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



## Form A3: Participant Family History

ADRC:	PTID:	<u> </u>	Form da	te:/_	/	Visit #:	initials:		
	de: In-person Remote <i>(reason):</i>		3= 4=	Too cognitive Too physical Homebound Refused in-p	ly impaired I or nursing I				
	tes are allowed if exac					•	gical and psychiatric mples, see the <b>UDS</b>		
Section 1 – E	iological pare	nts							
For any parent wi	th a neurological or <sub>l</sub>	osychiatric diagnos	is, the entire ro	v <u>must be 1</u>	illed out.				
= <b>Unknown</b> in the psychiatric diagnothe subsequent qu	nnot determine the pee Primary diagnosis osis, enter <b>00 = No k</b> estions in the row. Fo Secondary diagnosis	column, and skip t nown neurologica r a parent with a pr	he subsequent q al/psychiatric d	uestions in i iagnosis ir	<i>the row</i> . Fo	or a parent with no ary diagnosis colu	neurological or ımn, and then <i>skip</i>		
	Birth year	Age at death	Primary dx	Seco	ndary dx <sup>*</sup>		Age of onset		
	(6666=provided at previous visit, 9999=Unknown)	(666=provided at previous visit, 888=N/A, 999 = Unknown)	•••••	· SEE LIST	OF CODE	evaluation**  S	of primary dx (666=provided at previous visit, 999 = Unknown)		
1a. Mother						_			
1b. Father						_			
Codes									
*DIAGNOSES									
00 No known neurological/psychiatric diagnosis			**MET	**METHOD OF EVALUATION					
01 Alzheimer's Disease			<b>1</b> Pa	1 Participant/family report					
02 Lewy Body dementia (includes DLB and PDD)			2 M	2 Medical records					
03 Vascular dementia				3 Exam					
<b>04</b> Stroke				(co-enrolled family members)					
<b>05</b> FTLD* without motor neuron disease				4 Autopsy (if autopsy report available)					
<b>06</b> FTLD* with motor neuron disease			<b>6</b> Pr	6 Provided at previous visit					
07 Motor Neuron Disease									
08 Parkinson'									
09 Prion pathology			*FTLD i	*FTLD includes: bvFTD or FTD, PPA (any subtype), CBS or CBD, PSP					
10 Psychiatric condition			41.1	, , ,					
11 Dementia of unknown etiology				<b>Abbreviations:</b> bvFTD = behavioral variant frontotemporal dementia, CBS = corticobasal syndrome, CBD = corticobasal					
<ul><li>12 Other</li><li>66 Provided at previous visit</li></ul>				degeneration, DLB = dementia with Lewy bodies, FTD =					
	·			frontotemporal dementia, PDD = Parkinson's disease with dementia, PPA = primary progressive aphasia, PSP = progressive supranuclear					
	88 No secondary diagnosis  99 Specific diagnosis unknown (acceptable if method of evaluation is not by exam or autonsy)				palsy				

<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.								
	<b>Example:</b> 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 <b>FTLD Module Form A3a</b> , <i>if applicable</i> , 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, <i>enter</i> <b>9999=Unknown</b> .								
Section 2 - F	ull siblings							
2. Since the last UDS visit, is new information available concerning the status of the participant's full siblings?								
2a. How mar	ny full siblings does	the participant ha	ive?					
	(77 = participant	adopted or siblir	ngs unknown; 66 = p	rovided at previou	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			
For any full sibling with a neurological or psychiatric diagnosis, the entire row <u>must be filled out</u> .  If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter <b>99</b> = <b>Unknown</b> in the <b>Primary diagnosis</b> column, and <i>skip the subsequent questions in the row</i> . For a full sibling with no neurological or psychiatric diagnosis, enter <b>00</b> = <b>No known neurological/psychiatric diagnosis</b> in the <b>Primary diagnosis</b> column, and then <i>skip the subsequent questions in the row</i> . For a full sibling with a primary diagnosis but no secondary diagnosis, enter <b>88</b> = <b>No secondary diagnosis</b> 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)				
2b. Sibling 1	1							
2c. Sibling 2					_			
2d. Sibling 3								
2e. Sibling 4								
2f. Sibling 5					_			
2g. Sibling 6					_			
2h. Sibling 7								
2i. Sibling 8								
2j. Sibling 9								
2k. Sibling 10					_			
2l. Sibling 11			——	— —	_			
2m. Sibling 12					_			
2n. Sibling 13					_			
20. Sibling 14					_			
					_			
2p. Sibling 15			——		_			
TO SIBILIDA 16								
2q. Sibling 16					_			
2r. Sibling 17					_			
2r. Sibling 17 2s. Sibling 18			 		_ _ _			
2r. Sibling 17			 	 	_ _ _			

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

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Section 3 - B	Biological 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)} \\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \									
3a. How many biological children does the participant have?									
(66 = provided at previous visit)									
If particip	If participant has no biological children, <b>END FORM HERE</b> ; otherwise, provide information on all biological children.								
For any biological child with a neurological or psychiatric diagnosis, the entire row <u>must be filled out</u> .  If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter <b>99</b> = <b>Unknown</b> in the <b>Primary diagnosis</b> column, and <i>skip the subsequent questions in the row</i> . For a biological child with no neurological or psychiatric diagnosis, enter <b>00</b> = <b>No known neurological/psychiatric diagnosis</b> in the <b>Primary diagnosis</b> 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 <b>88</b> = <b>No secondary diagnosis</b> 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	E LIST OF CODES	evaluation**	of primary dx (666=provided at previous visit, 999=Unknown)			
3b. Child 1					_				
3c. Child 2					_				
3d. Child 3					_				
3e. Child 4					_				
3f. Child 5					_				
3g. Child 6					_				
3h. Child 7					_				
3i. Child 8					_				
3j. Child 9					_				
3k. Child 10					_				
3l. Child 11					_				
3m. Child 12					_				
3n. Child 13					_				
3o. Child 14					_				
3p. Child 15					_				

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