FOLLOW-UP VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0



Form A3: Participant Family History

ADRC:	PTID:		Form date	:/	_/	Visit #:	Examiner's initials:		
□1 English □	ode: 1 In-person 2 Remote (<i>reason</i>): 1 Telephone		3=F 4=F	oo cognitively oo physically i Iomebound o efused in-per Other	impaired r nursing ho	ome			
	: This form is to be cor ates are allowed if exac book, Form A3.		•						
Section 1 -	Biological pare	nts							
	st UDS visit, is new inf s biological mother o		concerning the s	tatus of the		0 No (SKIP TO	QUESTION 2) ETE QUESTIONS 1A-1B)		
For any parent w	vith a neurological or	osychiatric diagnos	is, the entire row	must be fill	ed out.				
= Unknown in the psychiatric diagrathe subsequent q	nnnot determine the p he Primary diagnosis nosis, enter 00 = No k <i>uestions in the row</i> . Fo e Secondary diagnosis	column, and <i>skip tl</i> nown neurologica r a parent with a pr	he subsequent qu Il/psychiatric dia	estions in the I gnosis in t	<i>e row</i> . For he Prima ı	a parent with no y diagnosis colu	neurological or ımn, and then <i>skip</i>		
	Birth year	Age at death	Primary dx*	Second	dary dx*	Method of evaluation**	Age of onset		
	(6666=provided at previous visit, 9999=Unknown)	(666=provided at previous visit, 888=N/A, 999=Unknown)		SEE LIST O	F CODES		of primary dx (666=provided at previous visit, 999 = Unknown)		
1a. Mother				_	_	_			
1b. Father				_	_	_			
Codes									
*DIAGNOSES									
00 No know	n neurological/psych	iatric diagnosis	**METH	**METHOD OF EVALUATION					
01 Alzheimer's Disease			1 Par	1 Participant/family report					
02 Lewy Body dementia (includes DLB and PDD)			2 Med	2 Medical records					
03 Vascular dementia				3 Exam					
04 Stroke				(co-enrolled family members)					
05 FTLD* without motor neuron disease				4 Autopsy (if autopsy report available)					
06 FTLD* with motor neuron disease			6 Pro	6 Provided at previous visit					
07 Motor Ne									
08 Parkinsor									
09 Prion pathology			*FTLD in	*FTLD includes: bvFTD or FTD, PPA (any subtype), CBS or CBD, PSP					
10 Psychiatric condition				· · ·					
11 Dementia of unknown etiology				Abbreviations: bvFTD = behavioral variant frontotemporal dementia, CBS = corticobasal syndrome, CBD = corticobasal					
12 Other			degenera	degeneration, DLB = dementia with Lewy bodies, FTD = frontotemporal dementia, PDD = Parkinson's disease with dementia, PPA = primary progressive aphasia, PSP = progressive supranuclear palsy					
	66 Provided at previous visit								
	88 No secondary diagnosis 99 Specific diagnosis unknown (acceptable if method of								
•	nagnosis unknown (a on is not bv exam or au	•	101						

YEAR OF BIRTH FOR FULL SIBLINGS & BIOLOGICAL CHILDREN: If birth year is unknown, please provide an approximate year on UDS Initial Visit Form A3 and UDS Follow-up Visit Form A3 so that the sibling or child with unknown birth year ends up in correct birth order relative to the other siblings/children.								
Example: A participant is the oldest of three children. The participant was born in 1940 and the middle sibling in 1943; the youngest sibling's birth year is unknown. An approximate birth year of 1944 or later should be assigned to the youngest sibling.								
Use that same birth year on FTLD Module Form A3a, if applicable, and across all UDS visits so that any new								
information on a particular sibling or child can be linked to previously submitted information. If it is impossible for the participant and co-participant to estimate the birth year, enter 9999=Unknown .								
		,						
Section 2 – Full siblings								
	Since the last UDS visit, is new information available concerning the status of the participant's full siblings? One (SKIP TO QUESTION 3) 1 Yes (COMPLETE 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, SKIP TO QUES	TION 3; otherwise, pr	ovide information	on all full siblings			
•	-		gnosis, the entire row					
			cal/psychiatric diagno e subsequent question					
psychiatric diagno	osis, enter 00 = No k	nown neurologic	al/psychiatric diagn	osis in the Primar	y diagnosis colui	mn, and then <i>skip</i>		
	<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, at previous 9999=Unknown) visit, 888=N/A, SEE LIST OF COD					(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								
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 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

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Section 3 – B	iological child	ren					
3. Since the last UDS visit, is new information available concerning the status of the participant's biological children? \[\begin{align*} 0 & \text{NO (END FORM HERE)} \\ \text{D1 Yes (COMPLETE QUESTIONS 3B-3P)} \end{align*} \]							
3.1. How many biological children does the participant have?							
(66 = provided at previous visit)							
If participant has no biological children, END FORM HERE ; otherwise, provide information on all biological children.							
For any biological	child with a neurolo	gical or psychiatric	diagnosis, the entire	e row <u>must be fille</u>	d out.		
If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter 99 = Unknown in the Primary diagnosis column, and <i>skip the subsequent questions in the row</i> . For a biological child with no neurological or psychiatric diagnosis, enter 00 = No known neurological/psychiatric diagnosis in the Primary diagnosis column, and then <i>skip the subsequent questions in the row</i> . For a biological child with a primary diagnosis but no secondary diagnosis, enter 88 = No secondary diagnosis in the Secondary diagnosis column.							
	Birth year	Age at death	Primary dx*	Secondary dx*	Method of	Age of onset	
	(6666=provided at previous visit, 9999=Unknown)	(666=provided at previous visit, 888=N/A, 999=Unknown)	SE	evaluation**	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