raceterx"/> <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown

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12. Subject's primary language: <b>primlang</b>	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Mandarin <input type="checkbox"/> 4 Cantonese <input type="checkbox"/> 5 Russian <input type="checkbox"/> 6 Japanese <input type="checkbox"/> 8 Other primary language (SPECIFY): <b>primlanx</b> <input type="checkbox"/> 9 Unknown
13. Subject's years of education — use the codes below to report the level achieved; if an attempted level is not completed, enter the number of years completed: <b>educ</b> 12=high school or GED 16=bachelor's degree 18=master's degree 20=doctorate 99=unknown	
14. Subject's <u>current</u> marital status: <b>maristat</b>	<input type="checkbox"/> 1 Married <input type="checkbox"/> 2 Widowed <input type="checkbox"/> 3 Divorced <input type="checkbox"/> 4 Separated <input type="checkbox"/> 5 Never married (or marriage was annulled) <input type="checkbox"/> 6 Living as married/domestic partner <input type="checkbox"/> 9 Unknown
15. What is the subject's living situation? <b>livsitua</b>	<input type="checkbox"/> 1 Lives alone <input type="checkbox"/> 2 Lives with one other person: a spouse or partner <input type="checkbox"/> 3 Lives with one other person: a relative, friend, or roommate <input type="checkbox"/> 4 Lives with caregiver who is not spouse/partner, relative, or friend <input type="checkbox"/> 5 Lives with a group (related or not related) in a private residence <input type="checkbox"/> 6 Lives in group home (e.g., assisted living, nursing home, convent) <input type="checkbox"/> 9 Unknown
16. What is the subject's level of independence? <b>independ</b>	<input type="checkbox"/> 1 Able to live independently <input type="checkbox"/> 2 Requires some assistance with complex activities <input type="checkbox"/> 3 Requires some assistance with basic activities <input type="checkbox"/> 4 Completely dependent <input type="checkbox"/> 9 Unknown
17. What is the subject's primary type of residence? <b>residenc</b>	<input type="checkbox"/> 1 Single- or multi-family private residence (apartment, condo, house) <input type="checkbox"/> 2 Retirement community or independent group living <input type="checkbox"/> 3 Assisted living, adult family home, or boarding home <input type="checkbox"/> 4 Skilled nursing facility, nursing home, hospital, or hospice <input type="checkbox"/> 9 Unknown
18. ZIP Code (first three digits) of subject's primary residence: <b>zip</b>	____ (If unknown, leave blank)
19. Is the subject left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)? <b>handed</b>	<input type="checkbox"/> 1 Left-handed <input type="checkbox"/> 2 Right-handed <input type="checkbox"/> 3 Ambidextrous <input type="checkbox"/> 9 Unknown



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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form A2: Co-participant Demographics**

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

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

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

1. Co-participant's month and year of birth (MM / YYYY):	<input checked="" type="checkbox"/> inbirmo	<input checked="" type="checkbox"/> inbiry	(99/9999 = unknown)
2. Co-participant's sex:	<input checked="" type="checkbox"/> insex	<input type="checkbox"/> 1 Male	<input type="checkbox"/> 2 Female
3. Does the co-participant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 4</b> )	<input type="checkbox"/> 1 Yes	<input checked="" type="checkbox"/> inhisp
3a. If yes, what are the co-participant's reported origins?	<input checked="" type="checkbox"/> inhispor	<input type="checkbox"/> 1 Mexican, Chicano, or Mexican-American	<input type="checkbox"/> 2 Puerto Rican
		<input type="checkbox"/> 3 Cuban	<input type="checkbox"/> 4 Dominican
		<input type="checkbox"/> 5 Central American	<input type="checkbox"/> 6 South American
		<input type="checkbox"/> 50 Other (SPECIFY):	<input checked="" type="checkbox"/> inhispor
		<input type="checkbox"/> 99 Unknown	
4. What does the co-participant report as his or her race?	<input checked="" type="checkbox"/> inrace	<input type="checkbox"/> 1 White	<input type="checkbox"/> 2 Black or African American
		<input type="checkbox"/> 3 American Indian or Alaska Native	<input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander
		<input type="checkbox"/> 5 Asian	<input checked="" type="checkbox"/> inracex
		<input type="checkbox"/> 50 Other (SPECIFY):	
		<input type="checkbox"/> 99 Unknown	
5. What additional race does the co-participant report?	<input checked="" type="checkbox"/> inrasec	<input type="checkbox"/> 1 White	<input type="checkbox"/> 2 Black or African American
		<input type="checkbox"/> 3 American Indian or Alaska Native	<input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander
		<input type="checkbox"/> 5 Asian	<input checked="" type="checkbox"/> inrasecx
		<input type="checkbox"/> 50 Other (SPECIFY):	
		<input type="checkbox"/> 88 None reported	
		<input type="checkbox"/> 99 Unknown	

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

**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form A3: Subject Family History

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

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

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

<p>1. Are there affected first-degree relatives (biological parents, full siblings, or biological children)?</p> <p><i>"Affected" = having dementia or one of the non-normal diagnoses listed in Appendix 1 on page 5</i></p>	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown <b>affamm</b>
<p>2a. In this family, is there evidence for an AD mutation? If Yes, select predominant mutation.</p> <p>NOTE: APOE should not be reported here.</p> <p><b>fadmut</b></p>	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 3a</b> ) <input type="checkbox"/> 1 Yes, APP <input type="checkbox"/> 2 Yes, PS-1 (PSEN-1) <input type="checkbox"/> 3 Yes, PS-2 (PSEN-2) <b>fadmutx</b> <input type="checkbox"/> 8 Yes, Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown whether mutation exists ( <b>SKIP TO QUESTION 3a</b> )
<p>2b. Source of evidence for AD mutation (check one):</p> <p><b>fadmuso</b></p>	<input type="checkbox"/> 1 Family report (no test documentation available) <input type="checkbox"/> 2 Commercial test documentation <input type="checkbox"/> 3 Research lab test documentation <input type="checkbox"/> 8 Other (SPECIFY): <b>fadmusox</b> <input type="checkbox"/> 9 Unknown
<p>3a. In this family, is there evidence for an FTLD mutation? If Yes, select predominant mutation.</p> <p><b>fftdmut</b></p>	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 4a</b> ) <input type="checkbox"/> 1 Yes, MAPT <input type="checkbox"/> 2 Yes, PGRN <input type="checkbox"/> 3 Yes, C9orf72 <input type="checkbox"/> 4 Yes, FUS <b>fftdmutx</b> <input type="checkbox"/> 8 Yes, Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown whether mutation exists ( <b>SKIP TO QUESTION 4a</b> )
<p>3b. Source of evidence for FTLD mutation (check one):</p> <p><b>fftdmuso</b></p>	<input type="checkbox"/> 1 Family report (no test documentation available) <input type="checkbox"/> 2 Commercial test documentation <input type="checkbox"/> 3 Research lab test documentation <input type="checkbox"/> 8 Other (SPECIFY): <b>fftdmusx</b> <input type="checkbox"/> 9 Unknown

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<p>4a. In this family, is there evidence for a mutation other than an AD or FTL mutation? (If No or Unknown, <b>SKIP TO QUESTION 5a</b>)</p>	<p><input type="checkbox"/> 0 No (<b>SKIP TO QUESTION 5a</b>)</p> <p><input checked="" type="checkbox"/> 1 Yes (SPECIFY): <b>fothmutx</b></p> <p><input type="checkbox"/> 9 Unknown (<b>SKIP TO QUESTION 5a</b>)</p>
<p>4b. Source of evidence for other mutation (check one):</p> <p><b>fothmuso</b></p>	<p><input type="checkbox"/> 1 Family report (no test documentation available)</p> <p><input type="checkbox"/> 2 Commercial test documentation</p> <p><input type="checkbox"/> 3 Research lab test documentation</p> <p><input type="checkbox"/> 8 Other (SPECIFY): <b>fothmusx</b></p> <p><input type="checkbox"/> 9 Unknown</p>

**BIOLOGICAL PARENTS**

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

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

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
See CODES, below						
5a. Mother	<b>mommob</b> / <b>momyob</b>	<b>momdage</b>	<b>momneur</b>	<b>momprdx</b>	<b>mommo</b>	<b>momageo</b>
5b. Father	<b>dadmob</b> / <b>dadyob</b>	<b>daddage</b>	<b>dadneur</b>	<b>dadprdx</b>	<b>dadmo</b>	<b>dadageo</b>

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

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

**\*\*CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

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

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

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

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

## FULL SIBLINGS

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

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

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

	Birth month/year (99/9999=Unknown)		Age at death (888=N/A, 999=unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
				See CODES on page 4			
6a. Sibling 1	<span style="border: 1px solid black; padding: 2px;">sib*mob</span>	<span style="border: 1px solid black; padding: 2px;">sib*yob</span>	<span style="border: 1px solid black; padding: 2px;">sib*dage</span>	<span style="border: 1px solid black; padding: 2px;">sib*neur</span>	<span style="border: 1px solid black; padding: 2px;">sib*prdx</span>	<span style="border: 1px solid black; padding: 2px;">sib*moe</span>	<span style="border: 1px solid black; padding: 2px;">sib*ageo</span>
6b. Sibling 2	__/_____	_____	____	__	____	__	____
6c. Sibling 3	__/_____	_____	____	__	____	__	____
6d. Sibling 4	__/_____	_____	____	__	____	__	____
6e. Sibling 5	__/_____	_____	____	__	____	__	____
6f. Sibling 6	__/_____	_____	____	__	____	__	____
6g. Sibling 7	__/_____	_____	____	__	____	__	____
6h. Sibling 8	__/_____	_____	____	__	____	__	____
6i. Sibling 9	__/_____	_____	____	__	____	__	____
6j. Sibling 10	__/_____	_____	____	__	____	__	____
6k. Sibling 11	__/_____	_____	____	__	____	__	____
6l. Sibling 12	__/_____	_____	____	__	____	__	____
6m. Sibling 13	__/_____	_____	____	__	____	__	____
6n. Sibling 14	__/_____	_____	____	__	____	__	____
6o. Sibling 15	__/_____	_____	____	__	____	__	____
6p. Sibling 16	__/_____	_____	____	__	____	__	____
6q. Sibling 17	__/_____	_____	____	__	____	__	____
6r. Sibling 18	__/_____	_____	____	__	____	__	____
6s. Sibling 19	__/_____	_____	____	__	____	__	____
6t. Sibling 20	__/_____	_____	____	__	____	__	____

**\* = sibling number**

## BIOLOGICAL CHILDREN

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

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

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

	Birth month/year (99/9999=Unknown)		Age at death (888=N/A, 999=unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
	See CODES, below						
7a. Child 1	<span style="border: 1px solid red; padding: 2px;">kid*mob</span>	<span style="border: 1px solid red; padding: 2px;">kid*yob</span>	<span style="border: 1px solid red; padding: 2px;">kid*dage</span>	<span style="border: 1px solid red; padding: 2px;">kid*neur</span>	<span style="border: 1px solid red; padding: 2px;">kid*prdx</span>	<span style="border: 1px solid red; padding: 2px;">kid*moe</span>	<span style="border: 1px solid red; padding: 2px;">kid*ageo</span>
7b. Child 2	/						
7c. Child 3	/						
7d. Child 4	/						
7e. Child 5	/						
7f. Child 6	/						
7g. Child 7	/						
7h. Child 8	/						
7i. Child 9	/						
7j. Child 10	/						
7k. Child 11	/						
7l. Child 12	/						
7m. Child 13	/						
7n. Child 14	/						
7o. Child 15	/						

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

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

### \*\*CODES for primary diagnosis

See Appendix 1 on page 5 of this form.

### \*\*\*CODES for method of evaluation

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

\* = child number

## \*\*APPENDIX 1: PRIMARY DIAGNOSIS CODES

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

**Neuropathology diagnosis from autopsy**

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

## \*\*\*APPENDIX 2: METHOD OF EVALUATION

**1. Autopsy**

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

**2. Examination**

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

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

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

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

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

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

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

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

See definition No. 4 above.

**7. Family report**

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



Taped:

Participant ID#

T-

Date:

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Taped:

**COMPLETED\_BY**

**N Health History Health History Obtained From: P \_\_\_ CS \_\_\_ Both P and CS \_\_\_**

\*105a. How would you rate his/her overall physical health at the present time? **(CS Rating)**

a. excellent (1) b. good (2) c. fair (3) d. poor (4) **int407**

**int403** \*104. Has he/she had physical health problems in the last 5 years? Describe: **int403desc**

Yes (1) \_\_\_ No (0) \_\_\_ Medical records for this year requested

**requestmedrec**

650. Falls? NO \_\_\_ YES \_\_\_ If yes, (651) Number of Falls: \_\_\_ **fallnum**

**falls**

652. If had falls, did he/she have injuries as a result of his/her falls? \_\_\_ No \_\_\_ Yes **fallinj**

Describe injuries: **fallinjdesc**

List Surgeries (in the last 5 years):

**surgdesc\***

List Hospitalizations (in the last 5 years):

**hospdesc\***

**\* = injury number (starts at 1 and varies)**

\*105. Has he/she been treated for a psychiatric illness (depression or emotional/behavioral problem)

**int416** in the last year? Yes \_\_\_ No \_\_\_ Describe: **int416desc**

120. In the last year, has he/she had problems with his/her:

**head** Head yes \_\_\_ no \_\_\_

Breathing yes \_\_\_ no \_\_\_ **breath**

**eyes** Eyes yes \_\_\_ no \_\_\_

Heart yes \_\_\_ no \_\_\_ **heart**

**ears** Ears yes \_\_\_ no \_\_\_

Bowels yes \_\_\_ no \_\_\_ **bowel**

**nose** Nose yes \_\_\_ no \_\_\_

Bladder yes \_\_\_ no \_\_\_ **bladder**

**throat** Throat yes \_\_\_ no \_\_\_

Mouth yes \_\_\_ no \_\_\_ **mouth**

**weight** 121. Weight yes \_\_\_ no \_\_\_

Describe yes responses from above:

**headdesc** **nosedesc** **breathdesc** **bladderdesc**

**eyesdesc** **throatdesc** **heartdesc** **mouthdesc**

**earsdesc** **weightdesc** **boweldesc**

Does the participant have any of the following illnesses?					
Data Code	Yes	No	DK	Onset	Illness
*106	<input type="text" value="int106_ev"/>			<input type="text" value="int106_ev_on"/>	Head Injury (w/LOC)? <input type="text" value="int106_ev_text"/>
*106a	<input type="text" value="int106a_ev"/>			<input type="text" value="int106a_ev_on"/>	Stroke/TIA <input type="text" value="int106a_ev_text"/>
*107	<input type="text" value="int107_ev"/>			<input type="text" value="int107_ev_on"/>	LOC/Fainting <input type="text" value="int107_ev_text"/>
*108	<input type="text" value="int108_ev"/>			<input type="text" value="int108_ev_on"/>	Diabetes <input type="text" value="int108_ev_text"/>
*109	<input type="text" value="int109_ev"/>			<input type="text" value="int109_ev_on"/>	Hypertension <input type="text" value="int109_ev_text"/>
	<input type="text" value="hychol_ev"/>			<input type="text" value="hychol_ev_on"/>	Hypercholesterolemia <input type="text" value="hychol_ev_text"/>
*110	<input type="text" value="int110_ev"/>			<input type="text" value="int110_ev_on"/>	Problems Walking <input type="text" value="int110_ev_text"/>
*111	<input type="text" value="int111_ev"/>			<input type="text" value="int111_ev_on"/>	Abnormal Movements <input type="text" value="int111_ev_text"/>
*112	<input type="text" value="int112_ev"/>			<input type="text" value="int112_ev_on"/>	Seizures <input type="text" value="int112_ev_text"/>
*113	<input type="text" value="int113_ev"/>			<input type="text" value="int113_ev_on"/>	Poison Exposure <input type="text" value="int113_ev_text"/>
*114	<input type="text" value="int114_ev"/>			<input type="text" value="int114_ev_on"/>	Chronic Lung Disease <input type="text" value="int114_ev_text"/>
*115	<input type="text" value="int115_ev"/>			<input type="text" value="int115_ev_on"/>	Heart Disease <input type="text" value="int115_ev_text"/>
*116	<input type="text" value="int116_ev"/>			<input type="text" value="int116_ev_on"/>	Liver Disease <input type="text" value="int116_ev_text"/>
*117	<input type="text" value="int117_ev"/>			<input type="text" value="int117_ev_on"/>	Kidney Disease <input type="text" value="int117_ev_text"/>
*118	<input type="text" value="int118_ev"/>			<input type="text" value="int118_ev_on"/>	Thyroid Disease <input type="text" value="int118_ev_text"/>
	<input type="text" value="vitab12_ev"/>			<input type="text" value="vitab12_ev_on"/>	Vitamin B-12 Deficiency <input type="text" value="vitab12_ev_text"/>
*119	<input type="text" value="int119_ev"/>			<input type="text" value="int119_ev_on"/>	Operations <input type="text" value="int119_ev_text"/>
*331	<input type="text" value="int331_ev"/>			<input type="text" value="int331_ev_on"/>	Glaucoma/Cataracts <input type="text" value="int331_ev_text"/>
*332	<input type="text" value="int332_ev"/>			<input type="text" value="int332_ev_on"/>	Tuberculosis <input type="text" value="int332_ev_text"/>
*333	<input type="text" value="int333_ev"/>			<input type="text" value="int333_ev_on"/>	Circulation Problems/Extremities <input type="text" value="int333_ev_text"/>
*334	<input type="text" value="int334_ev"/>			<input type="text" value="int334_ev_on"/>	Ulcers/Digestive System <input type="text" value="int334_ev_text"/>
*335	<input type="text" value="int335_ev"/>			<input type="text" value="int335_ev_on"/>	Cancer <input type="text" value="int335_ev_text"/>
*336	<input type="text" value="int336_ev"/>			<input type="text" value="int336_ev_on"/>	Anemia <input type="text" value="int336_ev_text"/>
*338	<input type="text" value="int338_ev"/>			<input type="text" value="int338_ev_on"/>	Pressure Sores/Leg Ulcers <input type="text" value="int338_ev_text"/>
*339	<input type="text" value="int339_ev"/>			<input type="text" value="int339_ev_on"/>	Fractures <input type="text" value="int339_ev_text"/>
*124a	<input type="text" value="int124a_ev"/>			<input type="text" value="int124a_ev_on"/>	Substance Abuse (Drug) <input type="text" value="int124a_ev_text"/>
*125c	<input type="text" value="int125c_ev"/>			<input type="text" value="int125c_ev_on"/>	Substance Misuse (Alcohol) <input type="text" value="int125c_ev_text"/>
*126b	<input type="text" value="int126b_ev"/>			<input type="text" value="int126b_ev_on"/>	Tobacco Use (present and past) <input type="text" value="int126b_ev_text"/>
*553	<input type="text" value="int553_ev"/>			<input type="text" value="int553_ev_on"/>	Autoimmune Disorders (Rheumatoid Arthritis, Lupus, etc.) <input type="text" value="int553_ev_text"/>
	<input type="text" value="moddis_ev"/>			<input type="text" value="moddis_ev_on"/>	Mood Disorders <input type="text" value="moddis_ev_text"/>
	<input type="text" value="sleepdis_ev"/>			<input type="text" value="sleepdis_ev_on"/>	Sleep Disorders <input type="text" value="sleepdis_ev_text"/>
*555	<input type="text" value="int555_ev"/>			<input type="text" value="int555_ev_on"/>	Other: <input type="text" value="int555_ev_text"/>

List Medication Allergies:

---

N551. Has he/she taken medication to stimulate, or enhance thinking; or been in a drug study for Alzheimer's disease)?

No \_\_\_ \*yes \_\_\_ If yes, complete dementia drug history below:

Name of Drug	Date Started		Date Stopped	
<input type="text" value="stim_ev"/>	<input type="text" value="stim*b_dy_ev"/>	<input type="text" value="stim*b_yr_ev"/>	<input type="text" value="stim*e_dy_ev"/>	<input type="text" value="stim*e_dy_ev"/>
<input type="text" value="stim*b_mo_ev"/>	<input type="text" value="stim*b_yr_ev"/>	<input type="text" value="stim*e_mo_ev"/>	<input type="text" value="stim*e_dy_ev"/>	<input type="text" value="stim*e_dy_ev"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Has the he/she participated in a research program in the last year that studies memory and thinking?

No \_\_\_ \*yes \_\_\_ If yes, list the studies and dates of participation below:

Taped:

Participant ID#

T-

Date:

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form A5: Subject Health History

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

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

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

### 1. History of cigarette smoking and alcohol use

#### CIGARETTE SMOKING

 1a. Has subject smoked within the last 30 days? **tobac30**  0 No  1 Yes  9 Unknown

 1b. Has subject smoked more than 100 cigarettes in her/his life?  0 No  1 Yes  9 Unknown  
 (If No or Unknown, **SKIP TO QUESTION 1F**) **tobac100**

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

 1d. Average number of packs smoked per day: **packsper**

- 1 1 cigarette to less than ½ pack
- 2 ½ pack to less than 1 pack
- 3 1 pack to less than 1½ packs
- 4 1½ packs to less than 2 packs
- 5 2 packs or more
- 9 Unknown

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

#### ALCOHOL USE

 1f. In the past three months, has the subject consumed any alcohol? **alcoccas**

- 0 No (**SKIP TO QUESTION 2a**)
- 1 Yes
- 9 Unknown (**SKIP TO QUESTION 2a**)

 1g. During the past three months, how often did the subject have at least one drink of any alcoholic beverage such as wine, beer, malt liquor, or spirits? **alcfreq**

- 0 Less than once a month
- 1 About once a month
- 2 About once a week
- 3 A few times a week
- 4 Daily or almost daily
- 9 Unknown

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

A CONDITION SHOULD BE CONSIDERED ...

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

2. Cardiovascular disease		Absent	Recent/ active	Remote/ inactive	Unknown
<b>cvhatt</b>	2a. Heart attack / cardiac arrest (If absent or unknown, <b>SKIP TO QUESTION 2b</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2a1. More than one heart attack? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<b>hattmult</b>			
<b>hattyear</b>	2a2. Year of most recent heart attack (9999 = unknown): _____				
	2b. Atrial fibrillation <b>cvafib</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2c. Angioplasty / endarterectomy / stent <b>cvangio</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2d. Cardiac bypass procedure <b>cvbypass</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2e. Pacemaker and/or defibrillator <b>cvpacdef</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2f. Congestive heart failure <b>cvchf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2g. Angina <b>cvangina</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	2h. Heart valve replacement or repair <b>cvhvalve</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
<b>cvothr</b>	2i. Other cardiovascular disease (SPECIFY): <b>cvothrx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
3. Cerebrovascular disease		Absent	Recent/ active	Remote/ inactive	Unknown
<b>cbstroke</b>	3a. Stroke — by history, not exam (imaging is not required) (If absent or unknown, <b>SKIP TO QUESTION 3b</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	3a1. More than one stroke? <input type="checkbox"/> 0 No <b>tiayear</b> <input type="checkbox"/> 9 Unknown	<b>strokmul</b>			
<b>strokyr</b>	3a2. Year of most recent stroke (9999 = unknown): _____				
<b>cbtia</b>	3b. Transient ischemic attack (TIA) (If absent or unknown, <b>SKIP TO QUESTION 4a</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	3b1. More than one TIA? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<b>tiamult</b>			
<b>tiayear</b>	3b2. Year of most recent TIA (9999 = unknown): _____				

4. Neurologic conditions		Absent	Recent/ active	Remote/ inactive	Unknown
<b>pd</b>	4a. Parkinson's disease (PD) (If Absent or Unknown, <b>SKIP TO QUESTION 4b</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1		<input type="checkbox"/> 9
	4a1. Year of PD diagnosis (9999 = unknown): _____ <b>pdyr</b>				
<b>pdothr</b>	4b. Other parkinsonism disorder (e.g., PSP, CBD) (If absent or unknown, <b>SKIP TO QUESTION 4c</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1		<input type="checkbox"/> 9
	4b1. Year of parkinsonism disorder diagnosis (9999 = unknown): _____ <b>pdothryr</b>				
	4c. Seizures <b>seizures</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	4d. Traumatic brain injury (TBI) <b>tbi</b> (If Absent or Unknown, <b>SKIP TO QUESTION 5a</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	4d1. TBI with brief loss of consciousness (<5 minutes) <b>tbi brief</b> <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Single <input type="checkbox"/> 2 Repeated/multiple <input type="checkbox"/> 9 Unknown				
	4d2. TBI with extended loss of consciousness (≥5 minutes) <b>tbi exten</b> <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Single <input type="checkbox"/> 2 Repeated/multiple <input type="checkbox"/> 9 Unknown				
	4d3. TBI without loss of consciousness (as might result from military detonations or sports injuries)? <b>tbi wolos</b> <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Single <input type="checkbox"/> 2 Repeated/multiple <input type="checkbox"/> 9 Unknown				
	4d4. Year of most recent TBI (9999 = unknown): _____ <b>tbi year</b>				
5. Medical conditions		Absent	Recent/ active	Remote/ inactive	Unknown
<i>If any of the conditions still require active management and/or medications, please select "Recent/active."</i>					
<b>diabetes</b>	5a. Diabetes (If absent or unknown, <b>SKIP TO QUESTION 5b</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	5a1. If Recent/active or Remote/inactive, which type? <input type="checkbox"/> 1 Type 1 <b>diabtype</b> <input type="checkbox"/> 2 Type 2 <input type="checkbox"/> 3 Other type (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes) <input type="checkbox"/> 9 Unknown				
	5b. Hypertension <b>hyperten</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	5c. Hypercholesterolemia <b>hypercho</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	5d. B12 deficiency <b>b12def</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	5e. Thyroid disease <b>thyroid</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
<b>arthritis</b>	5f. Arthritis (If absent or unknown, <b>SKIP TO QUESTION 5g</b> )	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
	5f1. Type of arthritis: <b>arthtype</b> <input type="checkbox"/> 1 Rheumatoid <input type="checkbox"/> 2 Osteoarthritis <input type="checkbox"/> 3 Other (SPECIFY): _____ <b>arthtypx</b> <input type="checkbox"/> 9 Unknown				
	5f2. Region(s) affected (check all that apply): 5f2a. <input type="checkbox"/> 1 Upper extremity <b>arthupex</b> 5f2b. <input type="checkbox"/> 1 Lower extremity <b>arthloex</b> 5f2c. <input type="checkbox"/> 1 Spine <b>arthspin</b> 5f2d. <input type="checkbox"/> 1 Unknown <b>arthunk</b>				



5. Medical conditions (cont.)		Absent	Recent/ active	Remote/ inactive	Unknown
5g. Incontinence — urinary	<b>incontu</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5h. Incontinence — bowel	<b>incontf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5i. Sleep apnea	<b>apnea</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5j. REM sleep behavior disorder (RBD)	<b>rbd</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5k. Hyposomnia/insomnia	<b>insomn</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
<b>othsleep</b> 5l. Other sleep disorder (SPECIFY):	<b>othsleex</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6. Substance abuse		Absent	Recent/ active	Remote/ inactive	Unknown
6a. Alcohol abuse: clinically significant impairment occurring over a 12-month period manifested in one of the following areas: work, driving, legal, or social.	<b>alcohol</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6b. Other abused substances: clinically significant impairment occurring over a 12-month period manifested in one of the following areas: work, driving, legal, or social. (If absent or unknown, <b>SKIP TO QUESTION 7a</b> )	<b>abusothr</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6b1. If recent/active or remote/inactive, specify abused substance:	<b>abusx</b>				
7. Psychiatric conditions, diagnosed or treated by a physician		Absent	Recent/ active	Remote/ inactive	Unknown
7a. Post-traumatic stress disorder (PTSD)	<b>ptsd</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7b. Bipolar disorder	<b>bipolar</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7c. Schizophrenia	<b>schiz</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7d. Depression					
7d1. Active depression in the last two years	<b>dep2yrs</b>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown	
7d2. Depression episodes more than two years ago	<b>depothr</b>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown	
7e. Anxiety	<b>anxiety</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7f. Obsessive-compulsive disorder (OCD)	<b>ocd</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7g. Developmental neuropsychiatric disorders (e.g., autism spectrum disorder [ASD], attention-deficit hyperactivity disorder [ADHD], dyslexia)	<b>npsydev</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7h. Other psychiatric disorders (If absent or unknown, <b>END FORM HERE.</b> )	<b>psycdis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7h1. If recent/active or remote/inactive, specify disorder:	<b>psycdisx</b>				

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MEDICATION NAME		DOSAGE	ROUTE	FREQ.	DATE MED. STARTED
medname*	drug*	dose*	route*	freq*	startdate*

\* = Medication Number

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Participant ID#

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Date:


**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form A4: Subject Medications

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

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

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

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

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

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

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

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

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

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

Medication name	DrugID
<input type="checkbox"/> ibuprofen (Advil, Motrin, Nuprin)	d00015
<input type="checkbox"/> loratadine (Alavert, Claritin, Dimetapp, Tavist)	d03050
<input type="checkbox"/> melatonin (Melatonin, Melatonin Time Release)	d04058
<input type="checkbox"/> multivitamin	d03140
<input type="checkbox"/> multivitamin with minerals	d03145
<input type="checkbox"/> polyethylene glycol 3350 (Miralax)	d05350
<input type="checkbox"/> psyllium (Fiberall, Metamucil)	d01018
<input type="checkbox"/> pyridoxine (Vitamin B6)	d00412
<input type="checkbox"/> ubiquinone (Co Q-10)	d04523
<input type="checkbox"/> vitamin E (Aquavite-E, Centrum Singles)	d00405

**If a medication is not listed above, specify the drug or brand name and determine its drugID by using the Lookup Tool on the NACC website at <https://www.alz.washington.edu/MEMBER/DrugCodeLookup.html>**

- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
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## COLLATERAL SOURCE INTERVIEW

\*DATE: \_\_\_\_\_

\*INTERVIEWED BY: tester\*REVIEWED BY: reviewed\_by

Clinician: \_\_\_\_\_

Note: Review previous health history pages before beginning interview.

Non-Physician: \_\_\_\_\_

If T-1, Social Worker \_\_\_\_\_

\*579. CS#: cs idsocialworker\*\*\*\* START TAPE \*\*\*\*

## 1. HISTORY OF PRESENT ILLNESS

(Summary of recent physical and mental health. Useful probes include ability to remember appointments, repeating questions or statements, misplacing items, word-finding difficulty, reduced ability in calculations, visuospatial problems, etc. Emphasis should be on **change** in cognitive abilities; distinguish from changes due to physical problems. If memory and thinking are impaired, when and how did it begin? Course?)

health\_history

(in the last six months) Ferman TJ et al Neurology 2004; 62: 181-187.

\*588. Is he/she drowsy and lethargic during the day despite getting enough drowsy YES NO DK\*586. Does he/she sleep 2 or more hours during the day (before 7 p.m.)? sleeps2hrs YES NO DK\*587. Are there times when his/her flow of ideas is disorganized, unclear or not logical? YES NO DK illogical\*588. Does he/she tend to stare into space for periods of time? stares YES NO DK19. Has there been any change in personality or behavior? changebehDescribe: changebeh\_textIf yes, for how long have these changes been present? \_\_\_\_\_ (in years) change\_lengthN.5. What was he/she told about why he/she is here today? int302**Depressed Mood**

6. In the past year has [P] appeared sad or blue, or depressed most of the day nearly every day for two weeks or more? Y \_\_\_ N \_\_\_

**Recurrent Thoughts of death/Suicidal Ideation**15. In the last year, has [P] said he/she feels that life is not worth living, or has [P] expressed a wish to die or talked about committing suicide? int311 Y \_\_\_ N \_\_\_

# Form B5: BEHAVIORAL ASSESSMENT Neuropsychiatric Inventory Questionnaire (NPI-Q<sup>1</sup>)

Taped:

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

*INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional based on co-participant interview, as described by the training video. (This is not to be completed by the subject as a paper-and-pencil self-report.) For information on NPI-Q Interviewer Certification, see UDS Coding Guidebook for Initial Visit Packet, Form B5. Check only one box for each category of response.*

Please answer the following questions based upon **changes in the past month**. Indicate Yes only if the symptom represents a change (i.e., a new symptom or an exacerbation of a previous symptom) in the past month; otherwise, select **0=No**. For each item marked Yes, indicate 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)

Participant ID#

npiqinf

1. **NPI CO-PARTICIPANT:**  1 Spouse  2 Child  3 Other (SPECIFY): npiqinfx

Yes	No	Unknown
-----	----	---------

SEVERITY			Unknown
Mild	Mod	Severe	

<p>2. <b>Delusions</b> — Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?</p>	<p>2a.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">del</span>	<p>2b.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">delsev</span>	
<p>3. <b>Hallucinations</b> — Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?</p>	<p>3a.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">hall</span>	<p>3b.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">hallsev</span>	
<p>4. <b>Agitation or aggression</b> — Is the patient stubborn and resistant to help from others?</p>	<p>4a.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">agit</span>	<p>4b.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">agitsev</span>	
<p>5. <b>Depression or dysphoria</b> — Does the patient act as if he or she is sad or in low spirits? Does he or she cry?</p>	<p>5a.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 0 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">depd</span>	<p>5b.</p>	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 9 <span style="border: 1px solid blue; padding: 2px;">depdsev</span>	

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Date:

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Please answer the following questions based upon **changes in the past month**. Indicate Yes only if the symptom represents a change (i.e., a new symptom or an exacerbation of a previous symptom) in the past month; otherwise, select **0=No**. For each item marked Yes, indicate 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)

30

					SEVERITY				
		Yes	No	Unknown	Mild	Mod	Severe	Unknown	
6. <b>Anxiety</b> — 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.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	6b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>anx</b>				<b>anxsev</b>			
7. <b>Elation or euphoria</b> — Does the patient appear to feel too good or act excessively happy?	7a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	7b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>elat</b>				<b>elatsev</b>			
8. <b>Apathy or indifference</b> — Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	8a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	8b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>apa</b>				<b>apasev</b>			
9. <b>Disinhibition</b> — 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.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	9b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>disn</b>				<b>disnsev</b>			
10. <b>Irritability or lability</b> — Is the patient impatient or cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	10a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	10b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>irr</b>				<b>irrsev</b>			
11. <b>Motor disturbance</b> — Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, or wrapping string?	11a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	11b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>mot</b>				<b>motsev</b>			
12. <b>Nighttime behaviors</b> — Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	12a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	12b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>nite</b>				<b>nitesev</b>			
13. <b>Appetite and eating</b> — Has the patient lost or gained weight, or had a change in the food he or she likes?	13a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	13b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>app</b>				<b>appsev</b>			

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Participant ID#

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Date:

## Collateral Source

(DK = Doesn't Know)

**MEMORY**

\*31. Does he/she have a problem with his/her memory or thinking? **int324** No (0) \_\_\_ Yes (1) \_\_\_

\*31b. If yes, is it a consistent problem (as opposed to inconstant)? **int415** No (0) \_\_\_ Yes (1) \_\_\_

\*32. Can he/she recall recent events? (Blessed) Usually (0) \_\_\_ Sometimes (.5) \_\_\_ Rarely (1) \_\_\_  
**BDS07**

\*33. Can he/she remember short lists (4 or 5 items) of items (shopping)? (Blessed)  
**BDS03** Usually (0) \_\_\_ Sometimes (.5) \_\_\_ Rarely (1) \_\_\_

\*45. Has there been some decline in memory during the past year? No (0) \_\_\_ Yes (1) \_\_\_  
**int334**

\*46. Is his/her memory impaired to such a degree that it would have interfered with his/her activities of daily life a few years ago (or preretirement activities)? (Collateral Source's opinion)  
**int335** No (0) \_\_\_ Yes (1) \_\_\_ DK (Q) \_\_\_

\*580. Does he/she have difficulty remembering appointments? No (0) \_\_\_ Yes (1) \_\_\_  
**int417**

\*581. Does he/she repeat questions, stories or statements? No (0) \_\_\_ Yes (1) \_\_\_  
**int418**

**IF PARTICIPANT HAS NO MEMORY PROBLEM, PROCEED TO PAGE 25**

\*38. Does he/she completely forget a major event (e.g., trip, party, family wedding) within a few weeks of the event? **int329** Rarely or Never (0) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_

Example: **int329\_example**

\*39. Does he/she forget pertinent details of the major event? Rarely or Never (0) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_  
**int330**

\*41. Does he/she completely forget important information of the distant past (e.g., birthdate, date of wedding, place of employment?) **int332** Rarely or Never (0) \_\_\_ Sometimes (1) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_

Example: **int332\_example**

\*43. Describe Onset: **int009** Sudden (1) \_\_\_\_\_  
Gradual (2) \_\_\_\_\_  
Fluctuating (3) \_\_\_\_\_  
Other (describe at left) (4) **int009\_other**

43a. How long ago did the memory/thinking problem start? (number of years to the nearest decimal) \_\_\_\_\_ **durat**

\*44. Course of memory problem: Stable (1) \_\_\_\_\_  
Gradually Worse (2) \_\_\_\_\_  
Episodically Worse (3) \_\_\_\_\_  
Fluctuating (4) \_\_\_\_\_  
Other (describe at left) (5) **int010\_other**

**int010**

**Collateral Source****ORIENTATION**

How often does he/she know the exact:

	Usually	Sometimes	Rarely or Never	CS Doesn't Know
*71. Date of the month?	____(2)	____(1)	____(0)	____(Q) <span style="border: 1px solid blue; padding: 2px;">int344</span>
*72. Month?	____(2)	____(1)	____(0)	____(Q) <span style="border: 1px solid blue; padding: 2px;">int345</span>
*73. Year?	____(2)	____(1)	____(0)	____(Q) <span style="border: 1px solid blue; padding: 2px;">int346</span>
*74. Day of the week?	____(2)	____(1)	____(0)	____(Q) <span style="border: 1px solid blue; padding: 2px;">int347</span>

\*75. Does he/she tend to dwell in the past?

(Blessed) Rarely(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Often(1)\_\_\_\_ BSB08

\*75a. Does he/she have difficulty with time relationships?

(When events happened in relation to each other) (Give example)

int396\_exampleRarely (0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Usually (1)\_\_\_\_ int396

\*77. Can he/she find his/her way about familiar streets? (Blessed)

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ BDS05\*78. How often does he/she know how to get from one place to another outside his/her neighborhood? int351

Usually(2)\_\_\_\_ Sometimes(1)\_\_\_\_ Rarely(0)\_\_\_\_ DK(Q)\_\_\_\_

(If usually is answered for 78, can skip 79, which will be entered also as usually)

\*79. How often can he/she find his/her way about indoors?

(own house or other familiar environment) (Blessed) BDS04

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_

**Collateral Source****JUDGMENT AND PROBLEM SOLVING**

\*80. In general, if you had to rate his/her abilities to handle and solve problems at the present time, would you consider them:

Example:

As good as they have ever been (1)\_\_\_\_

Good, but not as good as before (2)\_\_\_\_

Only fair (3)\_\_\_\_

Very poor (4)\_\_\_\_

No ability at all (5)\_\_\_\_

<u>No</u>	<u>Some</u>	<u>Severe</u>
<u>Loss</u>	<u>Loss</u>	<u>Loss</u>

\*96 Ability to cope with small sums of money

[Blessed] (eg, make change, leave a small tip)

0

0.5

1

\*96a Ability to handle more complicated financial or business transactions

(eg, balance checkbook, pay bills)

0

0.5

1

\*82. Can he/she handle a household emergency: (plumbing leak, small fire)

Better than before (1)\_\_\_\_

As well as before (2)\_\_\_\_

Worse than before because of trouble thinking (3)\_\_\_\_

Worse than before for another reason (why?) (4)\_\_\_\_

\*76. Can he/she understand situations or explanations? (Blessed)

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ DK(Q)\_\_\_\_

\*76a. Does he/she exercise appropriate judgment in social situations and interactions with other people?

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ DK(Q)\_\_\_\_

Taped:

Participant ID#  
**Collateral Source**

T- Date:  
**COMMUNITY AFFAIRS**

**Occupational**

**84.** Is the Participant still working? If NA, proceed to item 87. If yes, proceed to item 86,  
If no, proceed to item 85. **work**

NA \_\_\_ Yes \_\_\_ No \_\_\_

**85.** Did memory or thinking problems contribute to the Participant's decision to retire?

(Skip Question 86) **int357**

No(0)\_\_\_ Yes(1)\_\_\_ DK(Q)\_\_\_

**86.** Does the Participant have significant difficulty in his/her job because of problems with memory or thinking? **int358**

Rarely or Never(0)\_\_\_ Sometimes(1)\_\_\_ Usually(2)\_\_\_ DK(Q)\_\_\_

**Social**

**\*87.** Did he/she ever drive a car? **everdriv**

Yes \_\_\_ No \_\_\_

Does the Participant drive a car now? **drive**

Yes \_\_\_ No \_\_\_

If no, is this because of memory or thinking problems? **int359**

No(0)\_\_\_ Yes(1)\_\_\_

**\*87a.** If he/she is still driving, are there problems or risks because of poor thinking? **int397** **int397\_describe**  
No(0)\_\_\_ Yes(1)\_\_\_

**\*90a.** Is he/she (cognitively) able independently to shop for needs? **int412** **int412\_describe**  
**Usually(0)\_\_\_** **Sometimes(1)\_\_\_** **Rarely or never(2)\_\_\_**

**DK(Q)\_\_\_**  
(Shops for limited number of items, buys duplicate items or forgets needed items.)

(Needs to be accompanied on any shopping trip.)

**\*90b.** Is he/she (cognitively) able independently to carry out activities outside the home? **int413**

**Usually(0)\_\_\_** **Sometimes(1)\_\_\_** **Rarely or never(2)\_\_\_** **DK**  
**(Q)\_\_\_** **int413\_describe**

(Meaningful participation in activities, eg, voting.)

(Limited and/or routine; eg, superficial participation in church or meetings; trips to beauty parlor.)

(Generally unable to perform activities without help.)

**\*91.** Is he/she taken to social functions outside of family home? **int636** Yes(1)\_\_\_ No(0)\_\_\_

If no, why not? \_\_\_\_\_ **int636\_whynt**

**\*91b.** Would a casual observer of subject's behavior in community activities think the subject was ill? **int414** No(0)\_\_\_ Yes(1)\_\_\_  
NA(A)\_\_\_

**IMPORTANT:** Is there enough information available to rate the subject's level of impairment in community affairs? **not\_enough\_info**

**Community Affairs:** such as going to church, visiting with friends or family, political activities, professional organizations such as bar association, other professional groups, social clubs, service organizations, educational programs. If in nursing home, does he/she participate in programs or social activities?

## Form B7: FUNCTIONAL ASSESSMENT Functional Activities Questionnaire (FAQ<sup>1</sup>)

Taped:

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

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

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

Participant ID#

T-

Date:

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<sup>1</sup>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.

**Collateral Source HOME AND HOBBIES**

**Homemaking Tasks:** such as cooking, laundry, cleaning, grocery shopping, taking out garbage, yardwork, simple car maintenance, and basic home repair.

-- What changes have occurred in his/her (cognitive) abilities to perform household chores?

chn\_g\_hometask

-- What can he/she still do well?

well\_homestask

**Hobbies:** sewing, painting, handicrafts, reading, entertaining, photography, gardening, going to theater or symphony, woodworking, participation in sports.

-- What changes have occurred in his/her (cognitive) abilities to perform hobbies?

chn\_g\_hobby

-- What can he/she still do well?

well\_hobby

\*582. Because of memory and thinking problems has he/she had reduced interest in hobbies/activities?

int419

No \_\_\_ Yes \_\_\_ Don't Know \_\_\_

\*583. Because of memory and thinking has he/she had trouble learning how to use a tool, appliance, or gadget (e.g. VCR, remote control, computer, microwave etc.)?

int420

No \_\_\_ Yes \_\_\_ Don't Know \_\_\_

**Everyday Activities (Blessed)**

No Loss      Severe Loss

\*95. Ability to perform household tasks

BDS01

0      .5      1

\*549. The accuracy and reliability of the collateral source information are judged to be:

Good (0) \_\_\_\_\_ Questionable (0.5) \_\_\_\_\_ Poor (1) \_\_\_\_\_

CS\_Valid

Insufficient exposure \_\_\_\_\_ Denial/minimize \_\_\_\_\_ Secondary gain \_\_\_\_\_ Cognitive impairment \_\_\_\_\_

Other \_\_\_\_\_ Explain: CS\_insuf\_explain

CS\_insufexposure

**Important:** Is there enough information available to rate the subject's level of impairment in HOME& HOBBIES? A guide to level of function in household tasks is:

**No meaningful function (CDR 3):** nomeaningfulfunc

(Performs simple activities, such as making a bed, only with much supervision or not at all) \_\_\_\_\_

**Function in limited activities only (CDR 2):** funclimited

(With some supervision, washes dishes with acceptable cleanliness; sets table) \_\_\_\_\_

**Functions independently in some activities (CDR 1):** funcindep

(Operates appliances, such as a vacuum cleaner; prepares simple meals) \_\_\_\_\_

**Functions in usual activities but not at usual level (CDR 0.5):** funclowerlevel

**Normal function in usual activities (CDR 0):** funcnormal

IF APPLICABLE, COMPLETE APHASIA CHECKLIST (on tape)

## \*\*\* STOP TAPE \*\*\*

## Collateral Source

## PERSONAL CARE

(SCORE BASED ON SEVERITY OF COGNITIVE LOSS; NOT FREQUENCY)  
(SCORE DOES NOT CORRELATE DIRECTLY WITH CDR RATING)

What is your estimate of his/her mental ability in the following areas:

	<u>Unaided</u>	<u>Occ. Misplaced buttons, etc.</u>	<u>Wrong sequence, commonly forgotten items</u>	<u>Unable to dress</u>
<b>BDS10</b> N*97. dressing (Blessed)	0	1	2	3
<b>int371</b> N*99 washing, grooming	<u>Needs Unaided</u>	<u>Sometimes prompting</u>	<u>Always or nearly needs help</u>	<u>always needs help</u>
<b>BDS09</b> N*100. eating habits (Blessed)	<u>Cleanly, proper utensils</u>	<u>Messily, Spoon</u>	<u>Simple solids</u>	<u>Has to be fed Completely</u>
<b>BDS11</b> N*101. sphincter control (Blessed)	<u>Normal complete control</u>	<u>Occ. Wets bed</u>	<u>Freq. wets bed</u>	<u>Doubly incontinent</u>

## N\*Cognitive Milestones

	<u>Month</u>	<u>Year</u>	<u>NA</u>	<u>DK</u>
*Unable to help with dressing	<u>miles1_mn</u>	<u>miles1_yr</u>	<u>miles1_na_dk</u>	
*Unable to walk unassisted	<u>miles2_mn</u>	<u>miles2_yr</u>	<u>miles2_na_dk</u>	
*Unable to use spoon for eating	<u>miles3_mn</u>	<u>miles3_yr</u>	<u>miles3_na_dk</u>	
*Bladder or bowel incontinence once a week	<u>miles4_mn</u>	<u>miles4_yr</u>	<u>miles4_na_dk</u>	
*Bladder or bowel incontinence daily	<u>miles5_mn</u>	<u>miles5_yr</u>	<u>miles5_na_dk</u>	
*Permanent nursing home admission	<u>miles6_mn</u>	<u>miles6_yr</u>	<u>miles6_na_dk</u>	

**Clinician: Turn to page 34 to obtain CS recent events.**



## -Participant Interview-

\*\*\*START TAPE\*\*\*

## GENERAL HEALTH

(Sympathetic and interested conversation, taking lead from opening remarks)

UA = Unable to answer

DK = Don't know

202. Have you had any problems with your health lately? hlth\_prob Yes(1)\_\_\_\_ No(0)\_\_\_\_ UA(.C)\_\_\_\_ :  
 If yes, describe. hlth\_prob\_describe

\*203. Have you had any problem with your thinking or memory? int501 Yes(1)\_\_\_\_ No(0)\_\_\_\_ UA(.C)\_\_\_\_ If  
 yes: a. please describe: (record reply verbatim)  
int501\_describe

\*226. (Ask only if subject admits having memory or thinking problems.) How long have you been having  
 memory or thinking problems? (Subject's estimate in months) \_\_\_\_\_

int513

How consistent is the memory problem?

int513\_consistent

205. Why are you here today? Explain: why\_here\_explain Knows \_\_\_\_\_ Confabulates \_\_\_\_\_ DK \_\_\_\_\_  
why\_here

**Collateral Source**

**MEMORY**

**RECENT MEMORY EVALUATION TEST ITEMS**

2) Tell me about some recent events in his/her life that he/she should remember?  
(for later testing – pg 31)

**Within 1 week** event\_1wk\_cs

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**Within 1 month** event\_1mn\_cs

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**Examples:**

- Any injury or illness in him/her or someone else in home/close family?
- Any letters or phone calls from someone who doesn't usually contact him/her?
- Any visitors?
- Any trips?
- Any bad news?
- Any special events (holidays, family events)?

Taped:

Participant ID#

T-

Date:

## Participant

## MEMORY

### 227. RECENT MEMORY EVALUATION

Tell me about some things that have happened lately (illness, etc.)

Within 1 week

event\_1wk\_p

wk\_score\_p

1 – Largely correct \_\_\_\_\_ 0.5 \_\_\_\_\_ 0 – Largely incorrect \_\_\_\_\_

Within 1 month

event\_1mn\_p

1 – Largely correct \_\_\_\_\_ 0.5 \_\_\_\_\_ 0 – Largely incorrect \_\_\_\_\_

mn\_score\_p

\*228. Total correct  
(may give half credit)

int579

Taped:

Participant ID#

T-

Date:

**-INTENTIONALLY BLANK-**

**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form B6: BEHAVIORAL ASSESSMENT — Geriatric Depression Scale (GDS)<sup>1</sup>**

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

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

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

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

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

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

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

**gds**  
 \_\_\_\_

<sup>1</sup>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.

Taped:

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Date:

**DEPRESSIVE FEATURES BATTERY –  
Version 8/14/00**

**RESPONDENT: P**

**Depressed Mood**

215. In the past year, have you felt sad or blue or depressed most of the day nearly every day for two weeks or more?

int139

Y \_\_\_ N \_\_\_

**Recurrent Thoughts of Death/Suicidal Ideation**

224. In the last year, have you felt that life is not worth living or expressed a wish to die or talked about committing suicide?

suicide

Y \_\_\_ N \_\_\_

**Additional medical attention recommended (circle one)      Yes      No**

int148

**N**

Participant Interview

N206.B Expressive Language

(Show cookie theft picture) "Tell me everything you see going on in this picture."

Response: **N206**

## RATING SCALE PROFILE OF SPEECH CHARACTERISTICS

	0	1	2	3	4	5	6
a) MELODIC LINE intonational contour	Absent			Limited to short phrases and stereotyped expressions			Runs thru entire sentence
	<b>melodic_line</b>						
b) PHRASE LENGTH longest occasional (1/10) uninterrupted word runs	x 1 word	x	x	x 4 words	x	x	x 7 words
	<b>phrase_length</b>						
c) ARTICULATORY AGILITY facility at phonemic and syllable level	x always impaired or impossible	x	x	x normal only in familiar words and phases	x	x	x never impaired
	<b>articular_agility</b>						
d) GRAMMATICAL FORM variety of gram- matical construc- tion (even if incomplete)	x not available	x	x	x limited to simple declarative stereotypes	x	x	x normal range
	<b>grammar_form</b>						
e) PARAPHASIA IN RUNNING SPEECH	x present in every utterance	x	x	x once per minute of conversation	x	x	x absent
	<b>paraphasia</b>						
f) WORD FINDING informational content in relation to fluency	x fluent without information	x	x	x information proportional to fluency	x	x	x normal
	<b>word_find</b>						

\*207 Speech Score:

$$\left( \frac{\sum a \text{ to } f}{6} \right) = \frac{\quad}{6} = \underline{\text{int065}}$$

C. Oral Naming

Tell me the name of the thing I point to: Card 2)

	Correct	Incorrect	
Chair	1	0	<b>chair_n</b>
H	1	0	<b>h_n</b>
Square	1	0	<b>square_n</b>
Key	1	0	<b>key_n</b>
Glove	1	0	<b>glove_n</b>
Feather	1	0	<b>feather_n</b>

\*208. Oral Naming Score **int066****N**

Participant Interview

Taped:

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### D. Reading Comprehension

Read this card aloud; show me the answer for each line or do what it says

**Correct**      **Incorrect**

Make a fist       1 \_\_\_\_\_ 0

How many ears does a person have       1 \_\_\_\_\_ 0

Show what you do when your nose starts to itch       1 \_\_\_\_\_ 0

Point to the second word in this sentence       1 \_\_\_\_\_ 0

\*209. Reading Score

### E. Reception – Answer “Yes” or “No”

**Correct**      **Incorrect**

Will a wooden board generally sink in water? (No)       1 \_\_\_\_\_ 0

Will a stone sink in water? (Yes)       1 \_\_\_\_\_ 0

Is a hammer good for cutting wood? (No)       1 \_\_\_\_\_ 0

Do two pounds of flour weigh more than one pound? (Yes)       1 \_\_\_\_\_ 0

Will water go through a good pair of rubber boots? (No)       1 \_\_\_\_\_ 0

\*210. Reception Score

### F. Show me each after I name it (Card 2)

Chair       **Correct**      **Incorrect**  
1 \_\_\_\_\_ 0

L       1 \_\_\_\_\_ 0

Circle       1 \_\_\_\_\_ 0

Key       1 \_\_\_\_\_ 0

Glove       1 \_\_\_\_\_ 0

\*211. Show Score

### 2) Point to your:

**Correct**      **Incorrect**

ear       1 \_\_\_\_\_ 0

nose       1 \_\_\_\_\_ 0

shoulder      1 \_\_\_\_\_ 0

eyelid       1 \_\_\_\_\_ 0

neck       1 \_\_\_\_\_ 0

\*212. Point Score



Taped:

Participant ID#

T-

Date:

N

**Participant Interview**

**NH. Written Expression**

Write the name of the one I point to (Card 2)

**Correct      Incorrect**

Key	1 _____ 0	<u>key_w</u>
Chair	1 _____ 0	<u>chair_w</u>
Circle	1 _____ 0	<u>circle_w</u>
Square	1 _____ 0	<u>square_w</u>

\*213. Written Score int068

**\*214 Clinician's assessment of Aphasia:**

- 0 = Absent int074
- 1 = Questionable
- 2 = Present

1. Mini-Mental State Examination Summary for Form C1 <u>MMSELOC</u>	
1a. The administration of the MMSE was:	<input type="checkbox"/> 1. In ADC/clinic <input type="checkbox"/> 2. In home <input type="checkbox"/> 3. In person-other
1b. Orientation subscale score	
1) Time:	<u>MMSEORDA</u> (0 – 5) (MMSEORDA)
2) Place:	<u>MMSEORLO</u> (0 – 5) (MMSEORLO)
1c. Total MMSE score (using D-L-R-O-W)	<u>MMSE</u> (0 – 30) (MMSE)

Taped:

Participant ID#

T-

Date:

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Taped:

Participant ID#

T-

Date:

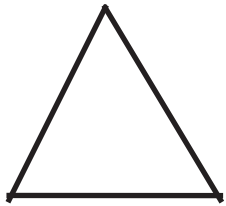
N

\*N287. Draw a clock with all the numbers; then show me 2:45 int073

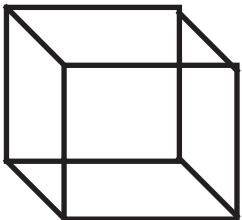
0 = Correct  
1 = Partially correct  
2 = Incorrect

**Participant to complete drawing on MoCA form.**

Please copy these drawings as closely as you can.

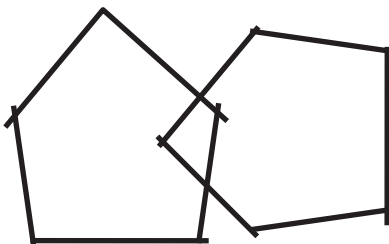


N\*288 int562  
0 = Correct  
1 = Partially correct  
2 = Incorrect



**Participant to complete drawing on MoCA form.**

N\*291 int565  
0 = Correct  
1 = Partially correct  
2 = Incorrect



(Not for data entry)  
N\*548 0 = Correct  
(MMSE) 2 = Incorrect  
(see MOO for correct scoring)

Taped:

Participant ID#

T-

Date:

MAP ID#: \_\_\_\_\_ Date: \_\_\_\_\_

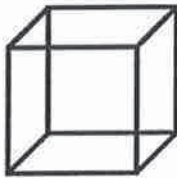
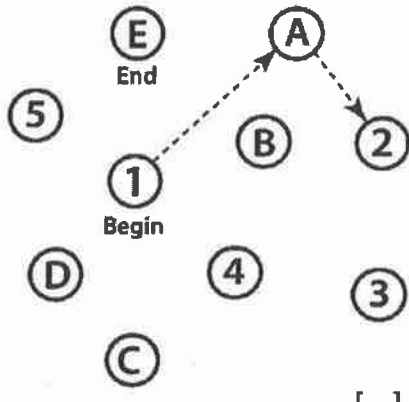
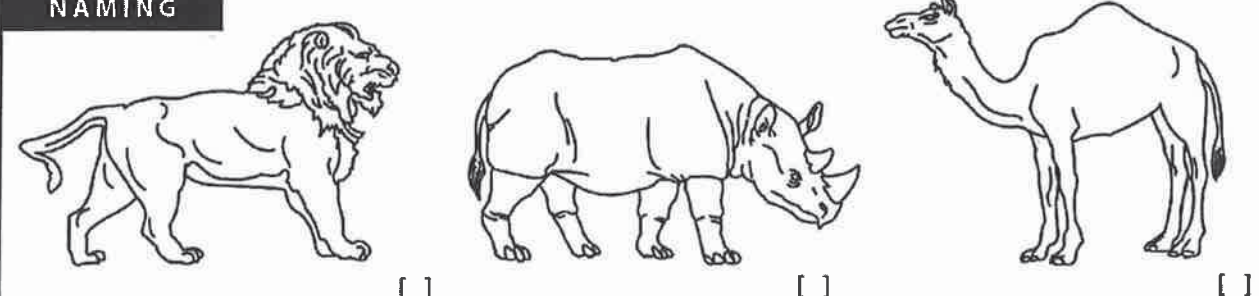
BP \_\_\_\_\_ Pulse \_\_\_\_\_ Ht: \_\_\_\_\_ Weight: \_\_\_\_\_

Abd. Girth: \_\_\_\_\_ Visual acuity OD: \_\_\_\_\_ OS: \_\_\_\_\_ Glasses Y or N

SPELLING OF WORDS

WRITING SENTENCE:

# Montreal Cognitive Assessment (MoCA)

<b>VISUOSPATIAL / EXECUTIVE</b>							Copy cube [ ] [ ]	Draw <b>CLOCK</b> (Ten past eleven) (3 points)	<b>POINTS</b>  ___/5
		[ ] [ ] [ ] [ ] [ ]					[ ] [ ] [ ] Contour      Numbers      Hands		
<b>NAMING</b>							[ ] [ ] [ ]		___/3
<b>MEMORY</b>	Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		FACE	VELVET	CHURCH	DAISY	RED	No points	
		1st trial							
		2nd trial							
<b>ATTENTION</b>	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2							___/2	
	Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] FBACMNAAJKLBAFAKDEAAAJAMOF AAB							___/1	
	Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: <b>3 pts</b> , 2 or 3 correct: <b>2 pts</b> , 1 correct: <b>1 pt</b> , 0 correct: <b>0 pt</b>							___/3	
<b>LANGUAGE</b>	Repeat: I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]							___/2	
	Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)							___/1	
<b>ABSTRACTION</b>	Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler							___/2	
<b>DELAYED RECALL</b>	Has to recall words WITH NO CUE FACE [ ] VELVET [ ] CHURCH [ ] DAISY [ ] RED [ ]						Points for UNCUED recall only	___/5	
<b>Optional</b>	Category cue Multiple choice cue								
<b>ORIENTATION</b>	[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City							___/6	
© Z.Nasreddine MD      www.mocatest.org      Normal ≥ 26 / 30		<b>TOTAL</b> ___/30 Add 1 point if ≤ 12 yr edu							

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form C2: Neuropsychological Battery Scores**

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

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

**INSTRUCTIONS:** This form is to be completed by ADC or clinic staff. For test administration and scoring, see Instructions for Neuropsychological Battery Form C2. Any new subjects who enroll in the UDS after the implementation of UDS3 must be assessed with the new neuropsychological test battery (Form C2).

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:

95 / 995 = Physical problem    96 / 996 = Cognitive/behavior problem    97 / 997 = Other problem    98 / 998 = Verbal refusal

**1. Montreal Cognitive Assessment (MoCA)**

1a. Was any part of the MoCA administered?

 mocacomp

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

 mocareas

 1 Yes (CONTINUE WITH QUESTION 1b)

1b. MoCA was administered:

 1 In ADC or clinic

 2 In home

 3 In person — other

 mocaloc

1c. Language of MoCA administration:

 1 English

 2 Spanish

 3 Other (SPECIFY): \_\_\_\_\_

 mocalanx

1d. Subject was unable to complete one or more sections due to visual impairment:

 0 No

 1 Yes

1e. Subject was unable to complete one or more sections due to hearing impairment:

 0 No

 1 Yes

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

 mocatots

Enter 88 if any of the following MoCA items were not administered:  
1g–1l, 1n–1t, 1w–1bb

\_\_\_\_\_ (0–30, 88)

1g. Visuospatial/executive — Trails

 mocatrai

\_\_\_\_\_ (0–1, 95–98)

1h. Visuospatial/executive — Cube

 mocacube

\_\_\_\_\_ (0–1, 95–98)

1i. Visuospatial/executive — Clock contour

 mocacloc

\_\_\_\_\_ (0–1, 95–98)

1j. Visuospatial/executive — Clock numbers

 mocaclon

\_\_\_\_\_ (0–1, 95–98)

1k. Visuospatial/executive — Clock hands

 mocacloh

\_\_\_\_\_ (0–1, 95–98)

1l. Language — Naming

 mocanami

\_\_\_\_\_ (0–3, 95–98)

1m. Memory — Registration (two trials)

 mocaregi

\_\_\_\_\_ (0–10, 95–98)

1n. Attention — Digits

 mocadigi

\_\_\_\_\_ (0–2, 95–98)

1o. Attention — Letter A

 mocalett

\_\_\_\_\_ (0–1, 95–98)

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

1p. Attention — Serial 7s	<b>mocaser7</b>	__ __ (0-3, 95-98)
1q. Language — Repetition	<b>mocarepe</b>	__ __ (0-2, 95-98)
1r. Language — Fluency	<b>mocaflue</b>	__ __ (0-1, 95-98)
1s. Abstraction	<b>mocaabst</b>	__ __ (0-2, 95-98)
1t. Delayed recall — No cue	<b>mocarecn</b>	__ __ (0-5, 95-98)
1u. Delayed recall — Category cue	<b>mocarecc</b>	__ __ (0-5; 88=Not applicable)
1v. Delayed recall — Recognition	<b>mocarecr</b>	__ __ (0-5; 88=Not applicable)
1w. Orientation — Date	<b>mocaordt</b>	__ __ (0-1, 95-98)
1x. Orientation — Month	<b>mocaormo</b>	__ __ (0-1, 95-98)
1y. Orientation — Year	<b>mocaoryr</b>	__ __ (0-1, 95-98)
1z. Orientation — Day	<b>mocaordy</b>	__ __ (0-1, 95-98)
1aa. Orientation — Place	<b>mocaorpl</b>	__ __ (0-1, 95-98)
1bb. Orientation — City	<b>mocaorct</b>	__ __ (0-1, 95-98)
<b>2. ADMINISTRATION OF THE REMAINDER OF THE BATTERY</b>		
2a. The tests following the MoCA were administered: <input type="checkbox"/> 1 In ADC or clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other		
2b. Language of test administration: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____		
<b>3. Craft Story 21 Recall (Immediate)</b>		
3a. Total story units recalled, verbatim scoring <i>(If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 4a.)</i>		__ __ (0-44, 95-98)
3b. Total story units recalled, paraphrase scoring		__ __ (0-25)
<b>4. Benson Complex Figure Copy</b>		
4a. Total score for copy of Benson figure <i>(If test not completed, enter reason code, 95-98)</i>		__ __ (0-17, 95-98)
<b>5. Number Span Test: Forward</b>		
5a. Number of correct trials <i>(If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 6a.)</i>		__ __ (0-14, 95-98)
5b. Longest span forward		__ __ (0, 3-9)

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**Collateral Source****PAST MEMORY EVALUATION**

- N49. Date of subject's birth N49 \_\_\_\_\_
- N50. Place of subject's birth N50 \_\_\_\_\_
- N51. How old is the subject N51 \_\_\_\_\_
- N52. Subject's mother's full maiden name N52 \_\_\_\_\_
- N53. Subject's last school: name N53a \_\_\_\_\_  
 grade N53b \_\_\_\_\_  
 place N53c \_\_\_\_\_
- N54 \*N54. Present status – married divorced widowed separated never married
- N55. Since int008 \_\_\_\_\_
- N56a. Has the subject been married more than once? N56 \_\_\_\_\_
- N57. Name of subject's current (most recent) spouse N57 \_\_\_\_\_  
N57a (or oldest sibling if never married and circle spouse or sibling)
- N59. Subject's present (home) telephone number N59 \_\_\_\_\_  
 If subject does not have a telephone, then subject's present address N59a \_\_\_\_\_  
 \_\_\_\_\_  
 (If currently in nursing home, use last phone and address before nursing home entry)
- N60. How many children? N60 \_\_\_\_\_
- N62. Subject's (or spouse's) main occupation? N62 \_\_\_\_\_  
 (Spouse's if subject not substantially employed)
- N62a. What was subject's or spouse's last major job? N62a \_\_\_\_\_
- N63. Subject's (or spouse's) retirement date? N63 \_\_\_\_\_
- Circumstances? N63\_circum \_\_\_\_\_

## Participant

- |   |   | <u>Correct</u> | <u>Incorrect</u> |
|---|---|----------------|------------------|
| *N232. What is your name? (Blessed II)  | <u>int516_text</u>                              | <u>int516</u>  | (1) _____ (0)    |
| *N233. When were you born?<br>(Exact month, day, year) (Pfeiffer)   | <u>MSQ06_mm</u> <u>MSQ06_dy</u> <u>MSQ06_yr</u> | <u>MSQ06</u>   | (0) _____ (1)    |
| *N234. Where were you born? (Blessed II)  | <u>int518_text</u>                              | <u>int518</u>  | (1) _____ (0)    |
| *N235. How old are you? (Pfeiffer)  | <u>MSQ05_text</u>                               | <u>MSQ05</u>   | (0) _____ (1)    |
| *N236. What was your mother's full maiden name? (Pfeiffer - *Any female first name and last name other than subjects own.)                          | <u>MSQ09_text</u>                               | <u>MSQ09</u>   | (0) _____ (1)    |
| What was the last school you attended?  |   |                |                  |
| *N237. Name (Blessed II)  | <u>int521_text</u>                              | <u>int521</u>  | (1) _____ (0)    |
| *N238. Grade  | <u>int522_text</u>                              | <u>int522</u>  | (1) _____ (0)    |
| *N239. Place (Blessed II)   | <u>int523_text</u>                              | <u>int523</u>  | (1) _____ (0)    |
| *N240. What is your marital status?<br>(year or # of years)   | <u>int524_text</u>                              | <u>int524</u>  | (1) _____ (0)    |
| *N241. How long?  | <u>int525_text</u>                              | <u>int525</u>  | (1) _____ (0)    |
| *N242. Have you been married more than once?  | <u>int526_text</u>                              | <u>int526</u>  | (1) _____ (0)    |
| *N243. What is (was) your spouse's name (or oldest sibling)?<br>(Blessed II)  | <u>int527_text</u>                              | <u>int527</u>  | (1) _____ (0)    |
| *N244. What is your (home) telephone number? (Pfeiffer)   | <u>MSQ04_text</u>                               | <u>MSQ04</u>   | (0) _____ (1)    |
| If person does not have a telephone, then ask: What is your address?<br>(If currently in nursing home, ask for last phone or address before entry?) |   |                |                  |
| *N246. How many children did you have?  | <u>int529_text</u>                              | <u>int529</u>  | (1) _____ (0)    |
| *N247. What was your main occupation (job)?<br>(Blessed II) (Spouse's if subject was not employed; cf. 62)  | <u>int530_text</u>                              | <u>int530</u>  | (1) _____ (0)    |
| *N248. What was your last major job?<br>(Blessed II)(Spouse's if subject not employed; cf. 62a)   | <u>int531_text</u>                              | <u>int531</u>  | (1) _____ (0)    |
| *N249. When did you (or spouse) retire and why?(cf. 63)<br>(year or # of years – not age at time of retirement)                                     | <u>int532_text</u>                              | <u>int532</u>  | (1) _____ (0)    |
| *N250. Who is the President of the U.S. now?<br>(last name sufficient)(Pfeiffer)  | <u>MSQ07_text</u>                               | <u>MSQ07</u>   | (0) _____ (1)    |
| *N251. Who was President just before him/her?<br>(last name sufficient)(Pfeiffer)   | <u>MSQ08_text</u>                               | <u>MSQ08</u>   | (0) _____ (1)    |
| *N252. Count aloud from 1 to 20 by 1 (Blessed II)   | 0 1 2 Errors                                    | <u>int533</u>  |                  |

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**Worksheet for MINI MENTAL STATE EXAMINATION (MMSE)**

**Instructions:** Words in boldface type should be read aloud clearly and slowly to the examinee. Item substitutions appear in parentheses. Administration should be conducted privately and in the examinee's primary language. Circle "0" if the response is incorrect, or "1" if the response is correct. Begin by asking the following two questions:

**Do you have any trouble with your memory?**

**May I ask you some questions about your memory?**

ORIENTATION TO TIME	RESPONSE	SCORE (circle one)
<b>What is the... year?</b>	<input type="text" value="KSBJ2R"/>	<input type="text" value="KSBJ2"/> 0    1
<b>season?</b>	<input type="text" value="seasR"/>	<input type="text" value="seas"/> 0    1
<b>month of the year?</b>	<input type="text" value="KSBJ1R"/>	<input type="text" value="KSBJ1"/> 0    1
<b>day of the week?</b>	<input type="text" value="MSQ02R"/>	<input type="text" value="MSQ02"/> 0    1
<b>date?</b>	<input type="text" value="MSQ01R"/>	<input type="text" value="MSQ01"/> 0    1

ORIENTATION TO PLACE	RESPONSE	SCORE (circle one)
(Alternative place words that are appropriate for the setting and increasingly precise may be substituted and noted.) <b>Where are we now? What is the... state (province)?</b>	<input type="text" value="locaR"/>	<input type="text" value="loca"/> 0    1
<b>county (city/town)?</b>	<input type="text" value="counR"/>	<input type="text" value="coun"/> 0    1
<b>city/town (or part of city/neighborhood)?</b>	<input type="text" value="int548R"/>	<input type="text" value="int548"/> 0    1
<b>building (name or type)?</b>	<input type="text" value="MSQ03R"/>	<input type="text" value="MSQ03"/> 0    1
<b>floor of the building (room number or address)?</b>	<input type="text" value="leveR"/>	<input type="text" value="leve"/> 0    1

REGISTRATION	RESPONSE	SCORE (circle one)
(Alternative word sets [e.g., PONY, QUARTER, ORANGE] may be substituted and noted when retesting an examinee.) <b>Listen carefully. I am going to say three words. You say them back after I stop. Ready?</b> <b>Here they are...APPLE [pause], PENNY [pause], TABLE [pause]. Now repeat those words back to me.</b> [Repeat up to 5 times, but score only the first trial.]		
APPLE	<input type="text" value="ballR"/>	<input type="text" value="ball"/> 0    1
PENNY	<input type="text" value="flagR"/>	<input type="text" value="flag"/> 0    1
TABLE	<input type="text" value="treeR"/>	<input type="text" value="tree"/> 0    1

**Now keep those words in mind. I am going to ask you to say them again in a few minutes.**

ATTENTION	RESPONSE	SCORE (circle one)
<b>The word WORLD is spelled W-O-R-L-D. Spell WORLD backwards.</b> [Allow additional trials if requested.]	<input type="text" value="int089aR1"/>	
	<input type="text" value="int089aR2"/>	
	<input type="text" value="int089aR3"/>	
	<input type="text" value="int089aR4"/>	
	<input type="text" value="int089aR5"/>	
	<input type="text" value="int089a"/>	
	(D=1)    (L=1)    (R=1)    (O=1)    (W=1)    (0 to 5)	

(continued) →

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<b>RECALL</b>				
<b>What were those words I asked you to remember?</b>				
APPLE	<u>ball2R</u>	<u>ball2</u>	0	1
PENNY	<u>flag2R</u>	<u>flag2</u>	0	1
TABLE	<u>tree2R</u>	<u>tree2</u>	0	1
<b>NAMING</b>		<b>RESPONSE</b>	<b>SCORE (circle one)</b>	
<b>What is this?</b> [ <i>Point to a pencil or pen.</i> ]		<u>pencR</u>	<u>penc</u>	0 1
<b>What is this?</b> [ <i>Point to a watch.</i> ]		<u>watcR</u>	<u>watc</u>	0 1
(Alternative common objects [e.g., eyeglasses, chair, keys] may be substituted and noted.)				
<b>REPETITION</b>				
<b>Now I am going to ask you to repeat what I say. Ready? "NO IFS, ANDS, OR BUTS." Now you say that.</b> [Repeat up to 5 times, but score only the first trial.]				
NO IFS, ANDS, OR BUTS	<u>phraR</u>	<u>phra</u>	0	1

Use the following 3-segment page for the remaining items (cut the page along the dotted lines). Use the upper portion of the page (blank) for the *Comprehension*, *Writing*, and *Drawing* items that follow. Use the middle portion of the page ("CLOSE YOUR EYES") as a stimulus form for the *Reading* item. Use the lower portion (intersecting pentagons) for the *Drawing* item.

<b>COMPREHENSION</b>				
<b>Listen carefully because I am going to ask you to do something.</b>				
<b>Take this paper in your right hand [pause], fold it in half [pause], and put it on the floor (or table).</b>				
TAKE IN RIGHT HAND	<u>righR</u>	<u>righ</u>	0	1
FOLD IN HALF	<u>foldR</u>	<u>fold</u>	0	1
PUT ON FLOOR (or TABLE)	<u>lapR</u>	<u>lap</u>	0	1
<b>READING</b>				
<b>Please read this and do what it says.</b> [Show examinee the words on the stimulus form.]				
CLOSE YOUR EYES	<u>redoR</u>	<u>redo</u>	0	1
<b>WRITING</b>				
(Place the blank piece of paper (unfolded) in front of the subject and provide a pen or pencil.)				
<b>Please write a sentence.</b> [If examinee does not respond, say: <b>Write about the weather.</b> ]				
		<u>sent</u>	0	1
Score 1 point if the sentence is comprehensible and contains a subject and a verb. Ignore errors in grammar or spelling.				
<b>DRAWING</b>				
<b>Please copy this design.</b> [Display the intersecting pentagons on the stimulus form.]				
		<u>draw</u>	0	1
Score 1 point if the drawing consists of two 5-sided figures that intersect to form a 4-sided figure.				

Assessment of level of consciousness. LOCAlert/  
Responsive

Drowsy

Stuporous

Comatose/  
UnresponsiveTotal Score = MMSE  
(Sum all item scores) (30 points max.)

March 2006



**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form B1: EVALUATION FORM** Physical

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

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

*INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B1. Check only one box per question.*

Subject physical measurements			
1. Subject height (inches)	<b>height</b>	____.____	(88.8=not assessed)
2. Subject weight (lbs.)	<b>weight</b>	_____	(888=not assessed)
3. Subject blood pressure at initial reading (sitting)	<b>bpsys</b> / <b>bpdias</b>	____ / ____	(888/888=not assessed)
4. Subject resting heart rate (pulse)	<b>hrate</b>	_____	(888=not assessed)
Additional physical observations			
5. Without corrective lenses, is the subject's vision functionally normal?	<b>vision</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
6. Does the subject usually wear corrective lenses? (If no or unknown, <b>SKIP TO QUESTION 7</b> )	<b>viscorr</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
6a. If yes, is the subject's vision functionally normal <u>with</u> corrective lenses?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9 <b>viswcorr</b>
7. Without a hearing aid(s), is the subject's hearing functionally normal?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9 <b>hearing</b>
8. Does the subject usually wear a hearing aid(s)? (If no or unknown, <b>END FORM HERE</b> )	<b>hearaid</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
8a. If yes, is the subject's hearing functionally normal <u>with</u> a hearing aid(s)?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9 <b>hearwaid</b>

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**ORIENTATION, MEMORY AND CONCENTRATION**

- \*229. I will give you a name and address to remember for a few minutes. Listen to me say the entire name and address, and then repeat it after me:

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

int515a\* int515b\* int515c\* int515d\* int515e\* \* = trial number (up to 3 trials)

(underline words repeated correctly in each trial)

Trials to criterion int515 (can't do in 3 trials = C)

Good, now remember that name and address for a few minutes.

- \*271. Without looking at your watch or clock, tell me about what time it is. Correct Incorrect

If response is vague, prompt for specific response.

ksbt3 0 1

(within 1 hour) (Katzman) ksbt3\_response

Actual time: ksbt3\_actual

- \*253. Count aloud backwards from 20 to 1 (Katzman) ksbt4 0 1 2 Errors

If Subject starts counting forward or forgets the task, repeat instructions and score one error.

(Mark correctly sequenced numerals) ksbt4\_\*

20 19 18 17 16 15 14 13 12 11

10 9 8 7 6 5 4 3 2 1

\* = \_ Number listed (up to 20)

- \*254. Name the months of the year starting with last month of the year and going backwards. (Katzman)

If the Clinician needs to prompt with name of the last month of the year, one error should be scored.

(Mark correctly sequenced months)

D N O S A JL JN MY AP MR F J ksbt5\_\* ksbt5 0 1 2 Errors

\* = \_ Number listed (up to 12)

- \*245. Repeat the name and address I asked you to remember. (Katzman)

The thoroughfare term (Street) is not required.

(John Brown, 42 Market Street, Chicago) ksbt6 0 1 2 3 4 5 Errors

ksbt6\_c

ksbt6\_a, ksb6\_b, , ksb6\_d, ksb6\_e

**Check correct items**

**JUDGMENT & PROBLEM SOLVING****Participant**

**ABSTRACTIONS** \*Instructions: If initial response by subject does not merit a grade 0, press the matter to identify the subject's best understanding of the problem. Circle score.

**A. Similarities** Example: How are a pencil and a pen alike? (writing instruments)

"How are these things alike?"

**Participant's Response:**

\*273. Turnip . . . . . cauliflower int551 int551R  
 (0 = vegetables)  
 (1 = edible foods, living things, can be cooked, etc.)  
 (2 = answers not pertinent; differences; buy them)

\*274. Desk . . . . . bookcase int552 int552R  
 (0 = furniture, office furniture; both hold books)  
 (1 = wooden, legs)  
 (2 = not pertinent, differences)

**B. Differences** Example: What is the difference between sugar and vinegar? (sweet vs sour)

"Can you tell me what is the difference between these things?"

**Participant's Response:**

\*275. Lie . . . . . mistake int533 int533R  
 (0 = one deliberate, one unintentional)  
 (1 = one bad, the other good – or explains only one)  
 (2 = anything else, similarities)

\*277. River . . . . . canal int555 int555R  
 (0 = natural – artificial)  
 (2 = anything else)

**C. Calculations**

	<u>Correct</u>	<u>Incorrect</u>
*278. a) How many nickels in a dollar? (20) <u>int556</u> (If <u>Incorrect</u> for 278, can skip 279, which will be entered also as <u>Incorrect</u> ) Check here if you have skipped question 279 _____	0	1
*279. b) How many quarters in \$6.75? (27) <u>int557</u>	0	1
*280. c) Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down. (Pfeiffer) <u>MSQ10</u>	0	1

**D. Judgment**

\*282. Upon arriving in a strange city, how would a person locate a friend there that they wished to see?  
 0 = try the telephone book, city directory, internet search, call a mutual friend  
 1 = call the police, call operator (usually will not give address)  
 2 = no clear response int560

Response:

int560R

\*284. Subject's assessment of disability and station in life and under standing of why he/she is present at the examination (may have been covered earlier, but rate here) **Explain:** int064R

Good insight 0 \_\_\_ Partial insight 1 \_\_\_ Little insight 2 \_\_\_

**IF APPLICABLE, COMPLETE APHASIA CHECKLIST (on tape)**

Taped:

Participant ID#

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Date:

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\*\*\*STOP TAPE\*\*\*

**Physical Examination**N576. Abdominal Girth abgirthN 577. Hgb A1C hgbVision (Rosenbaum Card at 14 inches) with **best correction**\*N296.OD visionod Better than 20/50 Yes \_\_\_\_\_ No rt20\_50visfield \*N297.OS visionos Better than 20/50 Yes \_\_\_\_\_ No lt20\_50\*295. **Visual fields** Normal \_\_\_\_\_ Abnormal \_\_\_\_\_ (describe) visfield\_describe298. **Extraocular movements:** Normal \_\_\_\_\_ extroculamovAbnormal (describe) \_\_\_\_\_ Nystagmus (describe) extroculamov\_describe**299. Pupil size**OD od\_pupil\_sizeOS os\_pupil\_size**Reactivity**od\_reactivityos\_reactivity**Optic Fundi**od\_optic\_fundios\_optic\_fundi300. **Cranial nerves**V cranV cranV\_describeVII cranVII cranVII\_describeVIII cranVIII cranVIII\_describeIX cranIX cranIX\_describecranX cranX\_describe XXI cranXI cranXI\_describecranXII cranXII\_describe XII301. Neck neck Bruits? bruits302. Sensory: pain (pinprick) pain Described Detailsposition positionvibration vibrationstereognosis stereognosis303. Reflexes Absent Weak or Normal Increased

Tendon \_\_\_\_\_

bicepsR Right biceps \_\_\_\_\_Right triceps tricepsR \_\_\_\_\_kneeR Right knee \_\_\_\_\_Right ankle ankleR \_\_\_\_\_bicepsL Left biceps \_\_\_\_\_Left triceps tricepsL \_\_\_\_\_kneeL Left knee \_\_\_\_\_Left ankle ankleL \_\_\_\_\_\*304. Abnormal plantar reflex Present 1 Absent 0 int116

<u>Motor:</u>	<u>Present</u>			<u>Absent</u>
	RUE(1)	LUE(2)	Other (describe)	
<u>Tone:</u>				
*309. Spasticity	<input type="text" value="int121"/>	___	<input type="text" value="int121_describe"/>	(0)___
*310. Cogwheel rigidity	<input type="text" value="int122"/>	___	<input type="text" value="int122_describe"/>	___
*311. Gegenhalten	<input type="text" value="int123"/>	___	<input type="text" value="int123_describe"/>	___
<u>Abnormal movements:</u>				
*312. Myoclonus	<input type="text" value="int566"/>	___	<input type="text" value="int566_describe"/>	___
*313. Resting tremor	<input type="text" value="int567"/>	___	<input type="text" value="int567_describe"/>	___
*314. Essential/senile tremor	<input type="text" value="int568"/>	___	<input type="text" value="int568_describe"/>	___
*315. Other (describe)	<input type="text" value="int569"/>	___	<input type="text" value="int569_describe"/>	___
*316. <u>Bradykinesia:</u>	Present (1)___		Absent (0)___	<input type="text" value="int124"/>
*317. <u>Extrapyramidal disorder:</u>	Present (1)___	Questionable (2)___	Absent (0)___	<input type="text" value="int570"/>
<input type="text" value="int571"/> *318. <u>Other neurological abnormalities:</u> (Describe)	<input type="text" value="int571_describe"/>			
*319. <u>Gait</u>	Normal(0)___	Abnormal(1)___		<input type="text" value="int572"/>
Define:	short steps___	shuffle___	lack of arm swing___	flexed/stooped posture___
	turns en bloc___	wide-based___	poor tandem___	Other(describe)___
<input type="text" value="int572_define"/>	<input type="text" value="int572_describe"/>			
*320. <u>Posture:</u>	Normal(0)___	Abnormal(1)___		<input type="text" value="int573"/>
(Explain)	<input type="text" value="int573_describe"/>			
*320a. Limb coordination	Normal (0)___	Abnormal (1)___		<input type="text" value="int581"/>
<u>Praxis</u>		<u>Normal</u> (0)	<u>Abnormal</u> (Explain) (1)	
*323. a. Dressing: Blouse/shirt or jacket/socks/shoes		<input type="text" value="prax1"/>	<input type="text" value="prax1_explain"/>	
b. Show use of: Toothbrush		<input type="text" value="prax2"/>	<input type="text" value="prax2_explain"/>	
c. Key		<input type="text" value="prax3"/>	<input type="text" value="prax3_explain"/>	
d. Pencil (Objects to be provided)		<input type="text" value="prax4"/>	<input type="text" value="prax4_explain"/>	
324. <u>Summary of important neurological findings</u>	<input type="text" value="nuero_notes"/>			

325. Summary of important non-neurological findings

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Participant ID#

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Date:

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form B8: EVALUATION FORM** Neurological Examination Findings

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

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

*INSTRUCTIONS: This form must be completed by a clinician with experience in assessing the neurological signs listed below and in attributing the observed findings to a particular syndrome. Please use your best clinical judgment in assigning the syndrome. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form B8.*

**1. Were there abnormal neurological exam findings?** **normexam**

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

**INSTRUCTIONS FOR QUESTIONS 2 – 8**

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

**CHECK ALL OF THE GROUPS OF FINDINGS / SYNDROMES THAT WERE PRESENT:**
**2. Parkinsonian signs** **parksign**

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

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

Parkinsonian signs	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
2a. Resting tremor — arm <b>resttrl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8 <b>resttr</b>
2b. Slowing of fine motor movements <b>slowingl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8 <b>slowingr</b>
2c. Rigidity — arm <b>rigidl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8 <b>rigidr</b>
			Yes	Not assessed
2d. Bradykinesia <b>brady</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8
2e. Parkinsonian gait disorder <b>parkgait</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8
2f. Postural instability <b>postinst</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8

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

**3. Neurological signs considered by examiner to be most likely consistent with cerebrovascular disease** cvdsigns

0 No (SKIP TO QUESTION 4)     1 Yes

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

Findings consistent with stroke/cerebrovascular disease	PRESENT	
	Yes	Not assessed
3a. Cortical cognitive deficit (e.g., aphasia, apraxia, neglect) <span style="border: 1px solid red; padding: 2px;">cortdef</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3b. Focal or other neurological findings consistent with SIVD (subcortical ischemic vascular dementia) <span style="border: 1px solid red; padding: 2px;">sivdfind</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
3c. Motor (may include weakness of combinations of face, arm, and leg; reflex changes; etc.) <span style="border: 1px solid red; padding: 2px;">cvdmotl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3d. Cortical visual field loss <span style="border: 1px solid red; padding: 2px;">cortvisl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3e. Somatosensory loss <span style="border: 1px solid red; padding: 2px;">somatl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8

cvdmotr    cortvisr    somatr

**4. Higher cortical visual problem suggesting posterior cortical atrophy (e.g., prosopagnosia, simultagnosia, Balint's syndrome) or apraxia of gaze**

0 No     1 Yes postcort

**5. Findings suggestive of progressive supranuclear palsy (PSP), corticobasal syndrome, or other related disorders**

0 No (SKIP TO QUESTION 6)     1 Yes pspcbs

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

Findings	PRESENT	
	Yes	Not assessed
5a. Eye movement changes consistent with PSP <span style="border: 1px solid red; padding: 2px;">eyepsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5b. Dysarthria consistent with PSP <span style="border: 1px solid red; padding: 2px;">dyspsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5c. Axial rigidity consistent with PSP <span style="border: 1px solid red; padding: 2px;">axialpsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5d. Gait disorder consistent with PSP <span style="border: 1px solid red; padding: 2px;">gaitpsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5e. Apraxia of speech <span style="border: 1px solid red; padding: 2px;">apraxsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT	
	Yes	Not assessed	Yes	Not assessed
5f. Apraxia consistent with CBS <span style="border: 1px solid red; padding: 2px;">apraxl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5g. Cortical sensory deficits consistent with CBS <span style="border: 1px solid red; padding: 2px;">cortsenl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5h. Ataxia consistent with CBS <span style="border: 1px solid red; padding: 2px;">ataxl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5i. Alien limb consistent with CBS <span style="border: 1px solid red; padding: 2px;">alienlml</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
<span style="border: 1px solid red; padding: 2px;">dystonl</span> 5j. Dystonia consistent with CBS, PSP, or related disorder	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5k. Myoclonus consistent with CBS <span style="border: 1px solid red; padding: 2px;">myocllt</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8

apraxr    cortsenr    ataxr    alienlmr    dystonr    myocltr

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

**6. Findings suggesting ALS (e.g., muscle wasting, fasciculations, upper motor neuron and/or lower motor neuron signs)**

- 0 No **alsfind**
- 1 Yes

**7. Normal-pressure hydrocephalus: gait apraxia**

- 0 No **gaitnph**
- 1 Yes

**8. Other findings (e.g., cerebellar ataxia, chorea, myoclonus) **othneur****  
(NOTE: For this question, do not specify symptoms that have already been checked above)

- 0 No
- 1 Yes (SPECIFY): **othneurx** \_\_\_\_\_

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Participant ID#

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Date:

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# Form B4: Global Staging — Clinical Dementia Rating (CDR) STANDARD AND SUPPLEMENTAL

Taped:

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

*INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Initial Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Initial Visit Packet, Form B4.*

## SECTION 1: STANDARD CDR<sup>1</sup>

Please enter score below:

		IMPAIRMENT				
		None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
75	1. Memory <b>memory</b> . . .	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 <b>orient</b> . . .	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only
	3. Judgment and problem solving <b>judgment</b> . . .	Solves everyday problems, handles business and financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
	4. Community affairs <b>commun</b> . . .	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities, although may still be engaged in some; appears normal to casual inspection	No pretense of independent function outside the home; appears well enough to be taken to functions outside the family home	No pretense of independent function outside the home; appears too ill to be taken to functions outside the family home
	5. Home and hobbies <b>homehobb</b> . . .	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 <b>perscare</b> . . . 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.    . . .	<b>STANDARD CDR SUM OF BOXES</b> <b>cdrsum</b>					
8.    . . .	<b>STANDARD GLOBAL CDR</b> <b>cdrglob</b>					

Participant ID#

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Date:

<sup>1</sup>Morris JC. The Clinical Dementia Rating (CDR): Current version and scoring rules. Neurology 43(11):2412-4, 1993. Copyright© Lippincott, Williams & Wilkins. Reproduced by permission.

*INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Initial Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Initial Visit Packet, Form B4.*

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**SECTION 2: SUPPLEMENTAL CDR**

	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
Please enter score below: <b>9. Behavior, comporment, and personality<sup>2</sup></b> cdrport    . . .	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
<b>10. Language<sup>3</sup></b> cdrlang    . . .	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

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Date:

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<sup>2</sup>Excerpted from the Frontotemporal Demential Multicenter Instrument & MR Study (Mayo Clinic, UCSF, UCLA, UW).

<sup>3</sup>Excerpted from the PPA-CDR: A modification of the CDR for assessing dementia severity in patients with primary progressive aphasia (Johnson N, Weintraub S, Mesulam MM), 2002.

## Assignment of CDR rating

Use all information and make the best judgment. Score each category (M, O, JPS, CA, HH, PC) as independently as possible. Mark in only one box, for each category, rating impairment as decline from the person's usual level due to cognitive loss alone, not impairment due to other factors, such as physical handicap or depression. Occasionally the evidence is ambiguous and the clinician's best judgment is that a category could be rated in either one of two adjacent boxes, such as mild (1) or moderate (2) impairment. In that situation the standard procedure is to check the box of greater impairment.

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

The global CDR is derived from the scores in each of the six categories ("box scores") as follows. Memory (M) is considered the primary category and all others are secondary.  $CDR = M$  if at least three secondary categories are given the same score as memory. Whenever three or more secondary categories are given a score greater or less than the memory score,  $CDR =$  score of majority of secondary categories on whichever side of M has the greater number of secondary categories. When three secondary categories are scored on one side of M and two secondary categories are scored on the other side of M,  $CDR=M$ .

When  $M = 0.5$ ,  $CDR = 1$  if at least three of the other categories are scored one or greater. If  $M = 0.5$ ,  $CDR$  cannot be 0; it can only be 0.5 or 1. If  $M = 0$ ,  $CDR = 0$  unless there is impairment (0.5 or greater) in two or more secondary categories, in which case  $CDR = 0.5$ .

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

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

**NOTES:**

- 1) Participants with questionable dementia (CDR 0.5) must be categorized either as “Uncertain dementia,” or as one of the dementing disorders, e.g., “DAT/SDAT”. That is, clinicians must decide, using their best judgment, whether or not the CDR 0.5 Participant is experiencing the very mildest (“earliest”) manifestations of a dementing illness versus a nondementing condition.
- 2) For purposes of data entry, the number of diagnoses for an individual Participant is limited to 5 or less.

DAT = Dementia of the Alzheimer Type

ProAphasia = Progressive Aphasia

PCD = Posterior Cortical Dysfunction

FLD = Frontal Lobe Dementia

MAP = Memory and Aging Project

“Relationship of Condition to DAT” refers to the relation of the onset of the unusual feature to the occurrence of DAT. For example, ProAphasia may occur before (prior), at the same time (with), or subsequent (after) to onset of DAT. In the situation where ProAphasia is an isolated condition (i.e., no other cognitive deficits), there is no clinical relationship to other cognitive syndromes (no DAT).



## Clinical Dementia Rating

### Supplemental Behavioral Checklist for subjects with significant aphasia

#### I Memory

Yes No

- \_\_\_ \_\_\_ a) Subject does normal daily routine about house without becoming upset and obviously confused. memorya
- \_\_\_ \_\_\_ b) Subject spontaneously prepares for routine household events (meals, prayers, bed) memoryb
- \_\_\_ \_\_\_ c) Subject spontaneously prepares for routine weekly events in home and community (church, routine family gatherings, etc.) memoryc
- \_\_\_ \_\_\_ d) Subject spontaneously prepares for major holidays and family member`s birthdays. memoryd
- \_\_\_ \_\_\_ e) Subject walks about local, familiar streets without getting lost. memorye
- \_\_\_ \_\_\_ f) Subject drives or takes the bus about community without getting lost. memoryf
- \_\_\_ \_\_\_ g) Subject operates washer/dryer, TV, radio in home without difficulty. memoryg
- \_\_\_ \_\_\_ h) Subject carries out operations outside the home in church, volunteer groups, or work without assistance. memoryh

#### II Orientation

- \_\_\_ \_\_\_ a) Subject responds to usual form of address orientationa
- \_\_\_ \_\_\_ b) Subject appears to recognize and react appropriately to close friends and relatives. orientationb
- \_\_\_ \_\_\_ c) Subject behaves appropriately in home, other dwellings, and public places (as though he/she knows where he/she is) orientationc
- \_\_\_ \_\_\_ d) Subject follows normal sleep/wakefulness pattern orientationd
- \_\_\_ \_\_\_ e) Subject prepares for temporally fixed events (such as meals, bedtime) at the correct time. orientatione

#### III Judgment and Problem Solving

- \_\_\_ \_\_\_ a) Subject behaves appropriately in routine household events judgmenta
- \_\_\_ \_\_\_ b) Subject solves minor household problems and minor emergencies without more help than usual. judgmentb
- \_\_\_ \_\_\_ c) Subject solves major problems arising outside the family environment without help. judgmentc

**IV Community Affairs**

Yes No

  **comaffairsa**

a) Subject behaves normally in immediate neighborhood outside home

  **comaffairsb**

b) Subject behaves appropriately at structured community events

  **comaffairsc**

c) Subject spontaneously takes up new outside activities and behaves appropriately

**V Home - Hobbies** a) Subject carries out routine, simple household chores normally (with or without reminding). **homehobbya** b) Subject maintains nonverbal hobbies normally. **homehobbyb****VI Personal Care** a) Subject uses toilet normally **personcarea** b) Subject uses bathing and grooming apparatus and appliances normally **personcareb** c) Subject dresses normally once clothes are selected **personcarec** d) Subject dresses normally without aid and always appears normally attired **personcared** e) Subject takes normal care of personal objects **personcaree**

Data Entry initials: \_\_\_\_\_

Date: \_\_\_\_\_

A. Presence or Absence of Dementia

1 NO DEMENTIA (Cognitively Normal)

2 UNCERTAIN DEMENTIA

List attributable factors (if any):

3 Alzheimer disease dementia (AD dementia)

50 AD dementia - 0.5 in Memory only

AD dementia WITH Unusual features:

Relationship of condition to AD dementia

Prior With After

Table with 4 columns: Feature, Prior, With, After. Rows include Language dysfunction, Disturbed social comportment, Visuospatial dysfunction, and Other: (specify): other\_a.

AD dementia WITH other potentially dementing illnesses

(more than one may be present); believed to contribute importantly to dementia

Table with 2 columns: NO, YES. Rows include cerebrovascular disease, idiopathic parkinsonism, depression, and other disorder(s); specify below.

NON-AD DEMENTIA

102 Uncertain
121 Incipient (Single Box Score Impaired)

Diagnosis

Table with 3 columns: Diagnosis, 1^0, 2^0. Rows include Vascular dementia, Dementia associated with Parkinson's Disease, Dementia with Lewy Bodies, Frontotemporal dementia, AD dementia (cannot be primary).

Other: other\_a

B. List of Potentially Dementing Disorders (may be present in absence of Dementia.)

ACTIVE: Defined as a current episode within the 3 months prior to the clinical assessment or an ongoing management problem with the potential to contribute to dementia

REMOTE: Defined as a condition resolved or having occurred greater than three months prior to the clinical assessment, or remains an ongoing but stable management problem.

Table with 3 columns: Active, Remote. Lists various disorders like Parkinsonism, Cerebrovascular disease, Mood disorder, etc., with corresponding box scores.

List: 1. other\_b
2. other\_b2

!!! Alert for potentially PRION disorders !!!
YES NO (If yes, mark below) has\_rap
Creutzfeldt-Jakob disease (CJD) or related prior disorder
76 clinically diagnosed
75 possible (e.g., unusual ataxia, visuospatial deficits, myoclonus)
74 Rapid course (not resulting in CJD diagnosis)

Other potential transmissible disorders:
HIV Hepatitis Other other\_trans
Specify: other\_transmis

\*\*\*\*\*

Special Processing. Enrolled in Study:

YES, TAPE REVIEW (not applicable at T1 unless ACS) NO TAPE REVIEW

Not Eligible at T1 (Explain)

Special or Expedited TR (Explain)

Thurs. Mtg. Disc. (Explain)

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Participant ID#

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Date:

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form B9: Clinician Judgment of Symptoms**

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

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

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

Declines in memory reported by subject and co-participant			
1. Does the subject report a decline in memory (relative to previously attained abilities)? <b>decsub</b>	<input type="checkbox"/> 0 No		
	<input type="checkbox"/> 1 Yes		
	<input type="checkbox"/> 8 Could not be assessed/subject is too impaired		
2. Does the co-participant report a decline in the subject's memory (relative to previously attained abilities)? <b>decin</b>	<input type="checkbox"/> 0 No		
	<input type="checkbox"/> 1 Yes		
	<input type="checkbox"/> 8 There is no co-participant		
Cognitive symptoms			
3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition? <b>decclcog</b>	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 8</b> )		
	<input type="checkbox"/> 1 Yes		
4. Indicate whether the subject currently is meaningfully impaired, <i>relative to previously attained abilities</i> , in the following cognitive domains, or has fluctuating cognition:		<b>No</b>	<b>Yes</b> <b>Unknown</b>
4a. <b>Memory</b> For example, does s/he forget conversations and/or dates, repeat questions and/or statements, misplace things more than usual, forget names of people s/he knows well? <b>cogmem</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>cogori</b> 4b. <b>Orientation</b> For example, does s/he have trouble knowing the day, month, and year, or not recognize familiar locations, or get lost in familiar locations?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>cogjudg</b> 4c. <b>Executive function — judgment, planning, problem-solving</b> Does s/he have trouble handling money (e.g., tips), paying bills, preparing meals, shopping, using appliances, handling medications, driving?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>coglang</b> 4d. <b>Language</b> Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>cogvis</b> 4e. <b>Visuospatial function</b> Does s/he have difficulty interpreting visual stimuli and finding his/her way around?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>cogattn</b> 4f. <b>Attention, concentration</b> Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4g. <b>Fluctuating cognition</b> Does the subject exhibit pronounced variation in attention and alertness, noticeably over hours or days — for example, long lapses or periods of staring into space, or times when his/her ideas have a disorganized flow? 4g1. If yes, at what age did the fluctuating cognition begin? ____ <b>cogflago</b> (The clinician must use his/her best judgment to estimate an age of onset.)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>cogothr</b> 4h. <b>Other (SPECIFY):</b> <b>cogothrx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

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INSTRUCTIONS: 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.

5. Indicate the <b>predominant</b> symptom that was first recognized as a decline in the subject's cognition:	<input type="checkbox"/> 1 Memory <input type="checkbox"/> 2 Orientation <input type="checkbox"/> 3 Executive function — judgment, planning, problem-solving <input type="checkbox"/> 4 Language <input type="checkbox"/> 5 Visuospatial function <input type="checkbox"/> 6 Attention/concentration <input type="checkbox"/> 7 Fluctuating cognition <input type="checkbox"/> 8 Other (SPECIFY): <b>cogfpred</b> <input type="checkbox"/> 99 Unknown						
6. Mode of onset of cognitive symptoms	<input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <input type="checkbox"/> 4 Other (SPECIFY): <b>cogmodex</b> <input type="checkbox"/> 99 Unknown						
7. Based on the clinician's assessment, at what age did the cognitive decline begin? (The clinician must use his/her best judgment to estimate an age of onset.)	<b>decage</b> _ _ _						
<b>Behavioral symptoms</b>							
8. Based on the clinician's judgment, is the subject currently experiencing any kind of behavioral symptoms?	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 13</b> ) <input type="checkbox"/> 1 Yes <b>decclbe</b>						
9. Indicate whether the subject currently manifests meaningful change in behavior in any of the following ways:	<table border="1"> <thead> <tr> <th>No</th> <th>Yes</th> <th>Unknown</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	No	Yes	Unknown	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
No	Yes	Unknown					
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9a. <b>Apathy, withdrawal</b> 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? <b>beapathy</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9b. <b>Depressed mood</b> Has the subject seemed depressed for more than two weeks at a time, e.g., shown loss of interest or pleasure in nearly all activities, sadness, hopelessness, loss of appetite, fatigue? <b>bedep</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9c. <b>Psychosis</b>							
9c1. Visual hallucinations <b>bevhall</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9c1a. If Yes, are the hallucinations well formed and detailed? <b>bevwell</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9c1b. If well formed, clear-cut visual hallucinations, at what age did these visual hallucinations begin? _ _ _ (888 = N/A, not well-formed) (The clinician must use his/her best judgment to estimate an age of onset.)	<b>bevhago</b>						
9c2. Auditory hallucinations <b>beahall</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9c3. Abnormal, false, or delusional beliefs <b>bedel</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
9d. <b>Disinhibition</b> 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? <b>bedisin</b>	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
<b>beirrit</b> 9e. <b>Irritability</b> Does the subject overreact, e.g., by shouting at family members or others?	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					
<b>beagit</b> 9f. <b>Agitation</b> Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	<table border="1"> <tbody> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </tbody> </table>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9			
<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9					

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		No	Yes	Unknown
9g. <b>Personality change</b>	Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account? <b>beperch</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>berem</b> 9h. <b>REM sleep behavior disorder</b>	While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)? 9h1. If yes, at what age did the REM sleep behavior disorder begin? ____ (The clinician must use his/her best judgment to estimate an age of onset.) <b>beremago</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>beanx</b> 9i. <b>Anxiety</b>	For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>beothr</b> 9j. <b>Other</b> (SPECIFY):	<b>beothrx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
10. Indicate the <b>predominant</b> symptom that was first recognized as a decline in the subject's behavior: <b>befpred</b>	<input type="checkbox"/> 1 Apathy/withdrawal <input type="checkbox"/> 2 Depressed mood <input type="checkbox"/> 3 Psychosis <input type="checkbox"/> 4 Disinhibition <input type="checkbox"/> 5 Irritability <input type="checkbox"/> 6 Agitation <input type="checkbox"/> 7 Personality change <input type="checkbox"/> 8 REM sleep behavior disorder <input type="checkbox"/> 9 Anxiety <b>befpredx</b> <input type="checkbox"/> 10 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown			
11. Mode of onset of behavioral symptoms: <b>bemode</b>	<input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <b>bemodex</b> <input type="checkbox"/> 4 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown			
12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? (The clinician must use his/her best judgment to estimate an age of onset.) <b>beage</b>	_____			
<b>Motor symptoms</b>				
13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms? <b>deccimot</b>	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 20</b> ) <input type="checkbox"/> 1 Yes			
14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas:		<b>No</b>	<b>Yes</b>	<b>Unknown</b>
14a. <b>Gait disorder</b>	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? <b>mogait</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14b. <b>Falls</b>	Does the subject fall more than usual? <b>mofalls</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14c. <b>Tremor</b>	Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue? <b>motrem</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14d. <b>Slowness</b>	Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive? <b>moslow</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

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INSTRUCTIONS: 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.

<p>15. Indicate the <b>predominant</b> symptom that was first recognized as a decline in the subject's motor function:</p> <p><b>mofrst</b></p>	<p><input type="checkbox"/> 1 Gait disorder</p> <p><input type="checkbox"/> 2 Falls</p> <p><input type="checkbox"/> 3 Tremor</p> <p><input type="checkbox"/> 4 Slowness</p> <p><input type="checkbox"/> 99 Unknown</p>
<p>16. Mode of onset of motor symptoms:</p> <p><b>momode</b></p>	<p><input type="checkbox"/> 1 Gradual</p> <p><input type="checkbox"/> 2 Subacute</p> <p><input type="checkbox"/> 3 Abrupt</p> <p><input type="checkbox"/> 4 Other (SPECIFY): <b>momodex</b></p> <p><input type="checkbox"/> 99 Unknown</p>
<p>17. Were changes in motor function suggestive of parkinsonism?</p> <p><b>momopark</b></p>	<p><input type="checkbox"/> 0 No    <input type="checkbox"/> 1 Yes    <input type="checkbox"/> 9 Unknown</p> <p>(If No or Unknown, <b>SKIP TO QUESTION 18</b>)</p>
<p>17a. If Yes, at what age did the motor symptoms suggestive of parkinsonism begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;"><b>parkage</b>    _ _ _ _</p>	
<p>18. Were changes in motor function suggestive of amyotrophic lateral sclerosis?</p> <p><b>momoals</b></p>	<p><input type="checkbox"/> 0 No    <input type="checkbox"/> 1 Yes    <input type="checkbox"/> 9 Unknown</p> <p>(If No or Unknown, <b>SKIP TO QUESTION 19</b>)</p>
<p>18a. If Yes, at what age did the motor symptoms suggestive of ALS begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;"><b>alsage</b>    _ _ _ _</p>	
<p>19. Based on the clinician's assessment, at what age did the motor changes begin? (The clinician must use his/her best judgment to estimate an age of onset of motor changes.)</p> <p style="text-align: right;"><b>moage</b>    _ _ _ _</p>	
<p><b>Overall course of decline and predominant domain</b></p>	
<p>20. Overall course of decline of cognitive/behavioral/motor syndrome:</p> <p><b>course</b></p>	<p><input type="checkbox"/> 1 Gradually progressive</p> <p><input type="checkbox"/> 2 Stepwise</p> <p><input type="checkbox"/> 3 Static</p> <p><input type="checkbox"/> 4 Fluctuating</p> <p><input type="checkbox"/> 5 Improved</p> <p><input type="checkbox"/> 8 N/A</p> <p><input type="checkbox"/> 9 Unknown</p>
<p>21. Indicate the <b>predominant</b> domain that was first recognized as changed in the subject:</p> <p><b>frstchg</b></p>	<p><input type="checkbox"/> 1 Cognition</p> <p><input type="checkbox"/> 2 Behavior</p> <p><input type="checkbox"/> 3 Motor function</p> <p><input type="checkbox"/> 8 N/A</p> <p><input type="checkbox"/> 9 Unknown</p>
<p><b>Candidate for further evaluation for Lewy body disease or frontotemporal lobar degeneration</b></p>	
<p>22. Is the subject a potential candidate for further evaluation for Lewy body disease?</p> <p><b>lbdeval</b></p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes</p>
<p>23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration?</p> <p><b>ftldeval</b></p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes</p>



**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form D1: Clinician Diagnosis

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

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

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

This form is divided into three main sections:

- Section 1 **Cognitive status:** Normal cognition / MCI / dementia and dementia syndrome  
 Section 2 **Biomarkers, imaging, and genetics:** Neurodegenerative imaging and CSF biomarkers, imaging evidence for CVD, and known genetic mutations for AD and FTLD  
 Section 3 **Etiological diagnoses:** presumed etiological diagnoses for the cognitive disorder

1. **Diagnosis method — responses in this form are based on diagnosis by:** **dxmethod**

- 1 A single clinician     2 A formal consensus panel     3 Other (e.g., two or more clinicians or other informal group)

### SECTION 1: Cognitive and behavioral status

2. **Does the subject have normal cognition (global CDR=0 and/or neuropsychological testing within normal range) and normal behavior (i.e., the subject does not exhibit behavior sufficient to diagnose MCI or dementia due to FTLD or LBD)?**

- 0 No (CONTINUE TO QUESTION 3) **normcog**  
 1 Yes (SKIP TO QUESTION 6)

### ALL-CAUSE DEMENTIA

The subject has cognitive or behavioral (neuropsychiatric) symptoms that meet all of the following criteria:

- Interfere with ability to function as before at work or at usual activities?
- Represent a decline from previous levels of functioning?
- Are not explained by delirium or major psychiatric disorder?
- Include cognitive impairment detected and diagnosed through a combination of 1) history-taking and 2) objective cognitive assessment (bedside or neuropsychological testing)?

#### AND

Impairment in one\* or more of the following domains.

- Impaired ability to acquire and remember new information
- Impaired reasoning and handling of complex tasks, poor judgment
- Impaired visuospatial abilities
- Impaired language functions
- Changes in personality, behavior, or comportment

*\* In the event of single-domain impairment (e.g., language in PPA, behavior in bvFTD, posterior cortical atrophy), the subject must not fulfill criteria for MCI.*

3. **Does the subject meet the criteria for dementia?**

- 0 No (SKIP TO QUESTION 5) **demented**  
 1 Yes (CONTINUE TO QUESTION 4)

**4. If the subject meets criteria for dementia, answer Questions 4a–4f below and then SKIP TO QUESTION 6.**

Based entirely on the history and examination (including neuropsychological testing), what is the cognitive/behavioral syndrome? **Select one or more as Present; all others will default to Absent in the NACC database.**

Dementia syndrome	Present
4a. Amnestic multidomain dementia syndrome <b>amndem</b>	<input type="checkbox"/> 1
4b. Posterior cortical atrophy syndrome (or primary visual presentation) <b>pea</b>	<input type="checkbox"/> 1
4c. Primary progressive aphasia (PPA) syndrome <b>ppasyn</b>	<input type="checkbox"/> 1
4c1. <input type="checkbox"/> 1 Meets criteria for semantic PPA <input type="checkbox"/> 2 Meets criteria for logopenic PPA <input type="checkbox"/> 3 Meets criteria for nonfluent/agrammatic PPA <input type="checkbox"/> 4 PPA other/not otherwise specified	
4d. Behavioral variant FTD (bvFTD) syndrome <b>ftdsyn</b>	<input type="checkbox"/> 1
4e. Lewy body dementia syndrome <b>lbdsyn</b>	<input type="checkbox"/> 1
4f. Non-amnestic multidomain dementia, not PCA, PPA, bvFTD, or DLB syndrome <b>namndem</b>	<input type="checkbox"/> 1

**5. If the subject does not have normal cognition or behavior and is not clinically demented, indicate the type of cognitive impairment below.**

**MCI CORE CLINICAL CRITERIA**

- Is the subject, the co-participant, or a clinician concerned about a change in cognition compared to the subject's previous level?
- Is there impairment in one or more cognitive domains (memory, language, executive function, attention, and visuospatial skills)?
- Is there largely preserved independence in functional abilities (no change from prior manner of functioning or uses minimal aids or assistance)?

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5a. Amnestic MCI, single domain (aMCI SD)	<input type="checkbox"/> 1	<b>mciamem</b>		
5b. Amnestic MCI, multiple domains (aMCI MD) <b>mciaplus</b>	<input type="checkbox"/> 1	<b>CHECK YES for at least one additional domain (besides memory):</b> 5b1. Language <b>mciaplan</b> 5b2. Attention <b>mciapatt</b> 5b3. Executive <b>mciapex</b> 5b4. Visuospatial <b>mciapvis</b>	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5c. Non-amnestic MCI, single domain (naMCI SD) <b>mcinon1</b>	<input type="checkbox"/> 1	<b>CHECK YES to indicate the affected domain:</b> 5c1. Language <b>mcin1lan</b> 5c2. Attention <b>mcin1att</b> 5c3. Executive <b>mcin1ex</b> 5c4. Visuospatial <b>mcin1vis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1
5d. Non-amnestic MCI, multiple domains (naMCI MD) <b>mcinon2</b>	<input type="checkbox"/> 1	<b>CHECK YES for at least two domains:</b> 5d1. Language <b>mcin2lan</b> 5d2. Attention <b>mcin2att</b> 5d3. Executive <b>mcin2ex</b> 5d4. Visuospatial <b>mcin2vis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1
5e. Cognitively impaired, not MCI	<input type="checkbox"/> 1	<b>impnomci</b>		

## SECTION 2: Biomarkers, imaging, and genetics

Section 2 must be completed for all subjects.

### 6. Indicate neurodegenerative biomarker status, using local standards for positivity.

Biomarker findings	No	Yes	Unknown/ not assessed
6a. Abnormally elevated amyloid on PET <b>amylpet</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6b. Abnormally low amyloid in CSF <b>amylcsf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6c. FDG-PET pattern of AD <b>fdgad</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6d. Hippocampal atrophy <b>hippatr</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6e. Tau PET evidence for AD <b>taupetad</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6f. Abnormally elevated CSF tau or ptau <b>csftau</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6g. FDG-PET evidence for frontal or anterior temporal hypometabolism for FTLD <b>fdgftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6h. Tau PET evidence for FTLD <b>tpetftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6i. Structural MR evidence for frontal or anterior temporal atrophy for FTLD <b>mrftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6j. Dopamine transporter scan (DATscan) evidence for Lewy body disease <b>datscan</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
<b>othbiom</b> 6k. Other (SPECIFY): _____ <b>othbiomx</b> _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

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

Imaging findings	No	Yes	Unknown/ not assessed
7a. Large vessel infarct(s) <b>imaglinf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7b. Lacunar infarct(s) <b>imaglac</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7c. Macrohemorrhage(s) <b>imagmach</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7d. Microhemorrhage(s) <b>imagmich</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7e. Moderate white-matter hyperintensity (CHS score 5–6) <b>imagmwmh</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7f. Extensive white-matter hyperintensity (CHS score 7–8+) <b>imagewmh</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

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

0 No  1 Yes  9 Unknown/not assessed **admut**

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

0 No  1 Yes  9 Unknown/not assessed **ftldmut**

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

**othmut**  0 No  1 Yes (SPECIFY): **othmutx**  9 Unknown/not assessed

## SECTION 3: Etiologic diagnoses

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as 1=Primary.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by marking Present, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses marked as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
11.	Alzheimer's disease <b>alzids</b>	<input type="checkbox"/> 1	11a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>alzdisif</b>
12.	Lewy body disease <b>lbdis</b>	<input type="checkbox"/> 1	12a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>lbdif</b>
12b.	<input type="checkbox"/> 1 Parkinson's disease <b>park</b>				
13.	Multiple system atrophy <b>msa</b>	<input type="checkbox"/> 1	13a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>msaif</b>
14.	Frontotemporal lobar degeneration				
14a.	Progressive supranuclear palsy (PSP) <b>psp</b>	<input type="checkbox"/> 1	14a1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>pspif</b>
14b.	Corticobasal degeneration (CBD) <b>cort</b>	<input type="checkbox"/> 1	14b1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>cortif</b>
14c.	FTLD with motor neuron disease <b>ftldmo</b>	<input type="checkbox"/> 1	14c1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ftldmoif</b>
14d.	FTLD NOS <b>ftldnos</b>	<input type="checkbox"/> 1	14d1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ftldnoif</b>
14e.	If FTLD (Questions 14a – 14d) is Present, specify FTLD subtype: <b>ftldsubst</b>				
	<input type="checkbox"/> 1 Tauopathy				
	<input type="checkbox"/> 2 TDP-43 proteinopathy <b>ftldsubx</b>				
	<input type="checkbox"/> 3 Other (SPECIFY): _____				
	<input type="checkbox"/> 9 Unknown				

**SECTION 3: Etiologic diagnoses (cont.)**

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1=Primary**.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
15.	Vascular brain injury (based on clinical or imaging evidence) <i>If significant vascular brain injury is absent, SKIP TO QUESTION 16.</i>	<input type="checkbox"/> 1	15a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
	<i>If significant vascular brain injury is absent, SKIP TO QUESTION 16.</i>				<b>cvdif</b>
15b.	Previous symptomatic stroke?				
	<input type="checkbox"/> 0 No (SKIP TO QUESTION 15c)				
	<input type="checkbox"/> 1 Yes				
15b1.	Temporal relationship between stroke and cognitive decline?				
	<input type="checkbox"/> 0 No				
	<input type="checkbox"/> 1 Yes				
15b2.	Confirmation of stroke by neuroimaging?				
	<input type="checkbox"/> 0 No				
	<input type="checkbox"/> 1 Yes				
	<input type="checkbox"/> 9 Unknown; no relevant imaging data available				
15c.	Is there imaging evidence of cystic infarction in cognitive network(s)?				
	<input type="checkbox"/> 0 No				
	<input type="checkbox"/> 1 Yes				
	<input type="checkbox"/> 9 Unknown; no relevant imaging data available				
15d.	Is there imaging evidence of cystic infarction, imaging evidence of extensive white matter hyperintensity (CHS grade 7–8+), and impairment in executive function?				
	<input type="checkbox"/> 0 No				
	<input type="checkbox"/> 1 Yes				
	<input type="checkbox"/> 9 Unknown; no relevant imaging data available				
16.	Essential tremor	<input type="checkbox"/> 1	16a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
					<b>esstreif</b>
17.	Down syndrome	<input type="checkbox"/> 1	17a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
					<b>downsif</b>
18.	Huntington's disease	<input type="checkbox"/> 1	18a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
					<b>huntif</b>
19.	Prion disease (CJD, other)	<input type="checkbox"/> 1	19a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
					<b>prion_if</b>

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
20.	Traumatic brain injury <b>brninj</b>	<input type="checkbox"/> 1	20a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>brninjif</b>
20b.	If Present, does the subject have symptoms consistent with chronic traumatic encephalopathy? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown <b>brnincte</b>				
21.	Normal-pressure hydrocephalus <b>hyceph</b>	<input type="checkbox"/> 1	21a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>hycephif</b>
22.	Epilepsy <b>epilep</b>	<input type="checkbox"/> 1	22a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>epilepif</b>
23.	CNS neoplasm <b>neop</b>	<input type="checkbox"/> 1	23a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>neopif</b>
23b.	<input type="checkbox"/> 1 Benign <input type="checkbox"/> 2 Malignant <b>neopstat</b>				
24.	Human immunodeficiency virus (HIV) <b>hiv</b>	<input type="checkbox"/> 1	24a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>hivif</b>
25.	Cognitive impairment due to other neurologic, genetic, or infectious conditions not listed above <b>othcog</b>	<input type="checkbox"/> 1	25a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>othcogif</b>
25b.	If Present, specify: _____ <b>othcogx</b> _____				

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1=Primary**.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Condition	Present	Primary	Contributing	Non-contributing
26. Active depression <b>dep</b>	<input type="checkbox"/> 1	26a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>depif</b>
26b. If Present, select one: <b>deptreat</b> <input type="checkbox"/> 0 Untreated <input type="checkbox"/> 1 Treated with medication and/or counseling				
27. Bipolar disorder <b>bipoldx</b>	<input type="checkbox"/> 1	27a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>bipoldif</b>
28. Schizophrenia or other psychosis <b>schizop</b>	<input type="checkbox"/> 1	28a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>schizoif</b>
29. Anxiety disorder <b>anxiet</b>	<input type="checkbox"/> 1	29a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>anxietif</b>
30. Delirium <b>delir</b>	<input type="checkbox"/> 1	30a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>delirif</b>
31. Post-traumatic stress disorder (PTSD) <b>ptsddx</b>	<input type="checkbox"/> 1	31a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ptsddxif</b>
32. Other psychiatric disease <b>othpsy</b>	<input type="checkbox"/> 1	32a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>othpsyif</b>
32b. If Present, specify: _____ <b>othpsyx</b> _____				

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33. Cognitive impairment due to alcohol abuse <b>alcdem</b> <input type="checkbox"/> 1 33b. Current alcohol abuse: <b>alcabuse</b> <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<input type="checkbox"/> 1	33a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>alcdemif</b>
<b>impsub</b> 34. Cognitive impairment due to other substance abuse <input type="checkbox"/> 1	<input type="checkbox"/> 1	34a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>impsubif</b>
35. Cognitive impairment due to systemic disease/ medical illness (as indicated on Form D2) <b>dysill</b> <input type="checkbox"/> 1	<input type="checkbox"/> 1	35a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>dysillif</b>
36. Cognitive impairment due to medications <b>meds</b> <input type="checkbox"/> 1	<input type="checkbox"/> 1	36a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>medsif</b>
37. Cognitive impairment NOS <b>cogoth</b> <input type="checkbox"/> 1 37b. If Present, specify: _____ <b>cogothx</b> _____	<input type="checkbox"/> 1	37a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogothif</b>
38. Cognitive impairment NOS <b>cogoth2</b> <input type="checkbox"/> 1 38b. If Present, specify: _____ <b>cogoth2x</b> _____	<input type="checkbox"/> 1	38a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogoth2f</b>
39. Cognitive impairment NOS <b>cogoth3</b> <input type="checkbox"/> 1 39b. If Present, specify: _____ <b>cogoth3x</b> _____	<input type="checkbox"/> 1	39a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogoth3f</b>

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

## Form D2: Clinician-assessed Medical Conditions

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

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

*INSTRUCTIONS: This form is to be completed by a physician, physician's assistant, nurse practitioner, or other qualified practitioner. For additional clarifications and examples, see UDS Coding Guidebook for Initial Visit Packet, Form D2.*

### Medical conditions and procedures

The following questions should be answered based on review of all available information, including new diagnoses made during the current visit, previous medical records, procedures, laboratory tests, and the clinical exam.

1. Cancer (excluding non-melanoma skin cancer), primary or metastatic

cancer

- 0 No (**SKIP TO QUESTION 2**)  
 1 Yes, primary/non-metastatic  
 2 Yes, metastatic  
 8 Not assessed (**SKIP TO QUESTION 2**)

1a. If yes, specify primary site: \_\_\_\_\_

cancsite

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

2. Diabetes
- 
- 0 No

diabet

- 1 Yes, Type I  
 2 Yes, Type II  
 3 Yes, other type (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes)  
 9 Not assessed or unknown

	No	Yes	Not assessed
3. Myocardial infarct <b>myoinf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4. Congestive heart failure <b>conghrt</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5. Atrial fibrillation <b>afibrill</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6. Hypertension <b>hypert</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7. Angina <b>angina</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
8. Hypercholesterolemia <b>hypchol</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
9. B12 deficiency <b>vb12def</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
10. Thyroid disease <b>thydis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

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

	No	Yes	Not assessed
11. Arthritis <i>If No or Not assessed, SKIP TO QUESTION 12</i> <b>arth</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
11a. If yes, what type? <b>arthtype</b>			
<input type="checkbox"/> 1 Rheumatoid			
<input type="checkbox"/> 2 Osteoarthritis			
<input type="checkbox"/> 3 Other (SPECIFY): <b>artypex</b>			
<input type="checkbox"/> 9 Unknown			
11b. If yes, regions affected (check at least one):			
11b1. <input type="checkbox"/> 1 Upper extremity <b>artupex</b>			
11b2. <input type="checkbox"/> 1 Lower extremity <b>artloex</b>			
11b3. <input type="checkbox"/> 1 Spine <b>artspin</b>			
11b4. <input type="checkbox"/> 1 Unknown <b>artunkn</b>			
12. Incontinence — urinary <b>urineinc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
13. Incontinence — bowel <b>bowlinc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
14. Sleep apnea <b>sleepap</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
15. REM sleep behavior disorder (RBD) <b>remdis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
16. Hyposomnia/insomnia <b>hyposom</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
<b>sleepoth</b> 17. Other sleep disorder (SPECIFY): <b>sleepotx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
18. Carotid procedure: angioplasty, endarterectomy, or stent <b>angiocp</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
19. Percutaneous coronary intervention: angioplasty and/or stent <b>angiopci</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
20. Procedure: pacemaker and/or defibrillator <b>pacemake</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
21. Procedure: heart valve replacement or repair <b>hvalve</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
22. Antibody-mediated encephalopathy <b>antienc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
22a. Specify antibody: <b>antiencx</b>			
23. Other medical conditions or procedures not listed above <b>othcond</b> (IF YES, SPECIFY): <b>othcondx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

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NACC UNIFORM DATA SET (UDS)

Form M1: Milestones (February 18 Final, rev. 2/20)

ADC ID: \_\_\_ Subject ID: \_\_\_\_\_ Form Date: \_\_\_/\_\_\_/\_\_\_\_\_ Examiner's initials: \_\_\_

Please submit a new Milestones Form as soon as possible after each milestone event has occurred.

INSTRUCTIONS: Review the types of milestone at right and complete the appropriate box below. Use only one box (A or B) per form submitted. For more information, see flow chart on reverse.

Table with 2 columns: What milestone are you reporting?, Complete:
1. Data-collection status CHANGE followed by CONTINUED CONTACT with subject. The subject's status in the UDS or FTLD Module has changed, such that s/he will continue to be followed (at least minimally) by ADC. Box A only
2. Change followed by NO FURTHER CONTACT with subject. Subject has DIED or been DROPPED FROM ADC with no further telephone contact and no minimal contact (such as to obtain autopsy). Box B only

BOX A — CHANGE WITH CONTINUED CONTACT
1. Date of status change (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
Complete the UDS and FTLD sections below, as appropriate.
UDS STATUS
2a. UDS data collection status changed; subject's new status is (CHECK ONE):
1 Annual UDS follow-up by telephone (CONTINUE TO QUESTION 2a1)
2 Minimal contact (CONTINUE TO QUESTION 2a1)
NOTE: Minimal contact status is reserved for subjects who can no longer participate for one of the reasons listed in Question 2b, below.
2a1. Autopsy consent on file? 0 No (CONTINUE TO QUESTION 2b) 1 Yes (CONTINUE TO QUESTION 2b)
3 Annual in-person UDS follow-up
2b. Reason(s) for change indicated in Question 2a (CHECK AT LEAST ONE):
1 Subject is too cognitively impaired
2 Subject is too ill or physically impaired
3 Subject refuses neuropsychological testing or clinical exam
4 Subject or co-participant unreachable, not available, or moved away
5 Subject has permanently entered nursing home
2b5a. Date permanently moved to nursing home: MM/DD/YYYY (Unknown = 99/99/YEAR REQUIRED)
6 Subject is REJOINING ADC
FTLD MODULE STATUS
3. 1 Subject will no longer receive FTLD Module follow-up, but annual in-person UDS visits will continue
3a. Reason (CHECK ONE): 1 ADC decision 2 Subject/informant refused 3 Informant not available 4 Other, specify below:
3a1. \_\_\_\_\_

BOX B — NO FURTHER CONTACT
4a. Subject has DIED (COMPLETE DEATH SECTION, BELOW)
4b. Subject has been DROPPED from ADC (COMPLETE DROPPED SECTION, BELOW)
DEATH
5a. Date of death (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
5b. ADC autopsy:
0 No ADC autopsy expected
1 An ADC autopsy has been done; data submitted or pending
END FORM HERE
DROPPED
DO NOT fill out this section if the subject has consented to autopsy or if you will maintain minimal contact. Instead, fill out Box A, UDS STATUS section.
6a. Date dropped from ADC (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
6b. Main reason for being dropped from ADC (CHECK ONE):
1 ADC decision or protocol
2 Subject or co-participant asked to be dropped



NACC UNIFORM DATA SET

# Follow-up Visit Packet

**Version 3.0, March 2015**

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

**Form A1: Subject Demographics**

Variable names are in red font in blue boxes

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

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

*INSTRUCTIONS: This form is to be completed by intake interviewer based on ADC scheduling records, subject interview, medical records, and co-participant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A1. Check only one box per question.*

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

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

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

## Form A2: Co-participant Demographics

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

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

*INSTRUCTIONS: This form is to be completed by intake interviewer based on co-participant's report. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A2. Check only one box per question.*

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

1. Co-participant's month and year of birth (MM / YYYY):	<input type="checkbox"/> inbirmo	<input type="checkbox"/> inbiry	(99/9999 = unknown)
2. Co-participant's sex:	<input type="checkbox"/> insex	<input type="checkbox"/> 1 Male	<input type="checkbox"/> 2 Female
3. Is this a new co-participant — i.e., one who was not a co-participant at any past UDS visit?	<input type="checkbox"/> newinf	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 9</b> )	<input type="checkbox"/> 1 Yes
4. Does the co-participant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?		<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 5</b> )	<input type="checkbox"/> inhispp
4a. If yes, what are the co-participant's reported origins?	<input type="checkbox"/> inhispor	<input type="checkbox"/> 1 Mexican, Chicano, or Mexican-American	
		<input type="checkbox"/> 2 Puerto Rican	
		<input type="checkbox"/> 3 Cuban	
		<input type="checkbox"/> 4 Dominican	
		<input type="checkbox"/> 5 Central American	
		<input type="checkbox"/> 6 South American	<input type="checkbox"/> inhisppox
		<input type="checkbox"/> 50 Other (SPECIFY): _____	
		<input type="checkbox"/> 99 Unknown	
5. What does the co-participant report as his or her race?	<input type="checkbox"/> inrace	<input type="checkbox"/> 1 White	
		<input type="checkbox"/> 2 Black or African American	
		<input type="checkbox"/> 3 American Indian or Alaska Native	
		<input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander	
		<input type="checkbox"/> 5 Asian	<input type="checkbox"/> inracex
		<input type="checkbox"/> 50 Other (SPECIFY): _____	
		<input type="checkbox"/> 99 Unknown	
6. What additional race does the co-participant report?	<input type="checkbox"/> inrasec	<input type="checkbox"/> 1 White	
		<input type="checkbox"/> 2 Black or African American	
		<input type="checkbox"/> 3 American Indian or Alaska Native	
		<input type="checkbox"/> 4 Native Hawaiian or other Pacific Islander	
		<input type="checkbox"/> 5 Asian	<input type="checkbox"/> inrasecx
		<input type="checkbox"/> 50 Other (SPECIFY): _____	
		<input type="checkbox"/> 88 None reported	
		<input type="checkbox"/> 99 Unknown	



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

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

## Form A3: Subject Family History

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

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

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

**For subjects who are receiving UDS Version 3 of Form A3 for the first time:** Please answer Question 1 and continue to provide all known information on all biological parents, full siblings, and biological children, even if you have provided similar information on a UDS Version 2 Form A3.

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

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

1. Since the last visit, is new information available concerning genetic mutations addressed by Questions 2a through 4b, below? <b>nwinfm</b>	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 5</b> ) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 5</b> )
2a. In this family, is there evidence for an AD mutation? If Yes, select predominant mutation.  NOTE: APOE should not be reported here. <b>fadmut</b>	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 3a</b> ) <input type="checkbox"/> 1 Yes, APP <input type="checkbox"/> 2 Yes, PS-1 (PSEN 1) <input type="checkbox"/> 3 Yes, PS-2 (PSEN 2) <b>fadmutx</b> <input type="checkbox"/> 8 Yes, other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown whether mutation exists ( <b>SKIP TO QUESTION 3a</b> )
2b. Source of evidence for AD mutation (check one): <b>fadmuso</b>	<input type="checkbox"/> 1 Family report (no test documentation available) <input type="checkbox"/> 2 Commercial test documentation <input type="checkbox"/> 3 Research lab test documentation <input type="checkbox"/> 8 Other (SPECIFY): <b>fadmusox</b> <input type="checkbox"/> 9 Unknown
3a. In this family, is there evidence for an FTL mutation? If Yes, select predominant mutation. <b>fftdmut</b>	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 4a</b> ) <input type="checkbox"/> 1 Yes, MAPT <input type="checkbox"/> 2 Yes, PGRN <input type="checkbox"/> 3 Yes, C9orf72 <input type="checkbox"/> 4 Yes, FUS <b>fftdmutx</b> <input type="checkbox"/> 8 Yes, other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown whether mutation exists ( <b>SKIP TO QUESTION 4a</b> )

<p>3b. Source of evidence for FTLN mutation (check one):</p> <p><b>fftdmuso</b></p>	<p><input type="checkbox"/> 1 Family report (no test documentation available)</p> <p><input type="checkbox"/> 2 Commercial test documentation</p> <p><input type="checkbox"/> 3 Research lab test documentation</p> <p><input type="checkbox"/> 8 Other (SPECIFY): <b>fftdmusx</b></p> <p><input type="checkbox"/> 9 Unknown</p>
<p>4a. In this family, is there evidence for a mutation other than an AD or FTLN mutation? (If No or Unknown, <b>SKIP TO QUESTION 5</b>)</p> <p><b>fothmut</b></p>	<p><input type="checkbox"/> 0 No (<b>SKIP TO QUESTION 5</b>)</p> <p><input type="checkbox"/> 1 Yes (SPECIFY): <b>fothmutx</b></p> <p><input type="checkbox"/> 9 Unknown (<b>SKIP TO QUESTION 5</b>)</p>
<p>4b. Source of evidence for other mutation (check one):</p> <p><b>fothmuso</b></p>	<p><input type="checkbox"/> 1 Family report (no test documentation available)</p> <p><input type="checkbox"/> 2 Commercial test documentation</p> <p><input type="checkbox"/> 3 Research lab test documentation</p> <p><input type="checkbox"/> 8 Other (SPECIFY): <b>fothmusx</b></p> <p><input type="checkbox"/> 9 Unknown</p>

**BIOLOGICAL PARENTS**

**newinfpar**

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

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

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

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
<b>See CODES below this table</b>						
5a. Mother	<b>mommob</b> / <b>momyob</b>	<b>momdage</b>	<b>momneur</b>	<b>momprdx</b>	<b>mommoie</b>	<b>momageo</b>
5b. Father	<b>dadmob</b> / <b>dadyob</b>	<b>daddage</b>	<b>dadneur</b>	<b>dadprdx</b>	<b>dadmoie</b>	<b>dadageo</b>

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

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

**\*\*CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

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

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

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

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

**FULL SIBLINGS**

**sib** 6. How many full siblings does the subject have?  0  1 If subject has no full siblings, **SKIP TO QUESTION 7.**

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

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

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

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

**\* = sibling number**

**BIOLOGICAL CHILDREN**

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

7a. Since the last UDS visit, is new information available concerning the status of the subject's biological children?  
 0 No (**END FORM HERE**)     1 Yes (**COMPLETE QUESTIONS 7aa–7ao, AS APPLICABLE**) nwinfkid

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

	Birth month/year (99/9999=Unknown)	Age at death (888 = N/A, 999 = unknown)	Primary neurological problem/ psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999 = unknown)
See CODES below this table						
7aa. Child 1	<span style="border: 1px solid red; padding: 2px;">kid*mob</span> <span style="border: 1px solid red; padding: 2px;">kid*yob</span>	<span style="border: 1px solid red; padding: 2px;">kid*dage</span>	<span style="border: 1px solid red; padding: 2px;">kid*neur</span>	<span style="border: 1px solid red; padding: 2px;">kid*prdx</span>	<span style="border: 1px solid red; padding: 2px;">kid*moe</span>	<span style="border: 1px solid red; padding: 2px;">kid*ageo</span>
7ab. Child 2	__/____	___	__	____	__	___
7ac. Child 3	__/____	___	__	____	__	___
7ad. Child 4	__/____	___	__	____	__	___
7ae. Child 5	__/____	___	__	____	__	___
7af. Child 6	__/____	___	__	____	__	___
7ag. Child 7	__/____	___	__	____	__	___
7ah. Child 8	__/____	___	__	____	__	___
7ai. Child 9	__/____	___	__	____	__	___
7aj. Child 10	__/____	___	__	____	__	___
7ak. Child 11	__/____	___	__	____	__	___
7al. Child 12	__/____	___	__	____	__	___
7am. Child 13	__/____	___	__	____	__	___
7an. Child 14	__/____	___	__	____	__	___
7ao. Child 15	__/____	___	__	____	__	___

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

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

**\*\*CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

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

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

\* = child number

## \*\*APPENDIX 1: PRIMARY DIAGNOSIS CODES

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

**Neuropathology diagnosis from autopsy**

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

## \*\*\*APPENDIX 2: METHOD OF EVALUATION

**1. Autopsy**

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

**2. Examination**

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

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

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

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

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

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

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

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

See definition No. 4 above.

**7. Family report**

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

Taped:

Participant ID#

T-

Date:

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Taped:

Participant ID#

T-

Date:

Q & A

# Documenting Participant<sup>N</sup> Understanding and Assent

(Circle the Participant's initial response. If the Participant gives incorrect response, discuss that element of consent to achieve understanding)  
**Ps in all studies (ACS, ADRC, HASD, GOLDIN, PROJECT 1) should respond to the bolded statements.**

*N564	You are here for a birthday party. <b>assent1</b>	Yes	No
*N565	You are here to volunteer for a research study. <b>assent2</b>	Yes	No
*N566	Part of today's tests include a chest x-ray. <b>assent3</b>	Yes	No
*N567	You will be asked questions to test your memory and thinking. <b>assent4</b>	Yes	No
*N568	Information from this research study may help people who have memory problems. <b>assent5</b>	Yes	No
*N569	You may benefit from learning about any memory problems you may have. <b>assent6</b>	Yes	No
*N570	A frequent side effect from taking part in this study is the development of a rash. <b>assent7</b>	Yes	No
*N571	You may become tired from answering questions. <b>assent8</b>	Yes	No
*N572	You will be asked to return for repeat evaluations every year. <b>assent9</b>	Yes	No
*N573	The confidential information we collect from you will be published in the newspaper. <b>assent10</b>	Yes	No
*N574	You can choose to stop answering our questions at any time. <b>assent11</b>	Yes	No
<b>N589</b>	<b>Do you agree to have the Collateral Source included in the feedback session?</b> <b>N589</b>	<b>Yes</b>	<b>No</b>
<b>N590</b>	<b>It is possible that the Collateral Source will learn about your personal health information as a result of their participation in this research interview.</b> <b>N590</b>	<b>Yes</b>	<b>No</b>
*N575	<b>Is it alright to continue with the testing today?</b> <b>assent12</b>	<b>Yes</b>	<b>No</b>

\_\_\_\_\_  
Signature of the Clinician

\_\_\_\_\_  
Initials of Participant

Comments (Note if there was discussion about any questions and if understanding is achieved):



Taped:

COMPLETED\_BY

N Health History Health History Obtained From: P \_\_\_ CS \_\_\_ Both P and CS \_\_\_

\*105a. How would you rate his/her overall physical health at the present time? (CS Rating)

a. excellent (1) b. good (2) c. fair (3) d. poor (4) int407

int403 \*104. Has he/she had physical health problems in the last 5 years? Describe: int403desc  
Yes (1) \_\_\_ No (0) \_\_\_ Medical records for this year requested

requestmedrec

falls

650. Falls? NO \_\_\_ YES \_\_\_ If yes, (651) Number of Falls: \_\_\_ fallnum

652. If had falls, did he/she have injuries as a result of his/her falls? \_\_\_ No \_\_\_ Yes fallinj  
Describe injuries: fallinjdesc

List Surgeries (in the last 5 years):

surgdesc\*

List Hospitalizations (in the last 5 years):

hospdesc\*

\* = injury number (starts at 1 and varies)

\*105. Has he/she been treated for a psychiatric illness (depression or emotional/behavioral problem)

int416 in the last year? Yes \_\_\_ No \_\_\_ Describe: int416desc

120. In the last year, has he/she had problems with his/her:

head	Head	yes	___	no	___	Breathing	yes	___	no	___	breath
eyes	Eyes	yes	___	no	___	Heart	yes	___	no	___	heart
ears	Ears	yes	___	no	___	Bowels	yes	___	no	___	bowel
nose	Nose	yes	___	no	___	Bladder	yes	___	no	___	bladder
throat	Throat	yes	___	no	___	Mouth	yes	___	no	___	mouth

weight 121. Weight yes \_\_\_ no \_\_\_

Describe yes responses from above:

headdesc	nosedesc	breathdesc	bladderdesc
eyesdesc	throatdesc	heartdesc	mouthdesc
earsdesc	weightdesc	boweldesc	

Does the participant have any of the following illnesses?					
Data Code	Yes	No	DK	Onset	Illness
*106	<input type="text" value="int106_ev"/>			<input type="text" value="int106_ev_on"/>	Head Injury (w/LOC)? <input type="text" value="int106_ev_text"/>
*106a	<input type="text" value="int106a_ev"/>			<input type="text" value="int106a_ev_on"/>	Stroke/TIA <input type="text" value="int106a_ev_text"/>
*107	<input type="text" value="int107_ev"/>			<input type="text" value="int107_ev_on"/>	LOC/Fainting <input type="text" value="int107_ev_text"/>
*108	<input type="text" value="int108_ev"/>			<input type="text" value="int108_ev_on"/>	Diabetes <input type="text" value="int108_ev_text"/>
*109	<input type="text" value="int109_ev"/>			<input type="text" value="int109_ev_on"/>	Hypertension <input type="text" value="int109_ev_text"/>
	<input type="text" value="hychol_ev"/>			<input type="text" value="hychol_ev_on"/>	Hypercholesterolemia <input type="text" value="hychol_ev_text"/>
*110	<input type="text" value="int110_ev"/>			<input type="text" value="int110_ev_on"/>	Problems Walking <input type="text" value="int110_ev_text"/>
*111	<input type="text" value="int111_ev"/>			<input type="text" value="int111_ev_on"/>	Abnormal Movements <input type="text" value="int111_ev_text"/>
*112	<input type="text" value="int112_ev"/>			<input type="text" value="int112_ev_on"/>	Seizures <input type="text" value="int112_ev_text"/>
*113	<input type="text" value="int113_ev"/>			<input type="text" value="int113_ev_on"/>	Poison Exposure <input type="text" value="int113_ev_text"/>
*114	<input type="text" value="int114_ev"/>			<input type="text" value="int114_ev_on"/>	Chronic Lung Disease <input type="text" value="int114_ev_text"/>
*115	<input type="text" value="int115_ev"/>			<input type="text" value="int115_ev_on"/>	Heart Disease <input type="text" value="int115_ev_text"/>
*116	<input type="text" value="int116_ev"/>			<input type="text" value="int116_ev_on"/>	Liver Disease <input type="text" value="int116_ev_text"/>
*117	<input type="text" value="int117_ev"/>			<input type="text" value="int117_ev_on"/>	Kidney Disease <input type="text" value="int117_ev_text"/>
*118	<input type="text" value="int118_ev"/>			<input type="text" value="int118_ev_on"/>	Thyroid Disease <input type="text" value="int118_ev_text"/>
	<input type="text" value="vitab12_ev"/>			<input type="text" value="vitab12_ev_on"/>	Vitamin B-12 Deficiency <input type="text" value="vitab12_ev_text"/>
*119	<input type="text" value="int119_ev"/>			<input type="text" value="int119_ev_on"/>	Operations <input type="text" value="int119_ev_text"/>
*331	<input type="text" value="int331_ev"/>			<input type="text" value="int331_ev_on"/>	Glaucoma/Cataracts <input type="text" value="int331_ev_text"/>
*332	<input type="text" value="int332_ev"/>			<input type="text" value="int332_ev_on"/>	Tuberculosis <input type="text" value="int332_ev_text"/>
*333	<input type="text" value="int333_ev"/>			<input type="text" value="int333_ev_on"/>	Circulation Problems/Extremities <input type="text" value="int333_ev_text"/>
*334	<input type="text" value="int334_ev"/>			<input type="text" value="int334_ev_on"/>	Ulcers/Digestive System <input type="text" value="int334_ev_text"/>
*335	<input type="text" value="int335_ev"/>			<input type="text" value="int335_ev_on"/>	Cancer <input type="text" value="int335_ev_text"/>
*336	<input type="text" value="int336_ev"/>			<input type="text" value="int336_ev_on"/>	Anemia <input type="text" value="int336_ev_text"/>
*338	<input type="text" value="int338_ev"/>			<input type="text" value="int338_ev_on"/>	Pressure Sores/Leg Ulcers <input type="text" value="int338_ev_text"/>
*339	<input type="text" value="int339_ev"/>			<input type="text" value="int339_ev_on"/>	Fractures <input type="text" value="int339_ev_text"/>
*124a	<input type="text" value="int124a_ev"/>			<input type="text" value="int124a_ev_on"/>	Substance Abuse (Drug) <input type="text" value="int124a_ev_text"/>
*125c	<input type="text" value="int125c_ev"/>			<input type="text" value="int125c_ev_on"/>	Substance Misuse (Alcohol) <input type="text" value="int125c_ev_text"/>
*126b	<input type="text" value="int126b_ev"/>			<input type="text" value="int126b_ev_on"/>	Tobacco Use (present and past) <input type="text" value="int126b_ev_text"/>
*553	<input type="text" value="int553_ev"/>			<input type="text" value="int553_ev_on"/>	Autoimmune Disorders (Rheumatoid Arthritis, Lupus, etc.) <input type="text" value="int553_ev_text"/>
	<input type="text" value="moddis_ev"/>			<input type="text" value="moddis_ev_on"/>	Mood Disorders <input type="text" value="moddis_ev_text"/>
	<input type="text" value="sleepdis_ev"/>			<input type="text" value="sleepdis_ev_on"/>	Sleep Disorders <input type="text" value="sleepdis_ev_text"/>
*555	<input type="text" value="int555_ev"/>			<input type="text" value="int555_ev_on"/>	Other: <input type="text" value="int555_ev_text"/>

List Medication Allergies:

---

N551. Has he/she taken medication to stimulate, or enhance thinking; or been in a drug study for Alzheimer's disease)?

No \_\_\_ \*yes \_\_\_ If yes, complete dementia drug history below:

Name of Drug	Date Started		Date Stopped	
<input type="text" value="stim_ev"/>	<input type="text" value="stim*b_dy_ev"/>		<input type="text" value="stim*e_dy_ev"/>	
	<input type="text" value="stim*b_mo_ev"/>	<input type="text" value="stim*b_yr_ev"/>	<input type="text" value="stim*e_mo_ev"/>	<input type="text" value="stim*e_dy_ev"/>

\* = allergy/drug number

Has the he/she participated in a research program in the last year that studies memory and thinking?

No \_\_\_ \*yes \_\_\_ If yes, list the studies and dates of participation below:

Taped:

Participant ID#

T-

Date:

MEDICATION NAME		DOSAGE	ROUTE	FREQ.	DATE MED. STARTED
<input type="text" value="medname*"/>	<input type="text" value="drug*"/>	<input type="text" value="dose*"/>	<input type="text" value="route*"/>	<input type="text" value="freq*"/>	<input type="text" value="startdate*"/>

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

## Form A4: Subject Medications

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

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

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

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

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

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

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

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

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

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

Medication name	DrugID
<input type="checkbox"/> ibuprofen (Advil, Motrin, Nuprin)	d00015
<input type="checkbox"/> loratadine (Alavert, Claritin, Dimetapp, Tavist)	d03050
<input type="checkbox"/> melatonin (Melatonin, Melatonin Time Release)	d04058
<input type="checkbox"/> multivitamin	d03140
<input type="checkbox"/> multivitamin with minerals	d03145
<input type="checkbox"/> polyethylene glycol 3350 (Miralax)	d05350
<input type="checkbox"/> psyllium (Fiberall, Metamucil)	d01018
<input type="checkbox"/> pyridoxine (Vitamin B6)	d00412
<input type="checkbox"/> ubiquinone (Co Q-10)	d04523
<input type="checkbox"/> vitamin E (Aquavite-E, Centrum Singles)	d00405

**If a medication is not listed above, specify the drug or brand name and determine its drugID by using the Lookup Tool on the NACC website at <https://www.alz.washington.edu/MEMBER/DrugCodeLookup.html>**

- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
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- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_
- (SPECIFY:) \_\_\_\_\_ d \_\_\_\_\_

Taped:

Participant ID#

T-

Date:

- INTENTIONALLY BLANK PAGE -

## COLLATERAL SOURCE INTERVIEW

\*DATE: \_\_\_\_\_

\*INTERVIEWED BY: tester\*REVIEWED BY: reviewed\_by

Clinician: \_\_\_\_\_

Note: Review previous health history pages before beginning interview.

Non-Physician: \_\_\_\_\_

If T-1, Social Worker \_\_\_\_\_

\*579. CS#: cs idtester2socialworker\*\*\*\* START TAPE \*\*\*\*

## 1. HISTORY OF PRESENT ILLNESS

(Summary of recent physical and mental health. Useful probes include ability to remember appointments, repeating questions or statements, misplacing items, word-finding difficulty, reduced ability in calculations, visuospatial problems, etc. Emphasis should be on **change** in cognitive abilities; distinguish from changes due to physical problems. If memory and thinking are impaired, when and how did it begin? Course?)

health\_history

(in the last six months) Ferman TJ et al Neurology 2004; 62: 181-187.

\*588. Is he/she drowsy and lethargic during the day despite getting enough drowsy YES NO DK\*586. Does he/she sleep 2 or more hours during the day (before 7 p.m.)? sleeps2hrs YES NO DK\*587. Are there times when his/her flow of ideas is disorganized, unclear or not logical? YES NO DK illogical\*588. Does he/she tend to stare into space for periods of time? stares YES NO DK19. Has there been any change in personality or behavior? changebehDescribe: changebeh textIf yes, for how long have these changes been present? \_\_\_\_\_ (in years) change\_length

N.5. What was he/she told about why he/she is here today?

int302**Depressed Mood**

6. In the past year has [P] appeared sad or blue, or depressed most of the day nearly every day for two weeks or more? Y \_\_\_ N \_\_\_

**Recurrent Thoughts of death/Suicidal Ideation**

15. In the last year, has [P] said he/she feels that life is not worth living, or has [P] expressed a wish to die or talked about committing suicide? Y \_\_\_ N \_\_\_

int311



# Form B5: BEHAVIORAL ASSESSMENT Neuropsychiatric Inventory Questionnaire (NPI-Q<sup>1</sup>)

Taped:

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

*INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional based on co-participant interview, as described by the training video. (This is not to be completed by the subject as a paper-and-pencil self-report.) For information on NPI-Q Interviewer Certification, see UDS Coding Guidebook for Follow-up Visit Packet, Form B5. Check only one box for each category of response.*

Please answer the following questions based upon **changes in the past month**. Indicate Yes only if the symptom represents a change (i.e., a new symptom or an exacerbation of a previous symptom) in the past month; otherwise, select **0=No**. For each item marked Yes, indicate 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)

Participant ID#

npiqinf

npiqinfx

1. **NPI CO-PARTICIPANT:**  1 Spouse  2 Child  3 Other (SPECIFY): \_\_\_\_\_

Yes	No	Unknown
-----	----	---------

	SEVERITY			Unknown
	Mild	Mod	Severe	

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  9

del

2b.  1  2  3  9

delsev

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  9

hall

3b.  1  2  3  9

hallsev

4. **Agitation or aggression** — Is the patient stubborn and resistant to help from others?

4a.  1  0  9

agit

4b.  1  2  3  9

agitsev

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  9

depd

5b.  1  2  3  9

depdsev

T-

Date:

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Please answer the following questions based upon **changes in the past month**. Indicate Yes only if the symptom represents a change (i.e., a new symptom or an exacerbation of a previous symptom) in the past month; otherwise, select **0=No**. For each item marked Yes, indicate 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)

22

		Yes	No	Unknown	SEVERITY			
					Mild	Mod	Severe	Unknown
6.	<b>Anxiety</b> — 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. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>anx</b>			<b>anxsev</b>			
7.	<b>Elation or euphoria</b> — Does the patient appear to feel too good or act excessively happy?	7a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>elat</b>			<b>elatsev</b>			
8.	<b>Apathy or indifference</b> — Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	8a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>apa</b>			<b>apasev</b>			
9.	<b>Disinhibition</b> — 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. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>disn</b>			<b>disnsev</b>			
10.	<b>Irritability or lability</b> — Is the patient impatient or cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	10a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>irr</b>			<b>irrsev</b>			
11.	<b>Motor disturbance</b> — Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, or wrapping string?	11a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>mot</b>			<b>motsev</b>			
12.	<b>Nighttime behaviors</b> — Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	12a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>nite</b>			<b>nitesev</b>			
13.	<b>Appetite and eating</b> — Has the patient lost or gained weight, or had a change in the food he or she likes?	13a. <input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
		<b>app</b>			<b>appsev</b>			

Taped:

Participant ID#:

T-

Date:

## Collateral Source

(DK = Doesn't Know)

**MEMORY**

- \*31. Does he/she have a problem with his/her memory or thinking? **int324** No (0) \_\_\_ Yes (1) \_\_\_
- \*31b. If yes, is it a consistent problem (as opposed to inconstant)? **int415** No (0) \_\_\_ Yes (1) \_\_\_
- \*32. Can he/she recall recent events? (Blessed) Usually (0) \_\_\_ Sometimes (.5) \_\_\_ Rarely (1) \_\_\_  
**BDS07**
- \*33. Can he/she remember short lists (4 or 5 items) of items (shopping)? (Blessed)  
**BDS03** Usually (0) \_\_\_ Sometimes (.5) \_\_\_ Rarely (1) \_\_\_
- \*45. Has there been some decline in memory during the past year? **int334** No (0) \_\_\_ Yes (1) \_\_\_
- \*46. Is his/her memory impaired to such a degree that it would have interfered with his/her activities of daily life a few years ago (or preretirement activities)? (Collateral Source's opinion)  
**int335** No (0) \_\_\_ Yes (1) \_\_\_ DK (Q) \_\_\_
- \*580. Does he/she have difficulty remembering appointments? **int417** No (0) \_\_\_ Yes (1) \_\_\_
- \*581. Does he/she repeat questions, stories or statements? **int418** No (0) \_\_\_ Yes (1) \_\_\_

**IF PARTICIPANT HAS NO MEMORY PROBLEM, PROCEED TO PAGE 25**

- \*38. Does he/she completely forget a major event (e.g., trip, party, family wedding) within a few weeks of the event? **int329** Rarely or Never (0) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_  
Example: **int329\_example**
- \*39. Does he/she forget pertinent details of the major event? **int330** Rarely or Never (0) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_
- \*41. Does he/she completely forget important information of the distant past (e.g., birthdate, date of wedding, place of employment?) **int332** Rarely or Never (0) \_\_\_ Sometimes (1) \_\_\_ Usually (2) \_\_\_ DK (Q) \_\_\_  
Example: **int332\_example**
- \*43. Describe Onset: **int009** Sudden (1) \_\_\_\_\_  
Gradual (2) \_\_\_\_\_  
Fluctuating (3) \_\_\_\_\_  
Other (describe at left) (4) **int009\_other**
- 43a. How long ago did the memory/thinking problem start? (number of years to the nearest decimal) \_\_\_\_\_ **durat**
- \*44. Course of memory problem: **int010** Stable (1) \_\_\_\_\_  
Gradually Worse (2) \_\_\_\_\_  
Episodically Worse (3) \_\_\_\_\_  
Fluctuating (4) \_\_\_\_\_  
Other (describe at left) (5) **int010\_other**

**Collateral Source****ORIENTATION**

How often does he/she know the exact:

	Usually	Sometimes	Rarely or Never	CS Doesn't Know	
*71. Date of the month?	____(2)	____(1)	____(0)	____(Q)	<b>int344</b>
*72. Month?	____(2)	____(1)	____(0)	____(Q)	<b>int345</b>
*73. Year?	____(2)	____(1)	____(0)	____(Q)	<b>int346</b>
*74. Day of the week?	____(2)	____(1)	____(0)	____(Q)	<b>int347</b>
*75. Does he/she tend to dwell in the past?					
	(Blessed)	Rarely(0)____	Sometimes(.5)____	Often(1)____	<b>BSB08</b>

\*75a. Does he/she have difficulty with time relationships?  
(When events happened in relation to each other) (Give example)

**int396\_example**Rarely (0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Usually (1)\_\_\_\_ **int396**

\*77. Can he/she find his/her way about familiar streets? (Blessed)

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ **BDS05**

\*78. How often does he/she know how to get from one place to another outside his/her neighborhood?

**int351**

Usually(2)\_\_\_\_ Sometimes(1)\_\_\_\_ Rarely(0)\_\_\_\_ DK(Q)\_\_\_\_

(If usually is answered for 78, can skip 79, which will be entered also as usually)

\*79. How often can he/she find his/her way about indoors?  
(own house or other familiar environment) (Blessed)

**BDS04**

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_

**Collateral Source****JUDGMENT AND PROBLEM SOLVING**

\*80. In general, if you had to rate his/her abilities to handle and solve problems at the present time, would you consider them:

Example:

As good as they have ever been (1)\_\_\_\_

Good, but not as good as before (2)\_\_\_\_

Only fair (3)\_\_\_\_

Very poor (4)\_\_\_\_

No ability at all (5)\_\_\_\_

No Loss	Some Loss	Severe Loss
------------	--------------	----------------

\*96 Ability to cope with small sums of money

[Blessed] (eg, make change, leave a small tip)

0	0.5	1
---	-----	---

\*96a Ability to handle more complicated financial or business transactions

(eg, balance checkbook, pay bills)

0	0.5	1
---	-----	---

\*82. Can he/she handle a household emergency: (plumbing leak, small fire)

Better than before (1)\_\_\_\_

As well as before (2)\_\_\_\_

Worse than before because of trouble thinking (3)\_\_\_\_

Worse than before for another reason (why?) (4)\_\_\_\_

\*76. Can he/she understand situations or explanations? (Blessed)

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ DK(Q)\_\_\_\_

\*76a. Does he/she exercise appropriate judgment in social situations and interactions with other people?

Usually(0)\_\_\_\_ Sometimes(.5)\_\_\_\_ Rarely(1)\_\_\_\_ DK(Q)\_\_\_\_

Taped:

Participant ID#  
**Collateral Source**

T- Date:  
**COMMUNITY AFFAIRS**

**Occupational**

**84.** Is the Participant still working? If NA, proceed to item 87. If yes, proceed to item 86, If no, proceed to item 85. **work**

NA \_\_\_ Yes \_\_\_ No \_\_\_

**85.** Did memory or thinking problems contribute to the Participant's decision to retire?

(Skip Question 86) **int357**

No(0) \_\_\_ Yes(1) \_\_\_ DK(Q) \_\_\_

**86.** Does the Participant have significant difficulty in his/her job because of problems with memory or thinking? **int358**

Rarely or Never(0) \_\_\_ Sometimes(1) \_\_\_ Usually(2) \_\_\_ DK(Q) \_\_\_

**Social**

**\*87.** Did he/she ever drive a car? **everdriv**

Yes \_\_\_ No \_\_\_

Does the Participant drive a car now? **drive**

Yes \_\_\_ No \_\_\_

If no, is this because of memory or thinking problems? **int359**

No(0) \_\_\_ Yes(1) \_\_\_

**\*87a.** If he/she is still driving, are there problems or risks because of poor thinking? **int397** **int397\_describe**

No(0) \_\_\_ Yes(1) \_\_\_

**\*90a.** Is he/she (cognitively) able independently to shop for needs? **int412**

**int412\_describe**

**Usually(0) \_\_\_**

**Sometimes(1) \_\_\_**

**Rarely or never(2) \_\_\_**

**DK(Q) \_\_\_**  
(Shops for limited number of items, buys duplicate items or forgets needed items.)

(Needs to be accompanied on any shopping trip.)

**\*90b.** Is he/she (cognitively) able independently to carry out activities outside the home? **int413**

**Usually(0) \_\_\_**

**Sometimes(1) \_\_\_**

**Rarely or never(2) \_\_\_ DK**

**(Q) \_\_\_**  
(Meaningful participation in activities, eg, voting.)

(Limited and/or routine; eg, superficial participation in church or meetings; trips to beauty parlor.)

(Generally unable to perform activities without help.)

**int413\_describe**

**\*91.** Is he/she taken to social functions outside of family home? **int636** Yes(1) \_\_\_ No(0) \_\_\_

If no, why not? **int636\_whynt**

**\*91b.** Would a casual observer of subject's behavior in community activities think the subject was ill? **int414**

No(0) \_\_\_ Yes(1) \_\_\_

NA(A) \_\_\_

**IMPORTANT:** Is there enough information available to rate the subject's level of impairment in community affairs? **not\_enough\_info**

**Community Affairs:** such as going to church, visiting with friends or family, political activities, professional organizations such as bar association, other professional groups, social clubs, service organizations, educational programs. If in nursing home, does he/she participate in programs or social activities?

## Form B7: FUNCTIONAL ASSESSMENT Functional Activities Questionnaire (FAQ<sup>1</sup>)

Taped:

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

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

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

Participant ID#

T-

Date:

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<sup>1</sup>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.

**Collateral Source HOME AND HOBBIES**

**Homemaking Tasks:** such as cooking, laundry, cleaning, grocery shopping, taking out garbage, yardwork, simple car maintenance, and basic home repair.

-- What changes have occurred in his/her (cognitive) abilities to perform household chores?

chn\_g\_hometask

-- What can he/she still do well?

well\_homestask

**Hobbies:** sewing, painting, handicrafts, reading, entertaining, photography, gardening, going to theater or symphony, woodworking, participation in sports.

-- What changes have occurred in his/her (cognitive) abilities to perform hobbies?

chn\_g\_hobby

-- What can he/she still do well?

well\_hobby

\*582. Because of memory and thinking problems has he/she had reduced interest in hobbies/activities?

int419

No \_\_\_ Yes \_\_\_ Don't Know \_\_\_

\*583. Because of memory and thinking has he/she had trouble learning how to use a tool, appliance, or gadget (e.g. VCR, remote control, computer, microwave etc.)?

int420

No \_\_\_ Yes \_\_\_ Don't Know \_\_\_

**Everyday Activities (Blessed)**

No Loss      Severe Loss

\*95. Ability to perform household tasks      BDS01

0      .5      1

\*549. The accuracy and reliability of the collateral source information are judged to be:

Good (0) \_\_\_\_\_ Questionable (0.5) \_\_\_\_\_ Poor (1) \_\_\_\_\_ CS\_Valid

Insufficient exposure \_\_\_\_\_ Denial/minimize \_\_\_\_\_ Secondary gain \_\_\_\_\_ Cognitive impairment \_\_\_\_\_

Other \_\_\_\_\_ Explain: CS\_insuf\_explain

CS\_insufexposure

**Important:** Is there enough information available to rate the subject's level of impairment in HOME& HOBBIES? A guide to level of function in household tasks is:

**No meaningful function (CDR 3):** nomeaningfulfunc

(Performs simple activities, such as making a bed, only with much supervision or not at all) \_\_\_\_\_

**Function in limited activities only (CDR 2):** funclimited

(With some supervision, washes dishes with acceptable cleanliness; sets table) \_\_\_\_\_

**Functions independently in some activities (CDR 1):** funcindep

(Operates appliances, such as a vacuum cleaner; prepares simple meals) \_\_\_\_\_

**Functions in usual activities but not at usual level (CDR 0.5):** funcflowerlevel

**Normal function in usual activities (CDR 0):** funcnormal

IF APPLICABLE, COMPLETE APHASIA CHECKLIST (on tape)



**\*\*\* STOP TAPE \*\*\*****Collateral Source****PERSONAL CARE**

**(SCORE BASED ON SEVERITY OF COGNITIVE LOSS; NOT FREQUENCY)  
(SCORE DOES NOT CORRELATE DIRECTLY WITH CDR RATING)**

What is your estimate of his/her mental ability in the following areas:

	<u>Unaided</u>	<u>Occ. Misplaced buttons, etc.</u>	<u>Wrong sequence, commonly forgotten items</u>	<u>Unable to dress</u>
<b>BDS10</b> N*97. dressing (Blessed)	0	1	2	3
<b>int371</b> N*99 washing, grooming	<u>Needs Unaided</u>	<u>Sometimes prompting</u>	<u>Always or nearly needs help</u>	<u>always needs help</u>
<b>BDS09</b> N*100. eating habits (Blessed)	<u>Cleanly, proper utensils</u>	<u>Messily, Spoon</u>	<u>Simple solids</u>	<u>Has to be fed Completely</u>
<b>BDS11</b> N*101. sphincter control (Blessed)	<u>Normal complete control</u>	<u>Occ. Wets bed</u>	<u>Freq. wets bed</u>	<u>Doubly incontinent</u>

## N\*Cognitive Milestones

	<u>Month</u>	<u>Year</u>	<u>NA</u>	<u>DK</u>
*Unable to help with dressing	<u>miles1_mn</u>	<u>miles1_yr</u>	<u>miles1_na_dk</u>	
*Unable to walk unassisted	<u>miles2_mn</u>	<u>miles2_yr</u>	<u>miles2_na_dk</u>	
*Unable to use spoon for eating	<u>miles3_mn</u>	<u>miles3_yr</u>	<u>miles3_na_dk</u>	
*Bladder or bowel incontinence once a week	<u>miles4_mn</u>	<u>miles4_yr</u>	<u>miles4_na_dk</u>	
*Bladder or bowel incontinence daily	<u>miles5_mn</u>	<u>miles5_yr</u>	<u>miles5_na_dk</u>	
*Permanent nursing home admission	<u>miles6_mn</u>	<u>miles6_yr</u>	<u>miles6_na_dk</u>	

**Clinician: Turn to page 34 to obtain CS recent events.**

## -Participant Interview-

\*\*\*START TAPE\*\*\*

## GENERAL HEALTH

(Sympathetic and interested conversation, taking lead from opening remarks)

UA = Unable to answer

DK = Don't know

hlth\_prob

202. Have you had any problems with your health lately? Yes(1)\_\_\_\_ No(0)\_\_\_\_ UA(.C)\_\_\_\_ :  
If yes, describe.

hlth\_prob\_describe

int501

\*203. Have you had any problem with your thinking or memory? Yes(1)\_\_\_\_ No(0)\_\_\_\_ UA(.C)\_\_\_\_ If  
yes: a. please describe: (record reply verbatim)

int501\_describe

\*226. (Ask only if subject admits having memory or thinking problems.) How long have you been having  
memory or thinking problems? (Subject's estimate in months) \_\_\_\_\_

int513

How consistent is the memory problem?

int513\_consistent

205. Why are you here today? Explain: Knows \_\_\_\_\_ Confabulates \_\_\_\_\_ DK \_\_\_\_\_

why\_here\_explain

why\_here

**Collateral Source**

**MEMORY**

**RECENT MEMORY EVALUATION TEST ITEMS**

2) Tell me about some recent events in his/her life that he/she should remember?  
(for later testing – pg 31)

**Within 1 week** event\_1wk\_cs

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**Within 1 month** event\_1mn\_cs

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**Examples:**

- Any injury or illness in him/her or someone else in home/close family?
- Any letters or phone calls from someone who doesn't usually contact him/her?
- Any visitors?
- Any trips?
- Any bad news?
- Any special events (holidays, family events)?

Taped:

Participant ID#

T-

Date:

**Participant**

**MEMORY**

**227. RECENT MEMORY EVALUATION**

Tell me about some things that have happened lately (illness, etc.)

**Within 1 week** event\_1wk\_p

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wk\_score\_p 1 – Largely correct \_\_\_\_\_ 0.5 \_\_\_\_\_ 0 – Largely incorrect \_\_\_\_\_

**Within 1 month** event\_1mn\_p

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1 – Largely correct \_\_\_\_\_ 0.5 \_\_\_\_\_ 0 – Largely incorrect \_\_\_\_\_

mn\_score\_p

\*228. Total correct (may give half credit) int579

Taped:

Participant ID#

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Date:

**-INTENTIONALLY BLANK-**

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

**Form B6: BEHAVIORAL ASSESSMENT — Geriatric Depression Scale (GDS)<sup>1</sup>**

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

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

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

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

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

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

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

**gds**

<sup>1</sup>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.

Taped:

Participant ID#

T-

Date:

**DEPRESSIVE FEATURES BATTERY -  
Version 8/14/00**

**RESPONDENT: P**

**Depressed Mood**

215. In the past year, have you felt sad or blue or depressed most of the day nearly every day for two weeks or more? int139

Y \_\_\_ N \_\_\_

**Recurrent Thoughts of Death/Suicidal Ideation**

224. In the last year, have you felt that life is not worth living or expressed a wish to die or talked about committing suicide? suicide

Y \_\_\_ N \_\_\_

**Additional medical attention recommended (circle one)**

**Yes**

**No**

int148

**N**

Participant Interview

## N206.B Expressive Language

(Show cookie theft picture) "Tell me everything you see going on in this picture."

Response: **N206**

## RATING SCALE PROFILE OF SPEECH CHARACTERISTICS

	0	1	2	3	4	5	6
a) MELODIC LINE intonational contour <b>melodic_line</b>	Absent			Limited to short phrases and stereotyped expressions			Runs thru entire sentence
b) PHRASE LENGTH longest occasional (1/10) uninterrupted word runs <b>phrase_length</b>	x 1 word	x	x	x 4 words	x	x	x 7 words
c) ARTICULATORY AGILITY facility at phonemic and syllable level <b>articular_agility</b>	x always impaired or impossible	x	x	x normal only in familiar words and phases	x	x	x never impaired
d) GRAMMATICAL FORM variety of gram- matical construc- tion (even if incomplete) <b>grammar_form</b>	x not available	x	x	x limited to simple declarative stereotypes	x	x	x normal range
e) PARAPHASIA IN RUNNING SPEECH <b>paraphasia</b>	x present in every utterance	x	x	x once per minute of conversation	x	x	x absent
f) WORD FINDING informational content in relation to fluency <b>word_find</b>	x fluent without information	x	x	x information proportional to fluency	x	x	x normal

\*207 Speech Score:

$$\left( \frac{\sum a \text{ to } f}{6} \right) = \frac{\quad}{6} = \text{int065}$$

## C. Oral Naming

Tell me the name of the thing I point to: Card 2)

	Correct	Incorrect
Chair	1	0 <b>chair_n</b>
H	<b>h_n</b> 1	0
Square	1	0 <b>square_n</b>
Key	<b>key_n</b> 1	0
Glove	1	0 <b>glove_n</b>
Feather	1	0 <b>feather_n</b>

\*208. Oral Naming Score **int066****N**

Participant Interview



Taped:

Participant ID#

T-

Date:

### D. Reading Comprehension

Read this card aloud; show me the answer for each line or do what it says

**Correct**      **Incorrect**

Make a fist       1 \_\_\_\_\_ 0

How many ears does a person have       1 \_\_\_\_\_ 0

Show what you do when your nose starts to itch       1 \_\_\_\_\_ 0

Point to the second word in this sentence       1 \_\_\_\_\_ 0

\*209. Reading Score

### E. Reception – Answer “Yes” or “No”

**Correct**      **Incorrect**

Will a wooden board generally sink in water? (No)      1 \_\_\_\_\_ 0

Will a stone sink in water? (Yes)       1 \_\_\_\_\_ 0

Is a hammer good for cutting wood? (No)       1 \_\_\_\_\_ 0

Do two pounds of flour weigh more than one pound? (Yes)       1 \_\_\_\_\_ 0

Will water go through a good pair of rubber boots? (No)       1 \_\_\_\_\_ 0

\*210. Reception Score

### F. Show me each after I name it (Card 2)

Chair       **Correct**      **Incorrect**  
1 \_\_\_\_\_ 0

L       1 \_\_\_\_\_ 0

Circle       1 \_\_\_\_\_ 0

Key       1 \_\_\_\_\_ 0

Glove       1 \_\_\_\_\_ 0

\*211. Show Score

### 2) Point to your:

**Correct**      **Incorrect**

ear       1 \_\_\_\_\_ 0

nose       1 \_\_\_\_\_ 0

shoulder      1 \_\_\_\_\_ 0

eyelid       1 \_\_\_\_\_ 0

neck       1 \_\_\_\_\_ 0

\*212. Point Score

Taped:

Participant ID#

T-

Date:

N

**Participant Interview**

**NH. Written Expression**

Write the name of the one I point to (Card 2)

**Correct      Incorrect**

Key	1 _____ 0	<u>key_w</u>
Chair	1 _____ 0	<u>chair_w</u>
Circle	1 _____ 0	<u>circle_w</u>
Square	1 _____ 0	<u>square_w</u>

\*213. Written Score int068

**\*214 Clinician's assessment of Aphasia:**

0 = Absent int074

1 = Questionable

2 = Present

**1. Mini-Mental State Examination Summary for Form C1 MMSELOC**

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

1b. Orientation subscale score

1) Time: MMSEORDA \_\_\_\_\_ (0 – 5) (MMSEORDA)

2) Place: MMSEORLO \_\_\_\_\_ (0 – 5) (MMSEORLO)

1c. Total MMSE score (using D-L-R-O-W) MMSE \_\_\_\_\_ (0 – 30) (MMSE)

Taped:

Participant ID#

T-

Date:

**THIS PAGE INTENTIONALLY BLANK**

Taped:

Participant ID#

T-

Date:

N

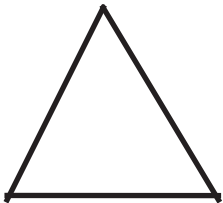
\*N287. Draw a clock with all the numbers; then show me 2:45 int073

0 = Correct  
1 = Partially correct  
2 = Incorrect

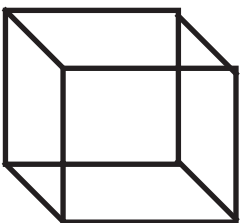
**Participant to complete drawing on MoCA form.**

Please copy these drawings as closely as you can.

N\*288 0 = Correct  
1 = Partially correct  
2 = Incorrect  
int562

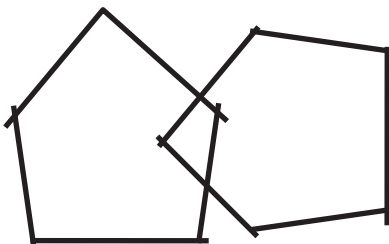


N\*291 0 = Correct  
1 = Partially correct  
2 = Incorrect  
int565



**Participant to complete drawing on MoCA form.**

(Not for data entry)  
N\*548 0 = Correct  
(MMSE) 2 = Incorrect  
(see MOO for correct scoring)



Taped:

Participant ID#

T-

Date:

MAP ID#: \_\_\_\_\_ Date: \_\_\_\_\_

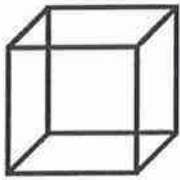
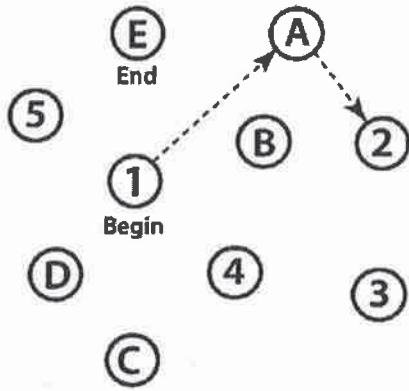
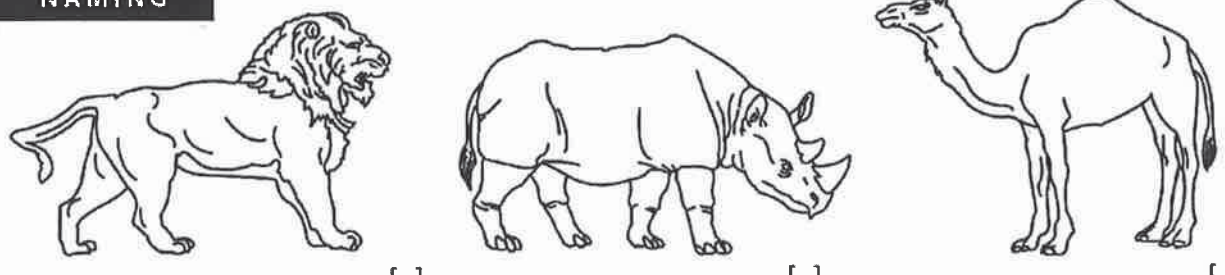
BP \_\_\_\_\_ Pulse \_\_\_\_\_ Ht: \_\_\_\_\_ Weight: \_\_\_\_\_

Abd. Girth: \_\_\_\_\_ Visual acuity OD: \_\_\_\_\_ OS: \_\_\_\_\_ Glasses Y or N

SPELLING OF WORDS

WRITING SENTENCE:

# Montreal Cognitive Assessment (MoCA)

<b>VISUOSPATIAL / EXECUTIVE</b>							Draw <b>CLOCK</b> (Ten past eleven) (3 points)	<b>POINTS</b>
		<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>					<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	___/5
<b>NAMING</b>							<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	___/3
<b>MEMORY</b>	Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.					FACE    VELVET    CHURCH    DAISY    RED	No points	
	1st trial							
	2nd trial							
<b>ATTENTION</b>	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2					___/2		
	Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					___/1		
	Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: <b>3 pts</b> , 2 or 3 correct: <b>2 pts</b> , 1 correct: <b>1 pt</b> , 0 correct: <b>0 pt</b>					___/3		
<b>LANGUAGE</b>	Repeat : I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]					___/2		
	Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)					___/1		
<b>ABSTRACTION</b>	Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler					___/2		
<b>DELAYED RECALL</b>	Has to recall words WITH NO CUE					Points for UNCUED recall only	___/5	
	FACE	VELVET	CHURCH	DAISY	RED			
<b>Optional</b>	Category cue Multiple choice cue							
<b>ORIENTATION</b>	[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City					___/6		
© Z.Nasreddine MD		www.mocatest.org		Normal ≥ 26 / 30		<b>TOTAL</b>	___/30	
						Add 1 point if ≤ 12 yr edu		

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**INITIAL VISIT PACKET** NACC UNIFORM DATA SET (UDS)

**Form C2: Neuropsychological Battery Scores**

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

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

**INSTRUCTIONS:** This form is to be completed by ADC or clinic staff. For test administration and scoring, see Instructions for Neuropsychological Battery Form C2. Any new subjects who enroll in the UDS after the implementation of UDS3 must be assessed with the new neuropsychological test battery (Form C2).

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:

95 / 995 = Physical problem    96 / 996 = Cognitive/behavior problem    97 / 997 = Other problem    98 / 998 = Verbal refusal

**1. Montreal Cognitive Assessment (MoCA)**

1a. Was any part of the MoCA administered?

mocacomp

 0 No (If No, enter reason code, 95 – 98): \_\_\_\_\_

(SKIP TO QUESTION 2a)

mocareas

 1 Yes (CONTINUE WITH QUESTION 1b)

1b. MoCA was administered:

 1 In ADC or clinic

 2 In home

 3 In person — other

mocaloc

1c. Language of MoCA administration:

 1 English

 2 Spanish

 3 Other (SPECIFY): \_\_\_\_\_

mocalanx

1d. Subject was unable to complete one or more sections due to visual impairment:

 0 No

 1 Yes

1e. Subject was unable to complete one or more sections due to hearing impairment:

 0 No

 1 Yes

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

mocatots

Enter 88 if any of the following MoCA items were not administered:  
1g–1l, 1n–1t, 1w–1bb

\_\_\_\_\_ (0–30, 88)

1g. Visuospatial/executive — Trails

mocatrai

\_\_\_\_\_ (0–1, 95–98)

1h. Visuospatial/executive — Cube

mocacube

\_\_\_\_\_ (0–1, 95–98)

1i. Visuospatial/executive — Clock contour

mocacloc

\_\_\_\_\_ (0–1, 95–98)

1j. Visuospatial/executive — Clock numbers

mocaclon

\_\_\_\_\_ (0–1, 95–98)

1k. Visuospatial/executive — Clock hands

mocacloh

\_\_\_\_\_ (0–1, 95–98)

1l. Language — Naming

mocanami

\_\_\_\_\_ (0–3, 95–98)

1m. Memory — Registration (two trials)

mocaregi

\_\_\_\_\_ (0–10, 95–98)

1n. Attention — Digits

mocadigi

\_\_\_\_\_ (0–2, 95–98)

1o. Attention — Letter A

mocalett

\_\_\_\_\_ (0–1, 95–98)

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

1p. Attention — Serial 7s	<b>mocaser7</b>	__ __ (0-3, 95-98)
1q. Language — Repetition	<b>mocarepe</b>	__ __ (0-2, 95-98)
1r. Language — Fluency	<b>mocaflue</b>	__ __ (0-1, 95-98)
1s. Abstraction	<b>mocaabst</b>	__ __ (0-2, 95-98)
1t. Delayed recall — No cue	<b>mocarecn</b>	__ __ (0-5, 95-98)
1u. Delayed recall — Category cue	<b>mocarecc</b>	__ __ (0-5; 88=Not applicable)
1v. Delayed recall — Recognition	<b>mocarecr</b>	__ __ (0-5; 88=Not applicable)
1w. Orientation — Date	<b>mocaordt</b>	__ __ (0-1, 95-98)
1x. Orientation — Month	<b>mocaormo</b>	__ __ (0-1, 95-98)
1y. Orientation — Year	<b>mocaoryr</b>	__ __ (0-1, 95-98)
1z. Orientation — Day	<b>mocaordy</b>	__ __ (0-1, 95-98)
1aa. Orientation — Place	<b>mocaorpl</b>	__ __ (0-1, 95-98)
1bb. Orientation — City	<b>mocaorct</b>	__ __ (0-1, 95-98)
<b>2. ADMINISTRATION OF THE REMAINDER OF THE BATTERY</b>		
2a. The tests following the MoCA were administered: <input type="checkbox"/> 1 In ADC or clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other		
2b. Language of test administration: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____		
<b>3. Craft Story 21 Recall (Immediate)</b>		
3a. Total story units recalled, verbatim scoring <i>(If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 4a.)</i>		__ __ (0-44, 95-98)
3b. Total story units recalled, paraphrase scoring		__ __ (0-25)
<b>4. Benson Complex Figure Copy</b>		
4a. Total score for copy of Benson figure <i>(If test not completed, enter reason code, 95-98)</i>		__ __ (0-17, 95-98)
<b>5. Number Span Test: Forward</b>		
5a. Number of correct trials <i>(If test not completed, enter reason code, 95-98, and SKIP TO QUESTION 6a.)</i>		__ __ (0-14, 95-98)
5b. Longest span forward		__ __ (0, 3-9)

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**Collateral Source****PAST MEMORY EVALUATION**

- N49. Date of subject's birth N49
- 
- N50. Place of subject's birth N50
- 
- N51. How old is the subject N51
- 
- N52. Subject's mother's full maiden name N52
- 
- N53. Subject's last school: name N53a
- 
- grade N53b
- 
- place N53c
- 
- N54 \*N54. Present status – married divorced widowed separated never married
- N55. Since int008
- 
- N56a. Has the subject been married more than once? N56
- 
- N57. Name of subject's current (most recent) spouse N57
- 
- N57a (or oldest sibling if never married and circle spouse or sibling)
- N59. Subject's present (home) telephone number N59
- 
- If subject does not have a telephone, then subject's present address N59a
- 
- (If currently in nursing home, use last phone and address before nursing home entry)
- N60. How many children? N60
- 
- N62. Subject's (or spouse's) main occupation? N62
- 
- (Spouse's if subject not substantially employed)
- N62a. What was subject's or spouse's last major job? N62a
- 
- N63. Subject's (or spouse's) retirement date? N63
- 
- Circumstances? N63\_circum
-

## Participant

- |   |   | <b>Correct</b> | <b>Incorrect</b> |
|---|---|----------------|------------------|
| *N232. What is your name? (Blessed II)  | <u>int516_text</u>                              | int516 (1)     | (0)              |
| *N233. When were you born?<br>(Exact month, day, year) (Pfeiffer)   | <u>MSQ06_mm</u> <u>MSQ06_dy</u> <u>MSQ06_yr</u> | MSQ06 (0)      | (1)              |
| *N234. Where were you born? (Blessed II)  | <u>int518_text</u>                              | int518 (1)     | (0)              |
| *N235. How old are you? (Pfeiffer)  | <u>MSQ05_text</u>                               | MSQ05 (0)      | (1)              |
| *N236. What was your mother's full maiden name? (Pfeiffer - *Any female first name and last name other than subjects own.)                          | <u>MSQ09_text</u>                               | MSQ09 (0)      | (1)              |
| What was the last school you attended?  |   |                |                  |
| *N237. Name (Blessed II)  | <u>int521_text</u>                              | int521 (1)     | (0)              |
| *N238. Grade  | <u>int522_text</u>                              | int522 (1)     | (0)              |
| *N239. Place (Blessed II)   | <u>int523_text</u>                              | int523 (1)     | (0)              |
| *N240. What is your marital status?<br>(year or # of years)   | <u>int524_text</u>                              | int524 (1)     | (0)              |
| *N241. How long?  | <u>int525_text</u>                              | int525 (1)     | (0)              |
| *N242. Have you been married more than once?  | <u>int526_text</u>                              | int526 (1)     | (0)              |
| *N243. What is (was) your spouse's name (or oldest sibling)?<br>(Blessed II)  | <u>int527_text</u>                              | int527 (1)     | (0)              |
| *N244. What is your (home) telephone number? (Pfeiffer)   | <u>MSQ04_text</u>                               | MSQ04 (0)      | (1)              |
| If person does not have a telephone, then ask: What is your address?<br>(If currently in nursing home, ask for last phone or address before entry?) |   |                |                  |
| *N246. How many children did you have?  | <u>int529_text</u>                              | int529 (1)     | (0)              |
| *N247. What was your main occupation (job)?<br>(Blessed II) (Spouse's if subject was not employed; cf. 62)  | <u>int530_text</u>                              | int530 (1)     | (0)              |
| *N248. What was your last major job?<br>(Blessed II)(Spouse's if subject not employed; cf. 62a)   | <u>int531_text</u>                              | int531 (1)     | (0)              |
| *N249. When did you (or spouse) retire and why?(cf. 63)<br>(year or # of years – not age at time of retirement)                                     | <u>int532_text</u>                              | int532 (1)     | (0)              |
| *N250. Who is the President of the U.S. now?<br>(last name sufficient)(Pfeiffer)  | <u>MSQ07_text</u>                               | MSQ07 (0)      | (1)              |
| *N251. Who was President just before him/her?<br>(last name sufficient)(Pfeiffer)   | <u>MSQ08_text</u>                               | MSQ08 (0)      | (1)              |
| *N252. Count aloud from 1 to 20 by 1 (Blessed II)   | 0 1 2 Errors <u>int533</u>                      |                |                  |

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**Worksheet for MINI MENTAL STATE EXAMINATION (MMSE)**

**Instructions:** Words in boldface type should be read aloud clearly and slowly to the examinee. Item substitutions appear in parentheses. Administration should be conducted privately and in the examinee's primary language. Circle "0" if the response is incorrect, or "1" if the response is correct. Begin by asking the following two questions:

**Do you have any trouble with your memory?**

**May I ask you some questions about your memory?**

ORIENTATION TO TIME	RESPONSE	SCORE (circle one)
<b>What is the... year?</b>	KSBJ2R	KSBJ2 0 1
<b>season?</b>	seasR	seas 0 1
<b>month of the year?</b>	KSBJ1R	KSBJ1 0 1
<b>day of the week?</b>	MSQ02R	MSQ02 0 1
<b>date?</b>	MSQ01R	MSQ01 0 1

**ORIENTATION TO PLACE**

(Alternative place words that are appropriate for the setting and increasingly precise may be substituted and noted.)

**Where are we now? What is the...**

**state** (province)?

locaR

loca

0 1

**county** (city/town)?

counR

coun

0 1

**city/town** (or part of city/neighborhood)?

int548R

int548

0 1

**building** (name or type)?

MSQ03R

MSQ03

0 1

**floor of the building** (room number or address)?

leveR

leve

0 1

**REGISTRATION**

(Alternative word sets [e.g., PONY, QUARTER, ORANGE] may be substituted and noted when retesting an examinee.)

**Listen carefully. I am going to say three words. You say them back after I stop. Ready?**

**Here they are...APPLE [pause], PENNY [pause], TABLE [pause]. Now repeat those words back to me.**

[Repeat up to 5 times, but score only the first trial.]

APPLE

ballR

ball

0 1

PENNY

flagR

flag

0 1

TABLE

treeR

tree

0 1

**Now keep those words in mind. I am going to ask you to say them again in a few minutes.**

**ATTENTION**

**The word WORLD is spelled W-O-R-L-D.**

**Spell WORLD backwards.**

[Allow additional trials if requested.]

int089aR1

(D=1)

(L=1)

int089aR3

(R=1)

(O=1)

int089aR5

(W=1)

int089a

(0 to 5)

int089aR2

int089aR4

(continued) →

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<b>RECALL</b>				
<b>What were those words I asked you to remember?</b>				
APPLE	<input type="text" value="ball2R"/>	<input type="text" value="ball2"/>	0	1
PENNY	<input type="text" value="flag2R"/>	<input type="text" value="flag2"/>	0	1
TABLE	<input type="text" value="tree2R"/>	<input type="text" value="tree2"/>	0	1
<b>NAMING</b>		<b>RESPONSE</b>	<b>SCORE (circle one)</b>	
<b>What is this?</b> [ <i>Point to a pencil or pen.</i> ]		<input type="text" value="pencR"/>	<input type="text" value="penc"/>	0 1
<b>What is this?</b> [ <i>Point to a watch.</i> ]		<input type="text" value="watcR"/>	<input type="text" value="watc"/>	0 1
(Alternative common objects [e.g., eyeglasses, chair, keys] may be substituted and noted.)				
<b>REPETITION</b>				
<b>Now I am going to ask you to repeat what I say. Ready? "NO IFS, ANDS, OR BUTS." Now you say that.</b> [Repeat up to 5 times, but score only the first trial.]				
NO IFS, ANDS, OR BUTS	<input type="text" value="phraR"/>	<input type="text" value="phra"/>	0	1
Use the following 3-segment page for the remaining items (cut the page along the dotted lines). Use the upper portion of the page (blank) for the <i>Comprehension</i> , <i>Writing</i> , and <i>Drawing</i> items that follow. Use the middle portion of the page ("CLOSE YOUR EYES") as a stimulus form for the <i>Reading</i> item. Use the lower portion (intersecting pentagons) for the <i>Drawing</i> item.				
<b>COMPREHENSION</b>				
<b>Listen carefully because I am going to ask you to do something.</b>				
<b>Take this paper in your right hand [pause], fold it in half [pause], and put it on the floor (or table).</b>				
TAKE IN RIGHT HAND	<input type="text" value="righR"/>	<input type="text" value="righ"/>	0	1
FOLD IN HALF	<input type="text" value="foldR"/>	<input type="text" value="fold"/>	0	1
PUT ON FLOOR (or TABLE)	<input type="text" value="lapR"/>	<input type="text" value="lap"/>	0	1
<b>READING</b>				
<b>Please read this and do what it says.</b> [Show examinee the words on the stimulus form.]				
CLOSE YOUR EYES	<input type="text" value="redoR"/>	<input type="text" value="redo"/>	0	1
<b>WRITING</b>				
(Place the blank piece of paper (unfolded) in front of the subject and provide a pen or pencil.)				
<b>Please write a sentence.</b> [If examinee does not respond, say: <b>Write about the weather.</b> ] <input type="text" value="sent"/>				
Score 1 point if the sentence is comprehensible and contains a subject and a verb. Ignore errors in grammar or spelling.				
<b>DRAWING</b>				
<b>Please copy this design.</b> [Display the intersecting pentagons on the stimulus form.] <input type="text" value="draw"/>				
Score 1 point if the drawing consists of two 5-sided figures that intersect to form a 4-sided figure.				

Assessment of level of consciousness. Alert/  
Responsive

Drowsy

Stuporous

Comatose/  
UnresponsiveTotal Score =   
(Sum all item scores) (30 points max.)

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

**Form B1: EVALUATION FORM Physical**

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

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

*INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B1. Check only one box per question.*

Subject physical measurements				
1. Subject height (inches)	<b>height</b>	____.____	(88.8=not assessed)	
2. Subject weight (lbs.)	<b>weight</b>	_____	(888=not assessed)	
3. Subject blood pressure at initial reading (sitting)	<b>bpsys</b> / <b>bpdias</b>	____ / ____	(888/888=not assessed)	
4. Subject resting heart rate (pulse)	<b>hrate</b>	_____	(888=not assessed)	
Additional physical observations				
		No	Yes	Unknown
5. Without corrective lenses, is the subject's vision functionally normal?	<b>vision</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
6. Does the subject usually wear corrective lenses? (If no or unknown, <b>SKIP TO QUESTION 7</b> )	<b>viscorr</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
6a. If yes, is the subject's vision functionally normal <u>with</u> corrective lenses?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9 <b>viswcorr</b>
7. Without a hearing aid(s), is the subject's hearing functionally normal?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9 <b>hearing</b>
8. Does the subject usually wear a hearing aid(s)? (If no or unknown, <b>END FORM HERE</b> )	<b>hearaid</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
8a. If yes, is the subject's hearing functionally normal <u>with</u> a hearing aid(s)?		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9 <b>hearwaid</b>

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**ORIENTATION, MEMORY AND CONCENTRATION**

- \*229. I will give you a name and address to remember for a few minutes. Listen to me say the entire name and address, and then repeat it after me:

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

John Brown, 42 Market Street, Chicago

int515a\*

int515b\*

int515d\*

int515e\*

\* = trial number (up to 3 trials)

(underline words repeated correctly in each trial)

Trials to criterion int515 (can't do in 3 trials = C)

Good, now remember that name and address for a few minutes.

- \*271. Without looking at your watch or clock, tell me about what time it is. Correct Incorrect

If response is vague, prompt for specific response.

ksbt3

0

1

(within 1 hour) (Katzman) ksbt3\_response

Actual time: ksbt3\_actual

- \*253. Count aloud backwards from 20 to 1 (Katzman) ksbt4 0 1 2 Errors

If Subject starts counting forward or forgets the task, repeat instructions and score one error.

(Mark correctly sequenced numerals) ksbt4\_\*

20 19 18 17 16 15 14 13 12 11

10 9 8 7 6 5 4 3 2 1

\* = \_ Number listed (up to 20)

- \*254. Name the months of the year starting with last month of the year and going backwards. (Katzman)

If the Clinician needs to prompt with name of the last month of the year, one error should be scored.

(Mark correctly sequenced months)

D N O S A JL JN MY AP MR F J ksbt5\_\*

ksbt5

0

1

2

Errors

\* = \_ Number listed (up to 12)

- \*245. Repeat the name and address I asked you to remember. (Katzman)

The thoroughfare term (Street) is not required.

(John Brown, 42 Market Street, Chicago)

ksbt6

0

1

2

3

4

5

Errors

ksbt6\_c

ksbt6\_a

ksbt6\_b

ksbt6\_d

ksbt6\_e

**Check correct items**

**JUDGMENT & PROBLEM SOLVING****Participant**

**ABSTRACTIONS** \*Instructions: If initial response by subject does not merit a grade 0, press the matter to identify the subject's best understanding of the problem. Circle score.

**A. Similarities**

Example: How are a pencil and a pen alike? (writing instruments)

"How are these things alike?"

**Participant's Response:**

- \*273. Turnip . . . . . cauliflower int551 int551R  
 (0 = vegetables)  
 (1 = edible foods, living things, can be cooked, etc.)  
 (2 = answers not pertinent; differences; buy them)
- \*274. Desk . . . . . bookcase int552 int552R  
 (0 = furniture, office furniture; both hold books)  
 (1 = wooden, legs)  
 (2 = not pertinent, differences)

**B. Differences**

Example: What is the difference between sugar and vinegar? (sweet vs sour)

"Can you tell me what is the difference between these things?"

**Participant's Response:**

- \*275. Lie . . . . . mistake int533 int533R  
 (0 = one deliberate, one unintentional)  
 (1 = one bad, the other good – or explains only one)  
 (2 = anything else, similarities)
- \*277. River . . . . . canal int555 int555R  
 (0 = natural – artificial)  
 (2 = anything else)

**C. Calculations**

- |  | <u>Correct</u> | <u>Incorrect</u> |
|--|----------------|------------------|
| *278. a) How many nickels in a dollar? (20) <u>int556</u><br>(If <u>Incorrect</u> for 278, can skip 279, which will be entered also as <u>Incorrect</u> )<br>Check here if you have skipped question 279 _____ | 0              | 1                |
| *279. b) How many quarters in \$6.75? (27) <u>int557</u>   | 0              | 1                |
| *280. c) Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down. (Pfeiffer) <u>MSQ10</u>   | 0              | 1                |

**D. Judgment**

- \*282. Upon arriving in a strange city, how would a person locate a friend there that they wished to see?  
 0 = try the telephone book, city directory, internet search, call a mutual friend  
 1 = call the police, call operator (usually will not give address) int560  
 2 = no clear response

Response:

int560R

- \*284. Subject's assessment of disability and station in life and under standing of why he/she is present at the examination (may have been covered earlier, but rate here) **Explain:** int064R

Good insight 0 \_\_\_      Partial insight 1 \_\_\_      Little insight 2 \_\_\_

**IF APPLICABLE, COMPLETE APHASIA CHECKLIST (on tape)**

\*\*\*STOP TAPE\*\*\*

**Physical Examination**N576. Abdominal Girth abgirthN 577. Hgb A1C hgbVision (Rosenbaum Card at 14 inches) **with best correction**\*N296.OD visionod Better than 20/50 Yes \_\_\_\_\_ No rt20\_50**visfield** \*N297.OS visionos Better than 20/50 Yes \_\_\_\_\_ No lt20\_50\*295. **Visual fields** Normal \_\_\_\_\_ Abnormal \_\_\_\_\_ (describe) visfield\_describe298. **Extraocular movements:** Normal \_\_\_\_\_ extroculamov  
Abnormal (describe) \_\_\_\_\_ Nystagmus (describe) extroculamov\_describe**299. Pupil size****Reactivity****Optic Fundi**OD od\_pupil\_sizeod\_reactivityod\_optic\_fundiOS os\_pupil\_sizeos\_reactivityos\_optic\_fundi

## 300. Cranial nerves

V cranV cranV\_describeVII cranVII cranVII\_describeVIII cranVIII cranVIII\_describeIX cranIX cranIX\_describecranX cranX\_describe XXI cranXI cranXI\_describecranXII cranXII\_describe XII301. Neck neck Bruits? bruits302. Sensory: pain (pinprick) pain Described Details \_\_\_\_\_  
position position \_\_\_\_\_  
vibration vibration \_\_\_\_\_  
stereognosis stereognosis \_\_\_\_\_

303. Reflexes Absent Weak or Normal Increased

Tendon \_\_\_\_\_

bicepsR Right biceps \_\_\_\_\_Right triceps tricepsR \_\_\_\_\_kneeR Right knee \_\_\_\_\_Right ankle ankleR \_\_\_\_\_bicepsL Left biceps \_\_\_\_\_Left triceps tricepsL \_\_\_\_\_kneeL Left knee \_\_\_\_\_Left ankle ankleL \_\_\_\_\_\*304. Abnormal plantar reflex Present 1 Absent 0 int116

<u>Motor:</u>	<u>Present</u>			<u>Absent</u>
	RUE(1)	LUE(2)	Other (describe)	
<u>Tone:</u>				
*309. Spasticity	<input type="text" value="int121"/>	___	<input type="text" value="int121_describe"/>	(0)___
*310. Cogwheel rigidity	<input type="text" value="int122"/>	___	<input type="text" value="int122_describe"/>	___
*311. Gegenhalten	<input type="text" value="int123"/>	___	<input type="text" value="int123_describe"/>	___
<u>Abnormal movements:</u>				
*312. Myoclonus	<input type="text" value="int566"/>	___	<input type="text" value="int566_describe"/>	___
*313. Resting tremor	<input type="text" value="int567"/>	___	<input type="text" value="int567_describe"/>	___
*314. Essential/senile tremor	<input type="text" value="int568"/>	___	<input type="text" value="int568_describe"/>	___
*315. Other (describe)	<input type="text" value="int569"/>	___	<input type="text" value="int569_describe"/>	___
*316. <u>Bradykinesia:</u>	Present (1)___	Absent (0)___	<input type="text" value="int124"/>	
*317. <u>Extrapyramidal disorder:</u>	Present (1) ___	Questionable (2)___	Absent (0) ___	<input type="text" value="int570"/>
<input type="text" value="int571"/> 318. <u>Other neurological abnormalities:</u> (Describe)	<input type="text" value="int571_describe"/>			
*319. <u>Gait</u>	Normal(0)___	Abnormal(1)___	<input type="text" value="int572"/>	
Define:	short steps___	shuffle___	lack of arm swing___	flexed/stooped posture___
	turns en bloc___	wide-based___	poor tandem___	Other(describe)___ <input type="text" value="int572_describe"/>
*320. <u>Posture:</u>	Normal(0)___	Abnormal(1)___	<input type="text" value="int573"/>	
(Explain)	<input type="text" value="int573_describe"/>			
*320a. Limb coordination	Normal (0)___	Abnormal (1)___	<input type="text" value="int581"/>	
<u>Praxis</u>		<u>Normal</u> (0)	<u>Abnormal</u> (Explain) (1)	
*323. a. Dressing: Blouse/shirt or jacket/socks/shoes		<input type="text" value="prax1"/>	<input type="text" value="prax1_explain"/>	
b. Show use of: Toothbrush		<input type="text" value="prax2"/>	<input type="text" value="prax2_explain"/>	
c. Key		<input type="text" value="prax3"/>	<input type="text" value="prax3_explain"/>	
d. Pencil (Objects to be provided)		<input type="text" value="prax4"/>	<input type="text" value="prax4_explain"/>	
324. <u>Summary of important neurological findings</u>	<input type="text" value="nuero_notes"/>			

325. Summary of important non-neurological findings

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

**Form B8: EVALUATION FORM** Neurological Examination Findings

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

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

*INSTRUCTIONS: This form must be completed by a clinician with experience in assessing the neurological signs listed below and in attributing the observed findings to a particular syndrome. Please use your best clinical judgment in assigning the syndrome. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form B8.*

**1. Were there abnormal neurological exam findings?** **normexam**

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

**INSTRUCTIONS FOR QUESTIONS 2 – 8**

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

**CHECK ALL OF THE GROUPS OF FINDINGS / SYNDROMES THAT WERE PRESENT:**
**2. Parkinsonian signs** **parksign**

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

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

Parkinsonian signs	LEFT		RIGHT		
	Yes	Not assessed	Yes	Not assessed	
2a. Resting tremor — arm <b>resttrl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<b>resttrr</b>
2b. Slowing of fine motor movements <b>slowingl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<b>slowingr</b>
2c. Rigidity — arm <b>rigidl</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<b>rigidr</b>
			<b>Yes</b>	<b>Not assessed</b>	
2d. Bradykinesia <b>brady</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8	
2e. Parkinsonian gait disorder <b>parkgait</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8	
2f. Postural instability <b>postinst</b>			<input type="checkbox"/> 1	<input type="checkbox"/> 8	



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

**3. Neurological signs considered by examiner to be most likely consistent with cerebrovascular disease** cvdsigns

0 No (SKIP TO QUESTION 4)     1 Yes

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

Findings consistent with stroke/cerebrovascular disease	PRESENT	
	Yes	Not assessed
3a. Cortical cognitive deficit (e.g., aphasia, apraxia, neglect) <span style="border: 1px solid red; padding: 2px;">cortdef</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3b. Focal or other neurological findings consistent with SIVD (subcortical ischemic vascular dementia) <span style="border: 1px solid red; padding: 2px;">sivdfind</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT		
	Yes	Not assessed	Yes	Not assessed	
3c. Motor (may include weakness of combinations of face, arm, and leg; reflex changes; etc.) <span style="border: 1px solid red; padding: 2px;">cvdmotl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">cvdmotr</span>
3d. Cortical visual field loss <span style="border: 1px solid red; padding: 2px;">cortvisl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">cortvisr</span>
3e. Somatosensory loss <span style="border: 1px solid red; padding: 2px;">somatl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">somatr</span>

**4. Higher cortical visual problem suggesting posterior cortical atrophy (e.g., prosopagnosia, simultagnosia, Balint's syndrome) or apraxia of gaze**

0 No     1 Yes postcort

**5. Findings suggestive of progressive supranuclear palsy (PSP), corticobasal syndrome, or other related disorders**

0 No (SKIP TO QUESTION 6)     1 Yes pspcbs

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

Findings	PRESENT	
	Yes	Not assessed
5a. Eye movement changes consistent with PSP <span style="border: 1px solid red; padding: 2px;">eyepsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5b. Dysarthria consistent with PSP <span style="border: 1px solid red; padding: 2px;">dyspsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5c. Axial rigidity consistent with PSP <span style="border: 1px solid red; padding: 2px;">axialpsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5d. Gait disorder consistent with PSP <span style="border: 1px solid red; padding: 2px;">gaitpsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5e. Apraxia of speech <span style="border: 1px solid red; padding: 2px;">apraxsp</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8

	LEFT		RIGHT		
	Yes	Not assessed	Yes	Not assessed	
5f. Apraxia consistent with CBS <span style="border: 1px solid red; padding: 2px;">apraxl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">apraxr</span>
5g. Cortical sensory deficits consistent with CBS <span style="border: 1px solid red; padding: 2px;">cortsenl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">cortsenr</span>
5h. Ataxia consistent with CBS <span style="border: 1px solid red; padding: 2px;">ataxl</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">ataxr</span>
5i. Alien limb consistent with CBS <span style="border: 1px solid red; padding: 2px;">alienlml</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">alienlmr</span>
<span style="border: 1px solid red; padding: 2px;">dystonl</span> 5j. Dystonia consistent with CBS, PSP, or related disorder	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">dystonr</span>
5k. Myoclonus consistent with CBS <span style="border: 1px solid red; padding: 2px;">myocllt</span>	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/> 8	<span style="border: 1px solid red; padding: 2px;">myocltr</span>

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

**6. Findings suggesting ALS (e.g., muscle wasting, fasciculations, upper motor neuron and/or lower motor neuron signs)**

0 No

**alsfind**

1 Yes

**7. Normal-pressure hydrocephalus: gait apraxia**

0 No

**gaitnph**

1 Yes

**8. Other findings (e.g., cerebellar ataxia, chorea, myoclonus)** **othneur**  
(NOTE: For this question, do not specify symptoms that have already been checked above)

0 No

1 Yes (SPECIFY):

**othneurx**

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Participant ID#

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Date:

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# Form B4: Global Staging — Clinical Dementia Rating (CDR) STANDARD AND SUPPLEMENTAL

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

*INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4.*

## SECTION 1: STANDARD CDR<sup>1</sup>

Please enter score below:

	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
<b>1. Memory</b> 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
<b>2. Orientation</b> orient . . .	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
<b>3. Judgment and problem solving</b> judgment . . .	Solves everyday problems, handles business and financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
<b>4. Community affairs</b> commun . . .	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
<b>5. Home and hobbies</b> homehobb . . .	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
<b>6. Personal care</b> perscare . . . 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. . . .	<b>STANDARD CDR SUM OF BOXES</b> cdrsum				
8. . . .	<b>STANDARD GLOBAL CDR</b> cdrglob				

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Date:

<sup>1</sup>Morris JC. The Clinical Dementia Rating (CDR): Current version and scoring rules. Neurology 43(11):2412-4, 1993. Copyright© Lippincott, Williams & Wilkins. Reproduced by permission.

*INSTRUCTIONS: For information on the required online CDR training, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4. This form is to be completed by the clinician or other trained health professional, based on co-participant report and behavioral and neurological exam of the subject. In the extremely rare instances when no co-participant is available, the clinician or other trained health professional must complete this form using all other available information and his/her best clinical judgment. Score only as decline from previous level due to cognitive loss, not impairment due to other factors, such as physical disability. For further information, see UDS Coding Guidebook for Follow-up Visit Packet, Form B4.*

**SECTION 2: SUPPLEMENTAL CDR**

Please enter score below:	IMPAIRMENT				
	None — 0	Questionable — 0.5	Mild — 1	Moderate — 2	Severe — 3
<b>9. Behavior, comporment, and personality<sup>2</sup></b> cdrport    . . .	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
<b>10. Language<sup>3</sup></b> cdrlang    . . .	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

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<sup>2</sup>Excerpted from the Frontotemporal Demential Multicenter Instrument & MR Study (Mayo Clinic, UCSF, UCLA, UW).

<sup>3</sup>Excerpted from the PPA-CDR: A modification of the CDR for assessing dementia severity in patients with primary progressive aphasia (Johnson N, Weintraub S, Mesulam MM), 2002.

## Assignment of CDR rating

Use all information and make the best judgment. Score each category (M, O, JPS, CA, HH, PC) as independently as possible. Mark in only one box, for each category, rating impairment as decline from the person's usual level due to cognitive loss alone, not impairment due to other factors, such as physical handicap or depression. Occasionally the evidence is ambiguous and the clinician's best judgment is that a category could be rated in either one of two adjacent boxes, such as mild (1) or moderate (2) impairment. In that situation the standard procedure is to check the box of greater impairment.

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

The global CDR is derived from the scores in each of the six categories ("box scores") as follows. Memory (M) is considered the primary category and all others are secondary.  $CDR = M$  if at least three secondary categories are given the same score as memory. Whenever three or more secondary categories are given a score greater or less than the memory score,  $CDR =$  score of majority of secondary categories on whichever side of M has the greater number of secondary categories. When three secondary categories are scored on one side of M and two secondary categories are scored on the other side of M,  $CDR=M$ .

When  $M = 0.5$ ,  $CDR = 1$  if at least three of the other categories are scored one or greater. If  $M = 0.5$ ,  $CDR$  cannot be 0; it can only be 0.5 or 1. If  $M = 0$ ,  $CDR = 0$  unless there is impairment (0.5 or greater) in two or more secondary categories, in which case  $CDR = 0.5$ .

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

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

**NOTES:**

- 1) Participants with questionable dementia (CDR 0.5) must be categorized either as “Uncertain dementia,” or as one of the dementing disorders, e.g., “DAT/SDAT”. That is, clinicians must decide, using their best judgment, whether or not the CDR 0.5 Participant is experiencing the very mildest (“earliest”) manifestations of a dementing illness versus a nondementing condition.
- 2) For purposes of data entry, the number of diagnoses for an individual Participant is limited to 5 or less.

DAT = Dementia of the Alzheimer Type

ProAphasia = Progressive Aphasia

PCD = Posterior Cortical Dysfunction

FLD = Frontal Lobe Dementia

MAP = Memory and Aging Project

“Relationship of Condition to DAT” refers to the relation of the onset of the unusual feature to the occurrence of DAT. For example, ProAphasia may occur before (prior), at the same time (with), or subsequent (after) to onset of DAT. In the situation where ProAphasia is an isolated condition (i.e., no other cognitive deficits), there is no clinical relationship to other cognitive syndromes (no DAT).

## Clinical Dementia Rating

### Supplemental Behavioral Checklist for subjects with significant aphasia

#### I Memory

Yes No

- \_\_\_ \_\_\_ a) Subject does normal daily routine about house without becoming upset and obviously confused. memorya
- \_\_\_ \_\_\_ b) Subject spontaneously prepares for routine household events (meals, prayers, bed) memoryb
- \_\_\_ \_\_\_ c) Subject spontaneously prepares for routine weekly events in home and community (church, routine family gatherings, etc.) memoryc
- \_\_\_ \_\_\_ d) Subject spontaneously prepares for major holidays and family member`s birthdays. memoryd
- \_\_\_ \_\_\_ e) Subject walks about local, familiar streets without getting lost. memorye
- \_\_\_ \_\_\_ f) Subject drives or takes the bus about community without getting lost. memoryf
- \_\_\_ \_\_\_ g) Subject operates washer/dryer, TV, radio in home without difficulty. memoryg
- \_\_\_ \_\_\_ h) Subject carries out operations outside the home in church, volunteer groups, or work without assistance. memoryh

#### II Orientation

- \_\_\_ \_\_\_ a) Subject responds to usual form of address orientationa
- \_\_\_ \_\_\_ b) Subject appears to recognize and react appropriately to close friends and relatives. orientationb
- \_\_\_ \_\_\_ c) Subject behaves appropriately in home, other dwellings, and public places (as though he/she knows where he/she is) orientationc
- \_\_\_ \_\_\_ d) Subject follows normal sleep/wakefulness pattern orientationd
- \_\_\_ \_\_\_ e) Subject prepares for temporally fixed events (such as meals, bedtime) at the correct time. orientatione

#### III Judgment and Problem Solving

- \_\_\_ \_\_\_ a) Subject behaves appropriately in routine household events judgmenta
- \_\_\_ \_\_\_ b) Subject solves minor household problems and minor emergencies without more help than usual. judgmentb
- \_\_\_ \_\_\_ c) Subject solves major problems arising outside the family environment without help. judgmentc



**IV Community Affairs**

Yes No

  comaffairsa

a) Subject behaves normally in immediate neighborhood outside home

  comaffairsb

b) Subject behaves appropriately at structured community events

  comaffairsc

c) Subject spontaneously takes up new outside activities and behaves appropriately

**V Home - Hobbies** a) Subject carries out routine, simple household chores normally (with or without reminding).  homehobbya b) Subject maintains nonverbal hobbies normally.  homehobbyb**VI Personal Care** a) Subject uses toilet normally  personcarea b) Subject uses bathing and grooming apparatus and appliances normally  personcareb c) Subject dresses normally once clothes are selected  personcarec d) Subject dresses normally without aid and always appears normally attired  personcared e) Subject takes normal care of personal objects  personcaree

Data Entry initials: \_\_\_\_\_

Date: \_\_\_\_\_

A. Presence or Absence of Dementia

1 NO DEMENTIA (Cognitively Normal)

2 UNCERTAIN DEMENTIA

List attributable factors (if any):

3 Alzheimer disease dementia (AD dementia)
AD dementia - 0.5 in Memory only

AD dementia WITH Unusual features:

Relationship of condition to AD dementia

Prior With After

Table with 4 columns: Feature, Prior, With, After. Rows include Language dysfunction, Disturbed social comportment, Visuospatial dysfunction, and Other:(specify): other\_a.

AD dementia WITH other potentially dementing illnesses (more than one may be present); believed to contribute importantly to dementia

Table with 2 columns: NO, YES. Rows include cerebrovascular disease, idiopathic parkinsonism, depression, and other disorder(s); specify below.

NON-AD DEMENTIA

102 Uncertain
121 Incipient (Single Box Score Impaired)

Diagnosis

1^0 2^0

Table with 2 columns: 1^0, 2^0. Rows include Vascular dementia, Dementia associated with Parkinson's Disease, Dementia with Lewy Bodies, Frontotemporal dementia, AD dementia (cannot be primary).

Other: other\_a

B. List of Potentially Dementing Disorders (may be present in absence of Dementia.)

ACTIVE: Defined as a current episode within the 3 months prior to the clinical assessment or an ongoing management problem with the potential to contribute to dementia

REMOTE: Defined as a condition resolved or having occurred greater than three months prior to the clinical assessment, or remains an ongoing but stable management problem.

Table with 2 columns: Active, Remote. Lists various disorders like Parkinsonism, Cerebrovascular disease, Mood disorder, etc., with corresponding box scores.

List: 1. other\_b
2. other\_b2

!!! Alert for potentially PRION disorders !!!
YES NO (If yes, mark below) has\_rap
Creutzfeldt-Jakob disease (CJD) or related prior disorder
76 clinically diagnosed
75 possible (e.g., unusual ataxia, visuospatial deficits, myoclonus)
74 Rapid course (not resulting in CJD diagnosis)

Other potential transmissible disorders:
HIV Hepatitis Other other\_trans
Specify: other\_transmis

\*\*\*\*\*
Special Processing. Enrolled in Study:
YES, TAPE REVIEW (not applicable at T1 unless ACS) NO TAPE REVIEW
Not Eligible at T1 (Explain)
Special or Expedited TR (Explain)
Thurs. Mtg. Disc. (Explain)
Rev.28MAR2016

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Date:

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

**Form B9: Clinician Judgment of Symptoms**

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

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

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

Declines in memory reported by subject and co-participant			
1. Does the subject report a decline in memory (relative to previously attained abilities)?	<b>decsub</b>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
		<input type="checkbox"/> 8 Could not be assessed/subject is too impaired	
2. Does the co-participant report a decline in the subject's memory (relative to previously attained abilities)?	<b>decin</b>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
		<input type="checkbox"/> 8 There is no co-participant	
Cognitive symptoms			
3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition?	<b>decclcog</b>	<input type="checkbox"/> 0 No (If No, <b>SKIP TO QUESTION 8</b> )	<input type="checkbox"/> 1 Yes
4. Indicate whether the subject currently is meaningfully impaired, <i>relative to previously attained abilities</i> , in the following cognitive domains, or has fluctuating cognition:			
		<b>No</b>	<b>Yes</b> <b>Unknown</b>
<b>cogmem</b> 4a. <b>Memory</b> For example, does s/he forget conversations and/or dates, repeat questions and/or statements, misplace things more than usual, forget names of people s/he knows well?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>cogori</b> 4b. <b>Orientation</b> For example, does s/he have trouble knowing the day, month, and year, or not recognize familiar locations, or get lost in familiar locations?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>cogjudg</b> 4c. <b>Executive function — judgment, planning, problem-solving</b> Does s/he have trouble handling money (e.g., tips), paying bills, preparing meals, shopping, using appliances, handling medications, driving?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>coglang</b> 4d. <b>Language</b> Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>cogvis</b> 4e. <b>Visuospatial function</b> Does s/he have difficulty interpreting visual stimuli and finding his/her way around?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>cogattn</b> 4f. <b>Attention, concentration</b> Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
<b>cogfluc</b> 4g. <b>Fluctuating cognition</b> Does the subject exhibit pronounced variation in attention and alertness, noticeably over hours or days — for example, long lapses or periods of staring into space, or times when his/her ideas have a disorganized flow?		<input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 9
4g1. If yes, at what age did the fluctuating cognition begin? _____ <b>cogflago</b>			
(777 = Age of onset provided at a previous UDS visit.)			
(The clinician must use his/her best judgment to estimate an age of onset.)			
<b>cogothr</b> 4h. <b>Other (SPECIFY):</b> _____ <b>cogothrx</b>		<input type="checkbox"/> 0	<input type="checkbox"/> 1

Taped:

Participant ID#

T-

Date:

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

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

7. Based on the clinician's assessment, at what age did the cognitive decline begin?  
(777 = Age of cognitive decline entered at a previous UDS visit) **decaage** \_\_\_\_\_

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

**Behavioral symptoms**

8. Based on the clinician's judgment, is the subject currently experiencing any kind of behavioral symptoms?  0 No (If No, **SKIP TO QUESTION 13**)  1 Yes **deccibe**

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

	No	Yes	Unknown
--	----	-----	---------

**beapathy** 9a. **Apathy, withdrawal** Has the subject lost interest in or displayed a reduced ability to initiate usual activities and social interaction, such as conversing with family and/or friends?  0  1  9

**bedep** 9b. **Depressed mood** Has the subject seemed depressed for more than two weeks at a time, e.g., shown loss of interest or pleasure in nearly all activities, sadness, hopelessness, loss of appetite, fatigue?  0  1  9

9c. **Psychosis**

9c1. Visual hallucinations **bevhall**

9c1a. If yes, are the hallucinations well formed and detailed? **bevwell**

9c1b. If well formed and clear-cut, at what age did these visual hallucinations begin? \_\_\_\_\_ **bevhago**  
(777 = Age of onset provided at a previous UDS visit; 888 = N/A, not well-formed)  
(The clinician must use his/her best judgment to estimate age of onset)

9c2. Auditory hallucinations **beahall**

9c3. Abnormal, false, or delusional beliefs **bedel**

	No	Yes	Unknown
9c1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c1a	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c2	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c3	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

9d. **Disinhibition** Does the subject use inappropriate coarse language or exhibit inappropriate speech or behaviors in public or in the home? Does s/he talk personally to strangers or have disregard for personal hygiene? **bedisin**

	No	Yes	Unknown
9d	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

**beirrit** 9e. **Irritability** Does the subject overreact, e.g., by shouting at family members or others?  0  1  9

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

<b>beagit</b>	9f. <b>Agitation</b> Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>beperch</b>	9g. <b>Personality change</b> Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>berem</b>	9h. <b>REM sleep behavior disorder</b> While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
	9h1. If yes, at what age did the REM sleep behavior disorder begin? _____ <b>beremago</b> (777 = Age of onset provided at a previous UDS visit.) (The clinician must use his/her best judgment to estimate an age of onset)			
<b>beanx</b>	9i. <b>Anxiety</b> For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>beothr</b>	9j. <b>Other</b> (SPECIFY): <b>beothrx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
	10. Indicate the <b>predominant</b> symptom that was first recognized as a decline in the subject's behavior: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i>	<input type="checkbox"/> 0	Assessed at a previous UDS visit	
<b>befpred</b>		<input type="checkbox"/> 1	Apathy/withdrawal	
		<input type="checkbox"/> 2	Depressed mood	
		<input type="checkbox"/> 3	Psychosis	
		<input type="checkbox"/> 4	Disinhibition	
		<input type="checkbox"/> 5	Irritability	
		<input type="checkbox"/> 6	Agitation	
		<input type="checkbox"/> 7	Personality change	
		<input type="checkbox"/> 8	REM sleep behavior disorder	
		<input type="checkbox"/> 9	Anxiety <b>befpredx</b>	
		<input type="checkbox"/> 10	Other (SPECIFY): _____	
		<input type="checkbox"/> 99	Unknown	
	11. Mode of onset of behavioral symptoms:	<input type="checkbox"/> 1	Gradual	
<b>bemode</b>		<input type="checkbox"/> 2	Subacute	
		<input type="checkbox"/> 3	Abrupt	
		<input type="checkbox"/> 4	Other (SPECIFY): <b>bemodex</b>	
		<input type="checkbox"/> 99	Unknown	
	12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? (777 = Age of onset provided at a previous UDS visit.) (The clinician must use her/his best judgment to estimate age of onset of behavioral symptoms.)	<b>beage</b>	_____	
<b>Motor symptoms</b>				
	13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms?	<input type="checkbox"/> 0	No (If No, <b>SKIP TO QUESTION 20</b> )	
<b>declmot</b>		<input type="checkbox"/> 1	Yes	
	14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas:	<b>No</b>	<b>Yes</b>	<b>Unknown</b>
<b>mogait</b>	14a. <b>Gait disorder</b> Has subject's walking changed, not specifically due to arthritis or an injury? Is s/he unsteady, or does s/he shuffle when walking, have little or no arm-swing, or drag a foot?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>mofalls</b>	14b. <b>Falls</b> Does the subject fall more than usual?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>motrem</b>	14c. <b>Tremor</b> Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>moslow</b>	14d. <b>Slowness</b> Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

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

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

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Candidate for further evaluation for Lewy body disease or frontotemporal lobar degeneration	
22. Is the subject a potential candidate for further evaluation for Lewy body disease? <b>lbdeval</b>	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration? <b>ftldeval</b>	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes



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

## Form D1: Clinician Diagnosis

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

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

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

This form is divided into three main sections:

- Section 1 **Cognitive status:** Normal cognition / MCI / dementia and dementia syndrome  
 Section 2 **Biomarkers, imaging, and genetics:** Neurodegenerative imaging and CSF biomarkers, imaging evidence for CVD, and known genetic mutations for AD and FTLD  
 Section 3 **Etiological diagnoses:** presumed etiological diagnoses for the cognitive disorder

1. **Diagnosis method** — responses in this form are based on diagnosis by: **dxmethod**

- 1 A single clinician     2 A formal consensus panel     3 Other (e.g., two or more clinicians or other informal group)

### SECTION 1: Cognitive and behavioral status

2. **Does the subject have normal cognition (global CDR=0 and/or neuropsychological testing within normal range) and normal behavior (i.e., the subject does not exhibit behavior sufficient to diagnose MCI or dementia due to FTLD or LBD)?**

- 0 No (CONTINUE TO QUESTION 3) **normcog**  
 1 Yes (SKIP TO QUESTION 6)

### ALL-CAUSE DEMENTIA

The subject has cognitive or behavioral (neuropsychiatric) symptoms that meet all of the following criteria:

- Interfere with ability to function as before at work or at usual activities?
- Represent a decline from previous levels of functioning?
- Are not explained by delirium or major psychiatric disorder?
- Include cognitive impairment detected and diagnosed through a combination of 1) history-taking and 2) objective cognitive assessment (bedside or neuropsychological testing)?

#### AND

Impairment in one\* or more of the following domains.

- Impaired ability to acquire and remember new information
- Impaired reasoning and handling of complex tasks, poor judgment
- Impaired visuospatial abilities
- Impaired language functions
- Changes in personality, behavior, or comportment

*\* In the event of single-domain impairment (e.g., language in PPA, behavior in bvFTD, posterior cortical atrophy), the subject must not fulfill criteria for MCI.*

3. **Does the subject meet the criteria for dementia?**

- 0 No (SKIP TO QUESTION 5) **demented**  
 1 Yes (CONTINUE TO QUESTION 4)

**4. If the subject meets criteria for dementia, answer Questions 4a–4f below and then SKIP TO QUESTION 6.**

Based entirely on the history and examination (including neuropsychological testing), what is the cognitive/behavioral syndrome? **Select one or more as Present; all others will default to Absent in the NACC database.**

Dementia syndrome	Present
4a. Amnestic multidomain dementia syndrome <b>amndem</b>	<input type="checkbox"/> 1
4b. Posterior cortical atrophy syndrome (or primary visual presentation) <b>pea</b>	<input type="checkbox"/> 1
4c. Primary progressive aphasia (PPA) syndrome <b>ppasyn</b>	<input type="checkbox"/> 1
4c1. <input type="checkbox"/> 1 Meets criteria for semantic PPA <b>ppasynt</b> <input type="checkbox"/> 2 Meets criteria for logopenic PPA <input type="checkbox"/> 3 Meets criteria for nonfluent/agrammatic PPA <input type="checkbox"/> 4 PPA other/not otherwise specified	
4d. Behavioral variant FTD (bvFTD) syndrome <b>ftdsyn</b>	<input type="checkbox"/> 1
4e. Lewy body dementia syndrome <b>lbdsyn</b>	<input type="checkbox"/> 1
4f. Non-amnestic multidomain dementia, not PCA, PPA, bvFTD, or DLB syndrome <b>namndem</b>	<input type="checkbox"/> 1

**5. If the subject does not have normal cognition or behavior and is not clinically demented, indicate the type of cognitive impairment below.**

**MCI CORE CLINICAL CRITERIA**

- Is the subject, the co-participant, or a clinician concerned about a change in cognition compared to the subject's previous level?
- Is there impairment in one or more cognitive domains (memory, language, executive function, attention, and visuospatial skills)?
- Is there largely preserved independence in functional abilities (no change from prior manner of functioning or uses minimal aids or assistance)?

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5a. Amnestic MCI, single domain (aMCI SD)	<input type="checkbox"/> 1	<b>mciamem</b>		
5b. Amnestic MCI, multiple domains (aMCI MD) <b>mciaplus</b>	<input type="checkbox"/> 1	<b>CHECK YES for at least one additional domain (besides memory):</b> 5b1. Language <b>mciaplan</b> 5b2. Attention <b>mciapatt</b> 5b3. Executive <b>mciapex</b> 5b4. Visuospatial <b>mciapvis</b>	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1

Select one syndrome from 5a–5e as being Present (all others will default to Absent in the NACC database), and then **CONTINUE TO QUESTION 6**. If you select MCI below, it should meet the MCI core clinical criteria outlined above.

Type	Present	Affected domains	No	Yes
5c. Non-amnestic MCI, single domain (naMCI SD) <b>mcinon1</b>	<input type="checkbox"/> 1	<b>CHECK YES to indicate the affected domain:</b> 5c1. Language <b>mcin1lan</b> 5c2. Attention <b>mcin1att</b> 5c3. Executive <b>mcin1ex</b> 5c4. Visuospatial <b>mcin1vis</b>	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1
5d. Non-amnestic MCI, multiple domains (naMCI MD) <b>mcinon2</b>	<input type="checkbox"/> 1	<b>CHECK YES for at least two domains:</b> 5d1. Language <b>mcin2lan</b> 5d2. Attention <b>mcin2att</b> 5d3. Executive <b>mcin2ex</b> 5d4. Visuospatial <b>mcin2vis</b>	<input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0 <input type="checkbox"/> 0	<input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1 <input type="checkbox"/> 1
5e. Cognitively impaired, not MCI	<input type="checkbox"/> 1	<b>imptomci</b>		

## SECTION 2: Biomarkers, imaging, and genetics

Section 2 must be completed for all subjects.

### 6. Indicate neurodegenerative biomarker status, using local standards for positivity.

Biomarker findings	No	Yes	Unknown/ not assessed
6a. Abnormally elevated amyloid on PET <b>amylpet</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6b. Abnormally low amyloid in CSF <b>amylcsf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6c. FDG-PET pattern of AD <b>fdgad</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6d. Hippocampal atrophy <b>hippatr</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6e. Tau PET evidence for AD <b>taupetad</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6f. Abnormally elevated CSF tau or ptau <b>csftau</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6g. FDG-PET evidence for frontal or anterior temporal hypometabolism for FTLD <b>fdgftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6h. Tau PET evidence for FTLD <b>tpetftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6i. Structural MR evidence for frontal or anterior temporal atrophy for FTLD <b>mrftld</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6j. Dopamine transporter scan (DATscan) evidence for Lewy body disease <b>datscan</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
<b>othbiom</b> 6k. Other (SPECIFY): <b>othbiomx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

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

Imaging findings	No	Yes	Unknown/ not assessed
7a. Large vessel infarct(s) <b>imaglinf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7b. Lacunar infarct(s) <b>imaglac</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7c. Macrohemorrhage(s) <b>imagmach</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7d. Microhemorrhage(s) <b>imagmich</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7e. Moderate white-matter hyperintensity (CHS score 5–6) <b>imagmwmh</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7f. Extensive white-matter hyperintensity (CHS score 7–8+) <b>imagewmh</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

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

0 No  1 Yes  9 Unknown/not assessed **admut**

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

0 No  1 Yes  9 Unknown/not assessed **ftldmut**

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

**othmut**  0 No  1 Yes (SPECIFY): **othmutx**  9 Unknown/not assessed

## SECTION 3: Etiologic diagnoses

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as 1=Primary.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by marking Present, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses marked as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses	Present			
		Primary	Contributing	Non-contributing
11. Alzheimer's disease <b>alzids</b>	<input type="checkbox"/> 1	11a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>alzdisif</b>
12. Lewy body disease <b>lbdis</b>	<input type="checkbox"/> 1	12a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>lbdif</b>
12b. <input type="checkbox"/> 1 Parkinson's disease <b>park</b>				
13. Multiple system atrophy <b>msa</b>	<input type="checkbox"/> 1	13a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>msaif</b>
14. Frontotemporal lobar degeneration				
14a. Progressive supranuclear palsy (PSP) <b>psp</b>	<input type="checkbox"/> 1	14a1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>pspif</b>
14b. Corticobasal degeneration (CBD) <b>cort</b>	<input type="checkbox"/> 1	14b1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>cortif</b>
14c. FTLN with motor neuron disease <b>ftldmo</b>	<input type="checkbox"/> 1	14c1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ftldmoif</b>
14d. FTLN NOS <b>ftldnos</b>	<input type="checkbox"/> 1	14d1 <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ftldnoif</b>
14e. If FTLN (Questions 14a – 14d) is Present, specify FTLN subtype: <b>ftldsubst</b>				
<input type="checkbox"/> 1 Tauopathy				
<input type="checkbox"/> 2 TDP-43 proteinopathy <b>ftldsubx</b>				
<input type="checkbox"/> 3 Other (SPECIFY): _____				
<input type="checkbox"/> 9 Unknown				

**SECTION 3: Etiologic diagnoses (cont.)**

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1=Primary**.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
15.	Vascular brain injury (based on clinical or imaging evidence) <i>If significant vascular brain injury is absent, SKIP TO QUESTION 16.</i>	<input checked="" type="checkbox"/> 1 <b>cvd</b>	15a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>cvdif</b>
15b.	Previous symptomatic stroke? <b>prevstk</b>	<input type="checkbox"/> 0 No (SKIP TO QUESTION 15c) <input type="checkbox"/> 1 Yes			
15b1.	Temporal relationship between stroke and cognitive decline? <b>strokedec</b>	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes			
15b2.	Confirmation of stroke by neuroimaging?	<input type="checkbox"/> 0 No <b>stkimag</b> <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available			
15c.	Is there imaging evidence of cystic infarction in cognitive network(s)?	<input type="checkbox"/> 0 No <b>infnetw</b> <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available			
15d.	Is there imaging evidence of cystic infarction, imaging evidence of extensive white matter hyperintensity (CHS grade 7–8+), and impairment in executive function?	<input type="checkbox"/> 0 No <b>infwmh</b> <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown; no relevant imaging data available			
16.	Essential tremor <b>esstrem</b>	<input type="checkbox"/> 1	16a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>esstreif</b>
17.	Down syndrome <b>downs</b>	<input type="checkbox"/> 1	17a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>downsif</b>
18.	Huntington's disease <b>hunt</b>	<input type="checkbox"/> 1	18a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>huntif</b>
19.	Prion disease (CJD, other) <b>prion</b>	<input type="checkbox"/> 1	19a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>prion_if</b>

Etiologic diagnoses		Present	Primary	Contributing	Non-contributing
20.	Traumatic brain injury <b>brninj</b>	<input type="checkbox"/> 1	20a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>brninjif</b>
20b.	If Present, does the subject have symptoms consistent with chronic traumatic encephalopathy? <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown <b>brnincte</b>				
21.	Normal-pressure hydrocephalus <b>hyceph</b>	<input type="checkbox"/> 1	21a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>hycephif</b>
22.	Epilepsy <b>epilep</b>	<input type="checkbox"/> 1	22a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>epilepif</b>
23.	CNS neoplasm <b>neop</b>	<input type="checkbox"/> 1	23a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>neopif</b>
23b.	<input type="checkbox"/> 1 Benign <input type="checkbox"/> 2 Malignant <b>neopstat</b>				
24.	Human immunodeficiency virus (HIV) <b>hiv</b>	<input type="checkbox"/> 1	24a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>hivif</b>
25.	Cognitive impairment due to other neurologic, genetic, or infectious conditions not listed above <b>othcog</b>	<input type="checkbox"/> 1	25a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>othcogif</b>
25b.	If Present, specify: _____ <b>othcogx</b> _____				

Section 3 must be filled out for all subjects. Indicate presumptive etiologic diagnoses of the cognitive disorder and whether a given diagnosis is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. **Select one or more diagnoses as Present; all others will default to Absent in the NACC database.** Only one diagnosis should be selected as **1=Primary**.

**For subjects with normal cognition:** Indicate the presence of any diagnoses by selecting **1=Present**, and leave the questions on whether the diagnosis was primary, contributing, or non-contributing blank. Subjects with positive biomarkers but no clinical symptoms of Alzheimer's disease, Lewy body disease, or frontotemporal lobar degeneration **should not** have these diagnoses selected as Present. Instead, the biomarker data from Section 2 can be used to identify the presence of preclinical disease.

Condition	Present	Primary	Contributing	Non-contributing
26. Active depression <b>dep</b>	<input type="checkbox"/> 1	26a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>depif</b>
26b. If Present, select one: <b>deptreat</b> <input type="checkbox"/> 0 Untreated <input type="checkbox"/> 1 Treated with medication and/or counseling				
27. Bipolar disorder <b>bipoldx</b>	<input type="checkbox"/> 1	27a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>bipoldif</b>
28. Schizophrenia or other psychosis <b>schizop</b>	<input type="checkbox"/> 1	28a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>schizoif</b>
29. Anxiety disorder <b>anxiet</b>	<input type="checkbox"/> 1	29a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>anxietif</b>
30. Delirium <b>delir</b>	<input type="checkbox"/> 1	30a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>delirif</b>
31. Post-traumatic stress disorder (PTSD) <b>ptsddx</b>	<input type="checkbox"/> 1	31a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>ptsddxif</b>
32. Other psychiatric disease <b>othpsy</b>	<input type="checkbox"/> 1	32a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 <b>othpsyif</b>
32b. If Present, specify: _____ <b>othpsyx</b> _____				

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33. Cognitive impairment due to alcohol abuse <b>alcdem</b> <input type="checkbox"/> 1 33b. Current alcohol abuse: <b>alcabuse</b> <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown	<input type="checkbox"/> 1	33a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>alcdemif</b>
<b>impsub</b> 34. Cognitive impairment due to other substance abuse <input type="checkbox"/> 1	<input type="checkbox"/> 1	34a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>impsubif</b>
35. Cognitive impairment due to systemic disease/ medical illness (as indicated on Form D2) <b>dysill</b> <input type="checkbox"/> 1	<input type="checkbox"/> 1	35a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>dysillif</b>
36. Cognitive impairment due to medications <b>meds</b> <input type="checkbox"/> 1	<input type="checkbox"/> 1	36a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>medsif</b>
37. Cognitive impairment NOS 37b. If Present, specify: _____ <b>cogothx</b> _____	<input type="checkbox"/> 1	37a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogothif</b>
38. Cognitive impairment NOS 38b. If Present, specify: _____ <b>cogoth2x</b> _____	<input type="checkbox"/> 1	38a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogoth2f</b>
39. Cognitive impairment NOS 39b. If Present, specify: _____ <b>cogoth3x</b> _____	<input type="checkbox"/> 1	39a <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<b>cogoth3f</b>



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

## Form D2: Clinician-assessed Medical Conditions

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

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

*INSTRUCTIONS: This form is to be completed by a physician, physician's assistant, nurse practitioner, or other qualified practitioner. For additional clarifications and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form D2.*

### Medical conditions and procedures

The following questions should be answered based on review of all available information, including new diagnoses made during the current visit, previous medical records, procedures, laboratory tests, and the clinical exam.

1. Cancer (excluding non-melanoma skin cancer), primary or metastatic **cancer**
- 0 No (**SKIP TO QUESTION 2**)
- 1 Yes, primary/non-metastatic
- 2 Yes, metastatic
- 8 Not assessed (**SKIP TO QUESTION 2**)
- 1a. If yes, specify primary site: **cancsite**

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

2. Diabetes  0 No
- diabet**  1 Yes, Type I
- 2 Yes, Type II
- 3 Yes, other type (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes)
- 9 Not assessed or unknown

	No	Yes	Not assessed
3. Myocardial infarct <b>myoinf</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4. Congestive heart failure <b>conghrt</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
5. Atrial fibrillation <b>afibrill</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
6. Hypertension <b>hypert</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
7. Angina <b>angina</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
8. Hypercholesterolemia <b>hypchol</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
9. B12 deficiency <b>vb12def</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
10. Thyroid disease <b>thydis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

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

	No	Yes	Not assessed
11. Arthritis <i>If No or Not assessed, SKIP TO QUESTION 12</i> <b>arth</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
11a. If yes, what type? <b>arthtype</b>			
<input type="checkbox"/> 1 Rheumatoid			
<input type="checkbox"/> 2 Osteoarthritis			
<input type="checkbox"/> 3 Other (SPECIFY): <b>artypex</b>			
<input type="checkbox"/> 9 Unknown			
11b. If yes, regions affected (check at least one):			
11b1. <input type="checkbox"/> 1 Upper extremity <b>artupex</b>			
11b2. <input type="checkbox"/> 1 Lower extremity <b>artloex</b>			
11b3. <input type="checkbox"/> 1 Spine <b>artspin</b>			
11b4. <input type="checkbox"/> 1 Unknown <b>artunkn</b>			
12. Incontinence — urinary <b>urineinc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
13. Incontinence — bowel <b>bowlinc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
14. Sleep apnea <b>sleepap</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
15. REM sleep behavior disorder (RBD) <b>remdis</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
16. Hyposomnia/insomnia <b>hyposom</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
<b>sleepoth</b> 17. Other sleep disorder (SPECIFY): <b>sleepotx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
18. Carotid procedure: angioplasty, endarterectomy, or stent <b>angiocp</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
19. Percutaneous coronary intervention: angioplasty and/or stent <b>angiopci</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
20. Procedure: pacemaker and/or defibrillator <b>pacemake</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
21. Procedure: heart valve replacement or repair <b>hvalve</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
22. Antibody-mediated encephalopathy <b>antienc</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
22a. Specify antibody: <b>antiencx</b>			
23. Other medical conditions or procedures not listed above <b>othcond</b> (IF YES, SPECIFY): <b>othcondx</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	

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NACC UNIFORM DATA SET (UDS)

Form M1: Milestones (February 18 Final, rev. 2/20)

ADC ID: \_\_\_ Subject ID: \_\_\_\_\_ Form Date: \_\_\_/\_\_\_/\_\_\_\_\_ Examiner's initials: \_\_\_

Please submit a new Milestones Form as soon as possible after each milestone event has occurred.

INSTRUCTIONS: Review the types of milestone at right and complete the appropriate box below. Use only one box (A or B) per form submitted. For more information, see flow chart on reverse.

Table with 2 columns: What milestone are you reporting?, Complete:
1. Data-collection status CHANGE followed by CONTINUED CONTACT with subject. The subject's status in the UDS or FTLD Module has changed, such that s/he will continue to be followed (at least minimally) by ADC. Box A only
2. Change followed by NO FURTHER CONTACT with subject. Subject has DIED or been DROPPED FROM ADC with no further telephone contact and no minimal contact (such as to obtain autopsy). Box B only

BOX A — CHANGE WITH CONTINUED CONTACT
1. Date of status change (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
Complete the UDS and FTLD sections below, as appropriate.
UDS STATUS
2a. UDS data collection status changed; subject's new status is (CHECK ONE):
1 Annual UDS follow-up by telephone (CONTINUE TO QUESTION 2a1)
2 Minimal contact (CONTINUE TO QUESTION 2a1)
NOTE: Minimal contact status is reserved for subjects who can no longer participate for one of the reasons listed in Question 2b, below.
2a1. Autopsy consent on file? 0 No (CONTINUE TO QUESTION 2b) 1 Yes (CONTINUE TO QUESTION 2b)
3 Annual in-person UDS follow-up
2b. Reason(s) for change indicated in Question 2a (CHECK AT LEAST ONE):
1 Subject is too cognitively impaired
2 Subject is too ill or physically impaired
3 Subject refuses neuropsychological testing or clinical exam
4 Subject or co-participant unreachable, not available, or moved away
5 Subject has permanently entered nursing home
2b5a. Date permanently moved to nursing home: MM/DD/YYYY (Unknown = 99/99/YEAR REQUIRED)
6 Subject is REJOINING ADC
FTLD MODULE STATUS
3. 1 Subject will no longer receive FTLD Module follow-up, but annual in-person UDS visits will continue
3a. Reason (CHECK ONE): 1 ADC decision 2 Subject/informant refused 3 Informant not available 4 Other, specify below:
3a1. \_\_\_\_\_

BOX B — NO FURTHER CONTACT
4a. Subject has DIED (COMPLETE DEATH SECTION, BELOW)
4b. Subject has been DROPPED from ADC (COMPLETE DROPPED SECTION, BELOW)
DEATH
5a. Date of death (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
5b. ADC autopsy:
0 No ADC autopsy expected
1 An ADC autopsy has been done; data submitted or pending
END FORM HERE
DROPPED
DO NOT fill out this section if the subject has consented to autopsy or if you will maintain minimal contact. Instead, fill out Box A, UDS STATUS section.
6a. Date dropped from ADC (Unknown = 99/99/YEAR REQUIRED): MM/DD/YYYY
6b. Main reason for being dropped from ADC (CHECK ONE):
1 ADC decision or protocol
2 Subject or co-participant asked to be dropped