



NACC UNIFORM DATA SET

Initial Visit Packet

UDSv4.0, January 2025

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Revisions made to this Initial Visit Packet (IVP) since release (December 2024)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected
2024-12-18	Fixed numbering error on A1a, subquestions of Q37.	A1a	Q37a1 - Q37a15
2025-02-14	Changed informative missing codes (88 and 99) to 888 and 999 throughout Section 7: Menstrual and Reproductive Health	A5-D2	Q7a-Q7b Q7d1-Q7d3 Q7e1-Q7e3
2025-02-14	Fixed typos on B4 and A5/D2	B4, A5-D2	N/A

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Form A1: Participant Demographics

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Administration: <input type="checkbox"/> 1 Self-administered <input type="checkbox"/> 2 Staff-administered	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 3 Mail <input type="checkbox"/> 4 Electronic (e.g., email)	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound/nursing home 4=Refused in-person visit 5=Other
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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.

Section 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)	Common codes: USA – United States; CAN – Canada; MEX – Mexico
3. What is your race and/or ethnicity? (Check all that apply and enter additional details in the space below.)	
3a. <input type="checkbox"/> 1 American Indian or Alaska Native (AIAN) (SPECIFY, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya): _____	3e. <input type="checkbox"/> 1 Middle Eastern or North African 3e1. <input type="checkbox"/> 1 Lebanese 3e2. <input type="checkbox"/> 1 Iranian 3e3. <input type="checkbox"/> 1 Egyptian 3e4. <input type="checkbox"/> 1 Syrian 3e5. <input type="checkbox"/> 1 Iraqi 3e6. <input type="checkbox"/> 1 Israeli 3e7. <input type="checkbox"/> 1 Other (SPECIFY, for example, Moroccan, Yemeni, Kurdish): _____
3b. <input type="checkbox"/> 1 Asian 3b1. <input type="checkbox"/> 1 Chinese 3b2. <input type="checkbox"/> 1 Asian Indian 3b3. <input type="checkbox"/> 1 Filipino 3b4. <input type="checkbox"/> 1 Vietnamese 3b5. <input type="checkbox"/> 1 Korean 3b6. <input type="checkbox"/> 1 Japanese 3b7. <input type="checkbox"/> 1 Other (SPECIFY, for example, Pakistani, Hmong, Afghan): _____	3f. <input type="checkbox"/> 1 Native Hawaiian or Pacific Islander 3f1. <input type="checkbox"/> 1 Native Hawaiian 3f2. <input type="checkbox"/> 1 Samoan 3f3. <input type="checkbox"/> 1 Chamorro 3f4. <input type="checkbox"/> 1 Tongan 3f5. <input type="checkbox"/> 1 Fijian 3f6. <input type="checkbox"/> 1 Marshallese 3f7. <input type="checkbox"/> 1 Other (SPECIFY, for example, Chuukese, Palauan, Tahitian): _____
3c. <input type="checkbox"/> 1 Black or African American 3c1. <input type="checkbox"/> 1 African American 3c2. <input type="checkbox"/> 1 Jamaican 3c3. <input type="checkbox"/> 1 Haitian 3c4. <input type="checkbox"/> 1 Nigerian 3c5. <input type="checkbox"/> 1 Ethiopian 3c6. <input type="checkbox"/> 1 Somali 3c7. <input type="checkbox"/> 1 Other (SPECIFY, for example, Trinidadian and Tobagonian, Ghanaian, Congolese): _____	3g. <input type="checkbox"/> 1 White 3g1. <input type="checkbox"/> 1 English 3g2. <input type="checkbox"/> 1 German 3g3. <input type="checkbox"/> 1 Irish 3g4. <input type="checkbox"/> 1 Italian 3g5. <input type="checkbox"/> 1 Polish 3g6. <input type="checkbox"/> 1 Scottish 3g7. <input type="checkbox"/> 1 Other (SPECIFY, for example, French, Swedish, Norwegian): _____
3d. <input type="checkbox"/> 1 Hispanic or Latino 3d1. <input type="checkbox"/> 1 Mexican 3d2. <input type="checkbox"/> 1 Puerto Rican 3d3. <input type="checkbox"/> 1 Salvadoran 3d4. <input type="checkbox"/> 1 Cuban 3d5. <input type="checkbox"/> 1 Dominican 3d6. <input type="checkbox"/> 1 Guatemalan 3d7. <input type="checkbox"/> 1 Other (SPECIFY, for example, Colombian, Honduran, Spaniard): _____	3h. <input type="checkbox"/> 1 Don't know

Section 1 — Demographics*continued...*

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.

4. Which term(s) best describes your current gender identity? <i>(Check all that apply)</i>	4a. <input type="checkbox"/> 1 Man 4b. <input type="checkbox"/> 1 Woman 4c. <input type="checkbox"/> 1 Transgender man 4d. <input type="checkbox"/> 1 Transgender woman 4e. <input type="checkbox"/> 1 Non-binary/genderqueer 4f. <input type="checkbox"/> 1 Two-Spirit (if you are AIAN) 4g. <input type="checkbox"/> 1 I use a different term (SPECIFY): _____ 4h. <input type="checkbox"/> 1 Don't know 4i. <input type="checkbox"/> 1 Prefer not to answer
5. What sex were you assigned at birth; on your original birth certificate?	<input type="checkbox"/> 1 Male <input type="checkbox"/> 2 Female <input type="checkbox"/> 9 Don't know <input type="checkbox"/> 8 Prefer not to answer
6. 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?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Don't know <input type="checkbox"/> 8 Prefer not to answer
7. Which term(s) best describes your sexual orientation? <i>(Check all that apply)</i>	7a. <input type="checkbox"/> 1 Lesbian or gay 7b. <input type="checkbox"/> 1 Straight/heterosexual 7c. <input type="checkbox"/> 1 Bisexual 7d. <input type="checkbox"/> 1 Two-Spirit (if you are AIAN) 7e. <input type="checkbox"/> 1 I use a different term (SPECIFY): _____ 7f. <input type="checkbox"/> 1 Don't know 7g. <input type="checkbox"/> 1 Prefer not to answer
8. What is your primary language? <i>(Primary language is defined as the predominant language you have used throughout your life. Please take into consideration first language learned as well as the length of use.)</i>	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Chinese dialect <input type="checkbox"/> 8 Other (SPECIFY): _____ <input type="checkbox"/> 9 Don't know
9. Are you left- or right-handed (<i>for example, which hand would normally be used for writing</i>)?	<input type="checkbox"/> 1 Left-handed <input type="checkbox"/> 2 Right-handed <input type="checkbox"/> 3 Ambidextrous <input type="checkbox"/> 9 Don't know
10a. How many years of education have you completed? (99 = Unknown)	____
10b. 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
11. What is your <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 Don't know

Section 1 — Demographics*continued...*

12.	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 (<i>related or not related</i>) in a private residence <input type="checkbox"/> 6 Live in group home (<i>e.g., assisted living, nursing home, convent</i>) <input type="checkbox"/> 9 Don't know
13.	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"/> 6 Do not have housing (<i>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</i>) <input type="checkbox"/> 9 Don't know
14.	What are the first three digits of the ZIP code of your primary residence? (For example, if your ZIP code is 12345, enter 123.)	<div style="display: flex; align-items: center;"> <div style="flex: 1;"> <div style="border-bottom: 1px solid black; width: 20px; height: 20px; display: flex; align-items: center; justify-content: center;"> <div style="width: 10px; height: 10px; border: 1px solid black; margin: 0 5px;"></div> <div style="width: 10px; height: 10px; border: 1px solid black; margin: 0 5px;"></div> <div style="width: 10px; height: 10px; border: 1px solid black; margin: 0 5px;"></div> </div> </div> <div style="flex: 1; text-align: right;"> <i>(If unknown, leave blank)</i> </div> </div>
15.	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 17) <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Don't know
16.	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
17.	How much time in total do you spend each week exercising or engaged in physically strenuous activities that cause increases in your 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

18.	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
19.	About how often do you have trouble remembering things?	<input type="checkbox"/> 1 Never <input type="checkbox"/> 2 Rarely <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 Often <input type="checkbox"/> 5 Very often <input type="checkbox"/> 9 Don't know / Prefer not to answer
20.	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 better <input type="checkbox"/> 2 A little better <input type="checkbox"/> 3 The same <input type="checkbox"/> 4 A little worse <input type="checkbox"/> 5 Much worse <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.

- 21.** ADI state-only decile: _____ (If unknown, leave blank)
- 22.** ADI national percentile: _____ (If unknown, leave blank)
- 23.** Participant's primary occupation throughout their working life
(Enter three number code from Appendix 2): _____ (If unknown, leave blank)
- 24.** 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)
- 25.** 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**)
- 26.** 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

Appendix 1: Birth Country*

Code	Country	Code	Country	Code	Country
AFG	Afghanistan	CHN	China	GRL	Greenland
XQZ	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
XAC	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
XBK	Baker Island	DGA	Diego Garcia	IRN	Iran
BGD	Bangladesh	DJI	Djibouti	IRQ	Iraq
BRB	Barbados	DMA	Dominica	IRL	Ireland
XBI	Bassas da India	DOM	Dominican Republic	IMN	Isle of Man
BLR	Belarus	ECU	Ecuador	ISR	Israel
BEL	Belgium	EGY	Egypt	ITA	Italy
BLZ	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
BOL	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
BWA	Botswana	FLK	Falkland Islands (Islas Malvinas)	XJN	Juan de Nova Island
BVT	Bouvet Island	FRO	Faroe Islands	KAZ	Kazakhstan
BRA	Brazil	FJI	Fiji	KEN	Kenya
IOT	British Indian Ocean Territory	FIN	Finland	XKR	Kingman Reef
BRN	Brunei	FRA	France	KIR	Kiribati
BGR	Bulgaria	GUF	French Guiana	PRK	North Korea
BFA	Burkina Faso	PYF	French Polynesia	KOR	South Korea
MMR	Burma	ATF	French Southern and Antarctic Lands	XKS	Kosovo
BDI	Burundi	GAB	Gabon	KWT	Kuwait
CPV	Cabo Verde	GMB	The Gambia	KGZ	Kyrgyzstan
KHM	Cambodia	XGZ	Gaza Strip	LAO	Laos
CMR	Cameroon	GEO	Georgia	LVA	Latvia
CAN	Canada	DEU	Germany	LBN	Lebanon
CYM	Cayman Islands	GHA	Ghana	LSO	Lesotho
CAF	Central African Republic	GIB	Gibraltar	LBR	Liberia
TCD	Chad	XGL	Glorioso Islands	LBY	Libya
CHL	Chile	GRC	Greece	LIE	Liechtenstein

*Codes were developed by the U.S. Government and endorsed by the Federal Geographic Data Committee.

<https://www.fgdc.gov/standards/news/GENC>

Appendix 1: Birth Country*

Code	Country	Code	Country	Code	Country
LTU	Lithuania	PRY	Paraguay	TWN	Taiwan
LUX	Luxembourg	PER	Peru	TJK	Tajikistan
MAC	Macau	PHL	Philippines	TZA	Tanzania
MDG	Madagascar	PCN	Pitcairn Islands	THA	Thailand
MWI	Malawi	POL	Poland	TLS	Timor-Leste
MYS	Malaysia	PRT	Portugal	TGO	Togo
MDV	Maldives	PRI	Puerto Rico	TKL	Tokelau
MLI	Mali	QAT	Qatar	TON	Tonga
MLT	Malta	REU	Reunion	TTO	Trinidad and Tobago
MHL	Marshall Islands	ROU	Romania	XTR	Tromelin Island
MTQ	Martinique	RUS	Russia	TUN	Tunisia
MRT	Mauritania	RWA	Rwanda	TUR	Turkey
MUS	Mauritius	BLM	Saint Barthelemy	TKM	Turkmenistan
MYT	Mayotte	SHN	Saint Helena, Ascension, and Tristan da Cunha	TCA	Turks and Caicos Islands
MEX	Mexico	KNA	Saint Kitts and Nevis	TUV	Tuvalu
FSM	Federated States of Micronesia	LCA	Saint Lucia	UGA	Uganda
XMW	Midway Islands	MAF	Saint Martin	UKR	Ukraine
MDA	Moldova	SPM	Saint Pierre and Miquelon	ARE	United Arab Emirates
MCO	Monaco	VCT	Saint Vincent and the Grenadines	GBR	United Kingdom
MNG	Mongolia	WSM	Samoa	USA	United States
MNE	Montenegro	SMR	San Marino	AX1	Unknown
MSR	Montserrat	STP	Sao Tome and Principe	URY	Uruguay
MAR	Morocco	SAU	Saudi Arabia	UZB	Uzbekistan
MOZ	Mozambique	SEN	Senegal	VUT	Vanuatu
NAM	Namibia	SRB	Serbia	VAT	Vatican City
NRU	Nauru	SYC	Seychelles	VEN	Venezuela
XNV	Navassa Island	SLE	Sierra Leone	VNM	Vietnam
NPL	Nepal	SGP	Singapore	VGB	British Virgin Islands
NLD	Netherlands	SXM	Sint Maarten	VIR	U.S. Virgin Islands
NCL	New Caledonia	SVK	Slovakia	XWK	Wake Island
NZL	New Zealand	SVN	Slovenia	WLF	Wallis and Futuna
NIC	Nicaragua	SLB	Soloman Islands	XWB	West Bank
NER	Niger	SOM	Somalia	ESH	Western Sahara
NGA	Nigeria	ZAF	South Africa	YEM	Yemen
NIU	Niue	SGS	South Georgia and South Sandwich Islands	ZMB	Zambia
NFK	Norfolk Island	SSD	South Sudan	ZWE	Zimbabwe
MKD	North Macedonia	ESP	Spain		
MNP	Northern Mariana Islands	XSP	Spratly Islands		
NOR	Norway	LKA	Sri Lanka		
OMN	Oman	SDN	Sudan		
PAK	Pakistan	SUR	Suriname		
PLW	Palau	XSV	Svalbard		
XPL	Palmyra Atoll	SWE	Sweden		
PAN	Panama	CHE	Switzerland		
PNG	Papua New Guinea	SYR	Syria		
XPR	Paracel Islands				

*Codes were developed by the U.S. Government and endorsed by the Federal Geographic Data Committee.

<https://www.fgdc.gov/standards/news/GENC>

Appendix 2: 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 (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	Major contractors	216	Jewelers	316	Dispatchers	416	Receptionists
117	Orthodontists	217	Labor relations consultants	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 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	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)				

Appendix 2: 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						

Form A1a: Social Determinants of Health

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Administration: <input type="checkbox"/> 1 Self-administered <input type="checkbox"/> 2 Staff-administered	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 3 Mail <input type="checkbox"/> 4 Electronic (e.g., email) <input type="checkbox"/> 0 Not completed (reason): ____ ____	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound/nursing home 4=Refused in-person visit 5=Other Key (not completed reason): 93=Concerns about reliability
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INSTRUCTIONS: The following questions are designed to gather information on your current and past life experience that we think may be important for brain health. There are no right or wrong answers, and you do not have to answer any question that makes you feel uncomfortable. If the question does not apply to your experience, feel free to check **Prefer not to answer**. You should fill out this form on your own, without help from your co-participant or study partner.

Section 1 — Transportation

In this section we are trying to understand the extent to which lack of reliable and consistent transportation is a barrier to accomplishing important activities, such as going to the doctor for appointments, going grocery shopping, or picking up medications (these are only examples).

1. Do you or someone in your household currently own a car?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
2. Do you have consistent access to transportation?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer

To get to the places they need to go, people might walk, bike, take a bus, train or taxi, drive a car, or get a ride. The next three questions are trying to assess whether or not you have had recent issues with transportation.


3. In the past 30 days, how often were you not able to leave the house when you wanted to because of a problem with transportation?	<input type="checkbox"/> 1 Often <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Never <input type="checkbox"/> 8 Prefer not to answer
4. In the past 30 days, how often did you worry about whether or not you would be able to get somewhere because of a problem with transportation?	<input type="checkbox"/> 1 Often <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Never <input type="checkbox"/> 8 Prefer not to answer
5. In the past 30 days, how often has a lack of transportation kept you from medical appointments or from doing things needed for daily living?	<input type="checkbox"/> 1 Often <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Never <input type="checkbox"/> 8 Prefer not to answer

Section 2 — Financial security

These next set of questions are designed to assess your current and past financial situation. If you do not feel comfortable with any question in this section, you can respond **Prefer not to answer**.

6. Which of these income groups represents your household income <u>for the past year</u> ? Include income from all sources such as wages, salaries, social security or retirement benefits, help from relatives, rent from property, and so forth. <i>This information will be kept confidential and will not be shared in a way that identifies you with any other person, organization or government entity.</i>	<input type="checkbox"/> 1 \$0 - \$14,999 <input type="checkbox"/> 2 \$15,000 - \$29,999 <input type="checkbox"/> 3 \$30,000 - \$74,999 <input type="checkbox"/> 4 \$75,000 and over <input type="checkbox"/> 8 Prefer not to answer <input type="checkbox"/> 9 Don't know
7. How satisfied are you with your current personal financial condition?	<input type="checkbox"/> 1 Completely satisfied <input type="checkbox"/> 2 Satisfied <input type="checkbox"/> 3 Somewhat satisfied <input type="checkbox"/> 4 Not very satisfied <input type="checkbox"/> 5 Not at all satisfied <input type="checkbox"/> 8 Prefer not to answer

Section 2 — Financial security*continued...*

8.	How difficult is it for you to meet monthly payments on your bills?	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 Slightly <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Very <input type="checkbox"/> 5 Extremely <input type="checkbox"/> 8 Prefer not to answer
9.	If you have had financial problems that lasted twelve months or longer, how upsetting has it been to you?	<input type="checkbox"/> 1 No financial problems for twelve months or longer <input type="checkbox"/> 2 Yes, financial problems for twelve months or longer, but not upsetting to me <input type="checkbox"/> 3 Yes, financial problems for twelve months or longer, and somewhat upsetting to me <input type="checkbox"/> 4 Yes, financial problems for twelve months or longer, and very upsetting to me <input type="checkbox"/> 8 Prefer not to answer
10.	At any time, did you ever eat less than you felt you should because there wasn't enough money to buy food?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
11.	<u>In the last 12 months</u> , did you ever eat less than you felt you should because there wasn't enough money to buy food?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
12.	At any time, have you ended up taking less medication than was prescribed for you because of the cost?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
13.	<u>In the last 12 months</u> , have you ended up taking less medication than was prescribed for you because of the cost?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Prefer not to answer
14.	<p>This is a picture of a ladder with 10 steps. Each step represents a level of status as far as money, education, and jobs. The highest step is step 10. This represents people with the most money, the most education, and the best jobs. Step 1 is the lowest step. This step represents people with the least money, least education, and the worst jobs or no job. Steps in between (2 through 9) represent those people who fall somewhere between those who are best off and those who are worst off.</p> <p>Where would you place yourself on this ladder compared to others in your community (or neighborhood)? The closer you are to step 10 the better off you think you are. Please mark the number where you would place yourself.</p>	
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> 88 Prefer not to answer
	10 9 8 7 6 5 4 3 2 1	
15.	What was your mother's (or primary person who raised you up until age 18) highest level of education completed at the time they were raising you?	<input type="checkbox"/> 1 Never attended school or only attended kindergarten <input type="checkbox"/> 2 Grades 1 through 8 (elementary) <input type="checkbox"/> 3 Grades 9 through 11 (some high school) <input type="checkbox"/> 4 Grade 12 or GED (high school graduate) <input type="checkbox"/> 5 College 1 year to 3 years (some college) <input type="checkbox"/> 6 College 4 years or more (college graduate) <input type="checkbox"/> 8 Prefer not to answer/Not applicable <input type="checkbox"/> 9 Do not know

Section 3 — Social connections, activities, and environment

These next set of questions are designed to learn what you think about your social connections, the types of activities you spend your time on, and how you view your home and neighborhood.

Following are some statements to learn how you describe yourself in general. For each statement, select the number that most closely represents your opinion.

16.	I experience a general sense of emptiness	<input type="checkbox"/> 1 Strongly disagree <input type="checkbox"/> 2 Disagree <input type="checkbox"/> 3 Neither disagree or agree <input type="checkbox"/> 4 Agree <input type="checkbox"/> 5 Strongly agree <input type="checkbox"/> 8 Prefer not to answer
17.	I miss having people around	<input type="checkbox"/> 1 Strongly disagree <input type="checkbox"/> 2 Disagree <input type="checkbox"/> 3 Neither disagree or agree <input type="checkbox"/> 4 Agree <input type="checkbox"/> 5 Strongly agree <input type="checkbox"/> 8 Prefer not to answer
18.	I feel like I don't have enough friends	<input type="checkbox"/> 1 Strongly disagree <input type="checkbox"/> 2 Disagree <input type="checkbox"/> 3 Neither disagree or agree <input type="checkbox"/> 4 Agree <input type="checkbox"/> 5 Strongly agree <input type="checkbox"/> 8 Prefer not to answer
19.	I often feel abandoned	<input type="checkbox"/> 1 Strongly disagree <input type="checkbox"/> 2 Disagree <input type="checkbox"/> 3 Neither disagree or agree <input type="checkbox"/> 4 Agree <input type="checkbox"/> 5 Strongly agree <input type="checkbox"/> 8 Prefer not to answer
20.	I miss having a really close friend	<input type="checkbox"/> 1 Strongly disagree <input type="checkbox"/> 2 Disagree <input type="checkbox"/> 3 Neither disagree or agree <input type="checkbox"/> 4 Agree <input type="checkbox"/> 5 Strongly agree <input type="checkbox"/> 8 Prefer not to answer

The next four questions are about how you spend your time.

21.	If your parents are still alive, how often do you have contact with them (including mother, father, mother-in-law, and father-in-law) either in person, by phone, mail, or email (e.g., any online interaction)?	<input type="checkbox"/> 0 Parents not living <input type="checkbox"/> 1 Once a year or less <input type="checkbox"/> 2 Several times a year <input type="checkbox"/> 3 Several times a month <input type="checkbox"/> 4 Several times a week <input type="checkbox"/> 5 Everyday or almost everyday <input type="checkbox"/> 8 Prefer not to answer
22.	If you have children, how often do you have contact with your children (including child[ren]-in-law and stepchild[ren]) either in person, by phone, mail, or email (e.g., any online interaction)?	<input type="checkbox"/> 0 Do not have children <input type="checkbox"/> 1 Once a year or less <input type="checkbox"/> 2 Several times a year <input type="checkbox"/> 3 Several times a month <input type="checkbox"/> 4 Several times a week <input type="checkbox"/> 5 Everyday or almost everyday <input type="checkbox"/> 8 Prefer not to answer

Section 3 — Social connections, activities, and environment*continued...*

23.	How often do you have contact with close friends either in person, by phone, mail, or email (e.g., any online interaction)?	<input type="checkbox"/> 0 Do not have close friends <input type="checkbox"/> 1 Once a year or less <input type="checkbox"/> 2 Several times a year <input type="checkbox"/> 3 Several times a month <input type="checkbox"/> 4 Several times a week <input type="checkbox"/> 5 Everyday or almost everyday <input type="checkbox"/> 8 Prefer not to answer
24.	How often do you participate in activities outside the home (e.g., religious activities, educational activities, volunteer work, paid work, or activities with groups or organizations)?	<input type="checkbox"/> 0 Do not participate in activities outside the home <input type="checkbox"/> 1 Once a year or less <input type="checkbox"/> 2 Several times a year <input type="checkbox"/> 3 Several times a month <input type="checkbox"/> 4 Several times a week <input type="checkbox"/> 5 Everyday or almost everyday <input type="checkbox"/> 8 Prefer not to answer

This next set of questions is about how safe you feel in different contexts.

25.	How safe do you feel in your home and community (or neighborhood)?	
25a.	Home	<input type="checkbox"/> 1 Very safe <input type="checkbox"/> 2 Mostly safe <input type="checkbox"/> 3 Unsafe at times <input type="checkbox"/> 4 Very unsafe <input type="checkbox"/> 8 Prefer not to answer
25b.	Community (or neighborhood)	<input type="checkbox"/> 1 Very safe <input type="checkbox"/> 2 Mostly safe <input type="checkbox"/> 3 Unsafe at times <input type="checkbox"/> 4 Very unsafe <input type="checkbox"/> 8 Prefer not to answer

Section 4 — Experiences with the healthcare system

These next five questions are about your experiences with the healthcare system over the past year. In answering the questions, please think about your regular medical doctors (not the doctors you see for this research study).

26.	In the past year, how often did you delay seeking medical attention for a problem that was bothering you?	<input type="checkbox"/> 1 All of the time <input type="checkbox"/> 2 Most of the time <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 None or almost none of the time <input type="checkbox"/> 5 Not applicable <input type="checkbox"/> 8 Prefer not to answer
27.	In the past year, how often did you experience challenges in filling a prescription?	<input type="checkbox"/> 1 All of the time <input type="checkbox"/> 2 Most of the time <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 None or almost none of the time <input type="checkbox"/> 5 Not applicable <input type="checkbox"/> 8 Prefer not to answer
28.	In the past year, how often did you miss a follow-up medical appointment that was scheduled?	<input type="checkbox"/> 1 All of the time <input type="checkbox"/> 2 Most of the time <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 None or almost none of the time <input type="checkbox"/> 5 Not applicable <input type="checkbox"/> 8 Prefer not to answer

Section 4 — Experiences with the healthcare system*continued...*

- | | | |
|-----|--|---|
| 29. | In the past year, how often did you follow a doctor's advice or treatment plan when it was given? | <input type="checkbox"/> 1 All of the time
<input type="checkbox"/> 2 Most of the time
<input type="checkbox"/> 3 Sometimes
<input type="checkbox"/> 4 None or almost none of the time
<input type="checkbox"/> 5 Not applicable
<input type="checkbox"/> 8 Prefer not to answer |
| 30. | Overall, which of these describes your health insurance, access to healthcare services, and access to medications? | <input type="checkbox"/> 1 Not available to any extent
<input type="checkbox"/> 2 Below the level of my needs
<input type="checkbox"/> 3 Able to meet my needs
<input type="checkbox"/> 4 Exceeds my needs
<input type="checkbox"/> 8 Prefer not to answer |

Section 5 — Experiences of Discrimination

Research has shown that experiences of unfair treatment in daily life, for any reason, can negatively affect health. Please answer the following questions about whether you have experienced unfair treatment in the following ways.

- | | | |
|-----|---|--|
| 31. | In your day-to-day life how often are you treated with less courtesy or respect than other people? | <input type="checkbox"/> 1 Almost every day
<input type="checkbox"/> 2 At least once a week
<input type="checkbox"/> 3 A few times a month
<input type="checkbox"/> 4 A few times a year
<input type="checkbox"/> 5 Less than once a year
<input type="checkbox"/> 6 Never
<input type="checkbox"/> 8 Prefer not to answer |
| 32. | In your day-to-day life how often do you receive poorer service than other people at restaurants or stores? | <input type="checkbox"/> 1 Almost every day
<input type="checkbox"/> 2 At least once a week
<input type="checkbox"/> 3 A few times a month
<input type="checkbox"/> 4 A few times a year
<input type="checkbox"/> 5 Less than once a year
<input type="checkbox"/> 6 Never
<input type="checkbox"/> 8 Prefer not to answer |
| 33. | In your day-to-day life how often do people act as if they think you are not smart? | <input type="checkbox"/> 1 Almost every day
<input type="checkbox"/> 2 At least once a week
<input type="checkbox"/> 3 A few times a month
<input type="checkbox"/> 4 A few times a year
<input type="checkbox"/> 5 Less than once a year
<input type="checkbox"/> 6 Never
<input type="checkbox"/> 8 Prefer not to answer |
| 34. | In your day-to-day life how often do people act as if they are afraid of you? | <input type="checkbox"/> 1 Almost every day
<input type="checkbox"/> 2 At least once a week
<input type="checkbox"/> 3 A few times a month
<input type="checkbox"/> 4 A few times a year
<input type="checkbox"/> 5 Less than once a year
<input type="checkbox"/> 6 Never
<input type="checkbox"/> 8 Prefer not to answer |
| 35. | In your day-to-day life how often are you threatened or harassed? | <input type="checkbox"/> 1 Almost every day
<input type="checkbox"/> 2 At least once a week
<input type="checkbox"/> 3 A few times a month
<input type="checkbox"/> 4 A few times a year
<input type="checkbox"/> 5 Less than once a year
<input type="checkbox"/> 6 Never
<input type="checkbox"/> 8 Prefer not to answer |

Section 5 — Experiences of Discrimination*continued...*

36.	How frequently do you receive poorer service or treatment from doctors or in hospitals compared to other people?	<input type="checkbox"/> 1 All of the time <input type="checkbox"/> 2 Most of the time <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 4 None or almost none of the time <input type="checkbox"/> 5 Not applicable <input type="checkbox"/> 8 Prefer not to answer																														
37.	When reflecting on the day-to-day experiences in questions 31 to 36, what do you think are the main reasons for these experiences? <i>(Check all that apply)</i>	<table border="0"> <tr> <td>37a1.</td> <td><input type="checkbox"/> 1 My ancestry or national origins</td> </tr> <tr> <td>37a2.</td> <td><input type="checkbox"/> 1 My gender</td> </tr> <tr> <td>37a3.</td> <td><input type="checkbox"/> 1 My race</td> </tr> <tr> <td>37a4.</td> <td><input type="checkbox"/> 1 My age</td> </tr> <tr> <td>37a5.</td> <td><input type="checkbox"/> 1 My religion</td> </tr> <tr> <td>37a6.</td> <td><input type="checkbox"/> 1 My height</td> </tr> <tr> <td>37a7.</td> <td><input type="checkbox"/> 1 My weight</td> </tr> <tr> <td>37a8.</td> <td><input type="checkbox"/> 1 Some other aspect of my physical appearance</td> </tr> <tr> <td>37a9.</td> <td><input type="checkbox"/> 1 My sexual orientation</td> </tr> <tr> <td>37a10.</td> <td><input type="checkbox"/> 1 My education or income level</td> </tr> <tr> <td>37a11.</td> <td><input type="checkbox"/> 1 A physical disability</td> </tr> <tr> <td>37a12.</td> <td><input type="checkbox"/> 1 My shade of skin color</td> </tr> <tr> <td>37a13.</td> <td><input type="checkbox"/> 1 Other</td> </tr> <tr> <td>37a14.</td> <td><input type="checkbox"/> 1 Not applicable - I do not have these experiences in my day-to-day life (END FORM HERE)</td> </tr> <tr> <td>37a15.</td> <td><input type="checkbox"/> 1 Prefer not to answer</td> </tr> </table>	37a1.	<input type="checkbox"/> 1 My ancestry or national origins	37a2.	<input type="checkbox"/> 1 My gender	37a3.	<input type="checkbox"/> 1 My race	37a4.	<input type="checkbox"/> 1 My age	37a5.	<input type="checkbox"/> 1 My religion	37a6.	<input type="checkbox"/> 1 My height	37a7.	<input type="checkbox"/> 1 My weight	37a8.	<input type="checkbox"/> 1 Some other aspect of my physical appearance	37a9.	<input type="checkbox"/> 1 My sexual orientation	37a10.	<input type="checkbox"/> 1 My education or income level	37a11.	<input type="checkbox"/> 1 A physical disability	37a12.	<input type="checkbox"/> 1 My shade of skin color	37a13.	<input type="checkbox"/> 1 Other	37a14.	<input type="checkbox"/> 1 Not applicable - I do not have these experiences in my day-to-day life (END FORM HERE)	37a15.	<input type="checkbox"/> 1 Prefer not to answer
37a1.	<input type="checkbox"/> 1 My ancestry or national origins																															
37a2.	<input type="checkbox"/> 1 My gender																															
37a3.	<input type="checkbox"/> 1 My race																															
37a4.	<input type="checkbox"/> 1 My age																															
37a5.	<input type="checkbox"/> 1 My religion																															
37a6.	<input type="checkbox"/> 1 My height																															
37a7.	<input type="checkbox"/> 1 My weight																															
37a8.	<input type="checkbox"/> 1 Some other aspect of my physical appearance																															
37a9.	<input type="checkbox"/> 1 My sexual orientation																															
37a10.	<input type="checkbox"/> 1 My education or income level																															
37a11.	<input type="checkbox"/> 1 A physical disability																															
37a12.	<input type="checkbox"/> 1 My shade of skin color																															
37a13.	<input type="checkbox"/> 1 Other																															
37a14.	<input type="checkbox"/> 1 Not applicable - I do not have these experiences in my day-to-day life (END FORM HERE)																															
37a15.	<input type="checkbox"/> 1 Prefer not to answer																															
38.	When you have had day-to-day experiences like those in questions 31 to 36, would you say they have been very stressful, moderately stressful, or not stressful?	<input type="checkbox"/> 1 Very stressful <input type="checkbox"/> 2 Moderately stressful <input type="checkbox"/> 3 Not stressful <input type="checkbox"/> 9 Don't know <input type="checkbox"/> 8 Prefer not to answer																														

Form A2: Co-participant Demographics

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 0 Not completed (reason): ____	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other	Key (not completed reason): 92=No co-participant 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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INSTRUCTIONS: This form is to be completed by intake interviewer based on co-participant's report. This form should not be provided directly to the co-participant. For additional clarification and examples, see the [UDS Coding Guidebook for Form A2](#). Check only one box per question.

Section 1 — Co-participant's Relationship to Participant

1.	What is the co-participant's relationship to the participant?	<input type="checkbox"/> 1 Spouse, partner, or companion (include ex-spouse, ex-partner, fiancé(e), boyfriend, girlfriend) <input type="checkbox"/> 2 Child (by blood or through marriage or adoption) <input type="checkbox"/> 3 Sibling (by blood or through marriage or adoption) <input type="checkbox"/> 4 Other relative (by blood or through marriage or adoption) <input type="checkbox"/> 5 Friend, neighbor, or someone known through family, friends, work, or community (e.g., church) <input type="checkbox"/> 6 Paid caregiver, health care provider, or clinician
2.	How long has the co-participant known the participant? (If the co-participant has known the participant for less than 1 year, use 0.)	____ Years (999 = Unknown)
3.	Does the co-participant live with the participant?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SKIP TO QUESTION 5)
4.	What is the primary mode of contact with the participant?	<input type="checkbox"/> 1 In-person <input type="checkbox"/> 4 Texting or email <input type="checkbox"/> 2 Telephone <input type="checkbox"/> 5 Social media platforms <input type="checkbox"/> 3 Video conferencing <input type="checkbox"/> 6 Other (SPECIFY): _____
4a1.	What is the approximate frequency of all types of contact?	<input type="checkbox"/> 1 Daily <input type="checkbox"/> 4 At least three times per month <input type="checkbox"/> 2 At least three times per week <input type="checkbox"/> 5 Monthly <input type="checkbox"/> 3 Weekly <input type="checkbox"/> 6 Less than once a month
4a2.	What is the average amount of time spent in contact with the participant during each encounter? (Please include an average of all encounter types)	<input type="checkbox"/> 1 Less than 5 minutes (appropriate for texting or email and may be applicable to other modes of contact as well) <input type="checkbox"/> 2 5-15 minutes <input type="checkbox"/> 3 15-30 minutes <input type="checkbox"/> 4 30-60 minutes <input type="checkbox"/> 5 Longer than one hour
5.	Is there a question about the co-participant's reliability?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

Section 2 — Co-participant's Judgment of Participant's Memory

Ask the next three questions **directly to the co-participant**.

6.	Do you feel like the participant's 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 Unknown
7.	About how often does the participant have trouble remembering things?	<input type="checkbox"/> 1 Never <input type="checkbox"/> 4 Often <input type="checkbox"/> 2 Rarely <input type="checkbox"/> 5 Very Often <input type="checkbox"/> 3 Sometimes <input type="checkbox"/> 9 Unknown
8.	Compared to 10 years ago, would you say that the participant's memory is much worse, a little worse, the same, a little better, or much better?	<input type="checkbox"/> 1 Much better <input type="checkbox"/> 4 A little worse <input type="checkbox"/> 2 A little better <input type="checkbox"/> 5 Much worse <input type="checkbox"/> 3 The same <input type="checkbox"/> 9 Unknown

Form A3: Participant Family History

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by a clinician with experience in evaluating participants with neurological and psychiatric diagnoses. Estimates are allowed if exact birth year or age at death is unknown. For additional clarification and examples, see the [UDS Coding Guidebook for Form A3](#).

Section 1 – Biological parents

For any parent with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and *skip the subsequent questions in the row*. For a parent with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then *skip the subsequent questions in the row*. For a parent with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the **Secondary diagnosis** column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
		 SEE LIST OF CODES			
1a. Mother	_____	_____	____	____	____	_____
1b. Father	_____	_____	____	____	____	_____

Codes

*DIAGNOSES

- 00 No known neurological/psychiatric diagnosis
- 01 Alzheimer's Disease
- 02 Lewy Body dementia (includes DLB and PDD)
- 03 Vascular dementia
- 04 Stroke
- 05 FTLD* without motor neuron disease
- 06 FTLD* with motor neuron disease
- 07 Motor Neuron Disease
- 08 Parkinson's Disease
- 09 Prion pathology
- 10 Psychiatric condition
- 11 Dementia of unknown etiology
- 12 Other
- 88 No secondary diagnosis
- 99 Specific diagnosis unknown (acceptable if method of evaluation is not by exam or autopsy)

**METHOD OF EVALUATION

- 1 Participant/family report
- 2 Medical records
- 3 Exam
(co-enrolled family members)
- 4 Autopsy
(if autopsy report available)

*FTLD includes: bvFTD or FTD, PPA (any subtype), CBS or CBD, PSP

Abbreviations: bvFTD = behavioral variant frontotemporal dementia, CBS = corticobasal syndrome, CBD = corticobasal degeneration, DLB = dementia with Lewy bodies, FTD = frontotemporal dementia, PDD = Parkinson's disease with dementia, PPA = primary progressive aphasia, PSP = progressive supranuclear palsy

YEAR OF BIRTH FOR FULL SIBLINGS & 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 participant is the oldest of three children. The participant 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 participant and co-participant to estimate the birth year, enter **9999=Unknown**.

Section 2 – Full siblings

2. How many full siblings does the participant have?

_____ (77 = participant adopted or siblings unknown)

If participant has no full siblings, **SKIP TO QUESTION 3**; otherwise, provide information on all full siblings.

For any full sibling with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and *skip the subsequent questions in the row*. For a full sibling with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then *skip the subsequent questions in the row*. For a full sibling with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the Secondary diagnosis column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
..... SEE LIST OF CODES						
2a. Sibling 1	_____	_____	_____	_____	_____	_____
2b. Sibling 2	_____	_____	_____	_____	_____	_____
2c. Sibling 3	_____	_____	_____	_____	_____	_____
2d. Sibling 4	_____	_____	_____	_____	_____	_____
2e. Sibling 5	_____	_____	_____	_____	_____	_____
2f. Sibling 6	_____	_____	_____	_____	_____	_____
2g. Sibling 7	_____	_____	_____	_____	_____	_____
2h. Sibling 8	_____	_____	_____	_____	_____	_____
2i. Sibling 9	_____	_____	_____	_____	_____	_____
2j. Sibling 10	_____	_____	_____	_____	_____	_____
2k. Sibling 11	_____	_____	_____	_____	_____	_____
2l. Sibling 12	_____	_____	_____	_____	_____	_____
2m. Sibling 13	_____	_____	_____	_____	_____	_____
2n. Sibling 14	_____	_____	_____	_____	_____	_____
2o. Sibling 15	_____	_____	_____	_____	_____	_____
2p. Sibling 16	_____	_____	_____	_____	_____	_____
2q. Sibling 17	_____	_____	_____	_____	_____	_____
2r. Sibling 18	_____	_____	_____	_____	_____	_____
2s. Sibling 19	_____	_____	_____	_____	_____	_____
2t. Sibling 20	_____	_____	_____	_____	_____	_____

Section 3 – Biological children

3. How many biological children does the participant have?

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

For any biological child with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and *skip the subsequent questions in the row*. For a biological child with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then *skip the subsequent questions in the row*. For a biological child with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the Secondary diagnosis column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
..... SEE LIST OF CODES						
3a. Child 1	_____	_____	_____	_____	_____	_____
3b. Child 2	_____	_____	_____	_____	_____	_____
3c. Child 3	_____	_____	_____	_____	_____	_____
3d. Child 4	_____	_____	_____	_____	_____	_____
3e. Child 5	_____	_____	_____	_____	_____	_____
3f. Child 6	_____	_____	_____	_____	_____	_____
3g. Child 7	_____	_____	_____	_____	_____	_____
3h. Child 8	_____	_____	_____	_____	_____	_____
3i. Child 9	_____	_____	_____	_____	_____	_____
3j. Child 10	_____	_____	_____	_____	_____	_____
3k. Child 11	_____	_____	_____	_____	_____	_____
3l. Child 12	_____	_____	_____	_____	_____	_____
3m. Child 13	_____	_____	_____	_____	_____	_____
3n. Child 14	_____	_____	_____	_____	_____	_____
3o. Child 15	_____	_____	_____	_____	_____	_____

Form A4: Participant Medications

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by the clinician or ADRC staff. The purpose of this form is to record all prescription medications taken by the participant within **the two weeks before the current visit**. If the participant is receiving any treatments known to significantly impact Alzheimer's disease (AD) or Alzheimer's disease related dementias (ADRD) biomarkers as part of their clinical care at the time of clinical assessment (e.g., they are receiving lecanemab infusions), the treatment should be included on both this form and the A4a ADRD-Specific Treatments form.

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. For additional clarification and examples, see [UDS Coding Guidebook for Form A4](#).

 Is the participant currently taking any medications? ☐ 0 No (END FORM HERE) ☐ 1 Yes

MEDICATION NAME	RXNorm	MEDICATION NAME	RXNorm
<input type="checkbox"/> acetaminophen-HYDROcodone (Hycet, Vicodin)	214182	<input type="checkbox"/> enalapril (Vasotec)	3827
<input type="checkbox"/> albuterol (Proventil, ProAir HFA, RespiClick, Ventolin)	435	<input type="checkbox"/> ergocalciferol (Calcidol, Calciferol, Disdol, Vitamin D2)	4018
<input type="checkbox"/> alendronate (Binosto, Fosamax)	46041	<input type="checkbox"/> escitalopram (Lexapro)	321988
<input type="checkbox"/> allopurinol (Aloprim, Duzallo, Zyloprim)	519	<input type="checkbox"/> esomeprazole (Nexium)	283742
<input type="checkbox"/> alprazolam (Xanax)	596	<input type="checkbox"/> estradiol (Estrace, Estrogel, Delestrogen, Yuvaferm)	4083
<input type="checkbox"/> amlodipine (Norvasc)	17767	<input type="checkbox"/> ezetimibe (Zetia)	341248
<input type="checkbox"/> apixaban (Eliquis)	1364430	<input type="checkbox"/> ferrous sulfate (Feosol, Iron Supplement, Slow FE)	24947
<input type="checkbox"/> atenolol (Tenormin)	1202	<input type="checkbox"/> fexofenadine (Allegra, Wal-Flex)	87636
<input type="checkbox"/> atorvastatin (Lipitor)	83367	<input type="checkbox"/> finasteride (Propecia, Proscar)	25025
<input type="checkbox"/> benazepril (Lotensin)	18867	<input type="checkbox"/> fluoxetine (Prozac, Sarafem)	4493
<input type="checkbox"/> bupropion (Aplenzin, Budeprion, Wellbutrin, Zyban)	42347	<input type="checkbox"/> fluticasone (Flovent)	41126
<input type="checkbox"/> calcium acetate (Calphron, Eliphos, PhosLo Phoslyra)	214342	<input type="checkbox"/> fluticasone nasal (Aller-Flo, Flonase)	1165656
<input type="checkbox"/> carbidopa-levodopa (Duopa, Rytary, Sinemet)	103990	<input type="checkbox"/> fluticasone-salmeterol (Advair, AirDuo)	284635
<input type="checkbox"/> carvedilol (Coreg)	20352	<input type="checkbox"/> furosemide (Lasix)	4603
<input type="checkbox"/> celecoxib (Celebrex)	140587	<input type="checkbox"/> gabapentin (Gralise, Horizant, Neurontin)	25480
<input type="checkbox"/> cetirizine (Aller-Tec, Zyrtec)	20610	<input type="checkbox"/> galantamine (Razadyne, Reminyl)	4637
<input type="checkbox"/> citalopram (Celexa)	2556	<input type="checkbox"/> glipizide (Glucotrol)	4821
<input type="checkbox"/> clonazepam (Klonopin)	2598	<input type="checkbox"/> hydrochlorothiazide (Esidrix, Hydrodiuril, Microzide)	5487
<input type="checkbox"/> clopidogrel (Plavix)	32968	<input type="checkbox"/> hydrochlorothiazide-triamterene (Dyazide, Maxzide)	548337
<input type="checkbox"/> cyanocobalamin (Nascobal, Vitamin B12)	11248	<input type="checkbox"/> latanoprost (Xalatan)	43611
<input type="checkbox"/> diclofenac (Flector, Cambia, Zipsor)	3355	<input type="checkbox"/> levothyroxine (Levoxyl, Synthroid, Tirosint)	10582
<input type="checkbox"/> diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac)	3443	<input type="checkbox"/> lisinopril (Prinivil, Qbrelis, Zestril)	29046
<input type="checkbox"/> donepezil (Adlarity, Aricept)	135447	<input type="checkbox"/> lorazepam (Ativan)	6470
<input type="checkbox"/> duloxetine (Cymbalta, Irenka)	72625	<input type="checkbox"/> losartan (Cozaar)	52175
		<input type="checkbox"/> lovastatin (Altacor, Altoprev, Mevacor)	6472

MEDICATION NAME	RXNorm
<input type="checkbox"/> meloxicam (Mobic, Vivlodex)	41493
<input type="checkbox"/> memantine (Namenda)	6719
<input type="checkbox"/> metformin (Glucophage, Glumetza, Riomet)	6809
<input type="checkbox"/> metoprolol (Lopressor, Toprol-XL)	6918
<input type="checkbox"/> mirtazapine (Remeron)	15996
<input type="checkbox"/> montelukast (Singulair)	88249
<input type="checkbox"/> naproxen (Aleve, Anaprox, Naprosyn)	7258
<input type="checkbox"/> niacin (Niacinol, Niacor, Niaspan, Nicotinic Acid)	7393
<input type="checkbox"/> nifedipine (Adalat, Afeditab CR, Procardia)	7417
<input type="checkbox"/> nitroglycerin (Nitro-Bid, Nitro-Dur, Nitro-Time, Nitrostat, Rectiv)	4917
<input type="checkbox"/> omega-3 polyunsaturated fatty acids (Omacor, Lovaza, Vascazen)	4301
<input type="checkbox"/> omeprazole (Prilosec, Zegerid)	7646
<input type="checkbox"/> oxybutynin (Ditropan, Oxytrol, Urotrol)	32675
<input type="checkbox"/> pantoprazole (Protonix)	40790
<input type="checkbox"/> paroxetine (Paxil, Paxil CR, Pexeva)	32937

MEDICATION NAME	RXNorm
<input type="checkbox"/> potassium chloride (K-Dur 10, K-Tab, Klor-con)	8591
<input type="checkbox"/> pravastatin (Pravachol)	42463
<input type="checkbox"/> quetiapine (Seroquel)	51272
<input type="checkbox"/> ranitidine (Wal-Zan, Zantac)	9143
<input type="checkbox"/> rivastigmine (Exelon)	183379
<input type="checkbox"/> rosuvastatin (Crestor, Ezallor)	301542
<input type="checkbox"/> sertraline (Zoloft)	36437
<input type="checkbox"/> sildenafil (Viagra, Revatio)	136411
<input type="checkbox"/> simvastatin (FloLipid, Zocor)	36567
<input type="checkbox"/> tamsulosin (Flomax)	77492
<input type="checkbox"/> terazosin (Hytrin)	37798
<input type="checkbox"/> tramadol (ConZip, Ryzolt, Ultram)	10689
<input type="checkbox"/> trazodone (Desyrel, Oleptro)	10737
<input type="checkbox"/> valsartan (Diovan)	69749
<input type="checkbox"/> venlafaxine (Effexor)	39786
<input type="checkbox"/> warfarin (Coumadin, Jantoven)	11289
<input type="checkbox"/> zolpidem (Ambien, Edluar, Intermezzo, Zolpimist)	39993

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

MEDICATION NAME	RXNorm
<input type="checkbox"/> acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol)	161
<input type="checkbox"/> ascorbic acid (Acerola C, C Complex, Vitamin C)	1151
<input type="checkbox"/> aspirin (Ecotrin)	1191
<input type="checkbox"/> biotin (Appearex, coenzyme R, Nail-ex, Vitamin H)	1588
<input type="checkbox"/> calcium acetate (Calphorn, Domeboro)	214342
<input type="checkbox"/> calcium carbonate (Caltrate, Rolaids, Tums)	1897
<input type="checkbox"/> calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D)	608343
<input type="checkbox"/> calcium carbonate/ergocalciferol (O Cal-D)	1008264
<input type="checkbox"/> cholecalciferol (Decara, Replesta, Vitamin D3)	2418
<input type="checkbox"/> chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)	1008567

MEDICATION NAME	RXNorm
<input type="checkbox"/> docusate (Colace, Dioctyl SS, Ducate Calcium, Dulcoease)	82003
<input type="checkbox"/> folic acid (Folic Acid, Folvite)	4511
<input type="checkbox"/> glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)	4845
<input type="checkbox"/> ibuprofen (Advil, Motrin, Nuprin)	5640
<input type="checkbox"/> loratadine (Alavert, Allerclear, Claritin, Tavist)	28889
<input type="checkbox"/> melatonin (Melatonin, Melatonin Time Release)	6711
<input type="checkbox"/> polyethylene glycol 3350 (Clearlax, Miralax)	221147
<input type="checkbox"/> turmeric (Curcumin, Turmeric Root)	1114883
<input type="checkbox"/> ubiquinol (Co Q-10)	21406
<input type="checkbox"/> vitamin E (Alpha E, Aquasol-E, Aquavite-E, Centrum Singles)	11256

If a medication is not listed above:

Specify the drug or brand name and determine its RXNorm code by using the RXNav: <https://lhncbc.nlm.nih.gov/RxNav/>

- ☐ SPECIFY: _____
- ☐ SPECIFY: _____
- ☐ SPECIFY: _____
- ☐ SPECIFY: _____
- ☐ SPECIFY: _____

Form A4a: ADRD-Specific Treatments

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form should be used to record treatments expected to significantly impact Alzheimer disease and related dementias (ADRD) biomarkers, whether a disease-modifying treatment that is FDA-approved for ADRD and received as part of clinical care or an investigational treatment received as part of a clinical trial. For treatments received as part of clinical care, only those that are FDA-approved for disease-modification of ADRD should be included on this form. If the participant is receiving one of these treatments as part of their clinical care at the time of clinical assessment (e.g., they are receiving lecanemab infusions), the treatment should be included on both this form and the A4 Medication form. Participation in any ADRD drug trial over an individual's lifetime should be included. If available, the ClinicalTrials.gov identifier should be entered into the "specific treatment and/or trial" cell. Information on the type of treatment can be found via ClinicalTrials.gov and is summarized in "Alzheimer's disease drug development pipeline." ¹ This form should be completed by the clinician based on participant interview and/or co-participant report. For additional clarification and examples, see [UDS Coding Guidebook for Form A4a](#). Check only one box per question, unless otherwise stated.

1. Has the participant ever been prescribed a treatment or been enrolled in a clinical trial of a treatment expected to modify ADRD biomarkers?
- ☐ 0 No (**END FORM HERE**)
☐ 1 Yes
☐ 9 Unknown (**END FORM HERE**)

2. Please provide information about the clinical treatment(s) and/or trial(s)
 (If participant is exposed to more than two treatments and/or trials, use extended table on Page 2):

Primary Drug Target (check all that apply)	Specific treatment and/or trial	Start date (99/9999 = Unknown)	End date (month/year) (99/9999=Unknown; 88/8888=Ongoing)	How was the treatment provided?	If clinical trial, in which group was the participant?
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____/____ ____-____-____	____/____ ____-____-____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____/____ ____-____-____	____/____ ____-____-____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown

3. Has the participant ever experienced amyloid related imaging abnormalities—edema (ARIA-E), amyloid related imaging abnormalities—hemorrhage (ARIA-H), or other major adverse events associated with treatments expected to modify ADRD biomarkers?
- ☐ 0 No (**END FORM HERE**)
☐ 1 Yes
☐ 9 Unknown (**END FORM HERE**)

3a. What major adverse events associated with treatments expected to modify ADRD biomarkers did they experience?
 (check all that apply)

3a1. ☐ 1 Amyloid related imaging abnormalities—edema (ARIA-E)
 3a2. ☐ 1 Amyloid related imaging abnormalities—hemorrhage (ARIA-H)

3a3. ☐ 1 Other issues

2. Please provide information about the clinical treatment(s) and/or trial(s)
(continued from Page 1):

Primary Drug Target (check all that apply)	Specific treatment and/ or trial	Start date (month/year) (99/9999 =Unknown)	End date (month/year) (99/9999=Unknown; 88/8888=Ongoing)	How was the treatment provided?	If clinical trial, in which group was the participant?
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown
<input type="checkbox"/> 1 Amyloid beta <input type="checkbox"/> 1 Tau <input type="checkbox"/> 1 Inflammation <input type="checkbox"/> 1 Synaptic plasticity/ neuroprotection <input type="checkbox"/> 1 Other target(s) _____	_____ NCT-_____	____ / ____ ____ - ____	____ / ____ ____ - ____	<input type="checkbox"/> 1 Clinical care <input type="checkbox"/> 2 Clinical trial <input type="checkbox"/> 3 Clinical care and clinical trial	<input type="checkbox"/> 1 Active treatment <input type="checkbox"/> 2 Placebo <input type="checkbox"/> 9 Unknown

¹ Cummings et al., "Alzheimer's disease drug development pipeline: 2024," Alzheimer's and Dementia. 2024 April 24; 10(2):e12465.

Form A5-D2: Participant Health History / Clinician-assessed Medical Conditions

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by the clinician or ADRC staff based on the medical history interview with the participant and co-participant, as well as review of any medical records that are available. Any conditions identified during the visit should be included on the form. For additional clarification and examples, see [UDS Coding Guidebook for Form A5/D2](#). Check only one box per question, unless otherwise stated.

Section 1 – Cigarette smoking, alcohol, and substance use

Cigarette smoking

1a.	Has the participant smoked <u>more than</u> 100 cigarettes in their life — (IF NO OR UNKNOWN, SKIP TO QUESTION 1f)	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
1b.	Total years smoked (99 = Unknown)	_____		
1c.	Average number of packs smoked per day:	<input type="checkbox"/> 1 1 cigarette to less than ½ pack <input type="checkbox"/> 2 ½ pack to less than 1 pack <input type="checkbox"/> 3 1 pack to less than 1½ packs	<input type="checkbox"/> 4 1½ packs to less than 2 packs <input type="checkbox"/> 5 2 packs or more <input type="checkbox"/> 9 Unknown	
1d.	Has the participant smoked within <u>the last 30 days</u> ?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
1e.	If the participant quit smoking, specify the age at which they last smoked (i.e., quit) (888 = N/A, 999 = unknown)	_____		

Alcohol use

1f.	In the past 12 months, how often has the participant had a drink containing alcohol? (IF NEVER OR UNKNOWN, SKIP TO QUESTION 1i)	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Monthly or less <input type="checkbox"/> 2 2-4 times a month	<input type="checkbox"/> 3 2-3 times a week <input type="checkbox"/> 4 4 or more times a week <input type="checkbox"/> 9 Unknown
1g.	On a day when the participant drinks alcoholic beverages, how many standard drinks does the participant typically consume? (Standard drink: 12oz of regular beer, 5oz of wine, 1.5oz of distilled spirits)	<input type="checkbox"/> 1 1 or 2 <input type="checkbox"/> 2 3 to 4 <input type="checkbox"/> 3 5 to 6	<input type="checkbox"/> 4 7 to 9 <input type="checkbox"/> 5 10 or more <input type="checkbox"/> 9 Unknown
1h.	In the past 12 months, how often did the participant have six or more drinks containing alcohol in one day?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Less than once a month <input type="checkbox"/> 2 Monthly	<input type="checkbox"/> 3 Weekly <input type="checkbox"/> 4 Daily or almost daily <input type="checkbox"/> 9 Unknown

Substance use

1i.	Has the participant used substances including prescription or recreational drugs that caused significant impairment in one or more of the following areas: work, driving, legal, social, or others.		
1i1.	Within the past 12 months	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 UNK
1i2.	Prior to 12 months ago	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 UNK
1j.	In the past 12 months, how often has the participant consumed cannabis (edibles, smoked, or vaporized)?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Monthly or less <input type="checkbox"/> 2 2-4 times a month	<input type="checkbox"/> 3 2-3 times a week <input type="checkbox"/> 4 4 or more times a week <input type="checkbox"/> 9 Unknown

In the following sections (*pages 2-7*) record the presence or absence of a **history of these conditions**, as determined by the clinician's best judgment following the medical history interview with the participant and co-participant, as well as review of any medical records that are available.

A CONDITION SHOULD BE CONSIDERED ...

Absent:	Recent/Active:	Remote/Inactive:	Unknown (UNK)
It has never been present.	It happened within the last year or still requires active management.	It existed or occurred in the past (<i>more than one year ago</i>) but was resolved or there is no treatment currently under way.	There is insufficient information available to assess this condition.

Section 2 – Cardiovascular disease

	ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
2a. Heart attack (<i>heart artery blockage</i>) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 2b)	<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 UNK
2a2. Age at most recent heart attack (999 = Unknown)	— — —			
2b. Cardiac arrest (heart stopped) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 2c)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2b1. Age at most recent cardiac arrest (999 = Unknown)	— — —			
2c. Atrial fibrillation	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2d. Coronary artery angioplasty / endarterectomy / stenting	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2e. Coronary artery bypass procedure — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 2f)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2e1. Age at most recent surgery (999 = Unknown)	— — —			
2f. Pacemaker and/or defibrillator implantation — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 2g)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2f1. Age at first implantation (999 = Unknown)	— — —			
2g. Congestive heart failure (including pulmonary edema)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2h. Heart valve replacement or repair — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 2i)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
2h1. Age at most recent procedure (999 = Unknown)	— — —			
2i. Other cardiovascular disease (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 3 – Cerebrovascular disease

	ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
3a. Stroke by history, not exam (<i>imaging is not required</i>) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 3b)	<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		<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
3a2. Age at most recent stroke (999 = Unknown)	— — —			
	NEVER IMPROVED	PARTIALLY IMPROVED	IMPROVED / BACK TO NORMAL	UNKNOWN
3a3. What is the status of stroke symptoms?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 3 – Cerebrovascular disease*continued...*

3a4.	Carotid artery surgery or stenting? (IF NO OR UNKNOWN, SKIP TO QUESTION 3b)	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
3a5.	Age at most recent carotid artery surgery or stenting (999 = Unknown)	____ _		
		ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE
3b.	Transient ischemic attack (TIA) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 4a)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
3b1.	Age at most recent TIA (999 = Unknown)	____ _		

Section 4 – Neurologic conditions

		ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
4a.	Parkinson's disease (PD) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 4b)	<input type="checkbox"/> 0	<input type="checkbox"/> 1		<input type="checkbox"/> 9
4a1.	Age at estimated PD symptom onset (999 = Unknown)	____ _			
4b.	Other parkinsonism disorder (e.g., DLB) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 4c)	<input type="checkbox"/> 0	<input type="checkbox"/> 1		<input type="checkbox"/> 9
4b1.	Age at parkinsonism disorder diagnosis (999 = Unknown)	____ _			
4c.	Epilepsy and/or history of seizures (excluding childhood febrile seizures) — (IF REMOTE/INACTIVE, SKIP TO QUESTION 4c2, IF ABSENT OR UNKNOWN, SKIP TO QUESTION 4d)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
4c1.	How many seizures has the participant had in the past 12 months?	<input type="checkbox"/> 0 None <input type="checkbox"/> 1 1 or 2 <input type="checkbox"/> 2 3 or more <input type="checkbox"/> 9 Unknown			
4c2.	Age at first seizure (excluding childhood febrile seizures) (999 = Unknown)	____ _			
4d.	Chronic headaches	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
4e.	Multiple sclerosis	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
4f.	Normal-pressure hydrocephalus	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
4g.	Repetitive head impacts (e.g. from contact sports, intimate partner violence, or military duty), regardless of whether it caused symptoms. (IF NO OR UNKNOWN, SKIP TO QUESTION 4h)	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK	
4g1.	Indicate the source(s) of exposure for repeated hits to the head: (Check all that apply)	4g1a. <input type="checkbox"/> 1 American football 4g1b. <input type="checkbox"/> 1 Soccer 4g1c. <input type="checkbox"/> 1 Ice hockey 4g1d. <input type="checkbox"/> 1 Boxing or mixed martial arts 4g1e. <input type="checkbox"/> 1 Other contact sport 4g1f. <input type="checkbox"/> 1 Intimate partner violence 4g1g. <input type="checkbox"/> 1 Military service 4g1h. <input type="checkbox"/> 1 Physical assault 4g1i. <input type="checkbox"/> 1 Other (SPECIFY): _____			
4g2.	Indicate the total length of time in years that the participant was exposed to repeated hits to the head (e.g. playing American football for 7 years) (999 = Unknown)	____ _			

Section 4 – Neurologic conditions*continued...*

4h.	Head injury (e.g. in a vehicle accident, being hit by an object, in a fall, while playing sports or biking, in an assault, or during military service) that resulted in a period of feeling "dazed or confused," being unable to recall details of the injury, or loss of consciousness (if multiple head injuries, consider most severe episode). (IF NO OR UNKNOWN, SKIP TO QUESTION 5a)	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
4h1.	After a head injury, what was the longest period of time that the participant was unconscious?	<input type="checkbox"/> 0 Less than 5 minutes <input type="checkbox"/> 1 5 minutes to less than 30 minutes <input type="checkbox"/> 2 30 minutes to less than 24 hours <input type="checkbox"/> 3 1 day to less than 7 days	<input type="checkbox"/> 4 7 days or more <input type="checkbox"/> 8 Not applicable, no loss of consciousness <input type="checkbox"/> 9 Unknown duration	
4h2.	After a head injury, what was the longest period that the participant was "dazed or confused" or unable to recall details of the injury?	<input type="checkbox"/> 0 Less than 5 minutes <input type="checkbox"/> 1 5 minutes to less than 30 minutes <input type="checkbox"/> 2 30 minutes to less than 24 hours <input type="checkbox"/> 3 1 day to less than 7 days	<input type="checkbox"/> 4 7 days or more <input type="checkbox"/> 8 Not applicable, never dazed and confused <input type="checkbox"/> 9 Unknown duration	
4h3.	Total number of head injuries in which the participant felt "dazed or confused," unable to recall details of the injury or experienced loss of consciousness?	<input type="checkbox"/> 0 None <input type="checkbox"/> 1 1-2 <input type="checkbox"/> 2 3-5	<input type="checkbox"/> 3 6-12 <input type="checkbox"/> 4 13 or more <input type="checkbox"/> 9 Unknown	
4h4.	Age of <u>first</u> head injury that resulted in a period of feeling "dazed or confused," being unable to recall details of the injury, or loss of consciousness: (999 = Unknown)	_____		
4h5.	Age of <u>most recent</u> head injury that resulted in a period of feeling "dazed or confused," being unable to recall details of the injury, or loss of consciousness: (999 = Unknown)	_____		

Section 5 – Medical conditions

If any of the conditions still require active management and/or medications, please select "Recent / Active."

		ABSENT	RECENT/ACTIVE	REMOTE/INACTIVE	UNKNOWN
5a.	Diabetes — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5b)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5a1.	Which type?	<input type="checkbox"/> 1 Type 1 <input type="checkbox"/> 2 Type 2 <input type="checkbox"/> 3 Other (diabetes insipidus, latent autoimmune diabetes/type 1.5, gestational diabetes, prediabetes) <input type="checkbox"/> 9 Unknown			
5a2.	Treated with (Check all that apply)	5a2a. <input type="checkbox"/> 1 Insulin 5a2b. <input type="checkbox"/> 1 Oral medications 5a2c. <input type="checkbox"/> 1 GLP-1 receptor agonist 5a2d. <input type="checkbox"/> 1 Other non-insulin, non-GLP-1 receptor agonist injection medication 5a2e. <input type="checkbox"/> 1 Diet 5a2f. <input type="checkbox"/> 1 Unknown			
5a3.	Age at diabetes diagnosis (999 = Unknown)	_____			
5b.	Hypertension (or taking medication for hypertension) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5c)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5b1.	Age at hypertension diagnosis (999 = Unknown)	_____			
5c.	Hypercholesterolemia (or taking medication for high cholesterol) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5d)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5c1.	Age at hypercholesterolemia diagnosis (999 = Unknown)	_____			
5d.	B12 deficiency	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5e.	Thyroid disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 5 – Medical conditions*continued...*

		ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
5f.	Arthritis — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5g)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5f1.	Type of arthritis (Check all that apply)	5f1a. <input type="checkbox"/> 1 Rheumatoid 5f1b. <input type="checkbox"/> 1 Osteoarthritis 5f1c. <input type="checkbox"/> 1 Other (SPECIFY): _____ 5f1d. <input type="checkbox"/> 1 Unknown			
5f2.	Regions affected (Check all that apply)	5f2a. <input type="checkbox"/> 1 Upper extremity 5f2b. <input type="checkbox"/> 1 Lower extremity 5f2c. <input type="checkbox"/> 1 Spine 5f2d. <input type="checkbox"/> 1 Unknown			
5g.	Incontinence — urinary (occurring at least weekly)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5h.	Incontinence — bowel (occurring at least weekly)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5i.	Sleep apnea — (IF ABSENT, REMOTE/INACTIVE, OR UNKNOWN, SKIP TO QUESTION 5j)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5i1.	Typical use of breathing machine (e.g. CPAP) at night over the past 12 months	<input type="checkbox"/> 0 None <input type="checkbox"/> 1 < 4 hours per night <input type="checkbox"/> 2 > 4 hours per night <input type="checkbox"/> 9 Unknown			
5i2.	Typical use of an oral device or implanted breathing pacemaker for sleep apnea at night over the past 12 months?	<input type="checkbox"/> 0 None <input type="checkbox"/> 1 < 4 hours per night <input type="checkbox"/> 2 > 4 hours per night <input type="checkbox"/> 9 Unknown			
5j.	REM sleep behavior disorder (RBD)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5k.	Hyposomnia/Insomnia (occurring at least weekly or requiring medication)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5l.	Other sleep disorder (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5m.	Cancer, primary or metastatic — (Report all known diagnoses. Exclude non-melanoma skin cancer. IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5n)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5m1.	Type of cancer (Check all that apply)	5m1a. <input type="checkbox"/> 1 Primary/non-metastatic 5m1b. <input type="checkbox"/> 1 Metastatic (CHECK ALL THAT APPLY) 5m1b1. <input type="checkbox"/> 1 Metastatic to brain 5m1b2. <input type="checkbox"/> 1 Metastatic to sites other than brain 5m1c. <input type="checkbox"/> 1 Unknown			
5m2.	Primary site of cancer: (Check all that apply)	5m2a. <input type="checkbox"/> 1 Blood 5m2b. <input type="checkbox"/> 1 Breast 5m2c. <input type="checkbox"/> 1 Colon 5m2d. <input type="checkbox"/> 1 Lung 5m2e. <input type="checkbox"/> 1 Prostate 5m2f. <input type="checkbox"/> 1 Other (SPECIFY): _____			
5m3.	Type of cancer treatment (Check all that apply)	5m3a. <input type="checkbox"/> 1 Radiation 5m3b. <input type="checkbox"/> 1 Surgical Resection 5m3c. <input type="checkbox"/> 1 Immunotherapy 5m3d. <input type="checkbox"/> 1 Bone marrow transplant 5m3e. <input type="checkbox"/> 1 Chemotherapy 5m3f. <input type="checkbox"/> 1 Hormone therapy 5m3g. <input type="checkbox"/> 1 Other (SPECIFY): _____			
5m4.	Age at most recent cancer diagnosis (999 = Unknown)	_____			

Section 5 – Medical conditions*continued...*

	ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
5n. COVID-19 infection — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5o)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5n1. Requiring hospitalization?	<input type="checkbox"/> 0 No		<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
5o. Asthma/COPD/pulmonary disease	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5p. Chronic kidney disease — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5q)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5p1. Age at diagnosis (999 = Unknown)	____			
5q. Liver disease — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5r)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5q1. Age at diagnosis (999 = Unknown)	____			
5r. Peripheral vascular disease — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5r1. Age at diagnosis (999 = Unknown)	____			
5s. Human Immunodeficiency Virus (HIV) — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5t)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5s1. Age at diagnosis (999 = Unknown)	____			
5t. Other medical conditions or procedures (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 6 – Psychiatric conditions

*In order to diagnose a disorder, **DSM-5-TR criteria require** that symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. For more guidance see the **UDS Coding Guidebook, Form A5/D2**.

	ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
6a. Depressive disorder				
6a1. Major depressive disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6a2. Other specified depressive disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6a3. If Recent/Active depressive disorder (Q6a1 or Q6a2), choose if treated or untreated.	<input type="checkbox"/> 0 Untreated <input type="checkbox"/> 1 Treated with medication and/or counseling			
6b. Bipolar disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6c. Schizophrenia or other psychosis disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6d. Anxiety disorder (DSM-5-TR criteria*) (IF ABSENT OR UNKNOWN, SKIP TO QUESTION 6e)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6d1. Generalized Anxiety Disorder	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6d2. Panic Disorder	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6d3. Obsessive–compulsive disorder (OCD)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6d4. Other (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6e. Post-traumatic stress disorder (PTSD) (DSM-5-TR criteria*)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 6 – Psychiatric conditions*continued...*

		ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
6f.	Developmental neuropsychiatric disorders (e.g., autism spectrum disorder [ASD], attention-deficit hyperactivity disorder [ADHD], dyslexia)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6g.	Other psychiatric disorders (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Section 7 – Menstrual and reproductive healthIf questions about menstrual and reproductive health are relevant to this participant, continue to question 7a. Otherwise, **END FORM HERE**.

7a.	How old was the participant when they had their first menstrual period? (888 = Never had a menstrual period, 999 = Unknown) (IF NEVER HAD A MENSTRUAL PERIOD, SKIP TO 7d)			____	____	____
7b.	How old was the participant when they had their last menstrual period? (888 = Still menstruating, 999 = Unknown) (IF STILL MENSTRUATING, SKIP TO QUESTION 7d)			____	____	____
7c.	If the participant has stopped having menstrual periods, please indicate the reason. (Check all that apply)	7c1.	<input type="checkbox"/> 1 Natural menopause			
		7c2.	<input type="checkbox"/> 1 Hysterectomy (surgical removal of uterus)			
		7c3.	<input type="checkbox"/> 1 Surgical removal of both ovaries			
		7c4.	<input type="checkbox"/> 1 Chemotherapy for cancer or another condition			
		7c5.	<input type="checkbox"/> 1 Radiation treatment or other damage/injury to reproductive organs			
		7c6.	<input type="checkbox"/> 1 Hormonal supplements (e.g. the Pill, injections, Mirena, HRT)			
		7c7.	<input type="checkbox"/> 1 Anti-estrogen medication such as Tamoxifen, anastrozole (Arimidex), exemestane (Aromasin), or letrozole (Femara)			
		7c8.	<input type="checkbox"/> 1 Unsure			
		7c9.	<input type="checkbox"/> 1 Other (SPECIFY): _____			
7d.	Has the participant taken female hormone replacement pills or patches (e.g. estrogen)? (IF NO OR UNKNOWN, SKIP TO QUESTION 7e)			<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
7d1.	How many years in total?	(999 = Unknown)	____			
7d2.	Age at first use	(999 = Unknown)	____			
7d3.	Age at last use	(888= Still presently using, 999 = Unknown)	____			
7e.	Has the participant ever taken birth control pills? (IF NO OR UNKNOWN, END FORM HERE)			<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 UNK
7e1.	How many years in total?	(999 = Unknown)	____			
7e2.	Age at first use	(999 = Unknown)	____			
7e3.	Age at last use	(888= Still presently using, 999 = Unknown)	____			

Form B1: EVALUATION FORM – Vital Signs and Anthropometrics

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

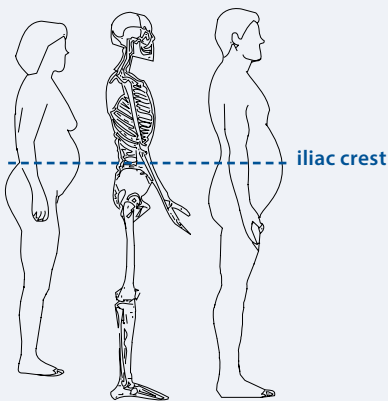
Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 0 Not completed (reason): ____	Key (not completed reason): 94=Remote visit 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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INSTRUCTIONS: This form is to be completed by the clinician or appropriately trained research personnel. For additional clarification and examples, see the [UDS Coding Guidebook for Form B1](#).

Section 1 – Participant vital signs and anthropometrics

- | | | | |
|----|-----------------------------|---------------|-----------------------|
| 1. | Participant height (inches) | _____ . _____ | (88.8 = not assessed) |
| 2. | Participant weight (lbs.) | _____ | (888 = not assessed) |

Instructions for measuring waist and hip circumference in adults



Waist circumference should be measured at the midpoint between the lower margin of the last palpable rib and the top of the iliac crest, using a stretch resistant tape. **Hip circumference** should be measured around the widest portion of the buttocks, with the tape parallel to the floor.

For both measurements: Participant should stand with feet close together, arms at the side and body weight evenly distributed, and should wear little clothing. The participant should be relaxed, and the measurements should be taken at the end of a normal expiration. Each measurement should be taken twice and entered here. If the difference between the two measurements exceeds 0.5 inches, the two measurements should be repeated.

Source: Waist circumference and waist-hip ratio: report of a WHO expert consultation, Geneva, 8–11 December 2008.

Source: NHLBI Obesity Education Initiative, nhlbi.nih.gov

- | | | | |
|----|--|-------|----------------------|
| 3. | Enter two waist circumference measurements (inches): | | |
| | • Measurement 1 | _____ | (888 = not assessed) |
| | • Measurement 2 | _____ | (888 = not assessed) |
| 4. | Enter two hip circumference measurements (inches): | | |
| | • Measurement 1 | _____ | (888 = not assessed) |
| | • Measurement 2 | _____ | (888 = not assessed) |

Section 1 – Participant vital signs and anthropometrics*continued...*

5.	Enter two readings spaced at least one minute apart for each arm. <i>See detailed instructions below.</i>		
5a.	Participant blood pressure - Left arm:		
•	Reading 1	____ / ____	(888/888= not assessed)
•	Reading 2	____ / ____	(888/888= not assessed)
5b.	Participant blood pressure - Right arm:		
•	Reading 1	____ / ____	(888/888= not assessed)
•	Reading 2	____ / ____	(888/888= not assessed)
6.	Participant resting heart rate (<i>pulse</i>) ____ (888 = not assessed)		

Steps for proper blood pressure measurement**STEP 1** - Properly prepare the participant:

- Have the participant relax, sitting in a chair (*feet on floor, back supported*) for >5 minutes
- The participant should avoid caffeine, exercise, and smoking for at least 30 minutes before measurement.
- Ensure that participant has emptied his/her bladder.
- Neither the participant nor the observer should talk during the rest period or during the measurement.
- Remove all clothing covering the location of cuff placement.
- Measurements made while the participant is sitting or lying on an examining table do not fulfill these criteria.

STEP 2 - Use proper technique for BP measurements

- Use a BP measurement device that has been validated and ensure that the device is calibrated periodically.
- Support the participant's arm (*e.g., have it resting on a desk*).
- Position the middle of the cuff on the participant's upper arm at the level of the right atrium (*midpoint of the sternum*).
- Use the correct cuff size, such that the bladder encircles 80% of the arm, and note if a larger- or smaller-than-normal cuff size is used.
- Either the stethoscope diaphragm or bell may be used for auscultatory readings.

STEP 3 - Take proper measurements

- Take two BP readings in both arms.
- Separate the second set of measurements from the first by one minute.
- For auscultatory determinations, use a palpated estimate of radial pulse obliteration pressure to estimate SBP. Inflate the cuff 20-30 mm Hg above this level for an auscultatory determination of the BP level.
- For auscultatory readings, deflate the cuff pressure 2 mm Hg per second, and listen for Korotkoff sounds.

STEP 4 - Properly document accurate BP readings

- Record SBP and DBP. If using the auscultatory technique, record SBP and DBP as onset of the first Korotkoff sound and disappearance of all Korotkoff sounds, respectively, using the nearest even number.
- Record the two readings of SBP and DBP in the left arm, and the two readings of SBP and DBP in the right arm.

STEP 5 - Give BP readings and interpretation to the participants

- It is recommended to provide participants with the SBP/DBP readings both orally, and in writing.

Source: Checklist for accurate measurement of BP adapted from AHA Guidelines, Whelton PK et al., *Hypertension*. 2018; 71: e13-e11.

Form B3: Unified Parkinson's Disease Rating Scale (UPDRS¹) - Motor Exam

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 0 Not completed (reason): ____	Key (not completed reason): 94=Remote visit 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional. The motor exam should be administered to *all* participants. Clinician should record results as observed regardless of whether there are non-parkinsonian contributions or explanations for the findings. This form is intended to 1) determine the degree of parkinsonism on any visit, and 2) track the degree of parkinsonism over time. The UPDRS is not intended to establish the presence or absence of parkinsonism. For additional clarification and scoring instructions, see [UDS Coding Guidebook for Form B3](#). Check only one box per question.

For video-recorded examples of administration, see Perlmutter JS. Assessment of Parkinson disease manifestations. *Curr Protoc Neurosci.* 2009 Oct; Chapter 10: Unit10.1. doi: 10.1002/0471142301.ns1001s49.

☐ (Optional) If the clinician completes the UPDRS examination and determines all items are normal, check this box. If this box is checked, all items will default to 0 in the database.

1. Speech

- ☐ 0 Normal
☐ 1 Slight loss of expression, diction and/or volume
☐ 2 Monotone, slurred but understandable; moderately impaired.
☐ 3 Marked impairment, difficult to understand.
☐ 4 Unintelligible
☐ 8 Untestable (SPECIFY): _____

2. Facial expression

- ☐ 0 Normal
☐ 1 Minimal hypomimia, could be normal "poker face"
☐ 2 Slight but definitely abnormal diminution of facial expression
☐ 3 Moderate hypomimia; lips parted some of the time
☐ 4 Masked or fixed facies with severe or complete loss of facial expression; lips parted ¼ inches or more
☐ 8 Untestable (SPECIFY): _____

3. Tremor at rest

3a. Face, lips, chin

- ☐ 0 Absent
☐ 1 Slight and infrequently present
☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present
☐ 3 Moderate in amplitude and present most of the time
☐ 4 Marked in amplitude and present most of the time
☐ 8 Untestable (SPECIFY): _____

3b. Right hand

- ☐ 0 Absent
☐ 1 Slight and infrequently present
☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present
☐ 3 Moderate in amplitude and present most of the time
☐ 4 Marked in amplitude and present most of the time
☐ 8 Untestable (SPECIFY): _____

3c. Left hand

- ☐ 0 Absent
☐ 1 Slight and infrequently present
☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present
☐ 3 Moderate in amplitude and present most of the time
☐ 4 Marked in amplitude and present most of the time
☐ 8 Untestable (SPECIFY): _____

¹Fahn S, Elton RL. UPDRS Development Committee. The Unified Parkinson's Disease Rating Scale. In Fahn S, Marsden CD, Calne DB, Goldstein M, eds. *Recent developments in Parkinson's disease*, Vol. 2. Florham Park, NJ: Macmillan Healthcare Information, 1987:153–163, 293–304. Reproduced by permission of the author.

3. Tremor at rest*continued...***3d. Right foot**

- ☐ 0 Absent
☐ 1 Slight and infrequently present
☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present
☐ 3 Moderate in amplitude and present most of the time
☐ 4 Marked in amplitude and present most of the time
☐ 8 Unstable (SPECIFY): _____

3e. Left foot

- ☐ 0 Absent
☐ 1 Slight and infrequently present
☐ 2 Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present
☐ 3 Moderate in amplitude and present most of the time
☐ 4 Marked in amplitude and present most of the time
☐ 8 Unstable (SPECIFY): _____

4. Action or postural tremor of hands**4a. Right hand**

- ☐ 0 Absent
☐ 1 Slight; present with action
☐ 2 Moderate in amplitude, present with action
☐ 3 Moderate in amplitude with posture holding as well as action
☐ 4 Marked in amplitude; interferes with feeding
☐ 8 Unstable (SPECIFY): _____

4b. Left hand

- ☐ 0 Absent
☐ 1 Slight; present with action
☐ 2 Moderate in amplitude, present with action
☐ 3 Moderate in amplitude with posture holding as well as action
☐ 4 Marked in amplitude; interferes with feeding
☐ 8 Unstable (SPECIFY): _____

5. Rigidity*(judged on passive movement of major joints with participant relaxed in sitting position; cogwheeling to be ignored)***5a. Neck**

- ☐ 0 Absent
☐ 1 Slight or detectable only when activated by mirror or other movements
☐ 2 Mild to moderate
☐ 3 Marked, but full range of motion easily achieved
☐ 4 Severe; range of motion achieved with difficulty
☐ 8 Unstable (SPECIFY): _____

5b. Right upper extremity

- ☐ 0 Absent
☐ 1 Slight or detectable only when activated by mirror or other movements
☐ 2 Mild to moderate
☐ 3 Marked, but full range of motion easily achieved
☐ 4 Severe; range of motion achieved with difficulty
☐ 8 Unstable (SPECIFY): _____

5c. Left upper extremity

- ☐ 0 Absent
☐ 1 Slight or detectable only when activated by mirror or other movements
☐ 2 Mild to moderate
☐ 3 Marked, but full range of motion easily achieved
☐ 4 Severe; range of motion achieved with difficulty
☐ 8 Unstable (SPECIFY): _____

5d. Right lower extremity

- ☐ 0 Absent
☐ 1 Slight or detectable only when activated by mirror or other movements
☐ 2 Mild to moderate
☐ 3 Marked, but full range of motion easily achieved
☐ 4 Severe; range of motion achieved with difficulty
☐ 8 Unstable (SPECIFY): _____

5. Rigidity*(judged on passive movement of major joints with participant relaxed in sitting position; cogwheeling to be ignored)***continued...****5e. Left lower extremity**

- ☐ 0 Absent
☐ 1 Slight or detectable only when activated by mirror or other movements
☐ 2 Mild to moderate
☐ 3 Marked, but full range of motion easily achieved
☐ 4 Severe; range of motion achieved with difficulty
☐ 8 Untestable (**SPECIFY**): _____

6. Finger taps*(participant taps thumb with index finger in rapid succession)***6a. Right hand**

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

6b. Left hand

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

7. Hand movements*(participant opens and closes hands in rapid succession)***7a. Right hand**

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

7b. Left hand

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

8. Rapid alternating movements of hands*(pronation-supination movements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously)***8a. Right hand**

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

8b. Left hand

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

9. Leg agility*(participant taps heel on the ground in rapid succession, picking up entire leg; amplitude should be at least 3 inches)***9a. Right leg**

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

9b. Left leg

- ☐ 0 Normal
☐ 1 Mild slowing and/or reduction in amplitude
☐ 2 Moderately impaired; definite and early fatiguing; may have occasional arrests in movement
☐ 3 Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement
☐ 4 Can barely perform the task.
☐ 8 Untestable (**SPECIFY**): _____

10. Arising from chair*(participant attempts to rise from a straight-backed chair, with arms folded across chest)*

- ☐ 0 Normal
☐ 1 Slow; or may need more than one attempt
☐ 2 Pushes self up from arms of seat.
☐ 3 Tends to fall back and may have to try more than one time, but can get up without help
☐ 4 Unable to arise without help
☐ 8 Untestable (**SPECIFY**): _____

11. Posture

- ☐ 0 Normal
☐ 1 Not quite erect, slightly stooped posture; could be normal for older person
☐ 2 Moderately stooped posture, definitely abnormal; can be slightly leaning to one side
☐ 3 Severely stooped posture with kyphosis; can be moderately leaning to one side
☐ 4 Marked flexion with extreme abnormality of posture
☐ 8 Untestable (**SPECIFY**): _____

12. Gait

- ☐ 0 Normal
☐ 1 Walks slowly; may shuffle with short steps, but no festination (hastening steps) or propulsion
☐ 2 Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion
☐ 3 Severe disturbance of gait requiring assistance
☐ 4 Cannot walk at all, even with assistance
☐ 8 Untestable (**SPECIFY**): _____

13. Posture stability*(response to sudden, strong posterior displacement produced by pull on shoulders while participant erect with eyes open and feet slightly apart; participant is prepared)*

- ☐ 0 Normal erect
☐ 1 Retropulsion, but recovers unaided
☐ 2 Absence of postural response; would fall if not caught by examiner
☐ 3 Very unstable, tends to lose balance spontaneously
☐ 4 Unable to stand without assistance
☐ 8 Untestable (**SPECIFY**): _____

14. Body bradykinesia and hypokinesia*(combining slowness, hesitancy, decreased arm swing, small amplitude, and poverty of movement in general)*

- ☐ 0 None
☐ 1 Minimal slowness, giving movement a deliberate character; could be normal for some persons; possibly reduced amplitude
☐ 2 Mild degree of slowness and poverty of movement which is definitely abnormal; alternatively, some reduced amplitude
☐ 3 Moderate slowness, poverty or small amplitude of movement
☐ 4 Marked slowness, poverty or small amplitude of movement
☐ 8 Untestable (**SPECIFY**): _____

15. Total UPDRS Score*(If one or more items are checked "8=Untestable", enter 888)* _____ (0-108, 888)

Form B4: CDR® Dementia Staging Instrument**PLUS NACC FTLD Behavior & Language Domains (CDR® Plus NACC FTLD)**

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: 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 participant. 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 information on the required online CDR training, see the [UDS Coding Guidebook for Form B4](#).

Section 1 – CDR® Dementia Staging Instrument¹

Impairment					
Please enter scores (below):	None = 0	Questionable = 0.5	Mild = 1	Moderate = 2	Severe = 3
1. 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
2. Orientation ____ • ____	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 & Problem Solving ____ • ____	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 ____ • ____	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 & Hobbies ____ • ____	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 ____ • <u>0</u>	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. CDR Sum of Boxes	____ • ____		8. Global CDR	____ • ____	

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

Section 2 - NACC FTLD Behavior & Language Domains**Impairment**

Please enter scores (below):	None = 0	Questionable = 0.5	Mild = 1	Moderate = 2	Severe = 3
9. Behavior, Comportment, & Personality² ____ • ____	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
10. Language³ ____ • ____	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

²Excerpted from the *Frontotemporal Dementia Multicenter Instrument & MR Study* (Mayo Clinic, UCSF, UCLA, UW).³Excerpted 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.

Form B5: BEHAVIORAL ASSESSMENT – Neuropsychiatric Inventory Questionnaire (NPI-Q¹)

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 0 Not completed (reason): ____	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other	Key (not completed reason): 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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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 participant as a paper-and-pencil self-report.) For information on NPI-Q Interviewer Certification, see [UDS Coding Guidebook for Form B5](#). Check only one box for each category of response.

Please answer the following questions based on changes that have occurred since the participant first began to experience memory (i.e., cognitive) problems. **Select 1=Yes only if the symptom(s) has been present in the last month. Otherwise, select 0=No.** (NOTE: for the UDS, please administer the NPI-Q to all participants.)

For each item marked **1=Yes**, rate the SEVERITY of the symptom (how it affects the participant):

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)

1. NPI CO-PARTICIPANT: ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (SPECIFY): _____

		SEVERITY							
		Yes	No	Unk	Mild	Mod	Sev	Unk	
2. Delusions – Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?	2a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	2b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
3. Hallucinations – Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?	3a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	3b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
4. Agitation/Aggression – Is the patient resistive to help from others at times, or hard to handle?	4a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	4b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
5. Depression/Dysphoria – Does the patient seem sad or say that he/she is depressed?	5a.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9	5b.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
6. Anxiety – Does the patient become upset when separated from you? Does he/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
7. Elation/Euphoria – 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
8. Apathy/Indifference – Does the patient seem less interested in his/her usual activities or 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
9. Disinhibition – Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying 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
10. Irritability/Lability – Is the patient impatient and cranky? Does he/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
11. Motor disturbance – Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	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
12. Nighttime behaviors – 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
13. Appetite/Eating – Has the patient lost or gained weight, or had a change in the type of food he/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

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Form B6: BEHAVIORAL ASSESSMENT – Geriatric Depression Scale (GDS)¹

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 0 Not completed (reason): ____	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other	Key (not completed reason): 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional, based on participant response. For additional clarification and examples, see [UDS Coding Guidebook for 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 participant:** 1.) does not attempt the GDS, or 2.) answers fewer than 12 questions.

Instruct the participant: "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?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2. Have you dropped many of your activities and interests?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
3. Do you feel that your life is empty?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
4. Do you often get bored?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
5. Are you in good spirits most of the time?	<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?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
7. Do you feel happy most of the time?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
8. Do you often feel helpless?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
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?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
11. Do you think it is wonderful to be alive now?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
12. Do you feel pretty worthless the way you are now?	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 9
13. Do you feel full of energy?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
14. Do you feel that your situation is hopeless?	<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?	<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)	_____		

¹Sheikh 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.

Form B7: FUNCTIONAL ASSESSMENT – NACC Functional Assessment Scale (FAS)¹

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video <input type="checkbox"/> 0 Not completed (reason): ____	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other	Key (not completed reason): 95=Physical problem 96=Cognitive/behavioral problem 97=Other 98=Verbal refusal
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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 Form B7](#). Indicate the level of performance for each activity by checking the one appropriate response.

In the past four weeks, did the participant 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	<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	<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	<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	<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	<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	<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	<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	<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	<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	<input type="checkbox"/> 8	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9

¹Adapted from table 4 of 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.

Form B8: EVALUATION FORM – Neurological Examination Findings

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

 Language:
☐ 1 English
☐ 2 Spanish

 Mode:
☐ 1 In-person
☐ 2 Remote (reason): ____
 ☐ 2 Video

 Key (remote reason): 1=Too cognitively impaired
 2=Too physically impaired
 3=Homebound or nursing home
 4=Refused in-person visit
 5=Other

INSTRUCTIONS: This form should be completed by a clinician with experience in performing a comprehensive neurologic examination, assessing the presence/absence of neurological signs, and rating the degree of any abnormalities. Additionally, the clinician should have experience in completing each of the assessment measures associated with the gateway questions if any key neurologic findings are present. For additional clarification and examples, see [UDS Coding Guidebook for Form B8](#). Check only one box per question.

Section 1 – Examiner & examination questions

- Which of the following was completed on this participant?
 - ☐ 0 No neurologic examination (**END FORM HERE**)
 - ☐ 1 Comprehensive neurologic examination as suggested in the UDS Coding Guidebook
 - ☐ 2 Focused or partial neurologic examination performed in-person
 - ☐ 3 Focused or partial neurologic examination performed via video
- Were there abnormal neurological exam findings?
 - ☐ 0 No abnormal findings (**END FORM HERE**; If this box is checked, all items will default to 0 = Absent in the database)
 - ☐ 1 Yes

Section 2 – Specific clinical findings

Section 2A – Parkinsonian signs

- ☐ 0 No abnormal signs in this section are present (**SKIP TO SECTION 2B**; If this box is checked, Q3a through Q3n will default to 0 = Absent in the database)
☐ 1 Yes (**IF YES** – complete questions 3a–3n and consider completing additional measures as described on page 3)
☐ 8 Not assessed (**SKIP TO SECTION 2B**; If this box is checked, Q3a through Q3n will default to 8 = Not Assessed in the database)

FINDING:	Absent	Focal or Unilateral	Bilateral & Largely Symmetric	Bilateral & Largely Asymmetric	Not Assessed
3a. Slowing of fine motor movements	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3b. Limb tremor at rest	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3c. Limb tremor - postural	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3d. Limb tremor - kinetic	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3e. Limb rigidity - arm	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3f. Limb rigidity - leg	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3g. Limb dystonia - arm	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3h. Limb dystonia - leg	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
3i. Chorea	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8

Section 2 – Specific clinical findings*continued...***Section 2A – Parkinsonian signs**

FINDING:	Absent	Present	Not Assessed
3j. Decrement in amplitude of fine motor movements	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3k. Axial rigidity	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3l. Postural instability	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3m. Facial masking	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
3n. Stooped posture	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

Section 2B – Cortical/pyramidal/other signs

- 4.** ☐ 0 No abnormal signs in this section are present (**SKIP TO SECTION 2C**; If this box is checked, Q4a through Q4q will default to 0=Absent in the database)
- ☐ 1 Yes (**IF YES** – complete questions 4a–4q and consider completing additional measures as described on page 3)
- ☐ 8 Not assessed (**SKIP TO SECTION 2C**; If this box is checked, Q4a through Q4q will default to 8 = Not Assessed in the database)

FINDING:	Absent	Focal or Unilateral	Bilateral & Largely Symmetric	Bilateral & Largely Asymmetric	Not Assessed
4a. Limb apraxia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
4b. Face or limb findings in UMN distribution*	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
4c. Face or limb findings in an LMN distribution*	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
4d. Visual field cut	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
4e. Limb ataxia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
4f. Myoclonus	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8

FINDING:	Absent	Present	Not Assessed
4g. Unilateral Somatosensory loss (<i>localized to the brain; disregard sensory changes localized to the spinal cord or peripheral nerves</i>)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4h. Aphasia (<i>disregard complaints of mild dysnomia if not viewed as reflecting a clinically significant change</i>)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4i. Alien limb phenomenon	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4j. Hemispatial neglect	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4k. Prosopagnosia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4l. Simultanagnosia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4m. Optic ataxia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4n. Apraxia of gaze	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4o. Vertical +/- horizontal gaze palsy**	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4p. Dysarthria*	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8
4q. Apraxia of speech	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 8

*UMN findings could include weakness in a pyramidal pattern, hyper-reflexia, Babinski or Hoffman sign present, or spasticity; LMN findings could include weakness due to neuromuscular dysfunction, muscle wasting/atrophy, or fasciculations. These findings could be consistent with a cerebrovascular insult or with a degenerative disorder such as ALS, PLS, SMA, PSP, CBS, etc.

**Do not mark Present if only reduction of upgaze is present.

Section 2 – Specific clinical findings*continued...***Section 2C – Gait**

5. ☐ 0 No abnormal signs in this section are present (**END FORM HERE**)
☐ 1 Yes (**IF YES** - complete question 5a and consider completing additional measures as described on page 3)
☐ 8 Not assessed (**END FORM HERE**)

5a. Finding:

- ☐ 1 Hemiparetic gait (spastic)
☐ 2 Foot drop gait (lower motor neuron)
☐ 3 Ataxic gait
☐ 4 Apractic magnetic gait
☐ 5 Hypokinetic/parkinsonian gait
☐ 6 Antalgic gait

☐ 7 Other (**SPECIFY**):

Section 2D – Additional measures

There are **several additional clinical measures** to consider for completion depending on the findings and the suspicion of the clinical syndrome; these include, but are not limited to, the following:

a) If there are any features of a movement disorder (e.g., bradykinesia, tremor, rigidity, postural instability, etc.):
Consider completing Form B3 UPDRS, or the MDS-UPDRS

b) If there are any features of ALS (e.g., upper motor neuron dysfunction and/or lower motor neuron dysfunction):
Consider completing the ALSFRS-R

c) If there are any features of PSP- Richardson's syndrome (e.g., parkinsonism, postural instability, supranuclear gaze palsy, etc.):
Consider completing the PSPRS

d) If there are any features of corticobasal syndrome (e.g., limb rigidity, limb apraxia, myoclonus, dystonia, cortical sensory loss, alien limb phenomenon, etc.):

Consider completing the PSPRS and/or the CBFS

e) If there are any features of complex visual processing dysfunction (e.g. hemineglect, visual agnosia, simultanagnosia, optic ataxia, ocular apraxia, apraxia of eyelid opening, etc.):
Consider completing a standardized measure assessing PCA

f) If there are any features of aphasia or apraxia of speech (e.g., NIH Stroke Scale, Progressive Aphasia Severity Scale, Western Aphasia Battery, etc.):
Consider completing a standardized measure assessing speech and language

g) If there are clinical and/or imaging findings suggesting a vascular contribution to the clinical presentation:
Consider completing NIH Stroke Scale, Hachinski Ischemic Scale, etc.

Section 2E – Glossary of abbreviations

ALS = Amyotrophic Lateral Sclerosis

ALSFRS-R = Amyotrophic Lateral Sclerosis Functional Rating Scale–Revised

CBS = Corticobasal Syndrome

CBFS = Cortical Basal ganglia Functional Scale

LMN = Lower Motor Neuron

MDS-UPDRS = Movement Disorders Society - Unified Parkinson's Disease Rating Scale

PCA = Posterior Cortical Atrophy

PLS = Primary Lateral Sclerosis

PSP = Progressive Supranuclear Palsy

PSPRS = Progressive Supranuclear Palsy Rating Scale

SMA = Spinal Muscular Atrophy

UMN = Upper Motor Neuron

UPDRS = Unified Parkinson's Disease Rating Scale

Form B9: Clinician Judgment of Symptoms

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by the clinician. Questions below are not intended for direct administration to participant or co-participant. For all questions the clinician must use their best judgment about whether symptoms are present and make their estimate when symptoms began based on information from participant and co-participant. For additional clarification and examples, see [UDS Coding Guidebook](#) for Form B9. Check only one box per question.

Section 1 – Changes across domains

Reported by participant

1.	Does the <u>participant</u> report a decline in any cognitive domain (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 Could not be assessed / participant is too impaired
2.	Does the <u>participant</u> report a change in any motor domain (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 Could not be assessed / participant is too impaired
3.	Does the <u>participant</u> report the development of any significant neuropsychiatric/behavioral symptoms (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 Could not be assessed / participant is too impaired

Reported by co-participant

4.	Does the <u>co-participant</u> report a decline in any cognitive domain (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 There is no co-participant
5.	Does the <u>co-participant</u> report a change in any motor domain (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 There is no co-participant
6.	Does the <u>co-participant</u> report the development of any significant neuropsychiatric/behavioral symptoms (relative to stable baseline prior to onset of current syndrome)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	<input type="checkbox"/> 8 There is no co-participant

Reported by clinician

7.	Does the participant have any neuropsychiatric/behavioral symptoms, decline in any cognitive domains, or changes in any motor domains?	<input type="checkbox"/> 0 No (END FORM HERE) <input type="checkbox"/> 1 Yes
----	--	---

In the following sections record the phenotype of clinically meaningful symptoms or absence of a **history of these symptoms**, as determined by the clinician's best judgment following the medical history interview with the participant and co-participant.

Section 2 – Cognitive impairment

Consider if the participant currently is meaningfully impaired, **relative to stable baseline prior to onset of current syndrome**:

8.	Based on the clinician's judgment, is the participant currently experiencing meaningful impairment in cognition?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 11) <input type="checkbox"/> 1 Yes		
9.	Indicate whether the participant is meaningfully impaired in the following cognitive domains or has fluctuating cognition:			
Cognitive		No	Yes	Unknown
9a.	Memory — Does the participant forget conversations or dates, repeat questions or statements, or misplace things more than usual?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9b.	Orientation — Does the participant have trouble knowing the day, month, and year, forget names of people they know well, get lost in familiar locations, or not recognize familiar locations?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
9c.	Executive function (judgment, planning, and problem-solving) — Does the participant have trouble planning complex activities like trips, financial transactions, parties, or group meetings?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

Section 2 – Cognitive impairment*continued...*

	No	Yes	Unknown
9d. Language — Does the participant have hesitant speech, have trouble finding words, use inappropriate words without self-correction, or have trouble with speech comprehension?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
9e. Visuospatial function — Does the participant have difficulty interpreting visual stimuli or finding their way around in familiar environments?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
9f. Attention/concentration — Does the participant have a short attention span or limited ability to concentrate? Are they easily distracted?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
9g. Fluctuating cognition — Does the participant 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 their ideas have a disorganized flow?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
9h. Other (SPECIFY): _____	<input type="checkbox"/> _0	<input type="checkbox"/> _1	
9i. If any of the cognitive symptoms in 9a-9h are present, at what age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms with different ages of onset are identified, denote the age of the earliest symptom.)	_____		
10. Mode of onset of cognitive impairment: Indicate the mode of onset for the most prominent cognitive problem that is causing the participant's complaints and/or affecting the participant's function.	<input type="checkbox"/> _1 Gradual <input type="checkbox"/> _4 Other (SPECIFY): _____ <input type="checkbox"/> _2 Subacute <input type="checkbox"/> _3 Abrupt <input type="checkbox"/> _99 Unknown		

Section 3 – Neuropsychiatric symptoms and behavioral changes

Consider if the participant manifests – **in the last month** – clinically meaningful neuropsychiatric symptoms or change in behavior **relative to stable baseline** (i.e., predominant behavioral state prior to the onset of the current syndrome). Clinically meaningful change refers to symptoms or changes that are evident most days in a given four-week period.

11. Based on the clinician's judgment, does the participant manifest clinically meaningful neuropsychiatric symptoms or meaningful change in behavior?	<input type="checkbox"/> _0 No (SKIP TO QUESTION 14) <input type="checkbox"/> _1 Yes		
12. Specify the phenotype of clinically meaningful neuropsychiatric symptoms or meaningful change in behavior that has manifested in the last month .			
Mood, motivation, and agitation	No	Yes	Unknown
12a. Apathy/withdrawal — Has the participant lost interest in the world around them, lost interest in doing things, or lack motivation for starting new activities?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12b. Depressed mood — Does the participant seem sad or depressed, or say that they feel sad or depressed?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12c. Anxiety — Does the participant seem very nervous, worried, or frightened for no apparent reason? Do they seem very tense or fidgety? Do they seem afraid to be apart from caregivers or from others that they trust?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12d. Euphoria — Does the participant seem too cheerful or too happy for no reason, manifest a persistent and abnormally good mood, or find humor where others do not?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12e. Irritability — Does the participant get irritated and easily disturbed? Are their moods very interchangeable? Are they abnormally impatient?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12f. Agitation — Is the participant easily distressed or angered, or hard to handle, or uncooperative, or resistive to care or to help from others?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12g. If any of the mood-related behavioral changes in 12a–12f are present, at what age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.)	_____		

Section 3 – Neuropsychiatric symptoms and behavioral changes*continued...*

Psychosis and impulse control		No	Yes	Unknown
12h.	Visual hallucinations - Does the participant exhibit visual perceptions without a stimulus?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12h1.	IF YES , do their hallucinations include patterns that are not definite objects, such as pixelation of flat uniform surfaces?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12h2.	IF YES , do their hallucinations include well-formed and detailed images of objects or people, either as independent images or as part of other objects?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12i.	Auditory hallucinations - Does the participant exhibit auditory perceptions without a stimulus?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12i1.	IF YES , do the auditory hallucinations include simple sounds like knocks or other simple sounds?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12i2.	IF YES , do the auditory hallucinations include complex sounds like voices speaking words, or music?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12j.	Delusions - Does the participant have fixed, idiosyncratic beliefs that are not true? For example, insisting that others are trying to harm them or steal from them? Have they said that family members or staff are not who they say they are, or that the house is not their home?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12k.	Aggression — Does the participant shout angrily, slam doors, attempt to hit or hurt others, or exhibit other verbally or physically aggressive behaviors?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12l.	If any of the psychosis and impulse control–related behavioral changes in 12h–12k are present, at what age did they begin? (<i>The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.</i>)			

Personality		No	Yes	Unknown
12m.	Disinhibition — Does the participant act impulsively without thinking, say things that are not usually done or said in public, or do things that are embarrassing to caregivers or others, or do they talk personally to strangers or have disregard for personal hygiene?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12n.	Personality change — Does the participant exhibit bizarre behavior or behavior uncharacteristic of the participant, such as unusual collecting, suspiciousness (<i>without delusions</i>), unusual dress, or unusual eating behaviors?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12o.	Loss of empathy — Does the participant fail to take others' feelings into account?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12p.	Obsessions and/or compulsions — Does the participant repeatedly and excessively focus on particular ideas or activities, or have they developed new habits, like physical behaviors or stereotypical verbal phrases?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12q.	Explosive anger — Does the participant have a "short fuse"? Do they display explosive outbursts of anger or rage?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12r.	Substance use — Does the participant currently show evidence of excessive consumption of recreational, psychoactive, or typically abused substances (<i>substantial increase compared with prior habits, and beyond medical necessity if prescribed substance</i>)?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12r1.	IF YES , record substance(s) involved: <i>(Check all that apply)</i>			
	12r1a. <input type="checkbox"/> _1 Alcohol 12r1b. <input type="checkbox"/> _1 Sedative/hypnotic 12r1c. <input type="checkbox"/> _1 Opiate 12r1d. <input type="checkbox"/> _1 Cocaine 12r1e. <input type="checkbox"/> _1 Cannabis 12r1f. <input type="checkbox"/> _1 Other (SPECIFY): _____			
12s.	If any of the personality–related behavioral changes in 12m–12r are present, at what age did they begin? (<i>The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.</i>)			

Section 3 – Neuropsychiatric symptoms and behavioral changes*continued...*

REM sleep		No	Yes	Unknown
12t.	REM sleep behavior disorder — While sleeping, does the participant appear to repeatedly act out their dreams (e.g., punch or flail their arms, shout, or scream)?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
12t1.	IF YES , at what age did the dream enactment behavior begin? (The clinician must use their best judgment to estimate an age of onset.)	_____		
12t2.	Was REM sleep behavior disorder confirmed by polysomnography?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
Other		No	Yes	Unknown
12u.	Other behavioral changes (SPECIFY): _____	<input type="checkbox"/> _0	<input type="checkbox"/> _1	
13.	Overall mode of onset for behavioral changes: Indicate the mode of onset for the most prominent behavioral problem that is causing the participant's complaints and/or affecting the participant's function.	<input type="checkbox"/> _1 Gradual <input type="checkbox"/> _4 Other (SPECIFY): _____ <input type="checkbox"/> _2 Subacute <input type="checkbox"/> _3 Abrupt <input type="checkbox"/> _99 Unknown		

Section 4 – Motor changes

Consider if the participant currently has meaningful change in motor function **that represents a change relative to a stable baseline prior to the current syndrome and is potentially due to a disorder affecting the central nervous system**:

14.	Based on the clinician's judgment, is the participant currently experiencing any meaningful changes in motor function?	<input type="checkbox"/> _0 No (SKIP TO QUESTION 19) <input type="checkbox"/> _1 Yes		
15.	Indicate whether the participant has meaningful change in motor function:			
Motor		No	Yes	Unknown
15a.	Gait disorder — Has the participant's walking changed, not specifically due to arthritis, injury, or peripheral neuropathy? Are they unsteady, or do they 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
15b.	Falls — Has the participant had an increase in frequency of falls compared with their stable baseline prior to the current syndrome?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
15c.	Slowness — Has the participant noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
15d.	Tremors — Has the participant 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
15e.	Limb weakness — Has the participant noticed a change (abrupt or gradual) in limb function such that an arm and/or leg is weak compared to their prior baseline?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
15f.	Change in facial expression — Has the participant's facial expression changed or become more "wooden," or masked and unexpressive?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
15g.	Change in speech — Has the participant noted a change in speech (abrupt or gradual) such that speech is slurred, or the ability to articulate the tongue and lips to form words and sentences has declined compared to their baseline?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
15h.	If changes in motor function are present in 15a–15g, at what age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.)	_____		
16.	Mode of onset for motor changes: Indicate the mode of onset for the most prominent motor problem that is causing the participant's complaints and/or affecting the participant's function.	<input type="checkbox"/> _1 Gradual <input type="checkbox"/> _4 Other (SPECIFY): _____ <input type="checkbox"/> _2 Subacute <input type="checkbox"/> _3 Abrupt <input type="checkbox"/> _99 Unknown		
		No	Yes	Unknown
17.	Were changes in motor function suggestive of parkinsonism?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9
18.	Were changes in motor function suggestive of amyotrophic lateral sclerosis (ALS) (e.g., changes in muscle strength, or muscle twitches in one or more limbs, or slurred speech)?	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _9

Section 5 – Overall course of decline and predominant domain

19.	Overall course of decline of cognitive/behavioral/motor syndrome:	<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 Not applicable <input type="checkbox"/> 9 Unknown
20.	Indicate the predominant domain that was first recognized as changed in the participant:	<input type="checkbox"/> 1 Cognition <input type="checkbox"/> 2 Behavior <input type="checkbox"/> 3 Motor function <input type="checkbox"/> 8 Not applicable <input type="checkbox"/> 9 Unknown

Form C2: Neuropsychological Battery Scores

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 1 In-person <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 2 Video	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by ADRC or clinic staff. For test administration and scoring, see [Instructions for Neuropsychological Battery, Form C2](#). Any new participants who enroll in the UDS after the implementation of UDSv4 must be assessed with the new neuropsychological test battery (Form C2 or C2T).

KEY: If the participant 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

Section 1 — Montreal Cognitive Assessment (MoCA)

1a.	Was any part of the MoCA administered?	<input type="checkbox"/> 0 No (If No, enter reason code, 95 – 98): ____ (SKIP TO QUESTION 2A) <input type="checkbox"/> 1 Yes (CONTINUE WITH QUESTION 1B)
1b.	MoCA was administered:	<input type="checkbox"/> 1 In ADRC or clinic <input type="checkbox"/> 2 In home <input type="checkbox"/> 3 In person — other
1c.	Language of MoCA administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____
1d.	Participant was unable to complete one or more sections due to visual impairment:	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1e.	Participant was unable to complete one or more sections due to hearing impairment:	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1f.	Total Raw Score — Uncorrected (Not corrected for education or visual/hearing impairment) (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	____ (0–1, 95–98)
1h.	Visuospatial/executive — Cube	____ (0–1, 95–98)
1i.	Visuospatial/executive — Clock contour	____ (0–1, 95–98)
1j.	Visuospatial/executive — Clock numbers	____ (0–1, 95–98)
1k.	Visuospatial/executive — Clock hands	____ (0–1, 95–98)
1l.	Language — Naming	____ (0–3, 95–98)
1m.	Memory — Registration (two trials)	____ (0–10, 95–98)
1n.	Attention — Digits	____ (0–2, 95–98)
1o.	Attention — Letter A	____ (0–1, 95–98)
1p.	Attention — Serial 7s	____ (0–3, 95–98)
1q.	Language — Repetition	____ (0–2, 95–98)
1r.	Language — Fluency	____ (0–1, 95–98)
1s.	Abstraction	____ (0–2, 95–98)
1t.	Delayed recall — No cue	____ (0–5, 95–98)
1u.	Delayed recall — Category cue	____ (0–5; 88=Not applicable)
1v.	Delayed recall — Recognition	____ (0–5; 88=Not applicable)
1w.	Orientation — Date	____ (0–1, 95–98)
1x.	Orientation — Month	____ (0–1, 95–98)
1y.	Orientation — Year	____ (0–1, 95–98)
1z.	Orientation — Day	____ (0–1, 95–98)
1aa.	Orientation — Place	____ (0–1, 95–98)
1bb.	Orientation — City	____ (0–1, 95–98)

Section 2 — Administration of the remainder of the battery2a. The tests following the MoCA were administered: ☐ 1 In ADRC or clinic ☐ 2 In home ☐ 3 In person — other2b. Language of test administration: ☐ 1 English ☐ 2 Spanish ☐ 3 Other (SPECIFY): _____**Section 3 — Craft Story 21 Recall (Immediate)**3a. Total story units recalled, verbatim scoring
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 4a.**) _____ (0–44, 95–98)

3b. Total story units recalled, paraphrase scoring _____ (0–25)

Section 4 — Benson Complex Figure Copy

4a. Total score for copy of Benson figure (If test not completed, enter reason code, 95–98) _____ (0–17, 95–98)

Section 5 — Number Span Test: Forward5a. Number of correct trials
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 6a.**) _____ (0–14, 95–98)

5b. Longest span forward _____ (0, 3–9)

Section 6 — Number Span Test: Backward6a. Number of correct trials
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 7a.**) _____ (0–14, 95–98)

6b. Longest span backward _____ (0, 2–8)

Section 7 — Category Fluency7a. Animals: Total number of animals named in 60 seconds
(If test not completed, enter reason code, 95–98) _____ (0–77, 95–98)7b. Vegetables: Total number of vegetables named in 60 seconds
(If test not completed, enter reason code, 95–98) _____ (0–77, 95–98)**Section 8 — Trail Making Test**8a. PART A: Total number of seconds to complete (if not finished by 150 seconds, enter 150)
(If test not completed, enter reason code, 995–998, and **SKIP TO QUESTION 8b.**) _____ (0–150, 995–998)

8a1. Number of commission errors _____ (0–40)

8a2. Number of correct lines _____ (0–24)

8b. PART B: Total number of seconds to complete (if not finished by 300 seconds, enter 300)
(If test not completed, enter reason code, 995–998, and **SKIP TO QUESTION 9a.**) _____ (0–300, 995–998)

8b1. Number of commission errors _____ (0–40)

8b2. Number of correct lines _____ (0–24)

Section 9 — Benson Complex Figure Recall9a. Total score for drawing of Benson figure following 10- to 15-minute delay
(If test not completed, enter reason code, 95–98, and **SKIP TO QUESTION 10a.**) _____ (0–17, 95–98)9b. Recognized original stimulus from among four options? ☐ 0 No ☐ 1 Yes

Section 10 — Craft Story 21 Recall (Delayed)

10a.	Total story units recalled, verbatim scoring (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 11a.)	____ (0–44, 95–98)
10b.	Total story units recalled, paraphrase scoring	____ (0–25)
10c.	Delay time (minutes) (99=Unknown)	____ (0–85 minutes)
10d.	Cue ("boy") needed	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

Section 11 — Verbal Fluency: Phonemic Test

11a.	Number of correct F-words generated in 1 minute (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 11d.)	____ (0–40, 95–98)
11b.	Number of F-words repeated in 1 minute	____ (0–15)
11c.	Number of non-F-words and rule violation errors in 1 minute	____ (0–15)
11d.	Number of correct L-words generated in 1 minute (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 12.)	____ (0–40, 95–98)
11e.	Number of L-words repeated in one minute	____ (0–15)
11f.	Number of non-L-words and rule violation errors in 1 minute	____ (0–15)
11g.	TOTAL number of correct F-words and L-words	____ (0–80)
11h.	TOTAL number of F-word and L-word repetition errors	____ (0–30)
11i.	TOTAL number of non-F/L words and rule violation errors	____ (0–30)

12. Which verbal learning test was administered?
☐ 1 Rey AVLT
(COMPLETE SECTIONS 12 & 13,
SKIP SECTIONS 14 & 15)

☐ 2 CERAD
(SKIP TO SECTION 14)
Section 12 — Rey Auditory Verbal Learning (Immediate)

Total number of words correctly recalled and number of intrusions

Trial	Total recall	# of intrusions
Trial 1	12a. ____ (0–15, 95–98) (If test was not completed, enter reason code, 95–98. SKIP TO QUESTION 16a.)	12b. ____ (No limit)
Trial 2	12c. ____ (0–15)	12d. ____ (No limit)
Trial 3	12e. ____ (0–15)	12f. ____ (No limit)
Trial 4	12g. ____ (0–15)	12h. ____ (No limit)
Trial 5	12i. ____ (0–15)	12j. ____ (No limit)
List B	12k. ____ (0–15)	12l. ____ (No limit)
Trial 6	12m. ____ (0–15)	12n. ____ (No limit)

Section 13 — Rey Auditory Verbal Learning (Delayed Recall and Recognition)

13a.	Total delayed recall (If test was not completed, enter reason code, 95–98. SKIP TO QUESTION 16a.)	____ (0–15, 95–98)
13b.	Intrusions	____ (No limit)
13c.	Delay time (minutes) (99=Unknown)	____ (0–85 minutes)
13d.	Method of recognition test administration	<input type="checkbox"/> 1 List shown <input type="checkbox"/> 2 List read
13e.	Recognition — Total correct	____ (0–15)
13f.	Recognition — Total false positive	____ (0–15)

Section 14 — CERAD Verbal Learning (Immediate)

J4 Word List Memory Task: Total number of words correctly recalled and number of intrusions

Trial	Total recall	Can't read	# of intrusions
Trial 1	14a. ____ (0–10, 95–98) (If test was not completed, enter reason code, 95–98. SKIP TO QUESTION 16a.)	14b. ____ (0–10)	14c. ____ (No limit)
Trial 2	14d. ____ (0–10)	14e. ____ (0–10)	14f. ____ (No limit)
Trial 3	14g. ____ (0–10)	14h. ____ (0–10)	14i. ____ (No limit)

Section 15 — CERAD Verbal Learning (Delayed Recall and Recognition)

15a.	Delay time (minutes) (99=Unknown)	____ (0–85 minutes)
15b.	J6 Word List Recall: Total number of words correctly recalled (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 16a.)	____ (0–10, 95–98)
15c.	J6 Word List Recall: Total number of intrusions	____ (No limit)
15d.	J7 Word List Recognition: Total YES correct (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 16a.)	____ (0–10, 95–98)
15e.	J7 Word List Recognition: Total NO correct	____ (0–10, 95–98)

Section 16 — Multilingual Naming Test (MINT)

16a.	Total score (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 17a.)	____ (0–32, 95–98)
16b.	Total correct without semantic cue	____ (0–32)
16c.	Semantic cues: Number given	____ (0–32)
16d.	Semantic cues: Number correct with cue (88 = Not applicable)	____ (0–32, 88)
16e.	Phonemic cues: Number given	____ (0–32)
16f.	Phonemic cues: Number correct with cue (88 = Not applicable)	____ (0–32, 88)

Section 17 — Overall appraisal

17a.	Per the clinician (e.g., neuropsychologist, behavioral neurologist, or other suitably qualified clinician), based on the UDS neuropsychological examination, the participant's cognitive status is deemed:	<input type="checkbox"/> 1 Better than normal for age <input type="checkbox"/> 2 Normal for age <input type="checkbox"/> 3 One or two test scores are abnormal <input type="checkbox"/> 4 Three or more scores are abnormal or lower than expected <input type="checkbox"/> 0 Clinician unable to render opinion
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Section 18 — Validity of participant's response

Please record your impression of whether hearing or other factors significantly influenced test results. It can be difficult to judge, but it is helpful in adjudication and data analysis to know that such an influence may have been present.

18a.	How valid do you think the participant's responses are?	<input type="checkbox"/> 1 Very valid, probably accurate indication of participant's cognitive abilities (END FORM HERE) <input type="checkbox"/> 2 Questionably valid, possibly inaccurate indication of participant's cognitive abilities <input type="checkbox"/> 3 Invalid, probably inaccurate indication of participant's cognitive abilities
18b.	What makes this participant's responses less valid? (Check all that apply)	18b1. <input type="checkbox"/> 1 Hearing impairment 18b2. <input type="checkbox"/> 1 Distractions 18b3. <input type="checkbox"/> 1 Interruptions 18b4. <input type="checkbox"/> 1 Lack of effort or disinterest 18b5. <input type="checkbox"/> 1 Fatigue 18b6. <input type="checkbox"/> 1 Emotional issues 18b7. <input type="checkbox"/> 1 Unapproved assistance 18b8. <input type="checkbox"/> 1 Other (SPECIFY): _____

Form C2T: Neuropsychological Battery Scores for T-cog

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language: <input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish	Mode: <input type="checkbox"/> 2 Remote (reason): ____ <input type="checkbox"/> 1 Telephone	Key (remote reason): 1=Too cognitively impaired 2=Too physically impaired 3=Homebound or nursing home 4=Refused in-person visit 5=Other
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INSTRUCTIONS: This form is to be completed by ADRC or clinic staff. For test administration and scoring, see [Instructions for Neuropsychological Battery, Form C2T](#). Any new participants who enroll in the UDS after the implementation of UDSv4 must be assessed with the new neuropsychological test battery (Form C2 or C2T).

KEY: If the participant 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

Section 1 — Montreal Cognitive Assessment (MoCA) Blind

1a.	Was any part of the MoCA administered?	<input type="checkbox"/> 0 No (If No, enter reason code, 95 – 98): ____ (SKIP TO QUESTION 2A) <input type="checkbox"/> 1 Yes (CONTINUE WITH QUESTION 1B)
1b.	Language of MoCA administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____
1c.	Participant was unable to complete one or more sections due to hearing impairment:	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1d.	Total Raw Score — Uncorrected (Not corrected for education or visual/hearing impairment) (Enter 88 if any of the following MoCA items were not administered: 1e – 1k, 1n – 1s)	____ (0–22, 88)
1e.	Attention — Digits	____ (0–2, 95–98)
1f.	Attention — Letter A	____ (0–1, 95–98)
1g.	Attention — Serial 7s	____ (0–3, 95–98)
1h.	Language — Repetition	____ (0–2, 95–98)
1i.	Language — Fluency	____ (0–1, 95–98)
1j.	Abstraction	____ (0–2, 95–98)
1k.	Delayed recall — No cue	____ (0–5, 95–98)
1l.	Delayed recall — Category cue	____ (0–5; 88=Not applicable)
1m.	Delayed recall — Recognition	____ (0–5; 88=Not applicable)
1n.	Orientation — Date	____ (0–1, 95–98)
1o.	Orientation — Month	____ (0–1, 95–98)
1p.	Orientation — Year	____ (0–1, 95–98)
1q.	Orientation — Day	____ (0–1, 95–98)
1r.	Orientation — Place	____ (0–1, 95–98)
1s.	Orientation — City	____ (0–1, 95–98)

Section 2 — Administration of the remainder of the battery

2a.	Language of test administration:	<input type="checkbox"/> 1 English <input type="checkbox"/> 2 Spanish <input type="checkbox"/> 3 Other (SPECIFY): _____
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Section 3 — Craft Story 21 Recall (Immediate)

3a.	Total story units recalled, verbatim scoring (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 4a.)	____ (0–44, 95–98)
3b.	Total story units recalled, paraphrase scoring	____ (0–25)

Section 4 — Number Span Test: Forward

4a.	Number of correct trials (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 5a.)	____ (0–14, 95–98)
4b.	Longest span forward	____ (0, 3–9)

Section 5 — Number Span Test: Backward

5a.	Number of correct trials (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 6.)	____ (0–14, 95–98)
5b.	Longest span backward	____ (0, 2–8)

6. Which verbal learning test was administered? ☐ **1** Rey AVLT (COMPLETE SECTIONS 6 & 13, SKIP SECTIONS 7 & 9) ☐ **2** CERAD (COMPLETE SECTIONS 7 & 9, SKIP SECTIONS 6 & 13)

Section 6 — Rey Auditory Verbal Learning (Immediate)

Total number of words correctly recalled and number of intrusions

Trial	Total recall	# of intrusions
Trial 1	6a. ____ (0–15, 95–98) (If test was not completed, enter reason code, 95–98, and SKIP TO QUESTION 8a.)	6b. ____ (No limit)
Trial 2	6c. ____ (0–15)	6d. ____ (No limit)
Trial 3	6e. ____ (0–15)	6f. ____ (No limit)
Trial 4	6g. ____ (0–15)	6h. ____ (No limit)
Trial 5	6i. ____ (0–15)	6j. ____ (No limit)
List B	6k. ____ (0–15)	6l. ____ (No limit)
Trial 6	6m. ____ (0–15)	6n. ____ (No limit)

Section 7 — CERAD Verbal Learning (Immediate)

J4 Word List Memory Task: Total number of words correctly recalled and number of intrusions

Trial	Total recall	# of intrusions
Trial 1	7a. ____ (0–10, 95–98) (If test was not completed, enter reason code, 95–98. SKIP TO QUESTION 8a and LEAVE 9a–9e BLANK.)	7b. ____ (No limit)
Trial 2	7c. ____ (0–10)	7d. ____ (No limit)
Trial 3	7e. ____ (0–10)	7f. ____ (No limit)

Section 8 — Category Fluency

8a.	Animals: Total number of animals named in 60 seconds (If test not completed, enter reason code, 95–98)	____ (0–77, 95–98)
8b.	Vegetables: Total number of vegetables named in 60 seconds (If test not completed, enter reason code, 95–98)	____ (0–77, 95–98)

Section 9 — CERAD Verbal Learning (Delayed Recall and Recognition)

9a.	Delay time (minutes) (99=Unknown)	____ (0–85 minutes)
9b.	J6 Word List Recall: Total number of words correctly recalled (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 9d.)	____ (0–10, 95–98)
9c.	J6 Word List Recall: Total number of intrusions	____ (No limit)
9d.	J7 Word List Recognition: Total YES correct (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 10a.)	____ (0–10, 95–98)
9e.	J7 Word List Recognition: Total NO correct	____ (0–10, 95–98)

Section 10 — Oral Trail Making Test (Optional)

10a.	PART A: Total number of seconds to complete (if not finished by 100 seconds, enter 100) (If test not completed, enter reason code, 995–998. If test was skipped because optional, enter 888. SKIP TO QUESTION 10b.)	____ (0–100, 888, 995–998)
	10a1. Number of commission errors	____ (No limit)
	10a2. Number of correct lines	____ (0–25)
10b.	PART B: Total number of seconds to complete (if not finished by 300 seconds, enter 300) (If test not completed, enter reason code, 995–998. If test was skipped because optional, enter 888. SKIP TO QUESTION 11a.)	____ (0–300, 888, 995–998)
	10b1. Number of commission errors	____ (No limit)
	10b2. Number of correct lines	____ (0–25)

Section 11 — Craft Story 21 Recall (Delayed)

11a.	Total story units recalled, verbatim scoring (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 12a.)	____ (0–44, 95–98)
11b.	Total story units recalled, paraphrase scoring	____ (0–25)
11c.	Delay time (minutes) (99=Unknown)	____ (0–85 minutes)
11d.	Cue ("boy") needed	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

Section 12 — Verbal Fluency: Phonemic Test

12a.	Number of correct F-words generated in 1 minute (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 12d.)	____ (0–40, 95–98)
12b.	Number of F-words repeated in 1 minute	____ (0–15)
12c.	Number of non-F-words and rule violation errors in 1 minute	____ (0–15)
12d.	Number of correct L-words generated in 1 minute (If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 13a.)	____ (0–40, 95–98)
12e.	Number of L-words repeated in one minute	____ (0–15)
12f.	Number of non-L-words and rule violation errors in 1 minute	____ (0–15)
12g.	TOTAL number of correct F-words and L-words	____ (0–80)
12h.	TOTAL number of F-word and L-word repetition errors	____ (0–30)
12i.	TOTAL number of non-F/L words and rule violation errors	____ (0–30)

Section 13 — Rey Auditory Verbal Learning (Delayed Recall and Recognition)

13a.	Total delayed recall (If test was not completed, enter reason code, 95-98. If test was skipped because optional, enter 88. SKIP TO QUESTION 14a.)	____ (0-15, 88, 95-98)
13b.	Intrusions	____ (No limit)
13c.	Delay time (minutes) (99=Unknown)	____ (0-85 minutes)
13d.	Recognition — Total correct	____ (0-15)
13e.	Recognition — Total false positive	____ (0-15)

Section 14 — Verbal Naming Test (Optional)

14a.	Total correct without a cue (If test was not completed, enter reason code, 95-98. If test was skipped because optional, enter 88.)	____ (0-50, 88, 95-98)
14b.	Total correct with phonemic cue (If test was not completed, enter reason code, 95-98. If test was skipped because optional or if no cues were given, enter 88.)	____ (0-50, 88, 95-98)

Section 15 — Overall appraisal

15a.	Per the clinician (e.g., neuropsychologist, behavioral neurologist, or other suitably qualified clinician), based on the UDS neuropsychological examination, the participant's cognitive status is deemed:	<input type="checkbox"/> 1 Better than normal for age <input type="checkbox"/> 2 Normal for age <input type="checkbox"/> 3 One or two test scores are abnormal <input type="checkbox"/> 4 Three or more scores are abnormal or lower than expected <input type="checkbox"/> 0 Clinician unable to render opinion
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Section 16 — Validity of participant's responses

Please record your impression of whether hearing or other factors significantly influenced test results. It can be difficult to judge, but it is helpful in adjudication and data analysis to know that such an influence may have been present.

16a.	How valid do you think the participant's responses are?	<input type="checkbox"/> 1 Very valid, probably accurate indication of participant's cognitive abilities (END FORM HERE) <input type="checkbox"/> 2 Questionably valid, possibly inaccurate indication of participant's cognitive abilities <input type="checkbox"/> 3 Invalid, probably inaccurate indication of participant's cognitive abilities
16b.	What makes this participant's responses less valid? (Check all that apply)	16b1. <input type="checkbox"/> 1 Hearing impairment 16b2. <input type="checkbox"/> 1 Distractions 16b3. <input type="checkbox"/> 1 Interruptions 16b4. <input type="checkbox"/> 1 Lack of effort or disinterest 16b5. <input type="checkbox"/> 1 Fatigue 16b6. <input type="checkbox"/> 1 Emotional issues 16b7. <input type="checkbox"/> 1 Unapproved assistance 16b8. <input type="checkbox"/> 1 Other (SPECIFY): _____

Form D1a: Clinical Syndrome

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

 Language:
☐ 1 English
☐ 2 Spanish

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see the [UDS Coding Guidebook for Form D1a](#). Check only one box per question.

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

☐ 1 Single clinician ☐ 2 Formal consensus panel ☐ 3 Other (e.g., Two or more clinicians or other informal group)

Section 1 – Level of impairment – Unimpaired cognition/behavior, SCD, MCI/MBI, or dementia

2. Does the participant have:

1. Unimpaired cognition (e.g., cognitive performance and functional status (i.e., CDR) judged to be unimpaired)?

AND

2. Unimpaired behavior (i.e., the participant does not exhibit behavior sufficient to diagnose MBI – see MBI section starting at Q7) or dementia due to FTLD or LBD and/or FTLD behavior and language domains=0?

☐ 0 No (SKIP TO QUESTION 3) ☐ 1 Yes (CONTINUE TO QUESTION 2a)

Note: For those with longstanding cognitive impairment that does not represent a decline from their usual functioning, consider checking **Question 5b** for a diagnosis of “**Cognitively Impaired, Not MCI/dementia**”.

Subjective Cognitive Decline

2a. Does the participant report 1) significant concerns about changes in cognition AND 2) no neuropsychological evidence of decline AND 3) no functional decline?

☐ 0 No (END FORM HERE)
☐ 1 Yes

2b. As a clinician, are you confident that the subjective cognitive decline is clinically meaningful?

☐ 0 No (END FORM HERE)
☐ 1 Yes (END FORM HERE)

Dementia criteria

Requirement #1:

 Participant 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; 2) objective assessment (bedside or neuropsychological testing)

Requirement #2:

 Participant must have 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, visuospatial in posterior cortical atrophy, etc.), the participant must not fulfill criteria for MCI.

3. Does the participant meet criteria for dementia?

☐ 0 No (CONTINUE TO QUESTION 4)
☐ 1 Yes (SKIP TO QUESTION 6a)

Section 1 – Level of impairment*continued...***MCI core clinical criteria**

Check all criteria that apply in Q4.

4. ☐ 1 Clinical concern about decline in cognition compared to participant's prior level of lifelong or usual cognitive function (e.g., based on input from participant, co-participant, and/or the clinician's judgment, CDR SB 0.5+, etc.)
- ☐ 1 Impairment in one or more cognitive domains, compared to participant's estimated prior level of lifelong or usual cognitive function, or supported by objective longitudinal neuropsychological evidence of decline
- ☐ 1 Largely preserved functional independence OR functional dependence that is not related to cognitive decline (e.g., based on clinical judgment)

If all three criteria are checked, choose **1=Yes** for Q4b. If less than 3 criteria are met, choose **0=No** for Q4b. If only some of the criteria from Q4 are checked, with the exception of the third MCI criteria **alone**, consider a diagnosis of **cognitively impaired, not MCI/dementia** on Q5b. If **only** the third MCI criteria is met in Q4, select **0=No** for Q5b.

- 4b. Does the participant meet all three of the above criteria for MCI (amnesic or non-amnesic)? ☐ 0 No (**CONTINUE TO QUESTION 5**) ☐ 1 Yes (**SKIP TO QUESTION 6a**)

Cognitively impaired, not MCI/dementia

The purpose of the "Cognitively impaired, not MCI/dementia" category is to capture those individuals with evidence of cognitive impairment or decline who do not meet formal MCI criteria.

Check all applicable criteria for cognitively impaired, not MCI/dementia in Q5, using any relevant data.

5. ☐ 1 Evidence of functional impairment (e.g., CDR SB>0 and/or FAS>0), but available cognitive testing is judged to be normal
- ☐ 1 Cognitive testing is abnormal but no clinical concern or functional decline (e.g., CDR SB=0 and FAS=0)
- ☐ 1 Longstanding cognitive difficulties, not representing a decline from their usual function (e.g., early developmental differences remote TBI, other medical condition with clear effects on cognition)
- ☐ 1 Other (**SPECIFY**): _____

If any of the criteria in Q5 are met choose **1=Yes** for Q5b.

- 5b. Does the participant meet any criteria for cognitively impaired, not MCI/dementia? ☐ 0 No (**SKIP TO QUESTION 7**) ☐ 1 Yes (**SKIP TO QUESTION 7**)

Affected Domains – Dementia and MCI

Choose domains that are impaired at the current visit based on clinical judgment informed by clinical history and neuropsychological testing. **Select one or more as Impaired**; all others will default to **unimpaired** in the NACC database.

Note on **behavior changes**: For patients with *dementia* who have behavior changes, record the presence of behavioral changes here (not in the following MBI section) by marking Q6f as **Impaired** and skipping the MBI section (**SKIP TO Q8**). For behavioral changes in the context of an MCI (or as an isolated) symptom, consider a diagnosis of MBI in the next section.

	Impaired
6a. Memory	<input type="checkbox"/> 1
6b. Language	<input type="checkbox"/> 1
6c. Attention	<input type="checkbox"/> 1
6d. Executive	<input type="checkbox"/> 1
6e. Visuospatial	<input type="checkbox"/> 1
6f. Behavioral (for participants with dementia only; see MBI for MCI participants)	<input type="checkbox"/> 1
6g. Apraxia	<input type="checkbox"/> 1

Section 1 – Level of impairment*continued...***Mild Behavioral Impairment (MBI) core clinical criteria**

- Participant, co-participant, or clinician identifies a change in the participant's affect, motivation, thought content, behavior, or personality that is clearly different from their usual affect, motivation, thought content, behavior, or personality
- Symptoms have been present at least intermittently for the last six months or longer
- Late onset (i.e., age > ~50, unless early onset neurodegenerative syndrome is suspected)
- Not explained by delirium, other psychiatric disorder by DSM criteria (including recent onset, longstanding or recurrence of longstanding disorder).
- Symptoms interfere with at least one of these: work, interpersonal relationships, social activities
- Largely preserved independence in other functional abilities (no change from prior manner/level of functioning, or uses minimal aids or assistance)

7. Does the participant meet criteria for MBI?
(If participant meets criteria for dementia an MBI diagnosis is excluded.)
- ☐ 0 No (**SKIP TO QUESTION 8**)
☐ 1 Yes (**CONTINUE TO QUESTION 7a**)

MBI affected domains — Select one or more affected domains

(Note: If "Yes" is indicated in any domain below, the participant should have a corresponding symptom checked on Form B9 — Clinician Judgment of Symptoms, either from among the specific symptoms denoted there, or in "other")

	No	Yes
7a. Motivation (e.g., apathy symptoms on Form B9)	<input type="checkbox"/> 0	<input type="checkbox"/> 1
7b. Affective regulation (e.g., anxiety, irritability, depression, and/or euphoria symptoms on Form B9)	<input type="checkbox"/> 0	<input type="checkbox"/> 1
7c. Impulse control (e.g., obsessions/compulsions, personality change, and/or substance abuse symptoms on Form B9)	<input type="checkbox"/> 0	<input type="checkbox"/> 1
7d. Social appropriateness (e.g., disinhibition, personality change, and/or loss of empathy symptoms on Form B9)	<input type="checkbox"/> 0	<input type="checkbox"/> 1
7e. Thought content/perception (e.g., delusions and/or hallucinations on Form B9)	<input type="checkbox"/> 0	<input type="checkbox"/> 1

Section 2 – Clinical syndrome

The purpose of Section 2 is to assign a predominant clinical syndrome to participants with dementia and, when appropriate MCI or MBI, using all available clinical, exam, and neuropsychiatric data. This should be done using clinical information and cognitive/neuropsychological testing, **ideally without reference to biomarker data** (which is incorporated into the Etiological Diagnoses section in Form D1b). This is not always possible and thus Q9 allows centers to record when biomarker data is known and may have influenced the clinical diagnosis.

8. Is there a predominant clinical syndrome?
Note that the participant may not meet any clinical criteria or may not have a predominant syndrome (for instance, this is common for MCI and "impaired, not MCI"). In this case, select "No."
- ☐ 0 No (**SKIP TO QUESTION 10**)
☐ 1 Yes

Select the predominant syndrome as present; all others will default to Absent in the NACC database.

	Present
8a. Amnestic predominant syndrome	<input type="checkbox"/> 1
8b. Dysexecutive predominant syndrome	<input type="checkbox"/> 1
8c. Primary visual presentation (such as posterior cortical atrophy (PCA) syndrome)	<input type="checkbox"/> 1
8d. Primary progressive aphasia (PPA) syndrome:	<input type="checkbox"/> 1
8d1. If present, select one: <input type="checkbox"/> 1 Semantic PPA <input type="checkbox"/> 2 Logopenic PPA <input type="checkbox"/> 3 Nonfluent/agrammatic PPA <input type="checkbox"/> 4 Primary progressive apraxia of speech <input type="checkbox"/> 5 PPA other/not otherwise specified	
8e. Behavioral variant frontotemporal (bvFTD) syndrome	<input type="checkbox"/> 1
8f. Lewy body syndrome	<input type="checkbox"/> 1
8f1. If present, select one: <input type="checkbox"/> 1 Dementia with Lewy bodies <input type="checkbox"/> 2 Parkinson's disease <input type="checkbox"/> 3 Parkinson's disease dementia syndrome	
8g. Non-amnestic multidomain syndrome, not PCA, PPA, bvFTD, or DLB syndrome	<input type="checkbox"/> 1

Section 2 – Clinical syndrome*continued...*

		Present
8h.	Primary supranuclear palsy (PSP) syndrome	<input type="checkbox"/> 1
8h1.	If present, select one: <input type="checkbox"/> 1 Richardson's syndrome criteria <input type="checkbox"/> 2 Non-Richardson's	
8i.	Traumatic encephalopathy syndrome	<input type="checkbox"/> 1
8j.	Corticobasal syndrome (CBS)	<input type="checkbox"/> 1
8k.	Multiple system atrophy (MSA) syndrome	<input type="checkbox"/> 1
8k1.	If present, select one: <input type="checkbox"/> 1 MSA-predominant cerebellar ataxia (MSA-C) <input type="checkbox"/> 2 MSA-predominant Parkinsonism (MSA-P) <input type="checkbox"/> 3 MSA-predominant dysautonomia	
8l.	Other (SPECIFY): _____	<input type="checkbox"/> 1

9. Indicate the source(s) of information used to assign the clinical syndrome:
 Select one or more as **Yes**; all others will default to **No** in the NACC database.

		Yes
9a.	Clinical information (history, CDR)	<input type="checkbox"/> 1
9b.	Cognitive testing	<input type="checkbox"/> 1
9c.	Biomarkers (MRI, PET, CSF, plasma)	<input type="checkbox"/> 1

Section 3 – Primary or contributing non-neurodegenerative or non-CVD conditions

The purpose of Section 3 is to identify conditions or disorders that are present and potentially contributing to the clinical syndrome. This must be filled out for those with cognitive or behavioral impairment (i.e., MCI, MBI, dementia, etc.) Indicate whether a given condition is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment.

Select one or more condition(s) as **Present**; if there are no primary or contributing non-neurodegenerative or non-CVD conditions, leave all conditions blank. All conditions left blank will default to **Absent** in the NACC database. *Only one diagnosis should be selected as 1 = Primary.*

*In order to diagnose a disorder, **DSM-5-TR criteria require** that symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. For more guidance see the **UDS Coding Guidebook, Form D1a**.

Condition		Present		Primary	Contributing	Non-contributing
10.	Major depressive disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	10a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
11.	Other specified depressive disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	11a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
12.	Bipolar disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	12a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
13.	Schizophrenia or other psychotic disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	13a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14.	Anxiety disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	14a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
If present, (SPECIFY) (check all that apply):						
14b.	<input type="checkbox"/> 1 Generalized anxiety disorder					
14c.	<input type="checkbox"/> 1 Panic disorder					
14d.	<input type="checkbox"/> 1 Obsessive-compulsive disorder (OCD)					
14e.	<input type="checkbox"/> 1 Other (SPECIFY) : _____					
15.	Post-traumatic stress disorder (PTSD)(DSM-5-TR criteria*)	<input type="checkbox"/> 1	15a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Section 3 – Primary or contributing non-degenerative or non-CVD conditions*continued...*

Condition		Present		Primary	Contributing	Non-contributing
16.	Developmental neuropsychiatric disorders (e.g., autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), dyslexia)	<input type="checkbox"/> 1	16a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
17.	Delirium (DSM-5-TR criteria*)	<input type="checkbox"/> 1	17a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
18.	Other psychiatric disorder (DSM-5-TR criteria*)	<input type="checkbox"/> 1	18a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
18b. If present, (SPECIFY): _____						
19.	Traumatic brain injury (Distinct from TES and CTE, which are documented as a Clinical Syndrome and Etiologic Diagnosis, respectively)	<input type="checkbox"/> 1	19a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
20.	Epilepsy	<input type="checkbox"/> 1	20a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
21.	Normal-pressure hydrocephalus	<input type="checkbox"/> 1	21a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
22.	CNS Neoplasm	<input type="checkbox"/> 1	22a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
22b. If present, select one: <input type="checkbox"/> 1 Benign <input type="checkbox"/> 2 Malignant						
23.	Human immunodeficiency virus (HIV) infection	<input type="checkbox"/> 1	23a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
24.	Post COVID-19 cognitive impairment	<input type="checkbox"/> 1	24a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
25.	Sleep apnea (i.e., obstructive, central, mixed or complex sleep apnea)	<input type="checkbox"/> 1	25a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
26.	Cognitive impairment due to other neurologic, genetic, infectious conditions (not listed above), or systemic disease/medical illness (as indicated on Form A5/D2)	<input type="checkbox"/> 1	26a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
26b. If present, (SPECIFY): _____						
27.	Cognitive impairment due to alcohol use or abuse	<input type="checkbox"/> 1	27a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
28.	Cognitive impairment due to substance use or abuse	<input type="checkbox"/> 1	28a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
29.	Cognitive impairment due to medications	<input type="checkbox"/> 1	29a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
30.	Cognitive impairment not otherwise specified (NOS)	<input type="checkbox"/> 1	30a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
30b. If present, (SPECIFY): _____						
31.	Cognitive impairment not otherwise specified (NOS)	<input type="checkbox"/> 1	31a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
31b. If present, (SPECIFY): _____						
32.	Cognitive impairment not otherwise specified (NOS)	<input type="checkbox"/> 1	32a.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
32b. If present, (SPECIFY): _____						

Form D1b: Etiological Diagnosis and Biomarker Support

ADRC: _____ PTID: _____ Form date: ____/____/____ Visit #: _____ Examiner's initials: _____

Language:
☐ 1 English
☐ 2 Spanish

INSTRUCTIONS: This form is to be completed by the clinician for all participants, including cognitively unimpaired. For additional clarification and examples, see [UDS Coding Guidebook for Form D1b](#). Check only one box per question.

1. Were any biomarker results used to support the current etiological diagnosis?
(Consider any biomarker results from any time that may be clinically relevant)
- ☐ 0 No (**SKIP TO QUESTION 12**)
☐ 1 Yes (**CONTINUE TO QUESTION 2**)

Section 1 – Biomarkers and imaging

Complete this section if any of the following biomarker measures were used to **support or exclude** a presumed etiological diagnosis, including unimpaired individuals who have biomarker characterization. Please complete the checklist below for each data source available and the related questions for each supporting data. Then complete **Section 2: Etiological Diagnosis**. This section is not intended to capture actual data values or register sample availability; instead this section's purpose is to record what information was used by the clinician (or at consensus) to inform an etiological diagnosis.

Fluids

2. **Fluid Biomarkers** – Were fluid biomarkers used for assessing the etiological diagnosis?
- ☐ 0 No (**SKIP TO QUESTION 5**)
☐ 1 Yes, only blood-based biomarkers were used
(**CONTINUE TO QUESTION 3, and SKIP QUESTIONS 4 – 4d**)
☐ 2 Yes, only CSF-based biomarkers were used (**SKIP TO QUESTION 4**)
☐ 3 Yes, both blood- and CSF-based biomarkers were used

Please use the following questions to indicate the results of the fluid biomarker test(s) used by the clinician (or at consensus) to determine the etiological diagnosis at this visit.

If a fluid biomarker was used to exclude an etiological diagnosis, select **0=Not consistent**. If a fluid biomarker was found to be consistent with a diagnosis, select **1=Yes, consistent**. If a fluid biomarker was found to be indeterminate, select **9**. In cases where one or more of the etiologies listed were not assessed using fluid biomarkers, select **8**.

3. Blood-based biomarkers		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
3a.	Consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
3b.	Consistent with FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
3c.	Consistent with LBD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
3d.	Consistent with other etiology (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8

4. CSF-based biomarkers		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
4a.	Consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
4b.	Consistent with FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
4c.	Consistent with LBD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
4d.	Consistent with other etiology (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8

Section 1 – Biomarkers and imaging*continued...***Imaging**

5. **Imaging** – Was imaging used for assessing etiological diagnosis?
- ☐ 0 No (**SKIP TO QUESTION 8**)
- ☐ 1 Yes, only PET/SPECT imaging was used
(**CONTINUE TO QUESTION 6, and SKIP QUESTIONS 7 – 7a3f**)
- ☐ 2 Yes, only MR imaging was used (**SKIP TO QUESTION 7**)
- ☐ 3 Yes, both PET/SPECT and MR imaging were used

Please use the following questions to indicate the results of the imaging used by the clinician (or at consensus) to determine the etiological diagnosis at this visit.

If imaging was used to exclude an etiological diagnosis, select **0=Not consistent**. If imaging was found to be consistent with a diagnosis, select **1=Yes, consistent**. If imaging was found to be indeterminate, select **9**. In cases where one or more of the etiologies listed were not assessed using imaging, select **8**.

6. PET/SPECT

- 6a. **Tracer-based PET** - Were tracer-based PET measures used in assessing an etiological diagnosis?
- ☐ 0 No (**SKIP TO QUESTION 6b**)
- ☐ 1 Yes, results were normal or abnormal
- ☐ 2 Yes, results were indeterminate

If used in diagnosis, indicate the results:

6a1. Elevated Amyloid

☐ 0

☐ 1

☐ 9

☐ 8

6a2. Elevated tau pathology

☐ 0

☐ 1

☐ 9

☐ 8

- 6b. **FDG PET** - Was FDG PET data or information used to support an etiological diagnosis?

- ☐ 0 No (**SKIP TO QUESTION 6c**)
- ☐ 1 Yes, results were normal or abnormal
- ☐ 2 Yes, results were indeterminate

**No,
inconsistent**

**Yes,
consistent**

Indeterminate

**Not
assessed**

6b1. Consistent with AD

☐ 0

☐ 1

☐ 9

☐ 8

6b2. Consistent with FTLD

☐ 0

☐ 1

☐ 9

☐ 8

6b3. Consistent with LBD

☐ 0

☐ 1

☐ 9

☐ 8

6b4. Consistent with other etiology (**SPECIFY**): _____

☐ 0

☐ 1

☐ 9

☐ 8

- 6c. **Dopamine Transporter (DAT) Scan** - Was DAT Scan data or information used to support an etiological diagnosis?

- ☐ 0 No
- ☐ 1 Yes, results were normal or abnormal
- ☐ 2 Yes, results were indeterminate

- 6d. **Other tracer-based imaging** - Were other tracer-based imaging used to support an etiological diagnosis?
(**SPECIFY**): _____

- ☐ 0 No (**SKIP TO QUESTION 7a**)
- ☐ 1 Yes, results were normal or abnormal
- ☐ 2 Yes, results were indeterminate

**No,
inconsistent**

**Yes,
consistent**

Indeterminate

**Not
assessed**

6d1. Consistent with AD

☐ 0

☐ 1

☐ 9

☐ 8

6d2. Consistent with FTLD

☐ 0

☐ 1

☐ 9

☐ 8

6d3. Consistent with LBD

☐ 0

☐ 1

☐ 9

☐ 8

6d4. Consistent with other etiology (**SPECIFY**): _____

☐ 0

☐ 1

☐ 9

☐ 8

Section 1 – Biomarkers and imaging*continued...***7. Structural Imaging****7a. Structural Imaging (i.e., MRI or CT) – Was structural imaging data or information used to support an etiological diagnosis?**

- ☐ 0 No (**SKIP TO QUESTION 8**)
☐ 1 Yes, results were normal or abnormal
☐ 2 Yes, results were indeterminate

		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
7a1.	Atrophy pattern consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a2.	Atrophy pattern consistent with FTLT	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3.	Consistent with Cerebrovascular disease (CVD)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
	If there is evidence for CVD on imaging, indicate the findings:	No	Yes	Indeterminate	Not assessed
7a3a.	Large vessel infarct(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3b.	Lacunar infarct(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3c.	Macrohemorrhage(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3d.	Microhemorrhage(s)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3e.	White matter hyperintensity	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
7a3e1.	If Yes , choose the severity: <input type="checkbox"/> 1 Moderate white-matter hyperintensity (CHS score 5-6) <input type="checkbox"/> 2 Extensive white-matter hyperintensity (CHS score 7-8+)				

Other biomarker modalities (e.g., tissues, skin, retinal imaging, etc.)

Please use the following questions to indicate the results of any additional biomarker modalities used by the clinician (or at consensus) to support the etiological diagnosis at this visit.

If a biomarker modality was used to exclude an etiological diagnosis, select **0=Not consistent**. If a biomarker modality was found to be consistent with a diagnosis, select **1=Yes, consistent**. If a biomarker was found to be indeterminate, select **9**. In cases where one or more of the etiologies listed were not assessed using a biomarker modality, select **8**.

8. Other biomarker modality - Was another biomarker modality used to support an etiological diagnosis?
(SPECIFY): _____

- ☐ 0 No (**SKIP TO QUESTION 11**)
☐ 1 Yes, results were normal or abnormal
☐ 2 Yes, results were indeterminate

		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
8a.	Consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
8b.	Consistent with FTLT	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
8c.	Consistent with LBD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
8d.	Consistent with other etiology (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8

Section 1 – Biomarkers and imaging*continued...*

9. **Other biomarker modality** - Was another biomarker modality used to support an etiological diagnosis?
(SPECIFY): _____

- ☐ 0 No (**SKIP TO QUESTION 11**)
☐ 1 Yes, results were normal or abnormal
☐ 2 Yes, results were indeterminate

		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
9a.	Consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
9b.	Consistent with FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
9c.	Consistent with LBD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
9d.	Consistent with other etiology (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8

10. **Other biomarker modality** - Was another biomarker modality used to support an etiological diagnosis?
(SPECIFY): _____

- ☐ 0 No (**SKIP TO QUESTION 11**)
☐ 1 Yes, results were normal or abnormal
☐ 2 Yes, results were indeterminate

		No, inconsistent	Yes, consistent	Indeterminate	Not assessed
10a.	Consistent with AD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
10b.	Consistent with FTLD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
10c.	Consistent with LBD	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8
10d.	Consistent with other etiology (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	<input type="checkbox"/> 8

Supportive genetics

11. Is there an autosomal dominant pathogenic variant to support an etiological diagnosis?

- ☐ 0 No
☐ 1 Yes
☐ 9 Unknown/Not disclosed

Section 2 – Etiological diagnoses

Using all the available data (i.e. clinical, cognitive, biomarker, etc) please provide an etiological diagnosis. For those with no biomarker data, enter a **presumed** etiological diagnosis.

Must be filled out for all participants. Indicate whether a given condition is a primary, contributing, or non-contributing cause of the observed impairment, based on the clinician's best judgment. Select one or more etiological diagnoses from questions (below) as **Present**; all others will default to **Absent** in the NACC database. *Only one diagnosis should be selected as 1 = Primary.*

For unimpaired participants: Proceed using your center's diagnostic philosophy to determine whether the etiology is present and primary, contributing, or non-contributing or leave the checkboxes blank.

Etiological Diagnoses		Present		Primary	Contributing	Non-contributing
12.	Alzheimer's disease	<input type="checkbox"/> ₁	12a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
13.	Lewy body disease	<input type="checkbox"/> ₁	13a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
14.	Frontotemporal lobar degeneration (FTLD)	<input type="checkbox"/> ₁				
If present , select all that apply:						
14a.	Progressive supranuclear palsy (PSP)	<input type="checkbox"/> ₁	14a1.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
14b.	Corticobasal degeneration (CBD)	<input type="checkbox"/> ₁	14b1.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
14c.	FTLD with motor neuron disease	<input type="checkbox"/> ₁	14c1.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
14d.	FTLD - not otherwise specified (NOS)	<input type="checkbox"/> ₁	14d1.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
14e.	If FTLD (QUESTION 14) is present , specify FTLD subtype: <input type="checkbox"/> ₁ Tauopathy <input type="checkbox"/> ₂ TDP-43 proteinopathy <input type="checkbox"/> ₃ Other (SPECIFY): _____ <input type="checkbox"/> ₉ Unknown					
15.	Vascular brain injury (based on clinical and imaging evidence according to your Center's standards)	<input type="checkbox"/> ₁	15a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
16.	Multiple system atrophy	<input type="checkbox"/> ₁	16a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
17.	Chronic traumatic encephalopathy (CTE)	<input type="checkbox"/> ₁	17a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
17b.	If CTE (QUESTION 17) is present , specify certainty: <input type="checkbox"/> ₁ Suggestive CTE <input type="checkbox"/> ₂ Possible CTE <input type="checkbox"/> ₃ Probable CTE					
18.	Down syndrome	<input type="checkbox"/> ₁	18a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
19.	Huntington's disease	<input type="checkbox"/> ₁	19a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
20.	Prion disease (CJD, other)	<input type="checkbox"/> ₁	20a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
21.	Cerebral amyloid angiopathy	<input type="checkbox"/> ₁	21a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
22.	LATE: Limbic-predominant age-related TDP-43 encephalopathy	<input type="checkbox"/> ₁	22a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
23.	Other (SPECIFY): _____	<input type="checkbox"/> ₁	23a.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃