INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0



Form A3: Participant Family History

ADRC nar	me:	Participant ID:	Form date:	/	/
Visi	t #:	Examiner's initials:			
	TRUCTIONS: This form is to be conditions. Estimate and examples,	' '	ear or age at death is unkno	wn. For additio	5 ,
1.	Are there affected first-degre or biological children)? "Affected"= having dementia (Appendix 1, Page 5)	· 3 ·	, 3,	□ 0 No □ 1 Yes □ 9 Unk	nown

SECTION 1 - Biologi	cal Parents					
See list of codes (below):	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999 = Unknown)
(below).			······ SEE LIS	T OF CODES	•••••	
2a. Mother			_		_	
2b . Father			_		_	

Codes

*NEUROLOGICAL PROBLEMS & PSYCHIATRIC CONDITIONS

- 1 No known neurological illness
- 2 Dementia syndrome typical of Alzheimer Disease (AD)
- 3 Dementia syndrome typical of non-AD disease (ex. LBD, FTLD, Vascular dementia)
- 4 Dementia syndrome of uncertain etiology or not typical of AD, LBD, FTLD, etc.
- 5 Other neurologic disorder including Parkinsonism, ALS
- 6 Psychiatric condition
- 8 Unknown

**PRIMARY DIAGNOSIS

See Appendix 1 on Page 5 of this form.

*** METHOD OF EVALUATION

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

/ Visit #:

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

3. How many full siblings does the participant ha	ve?
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If participant has no full siblings, **SKIP TO QUESTION 7**; otherwise, provide information on all full siblings.

For any full sibling with a neurological or psychiatric condition, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter 9=Unknown in the Primary neurological problem/psychiatric condition column, and then skip the subsequent questions in the row. For a sibling with no neurological or psychiatric problem, enter8=N/A—no neurological problem or psychiatric condition in the Primary neurological problem/psychiatric condition column, and then skip the subsequent questions in the row.

See list of codes (page 1):	Birth year 9999=Unknown	Age at death 888=N/A, 999=Unknown	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset 999=Unknown
(page 1).			······ SEE LIST	T OF CODES	•••••	
3a . Sibling 1			_		_	
3b . Sibling 2			_		_	
3c . Sibling 3			_		_	
3d . Sibling 4			_		_	
3e . Sibling 5			_		_	
3f. Sibling 6			_		_	
3g . Sibling 7			_		_	
3h . Sibling 8			_			

Participant ID:	Form date:	/ /	Visit #:

SECTION 2 - Full Sik	SECTION 2 - Full Siblings						
See list of codes	Birth year 9999=Unknown	Age at death 888=N/A, 999=Unknown	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset 999 = Unknown	
(page 1):			······ SEE LIST	······ SEE LIST OF CODES ······			
3i . Sibling 9			_		_		
3j . Sibling 10			_		_		
3k. Sibling 11			_		_		
3I. Sibling 12			_		_		
3m. Sibling 13			_		_		
3n . Sibling 14			_		_		
3o . Sibling 15			_		_		
3p . Sibling 16			_		_		
3q . Sibling 17			_		_		
3r. Sibling 18			_		_		
3s . Sibling 19			_		_		
3t . Sibling 20			_		_		

Participant ID:	Form date:	/ /	Visit #:

SECTION 3 - Biological Children

4. How many biological children does the participant have?

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

For any biological child with a neurological or psychiatric condition, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter 9=Unknown in the Primary neurological problem/psychiatric condition column, and then skip the subsequent questions in the row. For a biological child with no neurological or psychiatric problem, enter 8=N/A—no neurological problem or psychiatric condition in the Primary neurological problem/psychiatric condition column, and then skip the subsequent questions in the row.

See list of codes	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999 = Unknown)
(page 1):			······ SEE LIST	OF CODES	•••••	
4a . Child 1			_		_	
4b . Child 2			_		_	
4c . Child 3			_		_	
4d . Child 4			_		_	———
4e . Child 5			_		_	
4f . Child 6			_		_	
4g . Child 7			_		_	
4h . Child 8			_		_	
4i . Child 9			_		_	
4j . Child 10			_		_	
4k . Child 11			_		_	
4l . Child 12			_		_	
4m . Child 13			_		_	
4n . Child 14			_		_	
4o. Child 15			_		_	

Participant ID:	Form date:	/ /	Visit #:
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** A _l	ppendix 1: Diagnosis Codes
01	Alzheimer's Disease
02	Lewy Body dementia (includes DLB and PDD)
03	Vascular dementia
04	FTLD* without motor neuron disease
05	FTLD* with motor neuron disease
06	Motor Neuron Disease
07	Parkinson's Disease
08	Prion pathology
09	Other
99	Specific diagnosis unknown (acceptable if method of evaluation is not by exam or autopsy)

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

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