INITIAL VISIT PACKET

UNIFORM DATA SET (UDS) VERSION 4.0



Form A1: Participant Demographics

ADRC:	PTID:	Form date://	Visit #: initials:	_
Language:	Mode:	Key (remote reason): 1=Too cognitively impaired		
□1 English	□ 1 In-person	2=Too physically impaired		
☐2 Spanish	☐ 2 Remote (reason):	3=Homebound or nursing home		
	□1 Telephone □2 Video	4=Refused in-person visit		
		5=Other		

INSTRUCTIONS: This form may be completed by intake interviewer based on ADRC scheduling records, participant interview, medical records, and proxy co-participant report (according to what is deemed to be the most reliable source of information, except as indicated for specific questions that may be based on the participants perceptions and experience which only they can provide accurate information for). 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.

Secti	on 1 — Demographics		
1.	What is your month and year of birth (MM / YYYY)?	?/	_
2.	In which country or region did you spend most of your childhood? (Enter three character code from Appendix 1)	inknown, enter AX1)	Common codes: USA – United States; CAN – Canada; MEX – Mexico
3.	What is your ethnicity and race? (Check all that apple 3a. 1 White 3a1. 1 German 3a2. 1 Irish 3a3. 1 English 3a4. 1 Italian 3a5. 1 Polish 3a6. 1 French 3a7. 1 Other (SPECIFY): 3b. 1 Hispanic or Latino 3b1. 1 Mexican or Mexican American 3b2. 1 Puerto Rican 3b3. 1 Cuban 3b4. 1 Salvadoran 3b5. 1 Dominican 3b6. 1 Colombian 3b7. 1 Other (SPECIFY): 3c. 1 Black or African American 3c1. 1 African American 3c2. 1 Jamaican 3c3. 1 Haitian 3c4. 1 Nigerian 3c5. 1 Ethiopian 3c6. 1 Somali 3c7. 1 Other (SPECIFY): 1	3d. 1 Asian 3d1 3d2 3d3 3d4 3d5 3d6 3d7 3e. 1 Ame (SPE 3f. 1 Midd 3f1. 3f2. 3f3. 3f4. 3f5. 3f6. 3f7. 3g. 1 Nati 3g1 3g2 3g3 3g4 3g5 3g6 3g6 3g6	. 1 Chinese . 1 Filipino . 1 Asian Indian . 1 Vietnamese . 1 Korean . 1 Japanese . 1 Other (SPECIFY): . 1 Chiese . 1 Other (SPECIFY): . 2 Cle Eastern or North African . 1 Lebanese . 1 Iranian . 1 Egyptian . 1 Syrian . 1 Moroccan . 1 Israeli . 1 Other (SPECIFY): . 2 Ve Hawaiian or Pacific Islander . 1 Native Hawaiian . 1 Samoan . 1 Chamorro . 1 Tongan . 1 Tongan . 1 Marshallese . 1 Other (SPECIFY): . 3 Marshallese . 1 Other (SPECIFY): . 4 Marshallese . 5 I Other (SPECIFY): . 5 I Tongan . 6 I Marshallese . 7 I Other (SPECIFY): . 7 I Other (SPECIFY

NATIONAL ALZHEIMER'S COORDINATING CENTER <u>naccmail@uw.edu</u> naccdata.org

Particip	ant ID: Form dat	e: / / /	Visit #:
Secti	on 1 — Demographics		continued
will be	ext four questions ask about your gender identit used to help us improve health, well-being, an elf as being a man, woman, or a different gender orienta	d quality of care. By gender identity, w	ve mean the inner sense that you have of
4.	Which term(s) best describes your current gender identity? (Check all that apply)	4a. 1 Man 4b. 1 Woman 4c. 1 Transgender man 4d. 1 Transgender woman 4e. 1 Non-binary/genderqueer 4f. 1 Two-Spirit (if you are AIAN) 4g. 1 I use a different term (SPECII 4h. 1 Don't know 4i. 1 Prefer not to answer	FY):
5.	What sex were you assigned at birth, on your o	original birth certificate?	☐ 1 Male ☐ 2 Female ☐ 9 Don't know ☐ 8 Prefer not to answer
6.	Have you ever been diagnosed by a medical d with an intersex condition or a "Difference of S born with (or developed naturally in puberty) or chromosomal patterns that do not fit stand	Sex Development (DSD)" or were you genitals, reproductive organs, and/	0 No 1 Yes 9 Don't know 8 Prefer not to answer
7.	Which term(s) best describes your sexual orientation? (Check all that apply)	7a. 1 Lesbian or gay 7b. 1 Straight/heterosexual 7c. 1 Bisexual 7d. 1 Two-Spirit (if you are AIAN) 7e. 1 I use a different term (SPECII 7f. 1 Don't know 7g. 1 Prefer not to answer	FY):
8.	What is your primary language? (Primary language is defined as the predominan your life. Please take into consideration first lang length of use.)		1 English 2 Spanish 3 Chinese dialect 8 Other (SPECIFY):
9.	Are you left- or right-handed (for example, which writing)?	ch hand would normally be used for	1 Left-handed 2 Right-handed 3 Ambidextrous 9 Don't know
10a.	How many years of education have you comp	leted? (99 = Unknown)	
10b.	What is your highest achieved level of educati	on?	1 Less than high school 2 High school or GED 3 Some college 4 Bachelor's degree 5 Master's degree 6 Doctorate 9 Don't know
11.	What is your <u>current</u> marital status?	1 Married 2 Widowed 3 Divorced 4 Separated 5 Never married (or marriage was 6 Living with a domestic partner to	

Participant ID:

Secti	on 1 — Demographics		continued
12.	What is your living situation?	1 Live alone 2 Live with one other person: a sp 3 Live with one other person: a re 4 Live with caregiver who is not s 5 Live with a group (related or not 6 Live in group home (e.g., assiste	elative, friend, or roommate pouse/partner, relative, or friend erelated) in a private residence
13.	What is your primary type of residence?	1 Single- or multi-family private 2 Retirement community or inde 3 Assisted living, adult family hor 4 Skilled nursing facility, nursing 5 Do not have housing (e.g., staying outside on the street, on a beach, in a pont't know	ne, or boarding home home, hospital, or hospice g with others, in a hotel, in a shelter, living
14.	What are the first three digits of the ZIP code of (For example, if your ZIP code is 12345, enter 123.)	f your primary residence?	— — — (If unknown, leave blank)
15.	Have you ever served on active duty in the U.S. National Guard?	. Armed Forces, military Reserves, or	0 No (IF NO, SKIP TO QUESTION 17) 1 Yes 9 Don't know
16.	Have you ever obtained medical care or prescrit(VA) facility?	iption drugs from a Veterans Affairs	□ 0 No □ 1 Yes □ 9 Don't know
17.	How much time each week do you spend performereases in breathing or heart rate for at least (Include activity at work, traveling to and from placereational activities.)	10 minutes continuously?	1 None 2 1 hour or less 3 2.5 hours or less 4 More than 2.5 hours Prefer not to answer 9 Don't know
Secti	on 2 — Memory		
18.	Do you feel like your memory is becoming wor	rse?	□ 0 No □ 1 Yes, but this does not worry me □ 2 Yes, and this worries me □ 9 Don't know / Prefer not to answer
19.	About how often do you have trouble rememb	pering things?	☐ 1 Never ☐ 2 Rarely ☐ 3 Sometimes ☐ 4 Often ☐ 5 Very often ☐ 9 Don't know / Prefer not to answer
20.	Compared to 10 years ago, would you say that worse, the same, a little better, or much better?		1 Much better 2 A little better 3 The same 4 A little worse 5 Much worse 9 Don't know / Prefer not to answer

Form date: ____ / ___ / ___ __ Visit #: _

Participant ID:

Particip	ant ID:	Form date:	/	/	Visit #:	
For A	DRC use only:					
The n	ext two questions use th	ne Area Deprivation Index (ADI) Enter the particip				edicine.wisc.edu/mapping.
21.	ADI state-only decile:					(If unknown, leave blank)
22.	ADI national percentile	:				(If unknown, leave blank)
23.	Participant's primary of (Enter three number code for	ccupation throughout their wo	rking life			(If unknown, leave blank)
24.	ADRC enrollment type:	☐ 1 Participant is supported p Core or project) ☐ 2 Participant is supported p supporting FTLD Module p	orimarily by	a non-ADRC :		
25.	Principal referral source	□ 1 Self □ 2 Non-professional personal spouse/partner, relative, from the spouse/spouse/partner, relative, from the spouse/spou	riend, cowork participant vestigator (E ofessional (e. cian/staff/in RM HERE)	ker) (END FORM I END FORM HE g., clinician, r evestigator (n	HERE) RE) urse, social worker) (E	:ND FORM HERE)
26.	If the referral source was self-referral or a nonprofessional	Community outreach event 1 ADRC sponsored event 2 Event sponsored by an ex-	rternal organ	nization <i>(e a</i>	Alzheimer's Associati	on event institution

2 Event sponsored by an external organization (e.g., Alzheimer's Association event, institution

sponsored venue, community health fair, professional conference)

Other registries, websites, organizations, or media promotions

Other ADRC outreach

3 Newsletter (mailed or digital)

5 Center website
6 Center social media (SPECIFY): _

7 Center registry (SPECIFY): __

8 Website (SPECIFY): ___ 9 Media (SPECIFY): _ 10 Registry (SPECIFY): ___ 88 Other (SPECIFY): _

99 Unknown

4 Study flyer/brochure (mailed or digital)

contact, how did the

referral source learn

(choose most relevant

of the ADRC?

option)

	ndix 1: Birth Country*				
Code	Country	Code	Country	Code	Country
AFG	Afghanistan	CHN	China	GRL	Greenland
ΚQZ	Akrotiri	CXR	Christmas Island	GRD	Grenada
ALB	Albania	CPT	Clipperton Island	GLP	Guadeloupe
DZA	Algeria	CCK	Cocos (Keeling) Islands	GUM	Guam
ASM	American Samoa	COL	Colombia	AX2	Guantanamo Bay Naval Base
AND	Andorra	COM	Comoros	GTM	Guatemala
AGO	Angola	COG	Congo (Brazzaville)	GGY	Guernsey
AIA	Anguilla	COD	Congo (Kinshasa)	GIN	Guinea
ATA	Antarctica	COK	Cook Islands	GNB	Guinea-Bissau
ATG	Antigua and Barbuda	XCS	Coral Sea Islands	GUY	Guyana
ARG	Argentina	CRI	Costa Rica	HTI	Haiti
ARM	Armenia	CIV	Cote D'Ivoire	HMD	Heard Island and McDonald Islands
ABW	Aruba	HRV	Croatia	HND	Honduras
〈AC	Ashmore and Cartier Islands	CUB	Cuba	HKG	Hong Kong
AUS	Australia	CUW	Curacao	XHO	Howland Island
AUT	Austria	CYP	Cyprus	HUN	Hungary
AZE	Azerbaijan	CZE	Czechia	ISL	Iceland
BHS	The Bahamas	DNK	Denmark	IND	India
BHR	Bahrain	XXD	Dhekelia	IDN	Indonesia
KBK	Baker Island	DGA	Diego Garcia	IRN	Iran
3GD	Bangladesh	DJI	Djibouti	IRQ	Iraq
BRB	Barbados	DMA	Dominica	IRL	Ireland
(BI	Bassas da India	DOM	Dominican Republic	IMN	Isle of Man
3LR	Belarus	ECU	Ecuador	ISR	Israel
BEL	Belgium	EGY	Egypt	ITA	Italy
3LZ	Belize	SLV	El Salvador	JAM	Jamaica
BEN	Benin	GNQ	Equatorial Guinea	XJM	Jan Mayen
BMU	Bermuda	ERI	Eritrea	JPN	Japan
BTN	Bhutan	EST	Estonia	XJV	Jarvis Island
3OL	Bolivia	SWZ	Eswatini	JEY	Jersey
BES	Bonaire, Sint Eustatius, and Saba	ETH	Ethiopia	XJA	Johnston Atoll
BIH	Bosnia and Herzegovina	XEU	Europa Island	JOR	Jordan
3WA	Botswana	FLK	Falkland Islands (Islas Malvinas)	XJN	Juan de Nova Island
3VT	Bouvet Island	FRO	Faroe Islands	KAZ	Kazakhstan
3RA	Brazil	FJI	Fiji	KEN	Kenya
OT	British Indian Ocean Territory	FIN	Finland	XKR	Kingman Reef
BRN	Brunei	FRA	France	KIR	Kiribati
3GR	Bulgaria	GUF	French Guiana	PRK	North Korea
3FA	Burkina Faso	PYF	French Polynesia	KOR	South Korea
MMR	Burma	ATF	French Southern and Antarctic Lands	XKS	Kosovo
BDI	Burundi	GAB	Gabon	KWT	Kuwait
CD1/	Cabo Verde	GMB	The Gambia	KGZ	Kyrgyzstan
_PV	Cambodia	XGZ	Gaza Strip	LAO	Laos
	Carriboaia		Georgia	LVA	Latvia
KHM	Cameroon	GEO	acorgia		
CHM CMR		DEU	Germany	LBN	Lebanon
CHM CMR CAN	Cameroon		_		
CHM CMR CAN CYM	Cameroon Canada	DEU	Germany	LBN	Lebanon
CPV KHM CMR CAN CYM CAF	Cameroon Canada Cayman Islands	DEU GHA	Germany Ghana	LBN LSO	Lebanon Lesotho

^{*}Codes were developed by the U.S. Government and endorsed by the Federal Geographic Data Committee. https://www.fgdc.gov/standards/news/GENC

Code	Country	Code	Country	Code	Country
_TU	Lithuania	PRY	Paraguay	TWN	Taiwan
UX	Luxembourg	PER	Peru	TJK	Tajikistan
ЛАС	Macau	PHL	Philippines	TZA	Tanzania
ИDG	Madagascar	PCN	Pitcairn Islands	THA	Thailand
ЛWI	Malawi	POL	Poland	TLS	Timor-Leste
ЛYS	Malaysia	PRT	Portugal	TGO	Togo
1DV	Maldives	PRI	Puerto Rico	TKL	Tokelau
1LI	Mali	QAT	Qatar	TON	Tonga
1LT	Malta	REU	Reunion	TTO	Trinidad and Tobago
IHL	Marshall Islands	ROU	Romania	XTR	Tromelin Island
		RUS	Russia	TUN	Tunisia
1TQ 1RT	Martinique Mauritania	RWA	Rwanda	TUR	
					Turkey
1US	Mauritius	BLM	Saint Barthelemy	TKM	Turkmenistan
1YT	Mayotte	SHN	Saint Helena, Ascension, and Tristan da Cunha	TCA	Turks and Caicos Islands
ΛEX	Mexico	KNA	Saint Kitts and Nevis	TUV	Tuvalu
SM	Federated States of Micronesia	LCA	Saint Lucia	UGA	Uganda
MW	Midway Islands	MAF	Saint Martin	UKR	Ukraine
ΛDA	Moldova	SPM	Saint Pierre and Miquelon	ARE	United Arab Emirates
1CO	Monaco	VCT	Saint Vincent and the Grenadines	GBR	United Kingdom
ING	Mongolia	WSM	Samoa	USA	United States
INE	Montenegro	SMR	San Marino	AX1	Unknown
SR	Montserrat	STP	Sao Tome and Principe	URY	Uruguay
IAR	Morocco	SAU	Saudi Arabia	UZB	Uzbekistan
1OZ	Mozambique	SEN	Senegal	VUT	Vanuatu
AM	Namibia	SRB	Serbia	VAT	Vatican City
RU	Nauru	SYC	Seychelles	VEN	Venezuela
NV	Navassa Island	SLE	Sierra Leone	VNM	Vietnam
IPL	Nepal	SGP	Singapore	VGB	British Virgin Islands
ILD	Netherlands	SXM	Sint Maarten	VIR	U.S. Virgin Islands
ICL	New Caledonia	SVK	Slovakia	XWK	Wake Island
۱ZL	New Zealand	SVN	Slovenia	WLF	Wallis and Futuna
VIC .	Nicaragua	SLB	Soloman Islands	XWB	West Bank
IER	Niger	SOM	Somalia	ESH	Western Sahara
IGA	Nigeria	ZAF	South Africa	YEM	Yemen
IIU	Niue	SGS	South Georgia and South Sandwich Islands	ZMB	Zambia
IFK	Norfolk Island	SSD	South Sudan	ZWE	Zimbabwe
IKD	North Macedonia	ESP	Spain	~ V L	LITIDUDVIC
INP	Northern Mariana Islands	XSP	Spratly Islands		
OR	Norway	LKA	Sri Lanka		
MN	Oman	SDN	Sudan		
٩K	Pakistan	SUR	Suriname		
	Palau	XSV	Svalbard		
LW					
(PL	Palmyra Atoll	SWE	Sweden		
AN	Panama Panua Nau Cuinaa	CHE	Switzerland		
PNG	Papua New Guinea	SYR	Syria		

 $^{{\}rm *Codes\ were\ developed\ by\ the\ U.S.\ Government\ and\ endorsed\ by\ the\ Federal\ Geographic\ Data\ Committee.} \\ {\rm \underline{https://www.fgdc.gov/standards/news/GENC}}$

App	endix 2: NACC Occupa	tion C	odes			,	
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 (professionally trained)	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
116 117	Major contractors Orthodontists	216 217	Jewelers Labor relations consultants	316 317	Dispatchers Florists	416 417	Receptionists Route managers
118	Physicians	218	Librarians	318	Funeral directors	418	Sales clerks
119	Professor / University teachers	219	Manufacturing owners	319	Insurance agents	419	Secretaries / stenographe
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 managers	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
		229 230	Production managers (TV	329 330	Restaurant owners Sales representatives	429 430	Typists Utility workers
		231	/ radio) 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	732	Wildow stole tillilliels
		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)				

Code	Occupation	Code	Occupation	Code	Occupation	Code	Occupation
500	Skilled Manual	500	Skilled Manual	600	Machine Operators/	700	Unskilled Employees
	Employees		Employees (cont.)		Semiskilled 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 incarcerate
532	Millwrights			632	Wood workers		
533	Noncommissioned officers in the military (below rank of master sergeant / C.P.O.)			633	Wrappers (stores / factories)		
53/	Painters						
534							
535	Paperhangers Patrolmen						
536 537	Piano builders						