

Form A1: Participant Demographics

 In-person ☐ Remote ☐

ADRC name: _____ Participant ID: _____ Form date: ____ / ____ / ____

 Visit #: _____ Examiner's initials: _____ Language: English ☐ Spanish ☐

INSTRUCTIONS: This form may be completed by intake interviewer based on ADRC scheduling records, participant interview, medical records, and proxy co-participant report (as needed). This information can be collected by mail-in survey, electronic capture (web-based), phone or video interview, or during the in-person visit to accommodate and lessen participant visit burden. For additional clarification and examples, see the **UDS Coding Guidebook, Form A1**. Check only one box per question unless otherwise specified.

Section 1 — Demographics

1. What is your month and year of birth (MM / YYYY)? ____ / ____

 2. What is your ethnicity and race?
(Check all that apply)

- 2a. ☐ 1 White
 2b. ☐ 1 Black or African American
 2c. ☐ 1 American Indian or Alaska Native (AIAN)
 2d. ☐ 1 Native Hawaiian or other Pacific Islander
 2e. ☐ 1 Asian
 2f. ☐ 1 Hispanic
 2g. ☐ 1 Other (SPECIFY): _____
 2h. ☐ 1 Don't know

The next four questions ask about your gender identity, sex assigned at birth, sexual orientation, and intersex status. This information will be used to help us improve health, well-being, and quality of care. By gender identity, we mean the inner sense that you have of yourself as being a man, woman, or a different gender. Gender identity can be different from your sex assigned at birth or your sexual orientation, and it can change over time.

 3. Which term(s) best describes your current gender identity?
(Check all that apply)

- 3a. ☐ 1 Man
 3b. ☐ 1 Woman
 3c. ☐ 1 Transgender man
 3d. ☐ 1 Transgender woman
 3e. ☐ 1 Non-binary/genderqueer
 3f. ☐ 1 Two-Spirit (if you are AIAN)
 3g. ☐ 1 I use a different term (SPECIFY): _____
 3h. ☐ 1 Don't know
 3i. ☐ 1 Prefer not to answer

4. What sex were you assigned at birth, on your original birth certificate?

- ☐ 1 Male
☐ 2 Female
☐ 9 Don't know
☐ 8 Prefer not to answer

5. Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a "Difference of Sex Development (DSD)" or were you born with (or developed naturally in puberty) genitals, reproductive organs, and/or chromosomal patterns that do not fit standard definitions of male or female?

- ☐ 0 No
☐ 1 Yes
☐ 9 Don't know
☐ 8 Prefer not to answer

 6. Which term(s) best describes your sexual orientation?
(Check all that apply)

- 6a. ☐ 1 Lesbian or gay
 6b. ☐ 1 Straight/heterosexual
 6c. ☐ 1 Bisexual
 6d. ☐ 1 Two-Spirit (if you are AIAN)
 6e. ☐ 1 I use a different term (SPECIFY, e.g., asexual, queer, questioning): _____
 6f. ☐ 1 Don't know
 6g. ☐ 1 Prefer not to answer

7. What is your primary language?

(Primary language is defined as the predominant language you have used throughout your life. Please take into consideration first language learned and used as well as the length of use.)

- ☐ 1 English
☐ 2 Spanish
☐ 3 Chinese dialect
☐ 8 Other (SPECIFY): _____
☐ 9 Don't know

Section 1 — Demographics*continued...*

8.	Are you left- or right-handed (for example, which hand would normally be used for writing or throwing a ball)?	<input type="checkbox"/> 1 Left-handed <input type="checkbox"/> 2 Right-handed <input type="checkbox"/> 3 Ambidextrous <input type="checkbox"/> 9 Don't know
9a.	How many years of education have you completed? (99 = Unknown) ____	
9b.	What is your highest achieved level of education?	<input type="checkbox"/> 1 Less than high school <input type="checkbox"/> 2 High school or GED <input type="checkbox"/> 3 Some college <input type="checkbox"/> 4 Bachelor's degree <input type="checkbox"/> 5 Master's degree <input type="checkbox"/> 6 Doctorate <input type="checkbox"/> 9 Don't know
10.	What is your living situation?	<input type="checkbox"/> 1 Live alone <input type="checkbox"/> 2 Live with one other person: a spouse or partner <input type="checkbox"/> 3 Live with one other person: a relative, friend, or roommate <input type="checkbox"/> 4 Live with caregiver who is not spouse/partner, relative, or friend <input type="checkbox"/> 5 Live with a group (related or not related) in a private residence <input type="checkbox"/> 6 Live in group home (e.g., assisted living, nursing home, convent) <input type="checkbox"/> 9 Don't know
11.	What is your 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"/> 5 Do not have housing (e.g., staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, or in a park) <input type="checkbox"/> 9 Don't know
12.	What are the first three digits of the ZIP code of your primary residence? (For example, if your ZIP code is 12345, enter 123.)	____ (If unknown, leave blank)
13.	Have you ever served on active duty in the U.S. Armed Forces, military Reserves, or National Guard?	<input type="checkbox"/> 0 No (IF NO, SKIP TO QUESTION 15) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Don't know
14.	Have you ever obtained medical care or prescription drugs from a Veterans Affairs (VA) facility?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Don't know
15.	How much time each week do you spend performing activities that cause large increases in breathing or heart rate for at least 10 minutes continuously? (Include activity at work, traveling to and from places, fitness activities, and recreational activities.)	<input type="checkbox"/> 1 None <input type="checkbox"/> 2 1 hour or less <input type="checkbox"/> 3 2.5 hours or less <input type="checkbox"/> 4 More than 2.5 hours <input type="checkbox"/> 8 Prefer not to answer <input type="checkbox"/> 9 Don't know

Section 2 — Memory

16.	Do you feel like your memory is becoming worse?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes, but this does not worry me <input type="checkbox"/> 2 Yes, and this worries me <input type="checkbox"/> 9 Don't know / Prefer not to answer
17.	About how often do you have trouble remembering things?	<input type="checkbox"/> 1 Very often <input type="checkbox"/> 2 Often <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 Rarely <input type="checkbox"/> 5 Never <input type="checkbox"/> 9 Don't know / Prefer not to answer
18.	Compared to 10 years ago, would you say that your memory is much worse, a little worse, the same, a little better, or much better?	<input type="checkbox"/> 1 Much worse <input type="checkbox"/> 2 A little worse <input type="checkbox"/> 3 The same <input type="checkbox"/> 4 A little better <input type="checkbox"/> 5 Much better <input type="checkbox"/> 9 Don't know / Prefer not to answer

For ADRC use only:

The next two questions use the Area Deprivation Index (ADI) lookup at <https://www.neighborhoodatlas.medicine.wisc.edu/mapping>.
Enter the participant's state and full address.

19. ADI state-only decile:

____ (If unknown, leave blank)

20. ADI national percentile:

____ (If unknown, leave blank)

21. Participant's primary occupation throughout
their working life
(See Addendum on Pages 5-6 for codes):

____ (If unknown, leave blank)

22. ADRC enrollment type:

- ☐ 1 Participant is supported primarily by ADRC funding (*Clinical Core, Satellite Core, or other ADRC Core or project*)
☐ 2 Participant is supported primarily by a non-ADRC study (e.g., R01, including non-ADRC grants supporting FTLD Module participation)

23. Principal referral source

- ☐ 1 Self
☐ 2 Non-professional personal contact who is not a current or previous ADRC participant (e.g., spouse/partner, relative, friend, coworker)
☐ 3 Current or previous ADRC participant (**END FORM HERE**)
☐ 4 ADRC clinician, staff, or investigator (**END FORM HERE**)
☐ 5 Non-ADRC healthcare professional (e.g., clinician, nurse, social worker) (**END FORM HERE**)
☐ 6 Other research study clinician/staff/investigator (non-ADRC; e.g., ADNI, Women's Health Initiative, LEADS, ALL-FTD) (**END FORM HERE**)
☐ 8 Other (**SPECIFY**): _____ (**END FORM HERE**)
☐ 9 Unknown (**END FORM HERE**)

24. If the referral source was self-referral or a
nonprofessional contact, how did the referral
source learn of the ADRC?

(choose most relevant option)

Community outreach event

- ☐ 1 ADRC sponsored event
☐ 2 Event sponsored by an external organization (e.g., Alzheimer's Association event, institution sponsored venue, community health fair, professional conference)

Other ADRC outreach

- ☐ 3 Newsletter (mailed or digital)
☐ 4 Study flyer/brochure (mailed or digital)
☐ 5 Center website
☐ 6 Center social media (**SPECIFY**): _____
☐ 7 Center registry (**SPECIFY**): _____

Other registries, websites, organizations, or media promotions

- ☐ 8 Website (**SPECIFY**): _____
☐ 9 Media (**SPECIFY**): _____
☐ 10 Registry (**SPECIFY**): _____
☐ 88 Other (**SPECIFY**): _____
☐ 99 Unknown

Addendum: NACC Occupation Codes

Code	Occupation	Code	Occupation	Code	Occupation	Code	Occupation
100	Major professionals/ Higher Executives/ Proprietors of Large Concerns	200	Lesser Professionals/ Business Managers of Medium-sized Businesses	300	Administrative Personnel/Small Business Owners/ Minor Professionals	400	Clerical and Sales Workers/Technicians/ Owners of Little Businesses
101	Actuaries	201	Accountants	301	Actors	401	Bank tellers
102	Architects	202	Advertising executives	302	Administrative assistants	402	Bill collectors
103	Bank officers	203	Authors	303	Advertising agents	403	Bookkeepers
104	Certified public accountants	204	Branch managers	304	Artists	404	Claims examiners
105	Chief executives (CEO, CFO, COO)	205	Building contractors	305	Bakers	405	Drafters
106	Clergy	206	Business managers	306	Beauty shop owners	406	Driving teachers
107	Commissioned officers in the military	207	Chiropractors	307	Chefs	407	Factory supervisors
108	Dentists	208	Computer programmer	308	Chief clerks	408	Small farm owners / farmers
109	Economists	209	Computer specialists	309	Clergy (not professionally trained)	409	Flower shop workers
110	Engineers (Masters level and above)	210	Database developer	310	Court reporters	410	Human resources workers
111	Financial managers	211	Editors	311	Credit managers	411	Laboratory technicians
112	Federal government officials	212	Engineers (no advanced degree)	312	Dental hygienists	412	Newsstand operators
113	Large business owners	213	Executive managers	313	Department store managers	413	Post office clerks
114	Lawyers / judges	214	Industrial farm owners	314	Deputy sheriffs	414	Railroad conductors
115	Mathematicians	215	Furniture business owners	315	Dietitians / Nutritionists	415	Railroad train engineers
116	Major contractors	216	Jewelers	316	Dispatchers	416	Receptionists
117	Orthodontist	217	Labor relations consultant	317	Florists	417	Route managers
118	Physicians	218	Librarians	318	Funeral directors	418	Sales clerks
119	Professor / University teachers	219	Manufacturing owners	319	Insurance agents	419	Secretaries / stenographers
120	Psychologists	220	Medium business owners	320	Laboratory assistants	420	Shipping clerks
121	Research scientists	221	Musicians / composers	321	Landscape planners	421	Tailors
122	Urban and regional planners	222	Nurses	322	Noncommissioned officers in the military (at or above rank of master sergeant / C.P.O.)	422	Tax clerks
123	Veterinarians	223	Office manager	323	Morticians	423	Telephone company workers
124	VP of large business	224	Opticians	324	Newspaper / TV reporters	424	Telephone operators
		225	Personnel managers	325	Photographers	425	Timekeepers
		226	Pharmacists	326	Piano teachers	426	Toll collectors
		227	Pilots	327	Radio / TV announcers	427	Tower operators
		228	Police chief / sheriff	328	Real estate agents	428	Truck dispatchers
		229	Postmaster	329	Restaurant owners	429	Typists
		230	Production managers (TV / Radio)	330	Sales representatives	430	Utility workers
		231	Public administration officials	331	Service managers	431	Warehouse clerks
		232	Public health officers	332	Small business owners	432	Window store trimmers
		233	Purchasing managers	333	Store managers		
		234	Real estate brokers	334	Surveyors		
		235	Research assistants	335	Title searchers		
		236	Sales engineers	336	Tool designers		
		237	Sales managers	337	Traffic managers		
		238	Social workers	338	Travel agents		
		239	State / Local government officials	339	Yard masters (Railroad)		
		240	Teachers (Elementary & high school)				

Addendum: NACC Occupation Codes

Code	Occupation	Code	Occupation	Code	Occupation	Code	Occupation
500	Skilled Manual Employees	500	Skilled Manual Employees (cont.)	600	Machine Operators/ Semiskilled Employees	700	Unskilled Employees
501	Auto body repairers	538	Piano tuners	601	Apprentices (electrician / printers / etc.)	701	Amusement park workers
502	Barbers	539	Plumbers	602	Assembly line workers	702	Cafeteria workers
503	Boiler repairers	540	Police officers	603	Bartenders	703	Car cleaners
504	Bookbinders	541	Postal workers	604	Building superintendents	704	Child care workers (private household)
505	Brewers	542	Printers	605	Bus drivers	705	Construction laborers
506	Cabinet makers	543	Radio / TV maintenance	606	Cab / taxi drivers	706	Dairy workers
507	Carpenters	544	Railroad brake operators	607	Cashiers	707	Deck hands
508	Cement layers / finishers	545	Repair people	608	Child care workers (not private household)	708	Farm laborers
509	Checkers / examiners / inspectors	546	Seamstresses / seamsters	609	Cooks (short order)	709	Fishers
510	Cheese makers	547	Sheet metal workers	610	Corrections workers	710	Freight handlers
511	Construction forepeople	548	Ship smiths	611	Delivery people	711	Garbage collectors
512	Die makers	549	Shoe repairers	612	Dry cleaning pressers	712	Grave diggers
513	Electricians	550	Steelworkers	613	Elevator operators	713	Homemakers
514	Engravers	551	Tile layers	614	Enlisted military personnel (other than noncommissioned officers)	714	House cleaners
515	Exterminators	552	Tool makers	615	Factory machine operators	715	Janitors
516	Firefighters	553	Upholsterers	616	Factory workers	716	Junk / recycle sorters
517	Gardeners / landscapers	554	Utility line workers	617	Foundry workers	717	Laundry workers
518	Glassblowers	555	Weavers	618	Garage and gas station assistants	718	Messengers
519	Glaziers	556	Welders	619	Greenhouse workers	719	Peddlers
520	Gun smiths			620	Guards / security watch people	720	Porters
521	Hair stylists			621	Machine operators	721	Roofing laborers
522	Heavy equipment operators			622	Meat cutters / packers	722	Shoe shiners
523	Home repairs			623	Meter readers	723	Stagehands
524	Iron workers			624	Nursing aides / attendants	724	Stock handlers
525	Kitchen workers / cooks			625	Oil delivery people	725	Street cleaners
526	Locksmiths			626	Practical nurses	726	Unemployed
527	Machinists			627	Pump operators	727	Unskilled factory workers
528	Mail carriers			628	Receivers / checkers	728	Unspecified laborers
529	Maintenance forepeople			629	Servers (waiters / waitresses)	729	Window cleaners
530	Masons			630	Signal operators (railroad)	730	Woodchoppers
531	Mechanics			631	Truck drivers	731	Worked while incarcerated
532	Millwrights			632	Wood workers		
533	Noncommissioned officers in the military (below rank of master sergeant / C.P.O.)			633	Wrappers (stores / factories)		
534	Painters						
535	Paperhangers						
536	Patrolmen						
537	Piano builders						