

NACC Uniform Data Set (UDS) – Initial Visit Packet
Form A1: Subject Demographics

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

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

ADC Visit #: _____

Examiner's initials: _____

Source of Referral:

1. Subject enrolled in NACC MDS:	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
2. Primary reason for coming to ADC:	<input type="checkbox"/> 1 Participate in research study <input type="checkbox"/> 2 Clinical evaluation	<input type="checkbox"/> 3 Other (<i>specify</i>): _____ <input type="checkbox"/> 9 Unknown
3. Principal referral source:	<input type="checkbox"/> 1 Self/relative/friend <input type="checkbox"/> 2 Clinician <input type="checkbox"/> 3 ADC solicitation <input type="checkbox"/> 4 Non-ADC study <input type="checkbox"/> 5 Clinic sample	<input type="checkbox"/> 6 Population sample <input type="checkbox"/> 7 Non-ADC media appeal (e.g., Alzheimer's Association) <input type="checkbox"/> 8 Other (<i>specify</i>): _____ <input type="checkbox"/> 9 Unknown
4. Presumed disease status at enrollment:	<input type="checkbox"/> 1 Case/patient/proband <input type="checkbox"/> 2 Control/normal	<input type="checkbox"/> 3 No presumed disease status
5. Presumed participation:	<input type="checkbox"/> 1 Initial evaluation only	<input type="checkbox"/> 2 Longitudinal follow-up planned
6. ADC enrollment type:	<input type="checkbox"/> 1 Clinical Core <input type="checkbox"/> 2 Satellite Core	<input type="checkbox"/> 3 Other ADC Core/project <input type="checkbox"/> 4 Center-affiliated/non-ADC
7. Subject's month/year of birth: _____/_____		
8. Subject's sex:	<input type="checkbox"/> 1 Male	<input type="checkbox"/> 2 Female

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ADC Visit #: _____

9. Does the subject report being of Hispanic/Latino <u>ethnicity</u> (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 0 No	<input type="checkbox"/> 9 Unknown
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9a. If yes, what are the subject's reported origins?	<input type="checkbox"/> 1 Mexican/Chicano/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 (<i>specify</i>): _____ <input type="checkbox"/> 99 Unknown
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10. What does subject report as his/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 (<i>specify</i>): _____ <input type="checkbox"/> 99 Unknown
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11. What additional race does 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 (<i>specify</i>): _____ <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown
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12. What additional race, beyond what was indicated above in questions 10 and 11, does 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 (<i>specify</i>): _____ <input type="checkbox"/> 88 None reported <input type="checkbox"/> 99 Unknown
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ADC Visit #: _____

13. 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
14. Subject's years of education (report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended). High school/GED = 12; Bachelors degree = 16; Master's degree = 18; Doctorate = 20 years:	____ (99 = Unknown)	
15. What is the subject's living situation?	<input type="checkbox"/> 1 Lives alone <input type="checkbox"/> 2 Lives with spouse or partner <input type="checkbox"/> 3 Lives with relative or friend	<input type="checkbox"/> 4 Lives with group <input type="checkbox"/> 5 Other (specify): _____ <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 family residence <input type="checkbox"/> 2 Retirement community <input type="checkbox"/> 3 Assisted living/ boarding home/adult family home	<input type="checkbox"/> 4 Skilled nursing facility/ nursing home <input type="checkbox"/> 5 Other (specify): _____ <input type="checkbox"/> 9 Unknown
18. Subject's primary residence zip code (first 3 digits):	____ (leave blank if unknown)	
19. Subject's current 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 <input type="checkbox"/> 6 Living as married <input type="checkbox"/> 8 Other (specify): _____ <input type="checkbox"/> 9 Unknown
20. Is the subject left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)?	<input type="checkbox"/> 1 Left-handed <input type="checkbox"/> 2 Right-handed	<input type="checkbox"/> 3 Ambidextrous <input type="checkbox"/> 9 Unknown