

## NACC UNIFORM DATA SET

# Follow-Up Visit Packet

### UDSv4.0, December 2025

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## Form A1. Participant Demographics

ADRC:	PTID:		Form date:	_//	Visit #:	Examiner's initials:
Languag □1 Engl □2 Spai	lish 🔲 1 Self-administered	Mode:  □ 1 In-person □ 2 Remote (reason): □ 1 Telephone □ □ 3 Mail □		Key (remo	2= 3= 4=	Too cognitively impaired Too physically impaired Homebound/nursing home Refused in-person visit Other
medica (web-b	<b>UCTIONS</b> : This form may be only the on	cipant report (as need ew, or during the in-pe	led). This information car erson visit to accommodo	n be collected by m ate and lessen part	nail-in survey, e ticipant visit b	electronic capture urden. For additional
Section	on 1 — Demographics	5				
well-be	kt two questions ask about y ing, and quality of care. By nt gender. Gender identity ca	gender identity, we	mean the inner sense th	hat you have of yo	ourself as bei	ng a man, woman, or a
	Which term(s) best describe gender identity? (Check all that apply)	es your current	1a.	r woman /genderqueer f you are AIAN) rent term (SPECIF)	Y):	
	Which term(s) best describe orientation? (Check all that apply)	es your sexual	2a. 1 Lesbian or g 2b. 1 Straight/het 2c. 1 Bisexual 2d. 1 Two-Spirit (i 2e. 1 I use a differ 2f. 1 Don't know 2g. 1 Prefer not to	erosexual f you are AIAN) ent term (SPECIF)	Y):	
3.	What is your <u>current</u> marita	l status?	1 Married 2 Widowed 3 Divorced 4 Separated 5 Never married (or 6 Living as married of			
4.	What is your living situation	1?	1 Live alone 2 Live with one othe 3 Live with one othe 4 Live with caregive 5 Live with a group 6 Live in group hom 9 Don't know	er person: a relativer who is not spou (related or not rela	ve, friend, or r ise/partner, re ated) in a priva	elative, or friend ate residence
5.	What is your primary type o	of residence?	1 Single- or multi-f 2 Retirement comm 3 Assisted living, ad 4 Skilled nursing fac 6 Do not have hous outside on the street	nunity or independ ult family home, o cility, nursing hom ing (e.g., staying wit	dent group liver boarding here, hospital, of the others, in a ho	ome r hospice

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Particip	pant ID:	Form date:	_ /	/	Visit #:	
Secti	on 1 — Demographics					continued
6.	What are the first three digits of the Z (For example, if your ZIP code is 12345, enter	IP code of your prim 123.)	nary residenc	re?		(If unknown, leave blank)
7.	Have you ever obtained medical care (VA) facility?	or prescription drug	gs from a Vet	erans Affairs	□ 0 No □ 1 Yes □ 9 Don't know	ı
8.	How much time in total do you spend physically strenuous activities that ca for at least 10 minutes continuously? (Include activity at work, traveling to an activities.)	use increases in you	r breathing o	or heart rate	1 None 2 1 hour or le 3 2.5 hours o 4 More than 8 Prefer not t	r less 2.5 hours o answer
Secti	on 2 — Memory					
9.	Do you feel like your memory is beco	ming worse?			2 Yes, and thi	s does not worry me s worries me ı / Prefer not to answer
10.	About how often do you have trouble	remembering thing	gs?		1 Never 2 Rarely 3 Sometimes 4 Often 5 Very often 9 Don't know	ı / Prefer not to answer
11.	Compared to 10 years ago, would you worse, the same, a little better, or much		ory is much	worse, a little	1 Much bette 2 A little bett 3 The same 4 A little wors 5 Much wors	er se
For A	DRC use only:					
The r	next two questions use the Area Depriv I	ation Index (ADI) loo Enter the participant			orhoodatlas.medid	cine.wisc.edu/mapping.
12.	ADI state-only decile (If unknown, leave blank. For special codes, a	enter 884 for "PH", 885 fo	or "GQ", 886 for	· "PH-GQ", and 887	7 for "QDI".)	
13.	ADI national percentile: (If unknown, leave blank. For special codes, o	enter 884 for "PH", 885 fo	or "GQ", 886 for	"PH-GQ", and 887	7 for "QDI".)	



## Form A1a: Social Determinants of Health

ADRC:		PTID:	Form date:	_//				
Language:  ☐ 1 English ☐ 2 Spanish  Administration: ☐ 1 Self-administered ☐ 2 Staff-administered		Mode:  □1 In-person □2 Remote (reason): □1 Telephone □2 Video □3 Mail □4 Electronic (e.g., ema	1=Too cog 2=Too phy 3=Homeb	ote reason): nitively impaired rsically impaired ound/nursing home I in-person visit	Key (not completed reason): 88=Optional 93=Concerns about reliability			
may feel ι	<b>INSTRUCTIONS:</b> 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 <b>Prefer not to answer</b> . You should fill out this form on your own, without help from your co-participant or study partner.							
Sec	tion 1 — Tran	sportation						
acco	mplishing impor	trying to understand the extent to wh tant activities, such as going to the do re only examples).						
1.	Do you or some	one in your household currently own a	car?		☐ o No ☐ 1 Yes ☐ 8 Prefer not to answer			
2.	Do you have con	nsistent access to transportation?			□ 0 No □ 1 Yes □ 8 Prefer not to answer			
		hey need to go, people might walk, bil to assess whether or not you have had				iree		
3.		ays, how often were you <b>not</b> able to lead oblem with transportation?	ve the house w	/hen you wanted	to 1 Often 2 Sometimes 3 Never 8 Prefer not to answer			
4.		ays, how often did you worry about whe because of a problem with transportati		u would be able t	1 Often 2 Sometimes 3 Never 8 Prefer not to answer			
5.		ays, how often has a lack of transportati or from doing things needed for daily liv		om medical	☐ 1 Often☐ 2 Sometimes☐ 3 Never☐ 8 Prefer not to answer			
Sec	tion 2 — Fina	ncial 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 <b>Prefer not to answer</b> .								
6.	Include income benefits, help from This information w	income groups represents your househor from all sources such as wages, salaries, om relatives, rent from property, and so will be kept confidential and will not be shared in inization or government entity.	, social security forth.	y or retirement	1 \$0 - \$14,999 2 \$15,000 - \$29,999 3 \$30,000 - \$74,999 4 \$75,000 and over 8 Prefer not to answer 9 Don't know			
7.	How satisfied ar	e you with your current personal financ	ial condition?		1 Completely satisfied 2 Satisfied 3 Somewhat satisfied 4 Not very satisfied 5 Not at all satisfied 8 Prefer not to answer			

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Participant ID:	Form date:	/	/	Visit #:

Sec	tion 2 — Financial security	continued
8.	How difficult is it for you to meet monthly payments on your bills?	1 Not at all 2 Slightly 3 Moderately 4 Very 5 Extremely 8 Prefer not to answer
9.	months or longer, how upsetting has it been to you?  2 Yes, financial problems upsetting to me 3 Yes, financial problems somewhat upsetting t	for twelve months or longer for twelve months or longer, but not for twelve months or longer, and o me for twelve months or longer, and
10.	At any time, did you ever eat less than you felt you should because there wasn't enough money to buy food?	☐ 0 No ☐ 1 Yes ☐ 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?	☐ 0 No ☐ 1 Yes ☐ 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?	☐ 0 No ☐ 1 Yes ☐ 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?	☐ 0 No ☐ 1 Yes ☐ 8 Prefer not to answer
14.	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.  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.	Best off → 10  3  4  Worst off
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?  1 Never attended school 2 Grades 1 through 8 (electric time they were raising you?  3 Grades 9 through 11 (some 4 Grade 12 or GED (high 5 College 1 year to 3 year 6 College 4 years or more 8 Prefer not to answer/N 9 Do not know	ome high school) school graduate) rs (some college) e (college graduate)

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Sec	tion 3 — Social connections, activities, and environment	
	e next set of questions are designed to learn what you think about your social connections, time on, and how you view your home and neighborhood.	the types of activities you spend
	owing are some statements to learn how you describe yourself in general. For each statemen ely represents your opinion.	t, select the number that most
16.	I experience a general sense of emptiness	☐ 1 Strongly disagree ☐ 2 Disagree ☐ 3 Neither disagree or agree ☐ 4 Agree ☐ 5 Strongly agree ☐ 8 Prefer not to answer
17.	I miss having people around	1 Strongly disagree 2 Disagree 3 Neither disagree or agree 4 Agree 5 Strongly agree 8 Prefer not to answer
18.	I feel like I don't have enough friends	☐ 1 Strongly disagree ☐ 2 Disagree ☐ 3 Neither disagree or agree ☐ 4 Agree ☐ 5 Strongly agree ☐ 8 Prefer not to answer
19.	I often feel abandoned	1 Strongly disagree 2 Disagree 3 Neither disagree or agree 4 Agree 5 Strongly agree 8 Prefer not to answer
20.	I miss having a really close friend	☐ 1 Strongly disagree ☐ 2 Disagree ☐ 3 Neither disagree or agree ☐ 4 Agree ☐ 5 Strongly agree ☐ 8 Prefer not to answer
The r	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)?	0 Parents not living 1 Once a year or less 2 Several times a year 3 Several times a month 4 Several times a week 5 Everyday or almost everyday 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)?	□ 0 Do not have children □ 1 Once a year or less □ 2 Several times a year □ 3 Several times a month □ 4 Several times a week □ 5 Everyday or almost everyday □ 8 Prefer not to answer

Participant ID: \_\_\_\_\_ Form date: \_\_\_ / \_\_\_ / \_\_\_ Visit #: \_\_\_\_

Soc	tion	3 — Social connections, activities, and envi	ronment	continued
23.	How	often do you have contact with close friends either in p il (e.g., any online interaction)?		0 Do not have close friends 1 Once a year or less 2 Several times a year 3 Several times a month 4 Several times a week 5 Everyday or almost everyday 8 Prefer not to answer
24.	How educ orga	□ 0 Do not participate in activities outside the home □ 1 Once a year or less □ 2 Several times a year □ 3 Several times a month □ 4 Several times a week □ 5 Everyday or almost everyday □ 8 Prefer not to answer		
This	next s	et of questions is about how safe you feel in different co	ntexts.	
25.	How	safe do you feel in your home and community (or neigh	borhood)?	
	25a.	Home		☐ 1 Very safe ☐ 2 Mostly safe ☐ 3 Unsafe at times ☐ 4 Very unsafe ☐ 8 Prefer not to answer
	25b.	Community (or neighborhood)		1 Very safe 2 Mostly safe 3 Unsafe at times 4 Very unsafe 8 Prefer not to answer
Sec	tion	4 — Experiences with the healthcare syster	n	
		five questions are about your experiences with the hea ak about your regular medical doctors (not the doctors y		
26.		e past year, how often did you delay seeking medical ntion for a problem that was bothering you?	1 All of the time 2 Most of the time 3 Sometimes 4 None or almost none of 5 Not applicable 8 Prefer not to answer	f the time
27.		e past year, how often did you experience challenges ing a prescription?	1 All of the time 2 Most of the time 3 Sometimes 4 None or almost none of 5 Not applicable 8 Prefer not to answer	f the time
28.		e past year, how often did you miss a follow-up ical appointment that was scheduled?	1 All of the time 2 Most of the time 3 Sometimes 4 None or almost none of 5 Not applicable 8 Prefer not to answer	f the time

Participant ID: \_\_\_\_\_ Form date: \_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #: \_

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Sec	tion 4 — Experiences with the healthcare syster	n continued
29.	In the past year, how often did you follow a doctor's advice or treatment plan when it was given?	1 All of the time 2 Most of the time 3 Sometimes 4 None or almost none of the time 5 Not applicable 8 Prefer not to answer
30.	Overall, which of these describes your health insurance, access to healthcare services, and access to medications?	1 Not available to any extent 2 Below the level of my needs 3 Able to meet my needs 4 Exceeds my needs 8 Prefer not to answer
Sec	tion 5 — Experiences of Discrimination	
	arch has shown that experiences of unfair treatment in daily li wing questions about whether you have experienced unfair tr	fe, for any reason, can negatively affect health. Please answer the reatment in the following ways.
31.	In your day-to-day life how often are you treated with less courtesy or respect than other people?	1 Almost every day 2 At least once a week 3 A few times a month 4 A few times a year 5 Less than once a year 6 Never 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?	1 Almost every day 2 At least once a week 3 A few times a month 4 A few times a year 5 Less than once a year 6 Never 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?	1 Almost every day 2 At least once a week 3 A few times a month 4 A few times a year 5 Less than once a year 6 Never 8 Prefer not to answer
34.	In your day-to-day life how often do people act as if they are afraid of you?	1 Almost every day 2 At least once a week 3 A few times a month 4 A few times a year 5 Less than once a year 6 Never 8 Prefer not to answer
35.	In your day-to-day life how often are you threatened or harassed?	1 Almost every day 2 At least once a week 3 A few times a month 4 A few times a year 5 Less than once a year 6 Never 8 Prefer not to answer

Participant ID: \_\_\_\_\_ Form date: \_\_\_ / \_\_\_ / \_\_\_ Visit #: \_\_

Parti	cipant ID: Form date	//	Visit #:
Sec	tion 5 — Experiences of Discrimination		continued
36.	How frequently do you receive poorer service or t from doctors or in hospitals compared to other po	ple? 2 Most of the t	ost none of the time ole
37.	When reflecting on the day-to-day experiences in 31 to 36, what do you think are the main reasons experiences? (Check all that apply)	These 37a2.	y ancestry or national origins y gender y race y age y religion y height y weight me other aspect of my physical appearance y sexual orientation y education or income level ohysical disability y shade of skin color her ot applicable - I do not have these experiences

☐ 1 Very stressful
2 Moderately stressful
☐3 Not stressful
9 Don't know
8 Prefer not to answer

**37a15.** □ 1 Prefer not to answer

in my day-to-day life (END FORM HERE)



## Form A2: Co-participant Demographics

ADRC:	PTID:	Form date://	Visit #: initials:
Language:	Mode:	Key (remote reason): 1=Too cognitively impaired	Key (not completed reason):
☐1 English	□ 1 In-person	2=Too physically impaired	92=No co-participant
☐2 Spanish	□ 2 Remote (reason):	3=Homebound or nursing home	95=Physical problem
	□1 Telephone □2 Video	4=Refused in-person visit	96=Cognitive/behavioral problem
	□ o Not completed (reason):	5=Other	97=Other
			98=Verbal refusal

**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**, **Form A2**. Check only one box per question.

Sec	tion 1 — Co-participant's Relationship to Parti	cipant		
1.	Is this a new co-participant (i.e., one who was not a co- participant at any past UDS visit)?	□o No	□1 Yes	
2.	What is the co-participant's relationship to the participant?	<ul> <li>□ 1 Spouse, partner, or companion (include ex-spouse, ex-paniancé(e), boyfriend, girlfriend)</li> <li>□ 2 Child (by blood or through marriage or adoption)</li> <li>□ 3 Sibling (by blood or through marriage or adoption)</li> <li>□ 4 Other relative (by blood or through marriage or adoption)</li> <li>□ 5 Friend, neighbor, or someone known through family, friends, work, or community (e.g., church)</li> <li>□ 6 Paid caregiver, health care provider, or clinician</li> </ul>		
3.	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 ( <b>999 = Unknown</b> )	
4.	Does the co-participant live with the participant?	□o No	1 Yes (SKIP TO QUESTION 6)	
5.	What is the primary mode of contact with the participant?	1 In-person 2 Telephone 3 Video conferencing	4 Texting or email 5 Social media platforms 6 Other ( <b>SPECIFY</b> ):	
5	<b>a1.</b> What is the approximate frequency of all types of contact?	☐ 1 Daily ☐ 2 At least three times per week ☐ 3 Weekly	☐ 4 At least three times per month ☐ 5 Monthly ☐ 6 Less than once a month	
5	<ul><li>What is the average amount of time spent in contact with the participant during each encounter?</li><li>(Please include an average of all encounter types)</li></ul>	1 Less than 5 minutes (appropriate for texting or email and may be applicable to other modes of contact as well)	2 5-15 minutes 3 15-30 minutes 4 30-60 minutes 5 Longer than one hour	
6.	Is there a question about the co-participant's reliability?	□o No	□1 Yes	
Sec	tion 2 — Co-participant's Judgment of Particip	ant's Memory		
Ask t	he next three questions directly to the co-participant.			
7.	Do you feel like the participant's memory is becoming worse?	□ 0 No □ 1 Yes, but this does not worry me	2 Yes, and this worries me 9 Unknown	
	About how often does the participant have trouble remembering things?	☐ 1 Never ☐ 2 Rarely ☐ 3 Sometimes	☐4 Often ☐5 Very Often ☐9 Unknown	
9.	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?	☐ 1 Much better☐ 2 A little better☐ 3 The same	☐ 4 A little worse☐ 5 Much worse☐ 9 Unknown	

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## Form A3: Participant Family History

ADRC:		PTID:	·		Form date: _	/	_/	Visit #:	initials:
Language:  1 Englisl 2 Spanis	h □1	de: In-person Remote (reason):  1 Telephone		emote r	3=Hor	physically mebound o used in-per	impaired r nursing ho	ome	
diagnose	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 <a href="UDS">UDS</a> Coding Guidebook, Form A3.								
Sectio	n 1 – B	iological pare	nts						
		UDS visit, is new inf biological mother o		concei	rning the sta	tus of the		0 No (SKIP TO 1 Yes (COMPLI	QUESTION 2) ETE QUESTIONS 1A-1B)
For any p	arent wi	th a neurological or	psychiatric diagnos	sis, the	entire row <u>m</u>	ust be fill	ed out.		
= <b>Unkno</b> psychiatr the subse	own in the ric diagno equent qu	nnot determine the pee <b>Primary diagnosis</b> osis, enter <b>00 = No k</b> <i>estions in the row.</i> Fo Secondary diagnosis	column, and <i>skip t</i> nown neurologica r a parent with a pr	he subs al/psyc	sequent quest :hiatric diag	ions in th nosis in t	<i>e row</i> . For he <b>Prima</b> ı	a parent with no r <b>y diagnosis</b> colu	neurological or mn, and then skip
		Birth year	Age at death	Pri	mary dx*	Second	dary dx*	Method of	Age of onset
		(6666=provided at previous visit, 9999=Unknown)	(666=provided at previous visit, 888=N/A, 999=Unknown)		SI	evaluation** EE LIST OF CODES			of primary dx (666=provided at previous visit, 999 = Unknown)
1a. Mot	her					_	_	_	
1b. Fath	ner					_	_	_	
Code	es								
*DIAGN	OSES								
<b>00</b> No	o known	neurological/psych	iatric diagnosis		**METHOD OF EVALUATION				
<b>01</b> Al:	zheimer'	s Disease			1 Participant/family report				
<b>02</b> Le	wy Body	dementia (include:	s DLB and PDD)		2 Medical records				
<b>03</b> Va	scular de	ementia			3 Exam				
<b>04</b> St	roke				(co-enrolled family members)				
<b>05</b> FT	LD* with	out motor neuron	disease		4 Autopsy (if autopsy report available)				
<b>06</b> FT	TLD* with	n motor neuron dise	ase				evious vis	it	
<b>07</b> M	otor Neu	ron Disease			o Tronaca at premous visit				
<b>08</b> Pa	rkinson's	s Disease							
	ion path				*FTI D inclu	ıdes: hvF	TD or FTD	) PPA (any subtyn	e), CBS or CBD, PSP
<b>10</b> Ps	ychiatric	condition			T TED IIICIO	ides. Ovi	1001110	, I I A (ally saviy)	e), CD3 01 CDD, 1 31
11 Dementia of unknown etiology								vioral variant fror	•
<b>12</b> Ot								syndrome, CBD = with Lewy bodie.	
		t previous visit			frontotemp	oral dem	entia, PDE	) = Parkinson's di	sease with dementia,
		ary diagnosis			PPA = primary progressive aphasia, PSP = progressive supranuclear palsy				
		agnosis unknown <i>(d</i> Lis not by exam or al	•	d of	7)				

<b>YEAR OF BIRTH FOR FULL SIBLINGS &amp; BIOLOGICAL CHILDREN:</b> If birth year is unknown, please provide an approximate year on <b>UDS Initial Visit Form A3</b> and <b>UDS Follow-up Visit Form A3</b> 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.							
			<i>if applicable</i> , and acr					
			ed to previously sub ear, <i>enter</i> <b>9999=Unk</b> i		n. If it is impossik	ole for the		
		,						
Section 2 – F	-uii sibiings							
2. Since the last participant's		ormation available	e concerning the stat	us of the	O No (SKIP TO	QUESTION 3) TE QUESTIONS 2a-2u)		
2.1. How mar	ny full siblings does	the participant ha	ave?					
	(77 = participant	t adopted or siblir	ngs unknown; 66 = p	rovided at previo	us visit)			
If particip	oant has no full sibli	ngs, <b>SKIP TO QUES</b>	TION 3; otherwise, pr	ovide information	on all full siblings	<b>5.</b>		
•	-		gnosis, the entire row					
			cal/psychiatric diagno e subsequent question					
psychiatric diagno	osis, enter <b>00 = No k</b>	nown neurologic	al/psychiatric diagn	osis in the Primar	<b>y diagnosis</b> colui	mn, and then skip		
	<i>iestions in the row.</i> Fo Secondary diagnosis		n a primary diagnosis	but no secondary	diagnosis, enter t	88 = No secondary		
	Birth year	Age at death	Primary dx*	Secondary dx*	Method of	Age of onset		
	(6666=provided	(666=provided			evaluation**	of primary dx		
	at previous visit, 9999=Unknown)	at previous visit, 888=N/A,	SF	E LIST OF CODES		(666=provided at previous visit,		
		999 = Unknown)				999=Unknown)		
2a. Sibling 1					_			
2b. Sibling 2					_			
2c. Sibling 3					_			
2d. Sibling 4								
2e. Sibling 5					_			
					_			
2f. Sibling 6			 	 	_ _ _			
2f. Sibling 6 2g. Sibling 7			 	 	_ _ _	 		
					_ _ _ _			
2g. Sibling 7					_ _ _ _ _			
2g. Sibling 7 2h. Sibling 8								
2g. Sibling 7 2h. Sibling 8 2i. Sibling 9								
2g. Sibling 7 2h. Sibling 8 2i. Sibling 9 2j. Sibling 10								
2g. Sibling 7 2h. Sibling 8 2i. Sibling 9 2j. Sibling 10 2k. Sibling 11								
2g. Sibling 7 2h. Sibling 8 2i. Sibling 9 2j. Sibling 10 2k. Sibling 11 2l. Sibling 12 2m. Sibling 13								
2g. Sibling 7 2h. Sibling 8 2i. Sibling 9 2j. Sibling 10 2k. Sibling 11 2l. Sibling 12 2m. Sibling 13 2n. Sibling 14								
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								
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								
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								
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								
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								

\_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #: \_\_

Participant ID: \_\_\_

NATIONAL ALZHEIMER'S COORDINATING CENTER

naccmail@uw.edu

Section 3 – B	Section 3 – Biological children							
	3. Since the last UDS visit, is new information available concerning the status of the participant's biological children?							
3.1. How man	ny biological childre	n does the particip	oant have?					
	(66 = provided at	previous visit)						
If particip	oant has no biologic	al children, <b>END FC</b>	ORM HERE; otherwise	e, provide informa	tion on all biologi	cal children.		
For any biological	child with a neurolo	gical or psychiatric	diagnosis, the entire	e row <u>must be fille</u>	d out.			
<b>Unknown</b> in the lor psychiatric diag skip the subsequen	nnot determine the p Primary diagnosis co gnosis, enter <b>00 = No</b> Int questions in the rov Iosis in the Secondar	olumn, and <i>skip the</i> <b>known neurolog</b> v. For a biological c	subsequent question ical/psychiatric dia hild with a primary c	os in the row. For a gnosis in the Prim	biological child w nary diagnosis co	vith no neurological Dlumn, and then		
	Birth year	Age at death	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset		
	(6666=provided at previous visit, 9999=Unknown)	(666=provided at previous visit, 888=N/A, 999=Unknown)	SE	of primary dx (666=provided at previous visit, 999=Unknown)				
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					_			

Participant ID: \_\_\_\_\_ Form date: \_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #: \_\_\_

3o. Child 15



## Form A4: Participant Medications

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

**INSTRUCTIONS:** This form 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**, Form A4.

Is the participant currently taking any medications?  $\square_0$  No (END FORM HERE)  $\square_1$  Yes

MEDICATION NAMERXNormacetaminophen-HYDROcodone (Hycet, Vicodin)214182albuterol (Proventil, ProAir HFA, RespiClick, Ventolin)435alendronate (Binosto, Fosamax)46041allopurinol (Aloprim, Duzallo, Zyloprim)519alprazolam (Xanax)596amlodipine (Norvasc)17767apixaban (Eliquis)1364430atenolol (Tenormin)1202atorvastatin (Lipitor)83367benazepril (Lotensin)18867bupropion (Aplenzin, Budeprion, Wellbutrin, Zyban)42347calcium acetate (Calphron, Eliphos, PhosLo Phoslyra)214342carbidopa-levodopa (Duopa, Rytary, Sinemet)103990carvedilol (Coreg)20352celecoxib (Celebrex)140587cetirizine (Aller-Tec, Zyrtec)20610citalopram (Celexa)2556clonazepam (Klonopin)2598clopidogrel (Plavix)32968cyanocobalamin (Nascobal, Vitamin B12)11248diclofenac (Flector, Cambia, Zipsor)3355diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac)3443donepezil (Adlarity, Aricept)135447duloxetine (Cymbalta, Irenka)72625enalapril (Vasotec)3827		
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atorvastatin (Lipitor)  benazepril (Lotensin)  bupropion (Aplenzin, Budeprion, Wellbutrin, Zyban)  calcium acetate (Calphron, Eliphos, PhosLo Phoslyra)  carbidopa-levodopa (Duopa, Rytary, Sinemet)  carvedilol (Coreg)  carvedilol (Coreg)  celecoxib (Celebrex)  cetirizine (Aller-Tec, Zyrtec)  citalopram (Celexa)  clonazepam (Klonopin)  clopidogrel (Plavix)  cyanocobalamin (Nascobal, Vitamin B12)  diclofenac (Flector, Cambia, Zipsor)  diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac)  donepezil (Adlarity, Aricept)  duloxetine (Cymbalta, Irenka)  72625	apixaban (Eliquis)	1364430
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Zyban)  calcium acetate (Calphron, Eliphos, PhosLo Phoslyra)  carbidopa-levodopa (Duopa, Rytary, Sinemet) 103990  carvedilol (Coreg) 20352  celecoxib (Celebrex) 140587  cetirizine (Aller-Tec, Zyrtec) 20610  citalopram (Celexa) 2556  clonazepam (Klonopin) 2598  clopidogrel (Plavix) 32968  cyanocobalamin (Nascobal, Vitamin B12) 11248  diclofenac (Flector, Cambia, Zipsor) 3355  diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443  donepezil (Adlarity, Aricept) 135447  duloxetine (Cymbalta, Irenka) 72625	benazepril (Lotensin)	18867
Phoslyra)  carbidopa-levodopa (Duopa, Rytary, Sinemet) 103990  carvedilol (Coreg) 20352  celecoxib (Celebrex) 140587  cetirizine (Aller-Tec, Zyrtec) 20610  citalopram (Celexa) 2556  clonazepam (Klonopin) 2598  clopidogrel (Plavix) 32968  cyanocobalamin (Nascobal, Vitamin B12) 11248  diclofenac (Flector, Cambia, Zipsor) 3355  diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443  donepezil (Adlarity, Aricept) 135447  duloxetine (Cymbalta, Irenka) 72625		42347
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cetirizine (Aller-Tec, Zyrtec) 20610 citalopram (Celexa) 2556 clonazepam (Klonopin) 2598 clopidogrel (Plavix) 32968 cyanocobalamin (Nascobal, Vitamin B12) 11248 diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	carvedilol (Coreg)	20352
citalopram (Celexa) 2556 clonazepam (Klonopin) 2598 clopidogrel (Plavix) 32968 cyanocobalamin (Nascobal, Vitamin B12) 11248 diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	celecoxib (Celebrex)	140587
clonazepam (Klonopin) 2598 clopidogrel (Plavix) 32968 cyanocobalamin (Nascobal, Vitamin B12) 11248 diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	cetirizine (Aller-Tec, Zyrtec)	20610
clopidogrel (Plavix) 32968 cyanocobalamin (Nascobal, Vitamin B12) 11248 diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	citalopram (Celexa)	2556
cyanocobalamin (Nascobal, Vitamin B12) 11248 diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	clonazepam (Klonopin)	2598
diclofenac (Flector, Cambia, Zipsor) 3355 diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	clopidogrel (Plavix)	32968
diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac) 3443 donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	cyanocobalamin (Nascobal, Vitamin B12)	11248
donepezil (Adlarity, Aricept) 135447 duloxetine (Cymbalta, Irenka) 72625	diclofenac (Flector, Cambia, Zipsor)	3355
duloxetine (Cymbalta, Irenka) 72625	diltiazem (Cardizem, Cardia XT, DILT-XR, Tiazac)	3443
	donepezil (Adlarity, Aricept)	135447
enalapril (Vasotec) 3827	duloxetine (Cymbalta, Irenka)	72625
	enalapril (Vasotec)	3827

MEDICATION NAME	RXNorm
ergocalciferol (Calcidol, Calciferol, Disdol, Vitamin D2)	4018
escitalopram (Lexapro)	321988
esomeprazole (Nexium)	283742
estradiol (Estrace, Estrogel, Delestrogen, Yuvafem)	4083
ezetimibe (Zetia)	341248
ferrous sulfate (Feosol, Iron Supplement, Slow FE)	24947
fexofenadine (Allegra, Wal-Flex)	87636
finasteride (Propecia, Proscar)	25025
fluoxetine (Prozac, Sarafem)	4493
fluticasone (Flovent)	41126
fluticasone nasal (Aller-Flo, Flonase)	1165656
fluticasone-salmeterol (Advair, AirDuo)	284635
furosemide (Lasix)	4603
gabapentin (Gralise, Horizant, Neurontin)	25480
galantamine (Razadyne, Reminyl)	4637
glipizide (Glucotrol)	4821
hydrochlorothiazide (Esidrix, Hydrodiuril, Microzide)	5487
hydrochlorothiazide-triamterene (Dyazide, Maxzide)	258337
latanoprost (Xalatan)	43611
levothyroxine (Levoxyl, Synthroid, Tirosint)	10582
lisinopril (Prinivil, Qbrelis, Zestril)	29046
lorazepam (Ativan)	6470
losartan (Cozaar)	52175
lovastatin (Altocor, Altoprev, Mevacor)	6472

	ticipant ID: Form da									
ME	DICATION NAME	RXNorm	MEDICATION NAME	RXNorm						
	meloxicam (Mobic, Vivlodex)	41493	pravastatin (Pravachol)	42463						
	memantine (Namenda)	6719	quetiapine (Seroquel)	51272						
	metformin (Glucophage, Glumetza, Riomet)	6809	ranitidine (Wal-Zan, Zantac)	9143						
	metoprolol (Lopressor, Toprol-XL)	6918	rivastigmine (Exelon)	183379						
	mirtazapine (Remeron)	15996	rosuvastatin (Crestor, Ezallor)	301542						
	montelukast (Singulair)	88249	sertraline (Zoloft)	36437						
	naproxen (Aleve, Anaprox, Naprosyn)	7258	sildenafil (Viagra, Revatio)	136411						
	niacin (Niacinol, Niacor, Niaspan, Nicotinic Acid)	7393	simvastatin (FloLipid, Zocor)	36567						
	nifedipine (Adalat, Afeditab CR, Procardia)	7417	tamsulosin (Flomax)	77492						
	nitroglycerin (Nitro-Bid, Nitro-Dur, Nitro-Time,	4917	terazosin (Hytrin)	37798						
	Nitrostat, Rectiv) omega-3 polyunsaturated fatty acids	4301	tramadol (ConZip, Ryzolt, Ultram)	10689						
	(Omacor, Lovaza, Vascazen)	4301	trazodone (Desyrel, Oleptro)	10737						
	omeprazole (Prilosec, Zegerid)	7646	valsartan (Diovan)	69749						
	oxybutynin (Ditropan, Oxytrol, Urotrol)	32675	venlafaxine (Effexor)	39786						
	pantoprazole (Protonix)	40790	warfarin (Coumadin, Jantoven)	11289						
	paroxetine (Paxil, Paxil CR, Pexeva)	32937	zolpidem (Ambien, Edluar, Intermezzo,	39993						
	potassium chloride (K-Dur 10, K-Tab, Klor-con)	8591	Zolpimist)							
	Commonly reported medications that may be purchased over the counter  (but that may also be prescription):									
DAT	(but	that may al:	o be prescription):	DVNove						
ME	(but	RXNorm	o be prescription):  MEDICATION NAME	RXNorm						
ME	(but	that may al:	o be prescription):	<b>RXNorm</b> 82003						
ME	(but acetaminophen (Actamin, Feverall, Ofirmev,	RXNorm	<ul> <li>be prescription):</li> <li>MEDICATION NAME</li> <li>docusate (Colace, Dioctyl SS, Ducsate Calcium,</li> </ul>							
ME	(but  EDICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)	RXNorm 161 1151 1191	<ul> <li>be prescription):</li> <li>MEDICATION NAME</li> <li>docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)</li> <li>folic acid (Folic Acid, Folvite)</li> <li>glucosamine (Glucosamine Hydrochloride,</li> </ul>	82003						
ME	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin	RXNorm 161 1151	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)	82003 4511						
	(but  EDICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)	RXNorm 161 1151 1191	<ul> <li>be prescription):</li> <li>MEDICATION NAME</li> <li>docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)</li> <li>folic acid (Folic Acid, Folvite)</li> <li>glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)</li> </ul>	82003 4511 4845						
ME	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H)	RXNorm 161 1151 1191 1588	<ul> <li>be prescription):</li> <li>MEDICATION NAME</li> <li>docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)</li> <li>folic acid (Folic Acid, Folvite)</li> <li>glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)</li> <li>ibuprofen (Advil, Motrin, Nuprin)</li> </ul>	82003 4511 4845 5640						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick,	RXNorm 161 1151 1191 1588 214342	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease) folic acid (Folic Acid, Folvite) glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin) ibuprofen (Advil, Motrin, Nuprin) loratadine (Alavert, Allerclear, Claritin, Tavist)	82003 4511 4845 5640 28889						
	(but  CDICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D)	RXNorm 161 1151 1191 1588 214342 1897 608343	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)	82003 4511 4845 5640 28889 6711						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D)	RXNorm 161 1151 1191 1588 214342 1897 608343 1008264	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)  polyethylene glycol 3350 (Clearlax, Miralax)	82003 4511 4845 5640 28889 6711 221147						
	acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D) cholecalciferol (Decara, Replesta, Vitamin D3)	RXNorm 161 1151 1191 1588 214342 1897 608343 1008264 2418	MEDICATION NAME docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease) folic acid (Folic Acid, Folvite) glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin) ibuprofen (Advil, Motrin, Nuprin) loratadine (Alavert, Allerclear, Claritin, Tavist) melatonin (Melatonin, Melatonin Time Release) polyethylene glycol 3350 (Clearlax, Miralax) turmeric (Curcumin, Turmeric Root) ubidecarenone (Co Q-10) vitamin E (Alpha E, Aquasol-E, Aquavite-E,	82003 4511 4845 5640 28889 6711 221147 1114883						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin) biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D)	RXNorm 161 1151 1191 1588 214342 1897 608343 1008264	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)  polyethylene glycol 3350 (Clearlax, Miralax)  turmeric (Curcumin, Turmeric Root)  ubidecarenone (Co Q-10)	82003 4511 4845 5640 28889 6711 221147 1114883 21406						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)  biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D) cholecalciferol (Decara, Replesta, Vitamin D3) chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)	RXNorm 161 1151 1191 1588 214342 1897 608343 1008264 2418 1008567	MEDICATION NAME docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease) folic acid (Folic Acid, Folvite) glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin) ibuprofen (Advil, Motrin, Nuprin) loratadine (Alavert, Allerclear, Claritin, Tavist) melatonin (Melatonin, Melatonin Time Release) polyethylene glycol 3350 (Clearlax, Miralax) turmeric (Curcumin, Turmeric Root) ubidecarenone (Co Q-10) vitamin E (Alpha E, Aquasol-E, Aquavite-E,	82003 4511 4845 5640 28889 6711 221147 1114883 21406 11256						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)  biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D) cholecalciferol (Decara, Replesta, Vitamin D3) chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)	RXNorm  161  1151  1191  1588  214342  1897  608343  1008264  2418  1008567  edication in the street of the street	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)  polyethylene glycol 3350 (Clearlax, Miralax)  turmeric (Curcumin, Turmeric Root)  ubidecarenone (Co Q-10)  vitamin E (Alpha E, Aquasol-E, Aquavite-E, Centrum Singles)	82003 4511 4845 5640 28889 6711 221147 1114883 21406 11256						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)  biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D) cholecalciferol (Decara, Replesta, Vitamin D3) chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)  If a me	RXNorm  161  1151  1191  1588  214342  1897  608343  1008264  2418  1008567  edication in the street of the street	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)  polyethylene glycol 3350 (Clearlax, Miralax)  turmeric (Curcumin, Turmeric Root)  ubidecarenone (Co Q-10)  vitamin E (Alpha E, Aquasol-E, Aquavite-E, Centrum Singles)	82003 4511 4845 5640 28889 6711 221147 1114883 21406 11256						
	(but  DICATION NAME  acetaminophen (Actamin, Feverall, Ofirmev, Panadol, Tempra, Tylenol) ascorbic acid (Acerola C, C Complex, Vitamin C) aspirin (Ecotrin)  biotin (Appearex, coenzyme R, Nail-ex, Vitamin H) calcium acetate (Calphorn, Domeboro) calcium carbonate (Caltrate, Rolaids, Tums) calcium carbonate/cholecalciferol (Cal-Quick, Caltrate-Plus D) calcium carbonate/ergocalciferol (O Cal-D) cholecalciferol (Decara, Replesta, Vitamin D3) chondroitin-glucosamine (Cidaflex, Osteo Bi-Flex)  If a me Specify the drug or brand name and determine	RXNorm  161  1151  1191  1588  214342  1897  608343  1008264  2418  1008567  edication in its RXNorm	MEDICATION NAME  docusate (Colace, Dioctyl SS, Ducsate Calcium, Dulcoease)  folic acid (Folic Acid, Folvite)  glucosamine (Glucosamine Hydrochloride, Optiflex-G, Synovacin)  ibuprofen (Advil, Motrin, Nuprin)  loratadine (Alavert, Allerclear, Claritin, Tavist)  melatonin (Melatonin, Melatonin Time Release)  polyethylene glycol 3350 (Clearlax, Miralax)  turmeric (Curcumin, Turmeric Root)  ubidecarenone (Co Q-10)  vitamin E (Alpha E, Aquasol-E, Aquavite-E, Centrum Singles)  s not listed above:  code by using the RXNav: https://lhncbc.nlm.nih.gov/RxN	82003 4511 4845 5640 28889 6711 221147 1114883 21406 11256						

SPECIFY:



Examiner's

## Form A4a: ADRD–Specific Treatments

Mode	ADRC: _			PTID:		Form date:/	./ `	Visit #:	initials:	
dementics (ADRD) biomarkers, whether a disease-modifying treatment that is FDA-approved for ADRD and received as part of cilinical care or an investigational treatment received as part of a cilinical trial. For treatments received as part of cilinical care or an investigational treatment received as part of cilinical care or an investigational treatment received as part of the cilinical care or an investigational treatment and by a comparison 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 sessessment (e.g., they are receiving lecanemab influsions), the treatment should be included on both this form and the AM Medication form. Participation in any ADRD drug trial over an individual's lifetime should be included on the type of treatment can be found via ClinicalTrials. gov identifiers 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 "Natheimer's disease drug development pipeline." This form should be completed based on participant in interview and/or co-participant report. For additional clarification and examples, see UDS Coding Guidebook, 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 lab one of the participant's prescribed treatments or clinical trial (s) of a treatment expected to modify ADRD biomarkers?  2. Please provide information about the clinical treatment(s) and/or trial(s). INCLUDE ALL HISTORICAL CLINICAL TREATMENT(S) AND/OR TRIAL(S) even if there is no new information on those treatments. Trials. If there is a new treatment and/or trial to report, please add it after all of the historical information.  1. Amyloid beta   1 Amyloid related imaging abnormalities—dema (ARIA-E), amyloid related imaging abnormalities—dema (ARIA-E), amyloid related imaging abnormalities—dema	□1 Eng	lish	□1 In-person □2 Remote	(reason):	Key (remote r	2=Too physically ir 3=Homebound or 4=Refused in-perso	npaired nursing home			
treatment expected to modify ADRD biomarkers?    1 Yes   9 Unknown (END FORM HERE)	demen clinical those t of these treatm lifetime cell. Inf develo	NSTRUCTIONS: This form should be used to record treatments expected to significantly impact Alzheimer's disease and related lementias (ADRD) biomarkers, whether a disease-modifying treatment that is FDA-approved for ADRD and received as part of linical care or an investigational treatment received as part of a clinical trial. For treatments received as part of clinical care, only hose 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 reatment should be included on both this form and the A4 Medication form. Participation in any ADRD drug trial over an individual's ifetime should be included. If available, the ClinicalTrials.gov identifier should be entered into the "specific treatment and/or trial" ell. Information on the type of treatment can be found via ClinicalTrials.gov and is summarized in "Alzheimer's disease drug levelopment pipeline." 1 This form should be completed based on participant interview and/or co-participant report. For additional								
participant's prescribed treatments or clinical trial(s) of a treatment expected to modify ADRD biomarkers?  2. Please provide information about the clinical treatment(s) and/or trial(s). INCLUDE ALL HISTORICAL CLINICAL TREATMENT(S) AND/OR TRIAL(S) even if there is no new information on those treatments/trials. If there is a new treatment and/or trial to report, please add it after all of the historical information. (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)	1.					been enrolled in a clin	ical trial of a	1 Yes		
TREATMENT(S) AND/OR TRIAL(S) even if there is no new information on those treatments/trials. If there is a new treatment and/or trial to report, please add it after all of the historical information.  (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)	•	1a.	participant's	prescribed treatme				1 Yes		
Primary Drug Target (check all that apply)    Amyloid beta   Tau   Inflammation   Synaptic plasticity/ neuroprotection   Other target(s)    Ams the participant ever experienced amyloid related imaging abnormalities—edema (ARIA-E), amyloid related imaging abnormali	2.	TRE and	ATMENT(S) A I/or trial to re	ND/OR TRIAL(S) eve port, please add it af	n if there is no new fter all of the histor	v information on those rical information.	treatments/t			
1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)  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?  3a. Since the last UDS visit, is new information available concerning the participant's experience of amyloid related imaging abnormalities—edema (ARIA-E), amyloid related imaging abnormalities—edema (ARIA-E) amyloid related imaging abnormalities—edema (ARIA-E) abnormalities—e				treatment and/	(99/9999	(month/year) (99/9999=Unknown;	treatm	ent	which group was	
(ARIA-E), amyloid related imaging abnormalities—hemorrhage (ARIA-H), or other major adverse events associated with treatments expected to modify ADRD biomarkers?  3a. Since the last UDS visit, is new information available concerning the participant's experience of 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?  3b. What major adverse events associated with treatments expected to modify ADRD biomarkers abnormalities—edema (ARIA-E) to modify ADRD biomarkers did they 3b2. 1 Amyloid related imaging	1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection  NCT-		/	/	2 Clinical 3 Clinical	trial care	2 Placebo			
experience of 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?  3b. What major adverse events associated with treatments expected to modify ADRD biomarkers abnormalities-edema (ARIA-E) to modify ADRD biomarkers did they 3b2. 1 Amyloid related imaging abnormalities-edema (ARIA-E) 3b2. 1 Amyloid related imaging	3.	(ARIA-E), amyloid related imaging abnormalities—hemorrhage (ARIA-H), or other major								
associated with treatments expected abnormalities–edema (ARIA-E) to modify ADRD biomarkers did they 3b2. 1 Amyloid related imaging	experience of amyloid related imaging abnormalities–edema (ARIA-E), amyloid 1 Yes related imaging abnormalities–hemorrhage (ARIA-H), or other major adverse events 1 Yes				1 Yes					
abnormalities—hemorrhage (ARIA-H)		3b.	associated w to modify Al	vith treatments expe DRD biomarkers did	ected ak they <b>3b2.</b> 1 A	3b1. ☐ 1 Amyloid related imaging abnormalities-edema (ARIA-E) 3b3. ☐ 1 Other issues			Other issues	
abnormalities—hemorrhage (ARIA-H)								-		
					they <b>3b2.</b> 1 A	amyloid related imagin	g	-		

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

Participant ID:		Form date:	_ / /	Visit #:				
TREATMENT(S) A and/or trial to re	Please provide information about the clinical treatment(s) and/or trial(s). INCLUDE ALL HISTORICAL CLINICAL TREATMENT(S) AND/OR TRIAL(S) even if there is no new information on those treatments/trials. If there is a new treatment and/or trial to report, please add it after all of the historical information. (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?			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)	NCT	/	/	1 Clinical care 2 Clinical trial 3 Clinical care and clinical trial	1 Active treatment 2 Placebo 9 Unknown			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)		/	/	1 Clinical care 2 Clinical trial 3 Clinical care and clinical trial	1 Active treatment 2 Placebo 9 Unknown			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)		/	/	☐ 1 Clinical care ☐ 2 Clinical trial ☐ 3 Clinical care and clinical trial	1 Active treatment 2 Placebo 9 Unknown			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)		/	/	☐ 1 Clinical care ☐ 2 Clinical trial ☐ 3 Clinical care and clinical trial	1 Active treatment 2 Placebo 9 Unknown			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)		/	/	1 Clinical care 2 Clinical trial 3 Clinical care and clinical trial	☐ 1 Active treatment ☐ 2 Placebo ☐ 9 Unknown			
1 Amyloid beta 1 Tau 1 Inflammation 1 Synaptic plasticity/ neuroprotection 1 Other target(s)		/	/	1 Clinical care 2 Clinical trial 3 Clinical care and clinical trial	1 Active treatment 2 Placebo 9 Unknown			

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

ADRC:	PTID:	•	orm date:/			Examiner's initials:
Language  1 Engli  2 Span	: Mode: □ 1 In-person		on): 1=Too cognitivel, 2=Too physically 3=Homebound c 4=Refused in-per 5=Other	y impaired impaired or nursing home		
and co- included question	<b>CTIONS</b> : This form is to be completed by participant, as well as review of any med don the form. For additional clarification n, unless otherwise stated.	ical records that are and examples, see	e available. Any co <mark>UDS Coding Gui</mark>	nditions ident	tified during the vi	sit should be
Sectio	n 1 – Cigarette smoking, alcoh	ol, and substar	nce use			
Cigare	tte smoking					
1a.	Has the participant smoked <u>more than</u> in their life — ( <b>IF NO OR UNKNOWN, SKI</b>		[	□o No	□1 Yes	□9 UNK
1b.	Total years smoked (777 = years provide	d at previous UDS v	isit, 99 = Unknown)	)		
1c.	Average number of packs smoked per of	2 ½	igarette to less tha pack to less than 1 pack to less than 1	pack	☐ 4 1½ packs to ☐ 5 2 packs or m ☐ 9 Unknown	•
1d.	Has the participant smoked within the	last 30 days?		□o No	☐1 Yes	☐9 UNK
1e.	If the participant quit smoking, specify (i.e., quit) (777 = age provided at previous	_	•			
Alcoho	ol use					
1f.	In the past 12 months, how often has the had a drink containing alcohol? (IF NEVER OR UNKNOWN, SKIP TO QUES		☐ 0 Never ☐ 1 Monthly or I ☐ 2 2-4 times a r		3 2-3 times a v 4 4 or more tin 9 Unknown	
1g.	On a day when the participant drinks a beverages, how many standard drinks of participant typically consume? ( <b>Standa</b> regular beer, 5oz of wine, 1.5oz of distilled	does the I <b>rd drink:</b> 120z of	1 1 or 2 2 3 to 4 3 5 to 6		4 7 to 9 5 10 or more Unknown	
1h.	In the past 12 months, how often did the have six or more drinks containing alco	- 1 1	□ 0 Never □ 1 Less than on □ 2 Monthly		3 Weekly 4 Daily or almo 9 Unknown	st daily
Substa	ance use					
1i.	Has the participant used substances incor more of the following areas: work, di	• • • • • • • • • • • • • • • • • • • •		Irugs that cau	sed significant im	pairment in one
	Ii1. Within the past 12 months			□o No	□1 Yes	□9 UNK
	ii2. Prior to 12 months ago		_	□o No	□1 Yes	□9 UNK
1j.	In the past 12 months, how often has the consumed cannabis (edibles, smoked, or		□ 0 Never □ 1 Monthly or I □ 2 2-4 times a r	ess	3 2-3 times a v 4 4 or more tin 9 Unknown	veek

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Participant ID:	Form date:	/ /	Visit #:
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In the following sections (pages 2-7) record the presence or absence of a <u>history of these conditions</u>, 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 COND	ITION SHOULD BE CONSID	ERED				
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 (more than one year ago) but was resolved or there is no treatment currently under way.		There is insufficient information available to assess this condition.		
Section	on 2 – Cardiovascul	ar disease				
			ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
2a.		ery blockage) — NN, SKIP TO QUESTION 2b)	О	<b>□</b> 1	_2	<u></u> 9
:	<b>2a1.</b> More than one hea	art attack?		□o No	□1 Yes	☐9 UNK
2	2a2. Age at most recent	t heart attack (777 = age provided a	at previous UDS vi	sit, 999 = Unknow	n)	
2b.	Cardiac arrest (heart sto	opped) — NN, SKIP TO QUESTION 2c)	О	□ 1	<u></u>	9
2	<b>2b1.</b> Age at most recent	t cardiac arrest (777 = age provided	d at previous UDS	visit, 999 = Unkno	wn)	
2c.	Atrial fibrillation		О	□1	<u>2</u>	<u> </u>
2d.	Coronary artery angion stenting	olasty / endarterectomy /	О	□ 1	<b>□</b> <sub>2</sub>	<u> </u>
2e.	, , , , ,	s procedure — WN, SKIP TO QUESTION 2f)	О	<b>□</b> 1	<b>□</b> 2	<u> </u>
2e1. Age at most recent surgery (777 = age provided at previous UDS visit, 999 = Unknown)						
2f.	Pacemaker and/or defi	О	□ <sub>1</sub>	$\square_2$	<u></u> 9	
	<b>2f1.</b> Age at first implan	tation (777 = age provided at previ	ous UDS visit, 999	= Unknown)		
2g.	Congestive heart failur	e (including pulmonary edema)	О	<b>□</b> 1	$\square_2$	<u></u> 9
2h.	Heart valve replacement (IF ABSENT OR UNKNOW	nt or repair — WN, SKIP TO QUESTION 2i)	О	□ <sub>1</sub>	<b>□</b> <sub>2</sub>	<u> </u>
2	<b>2h1.</b> Age at most recent	t procedure (777 = age provided at	previous UDS visi	t, 999 = Unknown)		
2i.	Other cardiovascular d	isease ( <b>SPECIFY):</b>	О	<b>□</b> 1	$\square_2$	<u> </u>
Section	on 3 – Cerebrovascı	ular disease				
			ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
3a.		xam (imaging is not required) — NN, SKIP TO QUESTION 3b)	О	<u> </u>	_2	<u> </u>
3	<b>3a1.</b> More than one stro	oke?		□o No	□1 Yes	□9 UNK
3	<b>3a2.</b> Age at most recent	t stroke (777 = age provided at prev	vious UDS visit, 99	9 = Unknown)		
			NEVER IMPROVED	PARTIALLY IMPROVED	IMPROVED / BACK TO NORMAL	UNKNOWN
3	<b>3a3.</b> What is the status	of stroke symptoms?	o	□ <sub>1</sub>	□ <sub>2</sub>	<u></u> 9

Section	on 3	- Cerebrovascular disease					continued
:	3a4.	Carotid artery surgery or stenting? (IF NO OR UNKNOWN, SKIP TO QUESTION 3b)	<b>)</b>		□o No	□1 Yes	□9 UNK
	3a5.	Age at most recent carotid artery surgery o (777 = age provided at previous UDS visit, 999)	_	vn)			
				ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
3b.		nsient ischemic attack (TIA) — ABSENT OR UNKNOWN, SKIP TO QUESTION 4a	a)	О	<b>□</b> 1	_2	<u></u> 9
:	3b1.	Age at most recent TIA (777 = age provided	at previou	s UDS visit, 999 =	Unknown)		
Section	on 4	- Neurologic conditions					
						REMOTE/	
4-	D	diana, diana, (DD)		ABSENT	RECENT/ACTIVE	INACTIVE	UNKNOWN
4a.		kinson's disease (PD) — ABSENT OR UNKNOWN, SKIP TO QUESTION 4Ł	<b>o</b> )	О	□1		<u></u> 9
•	4a1.	Age at estimated PD symptom onset (777 =	= age provi	ded at previous U	DS visit, 999 = Unk	nown)	
4b.		ner parkinsonism disorder (e.g., DLB) — ABSENT OR UNKNOWN, SKIP TO QUESTION 40	:)	О	<u> </u>		<u> </u>
4	4b1.	Age at parkinsonism disorder diagnosis (77	77 = age pr	ovided at previou	s UDS visit, 999 = U	Inknown)	
4c.	feb (IF	lepsy and/or history of seizures (excluding cl orile seizures) — REMOTE/INACTIVE, SKIP TO QUESTION 4c2, IF UNKNOWN, SKIP TO QUESTION 4d)		□0	<b>□</b> 1		<u></u> 9
	4c1.	How many seizures has the participant had past 12 months?	in the	□ 0 None □ 1 1 or 2 □ 2 3 or more □ 9 Unknown			
	4c2.	Age at first seizure (excluding childhood fel (777 = age provided at previous UDS visit, 999)					
4d.	Ch	ronic headaches		□ <sub>0</sub>	□1	$\square_2$	<u></u> 9
4e.	Mu	Itiple sclerosis		□ <sub>0</sub>	□1	2	<u></u> 9
4f.	No	rmal–pressure hydrocephalus		□ <sub>0</sub>		$\square_2$	<u></u> 9
<b>4</b> g.	vio	petitive head impacts (e.g. from contact spor lence, or military duty), regardless of whethe NO OR UNKNOWN, SKIP TO QUESTION 4h)			□o No	□1 Yes	☐9 UNK
•	4g1.	Indicate the source(s) of exposure for repeated hits to the head: (Check all that apply)	4g1a. 4g1b. 4g1c. 4g1d. 4g1e. 4g1f. 4g1g. 4g1h. 4g1i.	1 American f 1 Soccer 1 Ice hockey 1 Boxing or r 1 Other cont 1 Intimate pa 1 Military ser 1 Physical ass	mixed martial arts cact sport ortner violence vice sault		
	4g2.	Indicate the total length of time in years the repeated hits to the head (e.g. playing Ame (777 = years provided at previous UDS visit, 9	erican footl	ball for 7 years)	osed to		

\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #: \_

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Section 4	- Neurologic conditions					continued
or i "da: (if i	ad injury (e.g. in a vehicle accident, being hit by a biking, in an assault, or during military service) th zed or confused," being unable to recall details multiple head injuries, consider most severe episo NO OR UNKNOWN, SKIP TO QUESTION 5a)	at result of the ir	ed in a period o	f feeling	□0 No □1 Y	es □9 UNK
4h1.	After a head injury, what was the longest period of time that the participant was unconscious?  O Less than 5 minutes  1 5 minutes to less than 30 minutes  2 30 minutes to less than 24 hours  3 1 day to less than 7 days  U 7 days or more  8 Not applicable, no loss of consciousness  9 Unknown duration					e, no loss of
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?	1 5 r 2 30	ss than 5 minutes ninutes to less th minutes to less t lay to less than 7	an 30 minutes han 24 hours	4 7 days or more 8 Not applicable and confused 9 Unknown dura	e, never dazed
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?	0 No	2		3 6-12 4 13 or more 9 Unknown	
4h4.	Age of <u>first</u> head injury that resulted in a period being unable to recall details of the injury, or (777 = age provided at previous UDS visit, 999 =	loss of c	onsciousness:	onfused,"		
4h5.	Age of most recent head injury that resulted i confused," being unable to recall details of the (777 = age provided at previous UDS visit, 999 =	injury,	or loss of consci			
Section 5	- Medical conditions					
	If any of the conditions still require active man	nageme	nt and/or medic	ations, please se	elect " <b>Recent / Act</b>	ive."
			ABSENT	RECENT/ACTIV	REMOTE/ E INACTIVE	UNKNOWN
<b>5a.</b> Dia	abetes — (IF ABSENT OR UNKNOWN, SKIP TO QUESTION	N 5B)	По	<b>□</b> 1	<b>□</b> 2	<u></u> 9
5a1.	Which type?			ional diabetes, pi	atent autoimmune ediabetes)	diabetes/type
5a2.					tor agonist	
5a3.	Age at diabetes diagnosis (777 = age provided	d at prev	ious UDS visit, 99	99 = Unknown)		
(IF	pertension (or taking medication for hypertensic ABSENT OR UNKNOWN, SKIP TO QUESTION 5c)		□ o	□ 1	□ <sub>2</sub>	<u></u> 9
	Age at hypertension diagnosis (777 = age prov		previous UDS visi	it, 999 = Unknov	vn)	
cho	percholesterolemia (or taking medication for higolesterol) — ABSENT OR UNKNOWN, SKIP TO QUESTION 5d)	gn	□ o	<b>□</b> 1	$\square_2$	<u></u> 9
	Age at hypercholesterolemia diagnosis (777 :	= age pro	ovided at previou	_	= Unknown)	
	2 deficiency		o	<u></u> 1		<u></u> 9
5e. Thy	yroid disease		0	□1	<u></u>	<u></u> 9
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\_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Visit #: \_

Participant ID: \_\_\_

Participant ID:	Form date:	/	Visit #:

Section	on 5	- Medical conditions					continued
			ABS	SENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
5f.		hritis — ABSENT OR UNKNOWN, SKIP TO QUESTION 5g)		]0	□ 1	□ 2	9
	5f1.	Type of arthritis (Check all that apply)	5f1a. 5f1b. 5f1c. 5f1d.	1 Os	neumatoid steoarthritis ther ( <b>SPECIFY):</b> _ nknown		
	5f2.	Regions affected (Check all that apply)	5f2a. 5f2b. 5f2c. 5f2d.	□1 Lc	oper extremity ower extremity oine nknown		
5g.	Inc	ontinence — urinary (occurring at least weekly)		]0	<u></u> 1	2	<u>9</u>
5h.	Inc	ontinence — bowel (occurring at least weekly)		]0	_1	2	<u></u> 9
5i.		ep apnea — (IF ABSENT, REMOTE/INACTIVE, OR KNOWN, SKIP TO QUESTION 5j)		]0	□ 1	□ <sub>2</sub>	<u>9</u>
	5i1.	Typical use of breathing machine (e.g. CPAP) at night over the past 12 months	<u>2</u> >	4 hours p	oer night oer night		
	5i2.	Typical use of an oral device or implanted breathing pacemaker for sleep apnea at night over the past 12 months?	<u>2</u> >	4 hours p	oer night oer night		
5j.	RE	N sleep behavior disorder (RBD)		]0	<u> </u>	_2	<u> </u>
5k.		posomnia/Insomnia (occurring at least weekly or uiring medication)		]0	□ 1	_2	<u></u> 9
5l.	Otł	ner sleep disorder (SPECIFY):		]0	<u> </u>	2	<u>9</u>
5m.	(Re	ncer, primary or metastatic — port all known diagnoses. Exclude non-melanoma skin ncer. IF ABSENT OR UNKNOWN, SKIP TO QUESTION 5n)		]0	<b>□</b> 1	<b>□</b> 2	<u></u> 9
5	m1.	Type of cancer	5m1a. 5m1b. 5m1c.	□1 M 5r	imary/non-metas etastatic (CHECK A n1b1.	ALL THAT APPLY) tatic to brain	er than brain
		Primary site of cancer: (Check all that apply)	5m2a.				
5	m3.	Type of cancer treatment (Check all that apply)	5m3a. 5m3b. 5m3c. 5m3d. 5m3e. 5m3f. 5m3g.	1 Su   1 Im   1 Bo	adiation urgical Resection nmunotherapy one marrow transp nemotherapy ormone therapy ther (SPECIFY):	plant	
5	m4.	Age at most recent cancer diagnosis (777 = age provi	ded at pı			nown)	

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Participa	ant iL	rorm date:	/ /	V	SIT #:	
Section	on 5	– Medical conditions				continued
			ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
5n.		VID-19 infection — ABSENT OR UNKNOWN, SKIP TO QUESTION 50)	□ <sub>0</sub>	□ 1	$\square_2$	<u>9</u>
5	in1.	Requiring hospitalization?		□o No	□1 Yes	□9 UNK
50.	Ast	hma/COPD/pulmonary disease	□0	□1	$\square_2$	<u>_</u> 9
5p.		onic kidney disease — ABSENT OR UNKNOWN, SKIP TO QUESTION 5q)	□ <sub>0</sub>	□ 1	$\square_2$	<u> </u>
5	р1.	Age at diagnosis (777 = age provided at previous UDS	visit, 999 = Unkno	own)		
5q.		er disease — ABSENT OR UNKNOWN, SKIP TO QUESTION 5r)	□ <sub>0</sub>	□ 1	<u>2</u>	<u> </u>
		Age at diagnosis (777 = age provided at previous UDS	visit, 999 = Unkno	own)		
5r.		ipheral vascular disease —  ABSENT OR UNKNOWN, SKIP TO QUESTION 5s)	□ <sub>0</sub>	□ 1	2	<u> </u>
	5r1.	Age at diagnosis (777 = age provided at previous UDS	visit, 999 = Unkno	own)		
5s.		man Immunodeficiency Virus (HIV) —  ABSENT OR UNKNOWN, SKIP TO QUESTION 5t)	□0	□ 1	2	<u></u> 9
!	5s1.	Age at diagnosis (777 = age provided at previous UDS	visit, 999 = Unkno	own)		
5t.		ner medical conditions or procedures  ECIFY):	□ <sub>0</sub>	□ 1	$\square_2$	<u></u> 9
Section	on 6	- Psychiatric conditions				
		liagnose a disorder, <b>DSM-5-TR criteria require</b> that sy II, or other important areas of functioning. For more gu				
		,,	ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
6a.	De	pressive disorder				
•	5a1.	Major depressive disorder (DSM-5-TR criteria*)	О	□ 1	2	<u></u> 9
(	5a2.	Other specified depressive disorder (DSM-5-TR criteria*)	□0	□1	$\square_2$	<u></u> 9
(	5a3.	If Recent/Active depressive disorder (Q6a1 or Q6a2), choose if treated or untreated.	0 Untreated 1 Treated wi	th medication and	l/or counseling	
6b.	Bip	olar disorder (DSM-5-TR criteria*)	О	□1	$\square_2$	<u></u> 9
6с.		nizophrenia or other psychosis disorder (DSM-5-TR eria*)	□ <sub>0</sub>	<b>□</b> 1	$\square_2$	<u></u> 9
6d.		kiety disorder (DSM-5-TR criteria*) ABSENT OR UNKNOWN, SKIP TO QUESTION 6e)	По	□ 1	□ 2	<u>9</u>
e	id1.	Generalized Anxiety Disorder	□ <sub>0</sub>	□ <sub>1</sub>	$\square_2$	<b>□</b> 9
e	id2.	Panic Disorder	$\square_0$	<b>□</b> 1	$\square_2$	<u>9</u>
e	id3.	Obsessive-compulsive disorder (OCD)	□ <sub>0</sub>	□ <sub>1</sub>	$\square_2$	<b>□</b> 9
e	id4.	Other (SPECIFY):	□ <sub>0</sub>	□ <sub>1</sub>	$\square_2$	<b>□</b> 9
6e.		st-traumatic stress disorder (PTSD) (DSM-5-TR eria*)	О	□ 1	<b>□</b> 2	<u></u> 9

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Participa	int ID:	Fo	rm date:	//_	v	isit #:	
Section	on 6 – Psychia	tric conditions					continued
				ABSENT	RECENT/ACTIVE	REMOTE/ INACTIVE	UNKNOWN
6f.	•	neuropsychiatric disord er [ASD], attention-defici dyslexia)	•	О		$\square_2$	<u></u> 9
6g.	Other psychiatri	c disorders		□0	<b>□</b> 1	□ <sub>2</sub>	<u></u> 9
Section	n 7 – Menstru	ual and reproduct	ive health				
If questi	ons about menstr	ual and reproductive hed	alth are relevant to	this participant, co	ontinue to questio	n 7a. Otherwise, <b>E</b>	ND FORM HERE.
7a.	(777 = age provid	e participant when they ded at previous UDS visit RUATING, SKIP TO QUES	, 888 = Still menstr		nown)		
7b.	b. If the participant has stopped having menstrual periods, please indicate the reason.  (Check all that apply)  7b1.				HRT)		
7c.		ant taken female horm (IF NO OR UNKNOWN, S			□o No	☐1 Yes	☐9 UNK
7	7c1. How many (777 = years	years in total?  provided at previous UE	OS visit, 999 = Unkn	own)			
7	7c2. Age at first (	use rovided at previous UDS	visit, 999 = Unkno	wn)			
7	<b>7c3.</b> Age at last u	•		•	= Unknown)		
7d.	Has the particip	ant ever taken birth cor OWN, END FORM HERE)			□o No	□1 Yes	□9 UNK
7	d1. How many		OS visit, 999 = Unkn	own)			
7	'd2. Age at first i	•					
7	'd3. Age at last u	use rovided at previous UDS	visit. 888= Still pre	esently using, 999	= Unknown)		



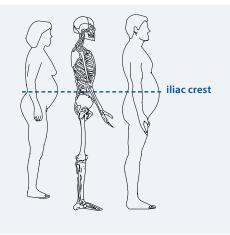
## Form B1: EVALUATION FORM – Vital Signs and Anthropometrics

ADRC:	PTID:	Form date:	/	/isit #: initials:
Language:	Mode:	Key (not completed reason):	94=Remote Visit	
□₁ English	□ 1 In-person		95=Physical problem	
☐2 Spanish	□ o Not completed (reason):		96=Cognitive/behavioral problem	
			97=Other	
			98=Verbal refusal	

**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**, Form **B1**.

## Section 1 - Participant vital signs and anthropometrics 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 (in	iches):	
	Measurement 1		(888 = not assessed)
	Measurement 2		(888 = not assessed)

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Sec	tion 1 – Participant vital sign:	s and anthropometrics		continued
5.	Enter two readings spaced at least or See detailed instructions below.	ne minute apart for each arm.		
	5a. Participant blood pressure - Left	: arm:		
	Reading 1	/	(888/888= not assessed)	
	Reading 2	/	(888/888= not assessed)	
	<b>5b.</b> Participant blood pressure - <b>Rig</b> l	ht arm:		
	Reading 1	/	(888/888= not assessed)	
	Reading 2	/	(888/888= not assessed)	
6.	Participant resting heart rate (pulse)		(888 = not assessed)	

Visit #:

### Steps for proper blood pressure measurement

### **STEP 1** - Properly prepare the participant:

Participant ID:

- 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.

Form date:

- 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
- 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.

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

ADRC:	PTID:	Form date: _	//	Visit #:	initials:
Language: Mode:  □ 1 English □ 1 In-perso  □ 2 Spanish □ 0 Not com	n ppleted ( <i>reason):</i>	Key (not completed reason):	94=Remote visit 95=Physical problem 96=Cognitive/behavio	oral problem	
			97=Other 98=Verbal refusal		
administered to <u>all</u> partice contributions or explanat track the degree of parkin additional clarification ar For video-recorded ex	ipants. Clinician should ions for the findings. The isonism over time. The U nd scoring instructions, s amples of administra	the clinician or other trained record results as observed re is form is intended to 1) dete IPDRS is not intended to estable EUDS Coding Guideboottion, see Perlmutter JS. A Unit10.1. doi: 10.1002/04	gardless of whether rmine the degree of p blish the presence of bk, Form B3. Check of ssessment of Park	there are non-poarkinsonism o r absence of pa only <u>one</u> box pe <b>cinson disease</b>	parkinsonian on any visit, and 2) rkinsonism. For er question.
1 1 1 -	<b>clinician completes th</b> ed, all items will default	ne <b>UPDRS examination and</b> to 0 in the database.	d determines all ite	ems are norma	al, check this box. If
1. Speech	2 Monotone, slurre	ression, diction and/or volued but understandable; modent, difficult to understand.			
2 Slight but defini 3 Moderate hypor		mia, could be normal "poker ely abnormal diminution of himia; lips parted some of th acies with severe or comple (IFY):	facial expression e time	ession; lips par	rted ¼ inches or more
3. Tremor at rest					
3a. Face, lips, chin	3 Moderate in amp	e and persistent; or modera ditude and present most of ude and present most of th	the time	only intermitte	ently present
3b. Right hand	3 Moderate in amp	uently present e and persistent; or modera olitude and present most of ude and present most of th (IFY):	the time	only intermitte	ently present
3c. Left hand	3 Moderate in amp	uently present e and persistent; or modera ditude and present most of ude and present most of th	the time	only intermitte	ently present

1-Fahn 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.

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3. Tremor at rest	continued
3d. Right foot	<ul> <li>Absent</li> <li>Slight and infrequently present</li> <li>Mild in amplitude and persistent; or moderate in amplitude, but only intermittently present</li> <li>Moderate in amplitude and present most of the time</li> <li>Marked in amplitude and present most of the time</li> <li>Untestable (SPECIFY):</li> </ul>
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 Untestable (SPECIFY):
4. Action or post	tural tremor of hands
4a. Right hand	<ul> <li>Absent</li> <li>1 Slight; present with action</li> <li>2 Moderate in amplitude, present with action</li> <li>3 Moderate in amplitude with posture holding as well as action</li> <li>4 Marked in amplitude; interferes with feeding</li> <li>8 Untestable (SPECIFY):</li></ul>
4b. Left hand	<ul> <li>O Absent</li> <li>1 Slight; present with action</li> <li>2 Moderate in amplitude, present with action</li> <li>3 Moderate in amplitude with posture holding as well as action</li> <li>4 Marked in amplitude; interferes with feeding</li> <li>8 Untestable (SPECIFY):</li></ul>
<b>5. Rigidity</b> (judged on passive m	ovement 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 Untestable (SPECIFY):
5b. Right upper extremity	<ul> <li>Absent</li> <li>Slight or detectable only when activated by mirror or other movements</li> <li>Mild to moderate</li> <li>Marked, but full range of motion easily achieved</li> <li>Severe; range of motion achieved with difficulty</li> <li>Untestable (SPECIFY):</li> </ul>
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 Untestable (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 Untestable (SPECIFY):

Form date: \_\_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #:

Participant ID:

<b>5. Rigidity</b> (judged on passive move	<b>continued</b> ment of major joints with participant relaxed in sitting position; cogwheeling to be ignored)
5e. Left lower extremity	<ul> <li>Absent</li> <li>Slight or detectable only when activated by mirror or other movements</li> <li>Mild to moderate</li> <li>Marked, but full range of motion easily achieved</li> <li>Severe; range of motion achieved with difficulty</li> <li>Untestable (SPECIFY):</li></ul>
6. Finger taps (participant taps thumb	with index finger in rapid succession)
6a. Right hand	o Normal  Mild slowing and/or reduction in amplitude  Moderately impaired; definite and early fatiguing; may have occasional arrests in movement  Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement  Can barely perform the task.  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 movement	closes hands in rapid succession)
7a. Right hand	O Normal  I Mild slowing and/or reduction in amplitude  Moderately impaired; definite and early fatiguing; may have occasional arrests in movement  Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement  Can barely perform the task.  B 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):
•	g movements of hands ovements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously)
8a. Right hand	o Normal  Mild slowing and/or reduction in amplitude  Moderately impaired; definite and early fatiguing; may have occasional arrests in movement  Severely impaired; frequent hesitation in initiating movements or arrests in ongoing movement  Can barely perform the task.  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):

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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)	O 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	<ul> <li>Normal</li> <li>1 Walks slowly; may shuffle with short steps, but no festination (hastening steps) or propulsion</li> <li>2 Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion</li> <li>3 Severe disturbance of gait requiring assistance</li> <li>4 Cannot walk at all, even with assistance</li> <li>8 Untestable (SPECIFY):</li> </ul>
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 chec "8=Untestable", enter 888)	cked (0-108, 888)

Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Visit #:

Participant ID:



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

ADRC:	PTID:	Form date://	Visit #:	initials:
Language:  1 English 2 Spanish	Mode:  1 In-person 2 Remote (reason): 1 Telephone 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 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**, Form **B4**.

### Section 1 - CDR® Dementia Staging Instrument<sup>1</sup>

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	Fully capable o	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	7. CDR Sum of Boxes 8. Global CDR					

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

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Participant ID:	Form date: /	/	Visit #:

## Section 2 - NACC FTLD Behavior & Language Domains

Impairment	Impairment						
Please enter scores (below): None = 0		Questionable = 0.5	Mild = 1	Moderate = 2	Severe = 3		
9. Behavior, Comportment, & Personality <sup>2</sup>	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. Language <sup>3</sup>	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		

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<sup>&</sup>lt;sup>2</sup>Excerpted from the Frontotemporal Dementia Multicenter Instrument & MR Study (Mayo Clinic, UCSF, UCLA, UW).
<sup>3</sup>Excerpted 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),



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

Language:       ☐ Mode:       Key (remote reason): 1=Too cognitively impaired       Key (not completed reason): 95=Physical problem         ☐ English       ☐ In-person       2=Too physically impaired       95=Physical problem         ☐ 2 Spanish       ☐ Remote (reason):       3=Homebound or nursing home       96=Cognitive/behavioral problem							
□ 1 Telephone □ 2 Video □ 0 Not completed (reason): □ 5=Other 97=Other 98=Verbal refusal	95=Physical problem 96=Cognitive/behavioral problem 97=Other						
<b>INSTRUCTIONS</b> : 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 <b>UDS Coding Guidebook</b> , <b>Form B5</b> . Check only one box for each category of response.							
Please answer the following questions based on <u>changes</u> that have occurred since the participant first began to experience memory (i.e., cognitive) problems. <b>Select 1=Yes <u>only</u> if the symptom(s) has been present <u>in the last month</u>. <b>Otherwise, select 0=No.</b> (NOTE: for the UDS, please administer the NPI-Q to all participants.)  For each item marked <b>1=Yes</b>, rate the SEVERITY of the symptom (how it affects the participant):</b>							
1= <b>Mild</b> (noticeable, but not a significant change) 2= <b>Moderate</b> (significant, but not a dramatic change) 3= <b>Severe</b> (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 U	Jnk						
<ul> <li>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?</li> <li>2a. □1 □0 □9</li> <li>2b. □1 □2 □3 □</li> </ul>	□ <sub>9</sub>						
<ul> <li>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?</li> <li>3a. □ 1 □ 0 □ 9</li> <li>3b. □ 1 □ 2 □ 3</li> </ul>	<u></u> 9						
4. Agitation/Aggression – Is the patient resistive to help from others at times, or hard to handle?  4a.   1  0  9  4b.  1  2  3  5	]9						
5. Depression/Dysphoria – Does the patient seem sad or say that he/she is depressed?  5a.   1  0  9  5b.  1  2  3  5	<u></u> 9						
<ul> <li>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? </li> <li>6a. □ 1 □ 0 □ 9</li> <li>6b. □ 1 □ 2 □ 3 □</li> </ul>	<u></u> 9						
7. Elation/Euphoria – Does the patient appear to feel too good or act excessively happy?  7a.   1  0  9  7b.  1  2  3	<u></u> 9						
usual activities or in the activities and plans of others?	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. 1 0 9 9b. 1 2 3 1 1 2 3 5	<u> </u>						
10. Irritability/Lability – Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?  10a.   10b.   10b.   10c.   1	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.   1   0  9  11b.  1  2  3  5	<u></u> 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.   12a.   10  10  10  10  11  10  10  11  10  10	9						
13. Appetite/Eating – Has the patient lost or gained weight, or had a change in the type of food he/she likes?  13a.   13a.   13b.   15b.   17c.   18c.   18	<u></u> 9						
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## Form B6: BEHAVIORAL ASSESSMENT — Geriatric Depression Scale (GDS)<sup>1</sup>

ADRC: _	PTID:	Form date://	Visit #:	initials:				
Langua □ 1 End □ 2 Sp	sh □ 1 In-person 2=Too physically impaired sh □ 2 Remote (reason): 3=Homebound or nursing home □ 1 Telephone □ 2 Video 4=Refused in-person visit		Key (not completed reason):  95=Physical problem  96=Cognitive/behavioral problem  97=Other  98=Verbal refusal					
	<b>INSTRUCTIONS</b> : This form is to be completed by the clinician or other trained health professional, based on participant response. For additional clarification and examples, see <b>UDS Coding Guidebook, Form B6</b> . Check only <u>one</u> answer per question.							
	Check this box and enter "88" below for to 2.) answers fewer than 12 questions.	ne Total GDS Score <b>if and only if the participant:</b>	1.) does not	attempt the	GDS, or			
ask yc		s interview, I will ask you questions about your feel I feel uncomfortable. For each question, please ans I <b>cluding today</b> ."						
			Yes	No	Did not answer			
1.	Are you basically satisfied with your life?		□ <sub>0</sub>	<b>□</b> 1	<u></u> 9			
2.	Have you dropped many of your activitie	□1	О	<u></u> 9				
3.	Do you feel that your life is empty?		<b>□</b> 1	□ <sub>0</sub>	<u></u> 9			
4.	Do you often get bored?			□ <sub>0</sub>	<u></u> 9			
5.	Are you in good spirits most of the time?	□0	□ <sub>1</sub>	<u>9</u>				
6.	Are you afraid that something bad is goin	ng to happen to you?	<b>□</b> 1	□ <sub>0</sub>	<u></u> 9			
7.	Do you feel happy most of the time?		□ <sub>0</sub>	□ <sub>1</sub>	<b>□</b> 9			
8.	Do you often feel helpless?		□1	$\square_0$	<u></u> 9			
9.	Do you prefer to stay at home, rather tha	n going out and doing new things?	<b>□</b> 1	□ <sub>0</sub>	<b>□</b> 9			
10.	Do you feel you have more problems wit	h memory than most?	□1	□ <sub>0</sub>	<u></u> 9			
11.	Do you think it is wonderful to be alive n	ow?	□ <sub>0</sub>	□ <sub>1</sub>	<b>□</b> 9			
12.	Do you feel pretty worthless the way you	□1	□ <sub>0</sub>	<u></u> 9				
13.	Do you feel full of energy?		□ <sub>0</sub>	□1	<b>□</b> 9			
14.	Do you feel that your situation is hopeles	s?	□1	О	<u></u> 9			
15.	Do you think that most people are better	off than you are?	<b>□</b> 1	□ <sub>0</sub>	<b>□</b> 9			
16.	Sum all checked answers for a Total GDS	Score (max score = 15; did not complete = 88)						

15heikh Jl, 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.

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## Form B7: FUNCTIONAL ASSESSMENT - NACC Functional Assessment Scale (FAS1)

ADRC:	PTID:	Form date://	Examiner's Visit #: initials:
Language:	Mode:	Key (remote reason): 1=Too cognitively impaired	Key (not completed reason):
□1 English	□1 In-person	2=Too physically impaired	95=Physical problem
☐2 Spanish	☐ 2 Remote (reason):	3=Homebound or nursing home	96=Cognitive/behavioral problem
	☐1 Telephone ☐2 Video	4=Refused in-person visit	97=Other
	□ o Not completed (reason):	5=Other	98=Verbal refusal

**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, 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	□8	□o	<b>□</b> 1	<u></u>	<b>□</b> 3	<u></u> 9
2. Assembling tax records, business affairs, or other papers	□8	О	<b>□</b> 1	<u></u>	□ 3	<u></u> 9
3. Shopping alone for clothes, household necessities, or groceries	□8	□ <sub>0</sub>	<b>□</b> 1	<b>□</b> 2	<b>□</b> 3	<u></u> 9
4. Playing a game of skill such as bridge or chess, working on a hobby	□8	□0	<b>□</b> 1	□ <sub>2</sub>	□ 3	<u></u> 9
5. Heating water, making a cup of coffee, turning off the stove	□8	О	<b>□</b> 1	<u></u>	<b>□</b> 3	<u></u> 9
6. Preparing a balanced meal	□8	О	<u> </u>	2	□ 3	<u> </u>
7. Keeping track of current events	□8	О	<u> </u>	2	Пз	<u> </u>
8. Paying attention to and understanding a TV program, book, or magazine	□8	О	□ 1	□ <sub>2</sub>	□ 3	<u> </u>
9. Remembering appointments, family occasions, holidays, medications	□8	□o	<b>□</b> 1	□ <sub>2</sub>	<b>□</b> 3	<b>□</b> 9
10. Traveling out of the neighborhood, driving, or arranging to take public transportation	□8	□о	□ 1	□2	□3	<u> </u>

'Adapted 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®  $1982. \, The \, Gerontological \, Society \, of \, America. \, Reproduced \, by \, permission \, of \, the \, publisher. \,$ 

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# **Form B8: EVALUATION FORM** – Neurological Examination Findings

ADRC:	PTID:	Forr	n date:/	'/	Visit #:	initia	ls:
Language □1 Englis □2 Spani	sh 🔲 1 In-person	Key (remote reason	2=Too physic 3=Homebou	tively impaired cally impaired ınd or nursing h n-person visit			
assessing experien present.	CTIONS: This form should be completed by a g the presence/absence of neurological signs ace in completing each of the assessment me. For additional clarification and examples,	, and rating the deg asures associated v see <b>UDS Coding C</b>	gree of any al vith the gatev	bnormalities. way question	Additionally, t s if any key neu	he clinician sh ırologic findin	ould have gs are
Sectio	on 1 – Examiner & examination qu	iestions					
	Vhich of the following was completed on  10 No neurologic examination (END FORM)  11 Comprehensive neurologic examinatio  12 Focused or partial neurologic examinat  13 Focused or partial neurologic examinat	HERE)  n as suggested in tion performed in-	person	ling Guidebo	ook		
	Vere there abnormal neurological exam fi  0 No abnormal findings (END FORM HER  1 Yes	_	d, all items wil	l default to 0 =	Absent in the da	tabase)	
Sectio	n 2 – Specific clinical findings						
Section	on 2A – Parkinsonian signs						
A	0 No abnormal signs in this section are p bsent in the database)  1 Yes (IF YES – complete questions 3a–3n and 8 Not assessed (SKIP TO SECTION 2B; If this	consider completing	additional med	asures as descr	ibed on page 3)		
FINDIN	NG:		Absent	Focal or Unilateral	Bilateral & Largely Symmetric	Bilateral & Largely Asymmetric	Not Assessed
3a.	Slowing of fine motor movements		О	□ 1	$\square_2$	Пз	□8
3b.	Limb tremor at rest		О	□ 1	$\square_2$	<b>□</b> 3	□8
3c.	Limb tremor - postural		О	□ 1	$\square_2$	<b>□</b> <sub>3</sub>	□8
3d.	Limb tremor - kinetic		О	□ 1	$\square_2$	<b>□</b> 3	□8
3e.	Limb rigidity - arm		О	□ 1	$\square_2$	□ 3	□8
3f.	Limb rigidity - leg		О	□ 1	_2	<u></u> 3	<b>□</b> 8
3g.	Limb dystonia - arm		О	□ 1	<u></u>	<b>□</b> 3	□8
3h.	Limb dystonia - leg		О	□ 1	<u></u>	<b>□</b> 3	<b>□</b> 8
3i.	Chorea		О	□ 1	$\square_2$	□3	□8

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Section	on 2 – Specific clinical findings					continued
Section	on 2A – Parkinsonian signs					
FINDII	NG:			Absent	Present	Not Assessed
3j.	Decrement in amplitude of fine motor movements			О	□ <sub>1</sub>	
3k.	Axial rigidity			О	□ 1	□8
31.	Postural instability			О	<u> </u>	8
3m.	Facial masking			□ <sub>0</sub>	□ 1	□8
3n.	Stooped posture			О	□ 1	8
Section 2B – Cortical/pyramidal/other signs						
4. [	4. O 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)					ult to
1 Yes ( <b>IF YES</b> – complete questions 4a–4q and consider completing additional measures as described on page 3)						
L	8 Not assessed ( <b>SKIP TO SECTION 2C;</b> If this box is checked, Q4a through Q4q will default to 8 = Not Assessed in the database)  Bilateral Bilateral					
FINDII	NG:	Absent	Focal or Unilateral	& Largely Symmetric	& Largely Asymmetric	Not Assessed
4a.	Limb apraxia	О	<b>□</b> 1	2	<u></u>	□8
4b.	Face or limb findings in UMN distribution*	□0	□ 1	$\square_2$	Пз	□8
4c.	Face or limb findings in an LMN distribution*	□ <sub>0</sub>	<b>□</b> 1	2	Пз	□8
4d.	Visual field cut	О	<b>□</b> 1	$\square_2$	Пз	□8
4e.	Limb ataxia	По	<b>□</b> 1	$\square_2$	<b>□</b> 3	<u></u> 8
4f.	Myoclonus	По	□ <sub>1</sub>	$\square_2$	<b>□</b> 3	□8
FINDII	NG:			Absent	Present	Not Assessed
4g.	<b>Unilateral Somatosensory loss</b> (localized to the brain; disregard to the spinal cord or peripheral nerves)	sensory chan	ges localized	□ <sub>0</sub>	<b>□</b> 1	□8
4h.	Aphasia (disregard complaints of mild dysnomia if not viewed as reflecting a	clinically signific	cant change)	О	□ 1	□8
4i.	Alien limb phenomenon			□o	□ 1	8
4j.	Hemispatial neglect			О	□ 1	8
4k.	Prosopagnosia			О	□ 1	8
41.	Simultanagnosia			О	□ 1	8
4m.	Optic ataxia			О	□ <sub>1</sub>	□8
4n.	Apraxia of gaze			□ <sub>0</sub>	□ <sub>1</sub>	□8
40.	Vertical +/- horizontal gaze palsy**			□ <sub>0</sub>	□ <sub>1</sub>	□8
4p.	Dysarthria*			О	□ 1	□8
4q.	Apraxia of speech			О	□ <sub>1</sub>	□8
*UMN fin	dings could include weakness in a pyradmidal pattern, hyper-re	eflexia, Babin	ski or Hoffma	ın sign present,	or spasticity;	

Form date: \_

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

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Participant ID:

Visit #:

<sup>\*</sup>UMN findings could include weakness in a pyradmidal 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.

Participant ID: Form date:	/ / Visit #:
Section 2 – Specific clinical findings  Section 2C – Gait	continued
5. O No abnormal signs in this section are present (END FOR 1 Yes (IF YES - complete question 5a and consider completing add 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 <u>several additional clinical measures</u> 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, corticol 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 L	Disease Rating Scale
PCA = Posterior Cortical Atrophy	5
PLS = Primary Lateral Sclerosis	
<b>PSP</b> = Progressive Supranuclear Palsy	
<b>PSPRS</b> = Progressive Supranuclear Palsy Rating Scale	
SMA = Spinal Muscular Atrophy	
UMN = Upper Motor Neuron	
<b>UPDRS</b> = Unified Parkinson's Disease Rating Scale	



## Form B9: Clinician Judgment of Symptoms

ADRC:	PTID:	•	/	Visit #:		kaminer's itials:
	nage: nglish panish □ 1 In-person □ 2 Remote (reason): □ 1 Telephone □ 2 Video	Key (remote reason): 1=Too cognitively ir 2=Too physically im 3=Homebound or n 4=Refused in-perso 5=Other	paired ursing home			
<u>or co</u> estir	RUCTIONS: This form is to be completed by -participant. For all questions the clinician hate when symptoms began based on inform IDS Coding Guidebook, Form B9. Check	must use their best judgment about whe mation from participant and co-particip	ther sympto	ms are pre	sent and	make their
	tion 1 – Changes across domains					
Repo	rted by participant					
1.	Does the <u>participant</u> report a decline in ar baseline prior to onset of current syndrome)		□ 0 No □ 1 Yes			e assessed / impaired
2.	Does the <u>participant</u> report a change in a baseline prior to onset of current syndrome		□0 No □1 Yes			e assessed / impaired
3.	Does the <u>participant</u> report the developm neuropsychiatric/behavioral symptoms (re of current syndrome)?		□0 No □1 Yes			e assessed / impaired
Repo	rted by co–participant					
4.	Does the <u>co-participant</u> report a decline in stable baseline prior to onset of current sync	, -	□0 No □1 Yes	□8 The	ere is no c	o-participant
5.	Does the <u>co-participant</u> report a change in baseline prior to onset of current syndrome)	· · · · · · · · · · · · · · · · · · ·	□0 No □1 Yes	□8 The	ere is no c	o-participant
6.	Does the <u>co-participant</u> report the develoneuropsychiatric/behavioral symptoms (reof current syndrome)?		0 No 1 Yes	□8 The	ere is no c	o-participant
Repo	rted by clinician					
7.	Does the participant have any neuropsych cognitive domains, or changes in any mot		any	□o No □1 Yes		RM HERE)
	e following sections record the phenotypermined by the clinician's best judgment fol					
Sec	tion 2 – Cognitive impairment					
Con	ider if the participant currently is meaning	fully impaired, <b>relative to stable baseli</b>	ne prior to	onset of o	current s	<u>yndrome</u> :
8.	Based on the clinician's judgment, is the p impairment in cognition?	articipant currently experiencing meani	ngful	□o No □1 Yes		QUESTION 11)
9.	Indicate whether the participant is meaning	ngfully impaired in the following cognit	ive domains	or has flu	ctuating	cognition:
C	ognitive			No	Yes	Unknown
	<b>9a. Memory</b> — Does the participant forgostatement, or misplace things more than u		ons or	По	<b>□</b> 1	<u> </u>
	<b>9b. Orientation</b> — Does the participant h forget names of people they know well, g familiar locations?			О	<u> </u>	<u> </u>
	<b>9c. Executive function</b> ( <i>judgment, plann</i> participant have trouble planning completor group meetings?			По	<b>□</b> 1	<u></u> 9

Soc	tion 2 – Cognitive impairment			continued
260	tion 2 – Cognitive impairment	NI.	V.	
	<b>9d. Language</b> — Does the participant have hesitant speech, have trouble finding words, u inappropriate words without self-correction, or have trouble with speech comprehension?	No Do	Yes	Unknown
	<b>9e. Visuospatial function</b> — Does the participant have difficulty interpreting visual stimul or finding their way around in familiar environments?	□о	<b>□</b> 1	<b>□</b> 9
	<b>9f. Attention/concentration</b> — Does the participant have a short attention span or limited ability to concentrate? Are they easily distracted?	□о	<b>□</b> 1	<u>9</u>
	<b>9g. Fluctuating cognition</b> — 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?		<b>□</b> 1	<u></u> 9
	9h. Other (SPECIFY):	□ <sub>0</sub>	□ <sub>1</sub>	
	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 symtpom.)  (777 = age provided at previous UDS visit)			
10.	Mode of onset of cognitive impairment:  Indicate the mode of onset for the most prominent cognitive problem that  1 Gradua 2 Subacu		her ( <b>SPEC</b>	IFY):
	is causing the participant's complaints and/or affecting the participant's function. $\hfill \hfill \hfill$	□99 U	nknown	
Sec	tion 3 – Neuropsychiatric symptoms and behavioral changes			
<u>rela</u>	sider if the participant manifests – <i>in the last month</i> – clinically meaningful neuropsychiatric tive to stable baseline (i.e., predominant behavioral state prior to the onset of the current synd rs 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?	□o No		QUESTION 14)
12.	Specify the phenotype of clinically meaningful neuropsychiatric symptoms or meaningful manifested <i>in the last month</i> .	hange in be	ehavior th	nat has
Мо	od, motivation, and agitation	No	Yes	Unknown
	<b>12a. Apathy/withdrawal</b> — Has the participant lost interest in the world around them, lost interest in doing things, or lack motivation for starting new activities?	О	<b>□</b> 1	<u>9</u>
	<b>12b. Depressed mood</b> — Does the participant seem sad or depressed, or say that they fee sad or depressed?	О		<u></u> 9
	<b>12c. Anxiety</b> — 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?	□о	<b>□</b> 1	<u></u> 9
	<b>12d. Euphoria</b> — Does the participant seem too cheerful or too happy for no reason, or manifest a persistent and abnormally good mood, or find humor where others do not?	О		<u></u> 9
	<b>12e. Irritability</b> — Does the participant get irritated and easily disturbed? Are their moods very interchangeable? Are they abnormally impatient?	О		<u></u> 9
	<b>12f. Agitation</b> — Is the participant easily distressed or angered, or hard to handle, or uncooperative, or resistive to care or to help from others?	О		<u>9</u>
	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 with different ages of onset are identified, denote the age of the earliest symtpom.) (777 = age provided at previous UDS visit)			

\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_ \_\_

Participant ID:	Form date: / / /	Visit#: _		
Section 3	- Neuropsychiatric symptoms and behavioral changes			continued
Psychosis a	nd impulse control	No	Yes	Unknown
12h. Vis	sual hallucinations - Does the participant exhibit visual perceptions without a s?	О	<b>□</b> 1	<u></u> 9
	<b>1. IF YES,</b> do their hallucinations include patterns that are not definite objects, such ixelation of flat uniform surfaces?	О	<b>□</b> 1	<u></u> 9
	<b>2. IF YES,</b> do their hallucinations include well-formed and detailed images of objects eople, either as independent images or as part of other objects?	□ <sub>0</sub>	<b>□</b> 1	<u></u> 9
<b>12i. Au</b> e stimulu	<b>ditory hallucinations</b> - Does the participant exhibit auditory perceptions without a s?	□ <sub>0</sub>	<b>□</b> 1	<u></u> 9
	. <b>IF YES</b> , do the auditory hallucinations include simple sounds like knocks or other ole sounds?	□0	<b>□</b> 1	<u></u> 9
	c. <b>IF YES</b> , do the auditory hallucinations include complex sounds like voices speaking ds, or music?	О	□ 1	<u> </u>
exampl	<b>usions</b> - Does the participant have fixed, idiosyncratic beliefs that are not true? For e, insisting that others are trying to harm them or steal from them? Have they said nily members or staff are not who they say they are, or that the house is not their	□o	<b>□</b> 1	<u>9</u>
_	<b>gression</b> — Does the participant shout angrily, slam doors, attempt to hit or hurt or exhibit other verbally or physically aggressive behaviors?	□0	□ 1	<u></u> 9
present age of o	ny of the psychosis and impulse control –related behavioral changes in 12h–12k are , at what age did they begin? (The clinician must use their best judgment to estimate an inset. If multiple symptoms with different ages of onset are identified, denote the age of iest symtpom.) (777 = age provided at previous UDS visit)			
Personality		No	Yes	Unknown
are not	<b>isinhibition</b> — Does the participant act impulsively without thinking, say things that usually done or said in public, do things that are embarrassing to caregivers or others, sey talk personally to strangers or have disregard for personal hygiene?	□ <sub>0</sub>	<u></u> 1	<u></u> 9
unchara	rsonality change — Does the participant exhibit bizarre behavior or behavior acteristic of the participant, such as unusual collecting, suspiciousness (without as), unusual dress, or unusual eating behaviors?	□o	<u> </u>	<u></u> 9
12o. <b>Lo</b>	ss of empathy — Does the participant fail to take others' feelings into account?	О	□ 1	<b>□</b> 9
focus o	rsessions and/or compulsions — Does the participant repeatedly and excessively in particular ideas or activities, or have they developed new habits, like physical ors or stereotypical verbal phrases?	□ <sub>0</sub>	<b>□</b> 1	<u> </u>
	<b>plosive anger</b> — Does the participant have a "short fuse"? Do they display explosive its of anger or rage?	О	<b>□</b> 1	<u></u> 9
consum	bstance use — Does the participant currently show evidence of excessive aption of recreational, psychoactive, or typically abused substances (substantial ecompared with prior habits, and beyond medical necessity if prescribed substance)?	О	<b>□</b> 1	<u> </u>
(Che	12r1c. ☐ <sub>1</sub> Opi 12r1d. ☐ <sub>1</sub> Coc 12r1e. ☐ <sub>1</sub> Can	ative/hyp ate aine		
age did	they begin? (The clinician must use their best judgment to estimate an age of onset. ole symptoms with different ages of onset are identified, denote the age of the earliest			

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	tion 3 – Neuropsychiatric symptoms and behavioral changes			continued
REN	A sleep	No	Yes	Unknown
	<b>12t. REM sleep behavior disorder</b> — While sleeping, does the participant appear to repeatedly act out their dreams (e.g., punch or flail their arms, shout, or scream)?	О		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.) (777 = age provided at previous UDS visit)			
	12t2. Was REM sleep behavior disorder confirmed by polysomnography?	О	□ 1	<b>□</b> 9
Oth	ner er e	No	Yes	Unknown
	12u. Other behavioral changes (SPECIFY):	О	□ 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.		her ( <b>SPEC</b> nknown	IFY):
	tion 4 – Motor changes	_	•	
	sider if the participant currently has meaningful change in motor function <b>that represents a ch</b> eline prior to the current syndrome and is potentially due to a disorder affecting the centr			
14.	Based on the clinician's judgment, is the participant currently experiencing any meaningful changes in motor function?	0 No		QUESTION 19)
15.	Indicate whether the participant has meaningful change in motor function:			
Mo	tor	No	Yes	Unknown
	<b>15a. Gait disorder</b> — 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?	o	<b>□</b> 1	<u></u> 9
	<b>15b. Falls</b> — Has the participant had an increase in frequency of falls compared with their stable baseline prior to the current syndrome?	О	□ 1	<u></u> 9
	<b>15c. Slowness</b> — Has the participant noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness?	О	□ <sub>1</sub>	<b>□</b> 9
	<b>15d. Tremors</b> — Has the participant had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?	□ <sub>0</sub>	□ 1	<u></u> 9
	<b>15e. Limb weakness</b> — 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?	□o	□ 1	<u></u> 9
	<b>15f. Change in facial expression</b> — Has the participant's facial expression changed or become more "wooden," or masked and unexpressive?	О	□ 1	<u></u> 9
	<b>15g. Change in speech</b> — Has the participant noted a change in speech ( <i>abrupt or gradual</i> ) 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?	□ <sub>0</sub>	<b>□</b> 1	<u> </u>
	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 with different ages of onset are identified, denote the age of the earliest symtpom.) (777 = age provided at previous UDS visit)			
16.	Mode of onset for motor changes:       ☐ 1 Gradual         Indicate the mode of onset for the most prominent motor problem that       ☐ 2 Subacute	□4 Otl	her (SPEC	IFY):
	is causing the participant's complaints and/or affecting the participant's $\  \  \  \  \  \  \  \  \  \  \  \  \ $	☐99 Uı	nknown	
		No	Yes	Unknown
17.	Were changes in motor function suggestive of parkinsonism?	О	□ 1	<u></u> 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)?	О	□ <sub>1</sub>	<u>9</u>

\_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_ \_\_ \_\_

Visit #:

Participant ID: \_\_\_

Sec	tion 5 – Overall course of decline and predominant domain	
19.	Overall course of decline of cognitive/behavioral/motor syndrome:	1 Gradually progressive 2 Stepwise 3 Static 4 Fluctuating 5 Improved 8 Not applicable 9 Unknown
20.	Indicate the <b>predominant</b> domain that was first recognized as changed in the participant:  NOTE: Enter 0 if this information was provided on a previously submitted Form B9.	o Assessed at a previous UDS visit from Cognition graphs Behavior graphs Motor function solution solut

\_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Visit #: \_\_\_



## Form C2: Neuropsychological Battery Scores

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

**INSTRUCTIONS**: This form is to be completed by ADRC or clinic staff. For test administration and scoring, see **Instructions for Neuropsychological Battery, Form C2**.

**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

Sectio	n 1 — Montreal Cognitive Assess	ment (MoCA)	
1a.	Was any part of the MoCA administered?	□ 0 No (If No, enter reason code, 95 – 98): ☐ 1 Yes (CONTINUE WITH QUESTION 1	
1b.	MoCA was administered:	$1$ In ADRC or clinic $\square$ 2 In home $\square$ 3 In person	on — other
1c.	Language of MoCA administration:	1 English 2 Spanish 3 Other (SPECIFY):	
1d.	Participant was unable to complete one o	r more sections due to visual impairment:	□ o No □ 1 Yes
1e.	Participant was unable to complete one o	r more sections due to hearing impairment:	□ o No □ 1 Yes
1f.	Total Raw Score — Uncorrected (Not corrected for education or visual/hearing) (Enter 88 if any of the following MoCA items were	•	(0-30, 88)
1g.	Visuospatial/executive — Trails		(0-1, 95-98)
1h.	Visuospatial/executive — Cube		(0-1, 95-98)
1i.	${\it Visuos patial/executive} - {\it Clock contour}$		(0-1, 95-98)
1j.	$\label{thm:local_problem} \mbox{Visuospatial/executive} \mbox{Clock numbers}$		(0-1, 95-98)
1k.	Visuospatial/executive — Clock hands		(0-1, 95-98)
11.	Language — Naming		(0-3, 95-98)
1m.	Memory — Registration (two trials)		(0-10, 95-98)
1n.	Attention — Digits		(0-2, 95-98)
10.	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)

Participa	nt ID:	isit #:
Sectio	n 2 — Administration of the remainder of the battery	
2a.	The tests following the MoCA were administered:   1 In ADRC or clinic   2 In home	☐3 In person — other
2b.	Language of test administration:	
Sectio	n 3 — Craft Story 21 Recall (Immediate)	
3a.	Total story units recalled, verbatim scoring	(0 –44, 95-98)
3b.	(If test not completed, enter reason code, 95–98, and <b>SKIP TO QUESTION 4a.</b> )  Total story units recalled, paraphrase scoring	(0-25)
	n 4 — Benson Complex Figure Copy	
	Total score for copy of Benson figure (If test not completed, enter reason code, 95–98)	(0 –17, 95-98)
	n 5 — Number Span Test: Forward	(0-17,93-90)
Section		
5a.	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)
Sectio	n 6 — Number Span Test: Backward	
ба.	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)
Sectio	n 7 — Category Fluency	
7a.	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)
Sectio	n 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 <b>SKIP TO QUESTION 8b.</b> )	(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 <b>SKIP TO QUESTION 9a.</b> )	(0-300, 995-998)
	8b1. Number of commission errors	(0 -40)
	8b2. Number of correct lines	(0-24)
Sectio	n 9 — Benson Complex Figure Recall	
9a.	Total score for drawing of Benson figure following 10- to 15-minute delay (If test not completed, enter reason code, 95–98, and <b>SKIP TO QUESTION 10a.</b> )	(0 –17, 95-98)
9b.	Recognized original stimulus from among four options?	□ o No □ 1 Yes

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Participa	nt ID: / / / V	isit #:
Section	n 10 — Craft Story 21 Recall (Delayed)	
Section		
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	□ o No □ 1 Yes
Sectio	n 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 <b>SKIP TO QUESTION 11d.</b> )	(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 <b>SKIP TO QUESTION 12.</b> )	(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)
	Which verbal learning test was 1 Rey AVLT (COMPLETE SECTIONS 12 & 13,	2 CERAD (SKIP TO SECTION 14)
a	SKIP SECTIONS 14 & 15)	(SKIF TO SECTION 14)
		(SKIF TO SECTION 14)
Sectio Total nu	SKIP SECTIONS 14 & 15)	
Sectio Total nu	n 12 — Rey Auditory Verbal Learning (Immediate)  mber of words correctly recalled and number of intrusions. (If test was not completed, enter	
Sectio Total nu QUESTI	n 12 — Rey Auditory Verbal Learning (Immediate)  mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)	reason code, 95-98. <b>SKIP TO</b>
Sectio Total nu QUESTI Trial	n 12 — Rey Auditory Verbal Learning (Immediate)  Imper of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall	reason code, 95-98. <b>SKIP TO</b> # of intrusions
Section Total nu QUESTI Trial Trial 1	m 12 — Rey Auditory Verbal Learning (Immediate)  mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a	reason code, 95-98. <b>SKIP TO</b> # of intrusions  12b (No limit)
Section Total nu QUESTI Trial Trial 1 Trial 2	m 12 — Rey Auditory Verbal Learning (Immediate)  mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a	reason code, 95-98. <b>SKIP TO</b> # of intrusions  12b (No limit)  12d (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3	m 12 — Rey Auditory Verbal Learning (Immediate)  mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98)  12c (0-15)  12e (0-15)	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4	mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98)  12c (0-15)  12g (0-15)	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5	Total recall	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6	Total recall	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)  12l (No limit)  12l (No limit)  12l (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6	Total recall	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)  12l (No limit)  12l (No limit)  12l (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6 Sectio	Total recall	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)  12l (No limit)  12l (No limit)  12n (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6 Section	mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98)  12c (0-15)  12e (0-15)  12g (0-15)  12i (0-15)  12k (0-15)  12m (0-15)  Total delayed recall  (If test was not completed, enter reason code, 95-98. SKIP TO QUESTION 16a.)	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)  12l (No limit)  12l (No limit)  12n (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6 Sectio 13a. 13b.	mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98)  12c (0-15)  12e (0-15)  12g (0-15)  12i (0-15)  12k (0-15)  12m (0-15)  Total delayed recall (If test was not completed, enter reason code, 95-98. SKIP TO QUESTION 16a.) Intrusions	# of intrusions  12b (No limit)  12d (No limit)  12f (No limit)  12h (No limit)  12j (No limit)  12l (No limit)  12n (No limit)  — (0-15, 95-98)  (No limit)
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6 Sectio 13a. 13b. 13c.	mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98)  12c (0-15)  12e (0-15)  12i (0-15)  12k (0-15)  12m (0-15)  Total delayed recall (If test was not completed, enter reason code, 95-98. SKIP TO QUESTION 16a.)  Intrusions  Delay time (minutes) (99=Unknown)	# of intrusions  12b
Sectio Total nu QUESTI Trial Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 List B Trial 6 Sectio 13a. 13b. 13c. 13d.	mber of words correctly recalled and number of intrusions. (If test was not completed, enter ON 16a.)  Total recall  12a (0-15, 95-98) 12c (0-15) 12e (0-15) 12g (0-15) 12i (0-15) 12k (0-15) 12m (0-15) 12m (0-15)  Total delayed recall (If test was not completed, enter reason code, 95-98. SKIP TO QUESTION 16a.)  Intrusions  Delay time (minutes) (99=Unknown)  Method of recognition test administration	reason code, 95-98. <b>SKIP TO</b> # of intrusions  12b

Sectio	n 14 — CERAD Verb	al Learning (Immedia	nte)				
		k: Total number of words co		nd number	of intrusion	ns	
Trial	Total recall	k. Total Humber of Words Co	orrectly recalled ar	Can't re			ntrusions
Trial 1	14a (0-10, 95-98)	ter reason code, 95-98. <b>SKIP TO</b>	QUESTION 16a.)				(No limit)
Trial 2	14d (0-10)		14f	(No limit)			
Trial 3	14g (0-10)						(No limit)
Sectio	n 15 — CERAD Verb	al Learning (Delayed	Recall and Re	cognitio	n)		
15a.	Delay time (minutes) (99						(0 –85 minutes)
15b.	J6 Word List Recall: Total	number of words correctly eason code, 95-98, and <b>SKIP TO</b>					(0-10, 95-98)
15c.	J6 Word List Recall: Total	number of intrusions					(No limit)
15d.	J7 Word List Recognition (If test not completed, enter re	: Total YES correct eason code, 95-98, and <b>SKIP TO</b>	QUESTION 16a.)				(0-10, 95-98)
15e.	J7 Word List Recognition	: Total NO correct					(0-10, 95-98)
Sectio	n 16 — Multilingual	Naming Test (MINT)					
16a.	Total score (If test not completed, enter re	eason code, 95–98, and <b>SKIP TC</b>	O QUESTION 17a)				(0-32, 95-98)
16b.	Total correct without sen	nantic cue				(0-32)	
16c.	Semantic cues: Number	given				(0-32)	
16d.	Semantic cues: Number	correct with cue (88 = Not ap	oplicable)			(0 –32, 88)	
16e.	Phonemic cues: Number	given					(0-32)
16f.	Phonemic cues: Number	correct with cue (88 = Not a	pplicable)				(0-32, 88)
Sectio	n 17 — Overall appr	aisal					
	Per the clinician (e.g., ne	uropsychologist, or other suitably qualified IDS neuropsychological	3 One or two t	ge est scores re scores a	are abnorm	al or low	er than expected
Sectio	n 18 — Validity of p	articipant's response					
		vhether hearing or other fa ta analysis to know that suc				s. It can b	pe difficult to judge, but
18a.	How valid do you think the participant's responses are?	1 Very valid, probably a 2 Questionably valid, p 3 Invalid, probably inac	ossibly inaccurate	indication	of particip	ant's co	gnitive abilities
18b.	What makes this participant's responses less valid?  (Check all that apply)	18b1.	or disinterest ues assistance				

\_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ \_\_

Participant ID: \_\_\_



### Form C2T: Neuropsychological Battery Scores for T-cog

ADRC:	PTID:	Form date://	Examiner's Visit #: initials:
Language □1 Englis □2 Spani	sh	Key (remote reason): 1=Too cognitively impai 2=Too physically impai 3=Homebound or nursi 4=Refused in-person vi: 5=Other	red ing home
Neurop KEY: If t	sychological Battery, Form C2T. the participant cannot complete any c	ADRC or clinic staff. For test administration at of the following exams, please give the reaso behavior problem 97 / 997 = Other problem	on by entering one of the following codes:
Sectio	n 1 — Montreal Cognitive Ass	sessment (MoCA) Blind	
1a.	Was any part of the MoCA administe	red?	de, 95 – 98): (SKIP TO QUESTION 2A)
1b.	Language of MoCA administration:	☐ 1 English ☐ 2 Spanish ☐ 3 Other ( <b>s</b>	PECIFY):
1c.	Participant was unable to complete	one or more sections due to hearing impairn	ment: 0 No 1 Yes
1d.	Total Raw Score — Uncorrected (Not corrected for education or visual/her (Enter 88 if any of the following MoCA item:		(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)
10.	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)
Sectio	n 2 — Administration of the r	emainder of the battery	
2a.	Language of test administration:	1 English ☐2 Spanish ☐3 Other (SPE	CIFY):
Sectio	n 3 — Craft Story 21 Recall (Ir	mmediate)	
3a.	Total story units recalled, verbatim so (If test not completed, enter reason code, 95		(0 -44, 95-98)
3b.	Total story units recalled, paraphrase	scoring	(0-25)

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Participa	ınt ID:	Form date:	/	/isit #:
Section	on 4 — Number Span	Test: Forward		
4a.	Number of correct trials			(0 –14, 95-98)
4b.	(If test not completed, enter re Longest span forward	eason code, 95–98, and <b>SKIP T</b> e	O QUESTION 5a.)	(0 , 3-9)
	on 5 — Number Span	Test: Backward		(0,33)
5a.	Number of correct trials			(0 –14, 95-98)
5b.	Longest span backward	eason code, 95–98, and <b>SKIP T</b> e	O QUESTION 6./	(0, 2-8)
	hich verbal learning te	st was administered?	1 Rey AVLT (COMPLETE SECTIONS 6 & 13, SKIP SECTIONS 7 & 9)	COMPLETE SECTIONS 7 & 9, SKIP SECTIONS 6 & 13)
Sectio	on 6 — Rey Auditory	Verbal Learning (Im	mediate)	
Total nu	•	called and number of intro	usions. (If test was not completed, enter	reason code, 95-98. <b>SKIP TO</b>
Trial		Total recall		# of intrusions
Trial 1		6a (0-15, 95-98)		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)
Sectio	on 7 — CERAD Verbal	Learning (Immediat	te)	
7.	J4 Word List Memory Tas	k: Total number of words c	orrectly recalled and number of intrusio	ns
Trial	Total recall			# of intrusions
Trial 1	7a (0-10, 95-98) (If test was not completed, en	ter reason code, 95-98. <b>SKIP TC</b>	D QUESTION 8a.)	7b (No limit)
Trial 2	7c (0-10)			7d (No limit)
Trial 3	7e (0-10)			7f (No limit)
Sectio	on 8 — Category Flue	ncy		
8a.	Animals: Total number of (If test not completed, enter re	f animals named in 60 secc eason code, 95–98)	onds	(0 –77, 95-98)
8b.	Vegetables: Total numbe (If test not completed, enter re	r of vegetables named in 6 eason code, 95–98)	60 seconds	(0 –77, 95-98)

Sectio	n 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 <b>SKIP TO QUESTION 9d.</b> )	(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 <b>SKIP TO QUESTION 10a.</b> )	(0-10, 95-98)
9e.	J7 Word List Recognition: Total NO correct	(0-10, 95-98)
Sectio	n 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. <b>SKIP TO QUESTION 10b.</b> )	(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. <b>SKIP TO QUESTION 11a.</b> )	(0-300, 888, 995-998)
	10b1. Number of commission errors	(No limit)
	10b2. Number of correct lines	(0-25)
Sectio	n 11 — Craft Story 21 Recall (Delayed)	
11a.	Total story units recalled, verbatim scoring (If test not completed, enter reason code, 95–98, and <b>SKIP TO QUESTION 12a.</b> )	(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	□ o No □ 1 Yes
Sectio	n 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 <b>SKIP TO QUESTION 13a.</b> )	(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)

Form date: \_\_\_\_ / \_\_\_ / \_\_\_ \_\_ \_\_ \_

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Sectio	n 13 — Rey Auditory Verbal Le	earning (D	elayed Recall and Recognition)	
13a.	Total delayed recall (If test was not completed, enter reason code TO QUESTION 14a.)	e, 95-98. If test w	as skipped because optional, enter 88. <b>SKIP</b>	(0 –15, 88, 95-98)
13b.	Intrusions			(No limit)
13c.	Delay time (minutes) (99=Unknown)			(0 –85 minutes)
13d.	Recognition — Total correct			(0-15, 95-98)
13e.	Recognition — Total false positive			(0-15, 95-98)
Sectio	n 14 — Verbal Naming Test (O)	ptional)		
14a.	Total correct without a cue (If test was not completed, enter reason code	e, 95-98. If test w	as skipped because optional, enter 88.)	(0 -50, 88, 95-98)
14b.	Total correct with phonemic cue (If test was not completed, enter reason code given, enter 88.)	e, 95-98. If test w	as skipped because optional or if no cues were	(0-50, 88, 95-98)
Sectio	n 15 — Overall appraisal			
15a.	Per the clinician (e.g., neuropsycholog behavioral neurologist, or other suital clinician), based on the UDS neuropsy examination, the participant's cognitive deemed:	bly qualified ychological	1 Better than normal for age 2 Normal for age 3 One or two test scores are abnormated three or more scores are abnormated to Clinician unable to render opinion	al or lower than expected
Sectio	n 16 — Validity of participant	's response	2S	
			actors significantly influenced test results ch an influence may have been present.	s. It can be difficult to judge, but
16a.	How valid do you think the participant's responses are?	FORM I	onably valid, possibly inaccurate indicati	on of participant's cognitive
16b.	What makes this participant's responses less valid?	16b1. □ 1 16b2. □ 1	Hearing impairment Distractions	
	(Check all that apply)	16b4.	Interruptions Lack of effort or disinterest Fatigue Emotional issues Unapproved assistance Other (SPECIFY):	

\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ / \_\_\_ \_\_\_ Visit #: \_\_

Participant ID:

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Examiner's

# Form D1a: Clinical Syndrome

ADRC:	PTID: F	Form date:/ Visit #: initials:
Language: ☐ 1 English ☐ 2 Spanish		
	<b>DNS:</b> This form is to be completed by the clinician. For ac Form D1a. Check only <u>one</u> box per question.	dditional clarification and examples, see the <b>UDS Coding</b>
	nosis method—responses in this form are based on diagonal single clinician $\square_2$ Formal consensus panel $\square_3$	
Section 1	– <b>Level of impairment</b> – <i>Unimpaired co</i>	gnition/behavior, SCD, MCI/MBI, or dementia
1. ↓ AND 2. ↓ □ 0 ↑ Note:	Q7) or dementia due to FTLD or LBD and/or FTLD behave No (SKIP TO QUESTION 3) $\Box$ 1 Yes (CONTINUE TO QUE	ibit behavior sufficient to diagnose MBI – see MBI section starting at ior and language domains=0?  ESTION 2a)  does not represent a decline from their usual functioning, consider
Subjective	e Cognitive Decline	
	oes the participant report 1) significant concerns abo	
	s a clinician, are you confident that the subjective cog clinically meaningful?	initive decline 0 No (END FORM HERE) 1 Yes (END FORM HERE)
Dementia	criteria	
	ent #1: has cognitive or behavioral (neuropsychiatric) hat meet <u>all of the following criteria</u> :	Requirement #2: Participant must have impairment in one* or more of the following domains:
<ul><li>usual ac</li><li>Represe</li><li>Are not</li><li>Include through</li></ul>	e with ability to function as before at work or at ctivities ent a decline from previous levels of functioning explained by delirium or major psychiatric disorder cognitive impairment detected and diagnosed a combination of: 1) history-taking; 2) objective nent (bedside or neuropsychological testing)	<ul> <li>Impaired ability to acquire and remember new information</li> <li>Impaired reasoning and handling of complex tasks, poor judgment</li> <li>Impaired visuospatial abilities</li> <li>Impaired language functions</li> <li>Changes in personality, behavior, or comportment</li> <li>* 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.</li> </ul>
	the participant meet criteria for dementia?  No (CONTINUE TO QUESTION 4) 1 Yes (SKIF	P TO QUESTION 6a)

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Participan	t ID:	_ Form date:	_ / /	Visit #:	
Section	n 1 – Level of impairme	nt			continued
MCI cor	e clinical criteria				
Check all	criteria that apply in Q4.				
	<ul> <li>Clinical concern about decline (e.g., based on input from partion)</li> <li>Impairment in one or more concognitive function, or support</li> <li>Largely preserved functional in based on clinical judgment)</li> </ul>	cipant, co-participant, or gnitive domains, com ed by objective longit	and/or the clinician's journed to participant' udinal neuropsychol	udgment, CDR SB 0.5+, etc.) s estimated prior level of life logical evidence of decline	long or usual
Q4 are ch	e criteria are checked, choose <b>1=Ye</b> ecked, with the exception of the thi <b>ly</b> the third MCI criteria is met in Q	ird MCI criteria <b>alone</b> , c			
4b.	Does the participant meet all the (amnestic or non-amnestic)?	ree of the above crite	ria for MCI	O No (CONTINUE TO QUESTION)  1 Yes (SKIP TO QUESTION)	
Cogniti	vely impaired, not MCI/de	mentia			
impairme	ose of the "Cognitively impaired, ent or decline who do not meet fo applicable criteria for cognitiv	ormal MCI criteria.			nce of cognitive
	Evidence of functional impairs     Cognitive testing is abnormal     Longstanding cognitive difficuremote TBI, other medical condition     Other (SPECIFY):	but no clinical concerrulties, not representing	n or functional declir g a decline from thei	ne (e.g., CDR SB=0 and FAS=0	))
•	he criteria in Q5 are met choose '				
5b.	Does the participant meet any dementia?	criteria for cognitively	impaired, not MCI/	O No (SKIP TO QUESTION 1 Yes (SKIP TO QUESTION)	
Affecte	d Domains – Dementia and	d MCI			
	omains that are impaired at the c chological testing. <u>Select one or</u>				
Note on <b>t</b> (not in th	pehavior changes: For patients we following MBI section) by mark ated) symptom, consider a diagn	rith <i>dementia</i> who hav ing Q6f as <b>Impaired</b> a	e behavior changes, nd Q7 as <b>0 = No</b> . For	record the presence of beha	vioral changes here
					Impaired
6a.	Memory				□ 1
6b.	Language				□ 1
6c.	Attention				□ 1
6d.	Executive				□ 1
6e.	Visuospatial				□ <sub>1</sub>
6f.	Behavioral (for participants with	dementia only; see MB	I for MCI participants	)	
6g.	Apraxia				□1

Participan	t ID: Form date: / / /		Visit #:		_
Sectio	n 1 – Level of impairment			continued	<i>I</i>
Mild Be	havioral Impairment (MBI) core clinical criteria				
pers Sym Late Not long Sym Larg mini 7. Do de M (N of	cipant, co-participant, or clinician identifies a change in the participant's after onality that is clearly different from their usual affect, motivation, thought comptoms have been present at least intermittently for the last six months or locally onset (i.e., age > ~50, unless early onset neurodegenerative syndrome is suexplained by delirium, other psychiatric disorder by DSM criteria (including standing disorder).  ptoms interfere with at least one of these: work, interpersonal relationships ely preserved independence in other functional abilities (no change from p mal aids or assistance)  pes the participant meet criteria for MBI? (If participant meets criteria for ementia an MBI diagnosis is excluded.)  BI affected domains — Select one or more affected domains ote: If "Yes" is indicated in any domain below, the participant should have a corresponding Symptoms, either from among the specific symptoms denoted there, or in "other")  Motivation (e.g., apathy symptoms on Form B9)  Affective regulation (e.g., anxiety, irritability, depression, and/or euphoria symptoms	ontent, behanger spected) recent onse social active rior manner,  0 No (S) 1 Yes (C) g symptom ch	avior, or personality t, longstanding or red ities /level of functioning, KIP TO QUESTION 8) CONTINUE TO QUESTION pecked on Form B9 — Clin	or uses  ON 7a)  nician Judgmen	ot   1   1
7c.	Impulse control (e.g., obsessions/compulsions, personality change, and/or substance	e abuse sympt	oms on Form B9)	□o □	1
7d.	Social appropriateness (e.g., disinhibition, personality change, and/or loss of empa	thy symptoms	on Form B9)	□ <sub>0</sub> □	1
7e.	Thought content/perception (e.g., delusions and/or hallucinations on Form B9)			□ <sub>0</sub> □	1
Sectio	n 2 – Clinical syndrome				
MCI or M cognitive Diagnose may have	pose of Section 2 is to assign a predominant clinical syndrome to participal, using all available clinical, exam, and neuropsychiatric data. This should /neuropsychological testing, ideally without reference to biomarker data is section in Form D1b). This is not always possible and thus Q9 allows center influenced the clinical diagnosis.  there a predominant clinical syndrome?  the that the participant may not meet any clinical criteria or may not have a predominant or instance, this is common for MCI and "impaired, not MCI"). In this case, select "No."	be done usir (which is in rs to record	ng clinical informatio corporated into the I	n and Etiological a is known an	ıd
	e predominant syndrome as present; all others will default to Absent in the	NACC datab	ase	Presen	t
8a.	Amnestic predominant syndrome				
8b.	Dysexecutive predominant syndrome				
8c.	Primary visual presentation (such as posterior cortical atrophy (PCA) syndi	rome)		□ 1	
8d.	Primary progressive aphasia (PPA) syndrome:			1	
86	11. If present, select one:  1 Semantic PPA 2 Logopenic PPA 3 Nonfluent/agrammatic PPA 5 Primary progressive apraxia of speech 4 PPA other/not otherwise specified				
8e.	Behavioral variant frontotemporal (bvFTD) syndrome			1	
8f.	Lewy body syndrome			□ <sub>1</sub>	
8	f1. If present, select one:  1 Dementia with Lewy bodies 2 Parkinson's disease 3 Parkinson's disease dementia syndrome				
8g.	Non-amnestic multidomain syndrome, not PCA, PPA, bvFTD, or DLB syndr	ome		<b>□</b> 1	

Sec	tion 2	2 – Clinical syndrome					C	ontinued
								Present
8	s <b>h.</b> Pr	imary supranuclear palsy (PSP) syndrome						
		If present, select one:  1 Richardson's syndrome criteria 2 Non-Richardson's						
	<b>8i.</b> Tr	aumatic encephalopathy syndrome						<b>□</b> 1
;	<b>8j.</b> Co	orticobasal syndrome (CBS)						□ <sub>1</sub>
8	sk. M	ultiple system atrophy (MSA) syndrome						□ 1
8k1. If present, select one:  1 MSA-predominant cerebellar ataxia (MSA-C) 2 MSA-predominant Parkinsonism (MSA-P) 3 MSA-predominant dysautonomia								
	<b>81.</b> Of	ther (SPECIFY):						□ 1
9.		ate the source(s) of information used to assign the cli tone or more as <b>Yes</b> ; all others will default to <b>No</b> in th	-					Yes
c	a. Cl	inical information (history, CDR)						
		ognitive testing						
		omarkers (MRI, PET, CSF, plasma)						
		- Primary or contributing non-neuro	al a mana			CVD conditi		
The po	urpose oust be	of Section 3 is to identify conditions or disorders tha filled out for those with cognitive or behavioral imparts primary, contributing, or non-contributing cause of	t are prese airment (i.e	nt and po ., MCI, MI	otentially co 31, dementia	ntributing to the a, etc.) Indicate v	e clinical vhether	a given
Select leave	one or	more condition(s) as <b>Present</b> ; if there are no primary ditions blank. All conditions left blank will default to a	or contrib	uting no	n-neurode <u>c</u>	generative or noi	n-CVD co	onditions,
*In ord	der to d	liagnose a disorder, <b>DSM-5-TR criteria require</b> that s ational, or other important areas of functioning. For I						
		Condition	Present		Primary	Contributing	Non-c	ontributing
10.	Major	depressive disorder (DSM-5-TR criteria*)	□ <sub>1</sub>	10a.	□ 1	$\square_2$		<b>□</b> <sub>3</sub>
11.	Other	specified depressive disorder (DSM-5-TR criteria*)	<b>□</b> 1	11a.	□ 1	$\square_2$		<b>□</b> <sub>3</sub>
12.	Bipola	ar disorder (DSM-5-TR criteria*)	□ 1	12a.	1	2		3
13.	Schizo criteri	ophrenia or other psychotic disorder (DSM-5-TR a*)		13a.	□ <sub>1</sub>	□ <sub>2</sub>		<b>□</b> <sub>3</sub>
14.	Anxie	ty disorder (DSM-5-TR criteria*)	□ 1	14a.	1	$\square_2$		□ 3
	If	present, (SPECIFY) (check all that apply):						
	14b.	1 Generalized anxiety disorder						
	14c.	☐ 1 Panic disorder						
	14d.	1 Obsessive-compulsive disorder (OCD)						
	14e.	1 Other (SPECIFY):						
15.	Post-t	raumatic stress disorder (PTSD)(DSM-5-TR criteria*)		15a.	□ 1	□ <sub>2</sub>		<b>□</b> <sub>3</sub>

Form date: \_\_\_ / \_\_\_ / \_\_\_ \_\_ \_\_

Participant ID:	Farm data	/	/	Visit #:	
rarticipant id:	Form date:	/	/	VISIL #:	

Sect	ion 3 – Primary or contributing non-degener	ative or r	non-CV	/D condit	ions	continued
	Condition	Present		Primary	Contributing	Non-contributing
16.	Developmental neuropsychiatric disorders (e.g., autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), dyslexia)	□ 1	16a.	□ 1	□ 2	□ <sub>3</sub>
17.	Delirium (DSM-5-TR criteria*)	□ <sub>1</sub>	17a.	□ 1	$\square_2$	3
18.	Other psychiatric disorder (DSM-5-TR criteria*)	□ 1	18a.	□ 1	$\square_2$	□ 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)	□ 1	19a.	<b>□</b> 1	<b>□</b> 2	<b>□</b> <sub>3</sub>
20.	Epilepsy	□ 1	20a.	□ 1	$\square_2$	3
21.	Normal-pressure hydrocephalus	□ 1	21a.	□ 1	$\square_2$	3
22.	CNS Neoplasm	□ 1	22a.	□ 1	$\square_2$	3
22	2b. If present, select one:  1 Benign 2 Malignant					
23.	Human immunodeficiency virus (HIV) infection	□ <sub>1</sub>	23a.	□ 1	<b>□</b> 2	3
24.	Post COVID-19 cognitive impairment	□ 1	24a.	□ 1	$\square_2$	3
25.	Sleep apnea (i.e., obstructive, central, mixed or complex sleep apnea)	□ <sub>1</sub>	25a.	□1	2	<b>□</b> 3
26.	Cognitive impairment due to other neurologic, genetic, infectious conditions ( <i>not listed above</i> ), or systemic disease/medical illness (as indicated on Form A5/D2)	□ 1	26a.	□ 1	_2	<b>□</b> 3
26	bb. If present, (SPECIFY):					
27.	Cognitive impairment due to alcohol use or abuse	□ 1	27a.	□ 1	$\square_2$	3
28.	Cognitive impairment due to substance use or abuse	□ 1	28a.	□ 1	$\square_2$	3
29.	Cognitive impairment due to medications	□ <sub>1</sub>	29a.	□ <sub>1</sub>	$\square_2$	3
30.	Cognitive impairment not otherwise specified (NOS)	□ 1	30a.	□ 1	$\square_2$	□ 3
30	b. If present, (SPECIFY):					
31.	Cognitive impairment not otherwise specified (NOS)	□1	31a.	□ <sub>1</sub>	$\square_2$	3
31	b. If present, (SPECIFY):					
32.	Cognitive impairment not otherwise specified (NOS)	□ 1	32a.	□ 1	_2	3
32	b. If present (SPECIFY):					



Examiner's

## Form D1b: Etiological Diagnosis and Biomarker Support

Langu □1 Er □2 Sp	nglish panish		/		als:
	<b>RUCTIONS:</b> This form is to be completed by the clinician for a cation and examples, see <a href="UDS Coding Guidebook">UDS Coding Guidebook</a> , Form				onal
	Were any biomarker results used to support the current e (Consider any biomarker results from any time that may be d		=*:	No (SKIP TO QUESTION Yes (CONTINUE TO QU	
Sect	tion 1 – Biomarkers and imaging				
diagr sourc not in	plete this section if any of the following biomarker measunesis, including unimpaired individuals who have biomarle available and the related questions for each supporting tended to capture actual data values or register sample aused by the clinician (or at consensus) to inform an etiology.	ker characterization g data. Then comple availability; instead	. Please complete te <b>Section 2: Eti</b>	e the checklist below ological Diagnosis. T	for each data his section is
Flui	ds				
		2 Yes, only CSF-ba	based biomarker QUESTION 3, and sased biomarkers w	rs were used SKIP QUESTIONS 4 – 40 were used (SKIP TO QU biomarkers were used	JESTION 4)
	e use the following questions to indicate the results of th	e fluid biomarker te	st(s) used by the	clinican (or at consen	sus) to
uetei	mine the etiological diagnosis at this visit.		,	(	3 0.3, 10
If a flo	rmine the etiological diagnosis at this visit. uid biomarker was used to exclude an etiological diagnos istent with a diagnosis, select <b>1=Yes, consistent</b> . If a fluid or more of the etiologies listed were not assessed using flu	is, select <b>0=Not co</b> l biomarker was fou	<b>nsistent</b> . If a fluid nd to be indetern	biomarker was found	l to be
If a fluction	uid biomarker was used to exclude an etiological diagnos stent with a diagnosis, select <b>1=Yes, consistent</b> . If a fluid	is, select <b>0=Not co</b> biomarker was fou	<b>nsistent</b> . If a fluid nd to be indetern	biomarker was found	l to be
If a fluction	uid biomarker was used to exclude an etiological diagnos istent with a diagnosis, select <b>1=Yes, consistent</b> . If a fluid or more of the etiologies listed were not assessed using fluod- ood-based biomarkers	is, select <b>0=Not co</b> biomarker was fou uid biomarkers, sele <b>No,</b>	nsistent. If a fluid nd to be indetern ect 8. Yes,	biomarker was founc ninate, select <b>9</b> . In cas	I to be es where <b>Not</b>
If a fluctors one of	uid biomarker was used to exclude an etiological diagnos istent with a diagnosis, select <b>1=Yes, consistent</b> . If a fluid or more of the etiologies listed were not assessed using flu <b>ood-based biomarkers</b> Consistent with AD	is, select <b>0=Not co</b> biomarker was fou uid biomarkers, sele <b>No,</b> <b>inconsistent</b>	nsistent. If a fluid nd to be indetern ect 8. Yes, consistent	biomarker was found ninate, select 9. In cas Indeterminate	Not assessed
If a fluctonsione of a sale and a sale a sal	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluod-based biomarkers  Consistent with AD	is, select <b>0=Not co</b> ll biomarker was fou uid biomarkers, select No, inconsistent	resistent. If a fluid not to be indeterment 8.  Yes,  consistent	biomarker was found ninate, select 9. In cas	Not assessed
If a fluctonsione of a sale and a sale a sal	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluood-based biomarkers  Consistent with AD  Consistent with FTLD  Consistent with other etiology (SPECIEV):	is, select <b>0=Not co</b> ll biomarker was fou uid biomarkers, select <b>No</b> , <b>inconsistent</b>	resistent. If a fluid and to be indeterment 8.  Yes,  consistent	I biomarker was found ninate, select <b>9</b> . In case Indeterminate	Not assessed
If a flictonsione of a Bl 3a. 3b. 3c. 3d.	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluood-based biomarkers  Consistent with AD  Consistent with FTLD  Consistent with other etiology (SPECIEV):	is, select <b>0=Not co</b> ll biomarker was fou uid biomarkers, select <b>No</b> , <b>inconsistent</b>	resistent. If a fluid and to be indeterment 8.  Yes, consistent	I biomarker was found ninate, select <b>9</b> . In case Indeterminate	Not assessed
If a flictonsione of a Bl 3a. 3b. 3c. 3d.	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluood-based biomarkers  Consistent with AD  Consistent with FTLD  Consistent with LBD  Consistent with other etiology (SPECIFY):	is, select <b>0=Not co</b> ll biomarker was fou uid biomarkers, select <b>No</b> , <b>inconsistent</b>	resistent. If a fluid and to be indeterment 8.  Yes, consistent  1  1  1  1  1  Yes,	I biomarker was found ninate, select <b>9</b> . In case Indeterminate	Not assessed  8  8  8  8  8  8  Not
If a flictonsione of a Bl 3a 3b 3c 3d 4. CS	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluood-based biomarkers  Consistent with AD  Consistent with FTLD  Consistent with LBD  Consistent with other etiology (SPECIFY):  SF-based biomarkers  Consistent with AD	is, select <b>0=Not co</b> ll biomarker was fou aid biomarkers, select <b>No</b> , <b>inconsistent</b> 0 0 0 0 No, No, inconsistent	resistent. If a fluid and to be indeterment 8.  Yes, consistent  1  1  1  Yes, consistent	Indeterminate  9  9  9  9  19  19	Not assessed  Not assessed  8  8  8  8  Not assessed
If a flictonsione of a Bl 3a. 3b. 3c. 3d. 4. CS	uid biomarker was used to exclude an etiological diagnosistent with a diagnosis, select 1=Yes, consistent. If a fluid or more of the etiologies listed were not assessed using fluood-based biomarkers  Consistent with AD  Consistent with FTLD  Consistent with other etiology (SPECIFY):  SF-based biomarkers  Consistent with AD  Consistent with AD	is, select <b>0=Not co</b> ll biomarker was fou uid biomarkers, select <b>No</b> , <b>inconsistent</b> 0 0 0 0 No, inconsistent	resistent. If a fluid and to be indeterment 8.  Yes, consistent  1  1  1  Yes, consistent	Indeterminate  9  9  9  9  19  19	Not assessed  Not assessed  R R R R R R R R R R R R R R R R R R

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Section 1 – Biomarkers and imaging continued									
Imaging									
5.	<b>Imag</b> diagn	osis?	o 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/CT imaging was used (SKIP TO QUESTION 7)  3 Yes, both PET/SPECT and MR/CT imaging were used						
	Please use the following questions to indicate the results of the imaging used by the clinican (or at consensus) to determine the etiological diagnosis at this visit.								
diag	gnosis,	was used to exclude an etiological diagnosis, select select <b>1=Yes, consistent</b> . If imaging was found to be not assessed using imaging, select <b>8</b> .							
6. F	PET/SF	PECT							
6	6a. Tracer-based PET - Were tracer-based PET measures used in assessing an etiological diagnosis? □ 1 Yes, results were normal □ 2 Yes, results were indeterminate								
	If use	d in diagnosis, indicate the results:		No	Yes	Indeterminate	Not assessed		
	6a1.	Elevated Amyloid		О	□ 1	<u> </u>	□8		
	6a2.	Elevated tau pathology		$\Box_0$	□ 1	<u> </u>	□8		
6	<b>FDG PET</b> - 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		es, istent	Indeterminate	Not assessed		
	6b1.	Consistent with AD	□ <sub>0</sub>		<b>]</b> 1	9	<b>□</b> 8		
	6b2.	Consistent with FTLD	$\square_0$		]1	<b>□</b> 9	□8		
	6b3.	Consistent with LBD	□ <sub>0</sub>	□ 1		<u></u> 9	8		
	<b>6b4.</b> Consistent with other etiology ( <b>SPECIFY</b> ):		О	□ 1		<u></u> 9	□8		
6	6c. Dopamine Transporter (DAT) Scan - Was DAT Scan data or informat 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? ☐ 1 Yes, results were norma ☐ 2 Yes, results were indete				ts were normal or abr					
			No, inconsistent		es, istent	Indeterminate	Not assessed		
	6d1.	Consistent with AD	o		]1	<u></u> 9	<b>□</b> 8		
	6d2.	Consistent with FTLD	□ <sub>0</sub>		]1	<u></u> 9	<b>□</b> 8		
	6d3.	Consistent with LBD	$\square_0$		<b>]</b> 1	<u></u> 9	□8		
	6d4.	Consistent with other etiology (SPECIFY):	О		<b>]</b> 1	<u></u> 9	□8		

Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ \_\_\_ \_\_\_

Section 1 – Biomarkers and imaging continued											
7. Structural Imaging											
7a. Structural Imaging (i.e., MRI or CT) – Was structural information used to support an etiological diagnosis?					maging data or	□ 0 No (SKIP TO QUESTION 8) □ 1 Yes, results were normal or abnormal □ 2 Yes, results were indeterminate					
					No, inconsistent		es, istent	Indeterminate	Not assessed		
7a1. Atrophy pattern consistent with AD				□ <sub>0</sub>		<b>]</b> 1	<u> </u>	□8			
78	a2.	Atroph	y pat	tern consiste	ent with FTLD		□ <sub>0</sub>			<u></u> 9	□8
78	a3.	Consist	Consistent with Cerebrovascular disease (CVD)			(CVD)	□ <sub>0</sub>		<b>]</b> 1	9	□8
		If there is evidence for CVD on imaging, indicate th				e findings:	No	Yes	Indeterminate	Not assessed	
	7a3	3a. Large vessel infarct(s)					О	□ 1	<u></u> 9	□8	
	<b>7a3b.</b> Lacunar infarct(s)				О	□ <sub>1</sub>	<u></u> 9	□8			
	<b>7a3c.</b> Macrohemorrhage(s)				О	□ 1	9	□8			
	<b>7a3d.</b> Microhemorrhage(s)				О	□ 1	<u></u> 9	□8			
<b>7a3e.</b> White matter hyperintensity				О	□ 1	9	8				
	7a3e1. If Yes, choose the severity:  1 Moderate white-matter hyperintensity (CHS score 5-6) 2 Extensive white-matter hyperintensity (CHS score 7-8+)										
Other biomarker modalities (e.g., tissues, skin, retinal imaging, etc.)											
							y additional bioma	rker mo	dalities u	sed by the clinician (o	rat
consensus) to support the etiological diagnosis at this visit.  If a biomarker modality was used to exclude an etiological diagnosis, select <b>0=Not consistent</b> . If a biomarker modality was found to be consistent with a diagnosis, select <b>1=Yes, consistent</b> . If a biomarker was found to be indeterminate, select <b>9</b> . In cases where one or more of the etiologies listed were not assessed using a biomarker modality, select <b>8</b> .											
8. Other biomarker modality - Was another biomarker modality used to support an etiological diagnosis?  (SPECIFY):											
							No, inconsistent		es, istent	Indeterminate	Not assessed
8a.	Con	sistent	with	AD			По		<b>]</b> 1	<u>9</u>	□8
8b.	8b. Consistent with FTLD			□ <sub>0</sub>		]1	<u></u> 9	□8			
8c.	8c. Consistent with LBD			□0		]1	<u> </u>	□8			
8d.	Consistent with other etiology (SPECIFY):		О		<b>]</b> 1	<u> </u>	□8				

\_\_\_\_ Form date: \_\_\_\_ / \_\_\_ / \_\_\_ \_\_ Visit #: \_\_

Parti	cipant ID: Form date:	_ / / _		Visit #:				
Sec	Section 1 – Biomarkers and imaging continued							
9.	Other biomarker modality - Was another biomarker module support an etiological diagnosis?  (SPECIFY):	dality used to	□ 0 No ( <b>SKIP TO QUESTION 11</b> ) □ 1 Yes, results were normal or abnormal □ 2 Yes, results were indeterminate					
		No, inconsistent	Yes, consistent	Indeterminate	Not assessed			
98	a. Consistent with AD	О	□ 1	<u></u> 9	□8			
91	o. Consistent with FTLD	□ <sub>0</sub>	□ 1	9	□8			
9	c. Consistent with LBD	□0	□ 1	9	□8			
90	Consistent with other etiology (SPECIFY):	□0	□ 1	<b>□</b> 9	<b>□</b> 8			
<ul><li>10. Other biomarker modality - Was another biomarker mod support an etiological diagnosis?</li><li>(SPECIFY):</li></ul>		dality used to	0 No ( <b>SKIP TO QUESTION 11</b> ) 1 Yes, results were normal or abnormal 2 Yes, results were indeterminate					
		No, inconsistent	Yes, consistent	Indeterminate	Not assessed			
10	a. Consistent with AD	□ <sub>0</sub>	□ 1	<u></u> 9	<b>□</b> 8			
10	o. Consistent with FTLD	□ <sub>0</sub>	□ 1	<u></u> 9	□8			
10	c. Consistent with LBD	□ <sub>0</sub>	□ 1	9	□8			
100	Consistent with other etiology (SPECIFY):	О	□ 1	<u></u> 9	□8			
Supportive genetics								
11. Is there an autosomal dominant pathogenic variant to support an diagnosis?			1 Yes	n/Not disclosed				

Participant ID:	Form date:	/ /	Visit #:

#### 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.

<u>Must be filled out for all participants</u>. 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**.

<u>For unimpaired participants:</u> 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.

	lary, contributing, or non-contributing or leave the chec					Non-
	Etiological Diagnoses	Present		Primary	Contributing	contributing
12.	Alzheimer's disease	□ 1	12a.	□ 1	_2	3
13.	Lewy body disease	□ 1	13a.	□ 1	_2	3
14.	Frontotemporal lobar degeneration (FTLD)	□ 1				
	If <b>present</b> , select all that apply:					
	<b>14a.</b> Progressive supranuclear palsy (PSP)	□ 1	14a1.	□ 1	$\square_2$	3
	<b>14b.</b> Corticobasal degeneration (CBD)	□ 1	14b1.	□ 1	$\square_2$	3
	<b>14c.</b> FTLD with motor neuron disease	□ 1	14c1.	□ 1	$\square_2$	3
	<b>14d.</b> FTLD - not otherwise specified (NOS)		14d1.	□ 1	$\square_2$	□ 3
	14e. If FTLD (QUESTION 14) is present, specify FTLD s  1 Tauopathy 2 TDP-43 proteinopathy 3 Other (SPECIFY): 9 Unknown	,,				
15.	Vascular brain injury (based on clinical and imaging evidence according to your Center's standards)	□ <sub>1</sub>	15a.	□ <sub>1</sub>	□2	□ 3
16.	Multiple system atrophy	□ 1	16a.	□ 1	$\square_2$	3
17.	Chronic traumatic encephalopathy (CTE)	□ 1	17a.	□ 1	$\square_2$	3
	17b. If CTE (QUESTION 17) is present, specify certaint  1 Suggestive CTE 2 Possible CTE 3 Probable CTE	y:				
18.	Down syndrome	□ 1	18a.	□ 1	_2	3
19.	Huntington's disease		19a.	□ 1	_2	3
20.	Prion disease (CJD, other)		20a.	□ 1	_2	3
21.	Cerebral amyloid angiopathy		21a.	□ 1	_2	3
22.	LATE: Limbic-predominant age-related TDP-43 encephalopathy	□1	22a.	□ 1	<u></u>	3
23.	Other (SPECIFY):	□ 1	23a.	□ 1	_2	3

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