

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

6. Subject's month and year of birth (MM/YYYY):	____ / _____
7. Subject's sex:	<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="checkbox"/> 0 No (If No, SKIP TO QUESTION 9) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown (If Unknown, SKIP TO QUESTION 9)
8a. If yes, what are the subject's reported origins?	<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="checkbox"/> 99 Unknown
9. What does the subject report as his or her 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="checkbox"/> 99 Unknown
10. What additional race does the subject report?	<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="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="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="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown

12. Subject's primary language:	<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): _____ <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:	____
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:	<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?	<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?	<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?	<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:	____ (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)?	<input type="checkbox"/> 1 Left-handed <input type="checkbox"/> 2 Right-handed <input type="checkbox"/> 3 Ambidextrous <input type="checkbox"/> 9 Unknown