



NACC UNIFORM DATA SET **FTLD MODULE**

## Follow-up Visit Packet

**Version 3.0, March 2015**

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This publication was funded by the National Institutes  
of Health through the National Institute on Aging  
(Cooperative Agreement U01 AG016976).

PLEASE SEE INSIDE COVER FOR LIST OF REVISIONS MADE  
TO THIS DOCUMENT SINCE UDS3 IMPLEMENTATION

Revisions made to this packet since UDS3 implementation (March 15, 2015)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected	Data element(s) affected
2015-09-14	Coding corrected for co-participant's relationship to subject (4=Parent, 5=Sibling)	C5F	N/A	FTDINFRE
2015-03-30	Allowable code of 88=Unknown or 88.88=Unknown added for consistency with DED	C2F	23, 24, 25, 26	FTDSNTOT, FTDSNTBS, FTDSNTOS, FTDSNRAT
2015-03-30	Allowable code of 88=Unknown added for consistency with DED	C4F	8	FTDBIST
2015-03-30	Allowable code of 88=Unknown added for consistency with DED	C5F	15, 16	FTDIRIEC, FTDIRIPT
2015-03-30	Allowable code of 88=Unknown added for consistency with DED	C6F	14, 15, 16	FTDSMSCR, FTDSPSCR, FTDRSMST

# Guide to abbreviations

AD	Alzheimer's disease
ADC	Alzheimer's Disease Center, any of 30 Centers across the United States participating in the Alzheimer's Disease Centers Program conducted by NIA
ADNI	Alzheimer's Disease Neuroimaging Initiative
ALS	Amyotrophic lateral sclerosis
bvFTD	Behavioral variant frontotemporal dementia
CBD	Corticobasal degeneration
DLB	Dementia with Lewy bodies
FTLD	Frontotemporal lobar degeneration
FTLD Module	A collection of data concerning FTLD on subjects in the NACC Uniform Data Set and appended to the UDS
IVP	Initial Visit Packet, the set of forms completed at a subject's initial evaluation for submission to NACC
MCI	Mild cognitive impairment
MMSE	Mini-mental state examination
MND	Motor neuron disease
NACC	National Alzheimer's Coordinating Center, funded by NIA and charged with collecting data from the ADCs
NIA	National Institute on Aging, one of the U.S. National Institutes of Health
PLS	Primary lateral sclerosis
PPA	Primary progressive aphasia
SMA	Spinal muscular atrophy
UDS	Uniform Data Set, the longitudinal database maintained by NACC; the other components of the NACC database are the Minimum Data Set (MDS) and the Neuropathologic Data Set (NP)
UPDRS	Unified Parkinson's Disease Rating Scale
VaD	Vascular dementia

## A note on form numbering

Each NACC form has a unique two- to four-character number (e.g., B9, E2F, Z1, A3aF). With the exception of Form A3a, all forms in the FTLD Module have numbers ending with **F**. As in the UDS, the **first character** of the form number indicates what kind of information is collected by the form:

- A: Family history (genetic) data
- B: Clinical data
- C: Neuropsychology data
- E: Imaging data
- Z: Used only for the Form Checklist

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

## Form Z1F: Form Checklist

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by clinic staff.*

NACC expects and intends that all FTLN forms will be attempted on all subjects being evaluated for the FTLN Module of the UDS, but we realize this may be impossible when the subject is terminally ill, or when there is no informant, or for other reasons. Nevertheless, NACC **requires** that Forms B3F, B9F, C1F, C2F, C3F, E2F, and E3F be submitted for a subject to be included in the FTLN Module of the UDS database, even though these forms may include some items with missing data.

For forms **not** designated as required, if it is not feasible to collect all or almost all of the data elements for a subject, and the ADC therefore decides not to attempt collection of those data, an explanation should be provided. Please indicate this decision by including the appropriate explanatory code and any additional comments.

**KEY:** If the specified form was not completed, please enter one of the following codes:  
**95=Physical problem**   **96=Cognitive/behavior problem**   **97=Other problem**   **98=Verbal refusal**   **99=Unknown or inadequate information**

Form	Description	Submitted:		If not submitted, specify reason (see key, above)	Comments (provide if needed)
		Yes	No		
A3a	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
B3F	Supplemental UPDRS	<b>Required</b>			
B9F	Clinical PPA and bvFTD Features	<b>Required</b>			
C1F	Neuropsychological Battery Summary Scores	<b>Required</b>			
C2F	Social Norms Questionnaire	<b>Required</b>			
C3F	Social Behavior Observer Checklist	<b>Required</b>			
C4F	Behavioral Inhibition Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
C5F	Interpersonal Reactivity Index	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
C6F	Revised Self-monitoring Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
E2F	Imaging Available	<b>Required</b>			
E3F	Imaging in Diagnosis	<b>Required</b>			

# Form Z1X: Form Checklist

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by clinic personnel.*

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no co-participant, or for other reasons. An explanation is required below for forms that are not submitted.

## UDS

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY):
	English	Spanish		Yes	No	
A1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Demographics	<b>Required</b>		
A2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Co-participant Demographics	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A3	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Family History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Medications	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Health History	<b>Required</b>		
B1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Physical	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Global Staging — CDR: Standard and Supplemental	<b>Required</b>		
B5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT NPI-Q	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B6	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT GDS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	FUNCTIONAL ASSESSMENT NACC FAS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B8	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Neurological Examination Findings	<b>Required</b>		
B9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Judgment of Symptoms	<b>Required</b>		
C1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	<b>Either C1 or C2 is required</b>		
C2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Scores			
D1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Diagnosis	<b>Required</b>		
D2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician-assessed Medical Conditions	<b>Required</b>		

## FTLD MODULE

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY*):
	English	Spanish		Yes	No	
A3a	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Supplemental UPDRS	<b>Required</b>		
B9F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinical PPA and bvFTD Features	<b>Required</b>		
C1F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	<b>Required</b>		
C2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Norms Questionnaire	<b>Required</b>		
C3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Behavior Observer Checklist	<b>Required</b>		
C4F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Behavioral Inhibition Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C5F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Interpersonal Reactivity Index	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C6F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Revised Self-monitoring Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
E2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging Available	<b>Required</b>		
E3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging in Diagnosis	<b>Required</b>		

## CLS FORM

Form	Language:		Description	Submitted:		
	English	Spanish		Yes	No	
CLS	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject's Language History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<b>Submit only once</b>

**KEY:** If the specified form was not completed, please enter one of the following codes: 95=Physical problem 96=Cognitive or behavioral problem 97=Other problem 98=Verbal refusal  
 \*KEY FOR FTLD MODULE ONLY: Allowable codes are 95 – 98 as above, as well as 99=Unknown or inadequate information.

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

# Form A3a: Record of Consent for Biologic Specimen Use

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by clinic staff responsible for obtaining consents, based on an existing consent at clinic. For additional clarification and examples, see FTLD Coding Guidebook for Initial Visit Packet, Form A3aF.*

**One of these forms will be completed for each relative who provides a specimen.**

**1. What relative's consent is being recorded on this form?**

**NOTE:** "Unknown" (9999) is not a permissible value for sibling's or child's birth year. If birth year is unknown, please provide an approximate year on **UDS Initial Visit Form A3** so that the sibling or child ends up in correct birth order relative to the other siblings or children.

**"Sibling's birth year" or "child's birth year" on this form MUST agree with the birth year listed for that person on UDS Initial Visit or UDS Follow-up Visit Form A3.**

- 1 Mother
- 2 Father
- 3 Sibling (sibling's birth year: \_\_\_\_\_ )
- 4 Child (child's birth year: \_\_\_\_\_ )

**Please indicate that the above relative provided consent for the following. The wording need not be identical but should explicitly express the same points.**

<b>1a.</b>	I permit my sample to be stored and used in future research of neurologic disease at (home institution).	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
<b>1b.</b>	I permit my sample to be stored and used in future research at (home institution) to learn about, prevent, or treat other health problems.	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
<b>1c.</b>	There is a small chance that some commercial value may result from my sample at the National Cell Repository for Alzheimer's Disease (NCRAD). If that were to happen, I would not be offered a share in any profits. I permit (home institution) to give my sample to researchers at other institutions.	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

# Form B3F: Supplemental UPDRS

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional. For additional clarification and examples, see FTLD Module Coding Guidebook for Follow-up Visit Packet, Form B3F. Check only one box per question.*

	Not to a degree that would justify such a diagnosis	Yes — with asymmetry		Yes — without major asymmetry
		L>R	R>L	
<b>SECTION A</b>				
<b>A1.</b> Does the subject have limb or torso fasciculations consistent with a diagnosis of spinal muscular atrophy (SMA) or amyotrophic lateral sclerosis (ALS)*?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
<b>A2.</b> Does the subject have limb weakness and/or hyperreflexia consistent with a diagnosis of primary lateral sclerosis (PLS) or ALS*?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
<b>A3.</b> Does the subject have bulbar weakness and/or fasciculations consistent with a diagnosis of ALS*?	<input type="checkbox"/> 0			<input type="checkbox"/> 3
<b>SECTION B Gait disturbances</b>				
<b>B1.</b> Gait disturbance — severity	<input type="checkbox"/> 0 Normal <input type="checkbox"/> 1 Slight alteration in speed or fluidity of gait <input type="checkbox"/> 2 Walks with difficulty but requires no assistance <input type="checkbox"/> 3 Severe disturbance <input type="checkbox"/> 4 Cannot walk at all <input type="checkbox"/> 8 Untestable (SPECIFY REASON): _____			
<b>B2.</b> Gait disturbance — type	<input type="checkbox"/> 0 Normal <input type="checkbox"/> 1 Hemiparetic (spastic) <input type="checkbox"/> 2 Foot drop gait (lower motor neuron) <input type="checkbox"/> 3 Ataxic gait <input type="checkbox"/> 4 Parkinsonian gait <input type="checkbox"/> 5 Apractic gait (“magnetic gait”) <input type="checkbox"/> 6 Antalgic gait <input type="checkbox"/> 7 Other gait disorder not listed above (SPECIFY): _____ <input type="checkbox"/> 8 Untestable (SPECIFY REASON): _____			

\*NOTE: For the items marked with an asterisk, definitions and explanations can be found in the FTLD Module Coding Guidebook for Follow-up Visit Packet, Form B3F.

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) FTLD MODULE

# Form B9F: Clinical PPA and bvFTD Features

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by a clinician with experience in evaluating subjects with frontotemporal lobar degeneration. For additional clarification, see FTLD Coding Guidebook for Follow-up Visit Packet, Form B9F. Check only one box per question.*

Gateway question for primary progressive aphasia (PPA)				
1. Is an acquired disorder of language a prominent element of the clinical presentation of the subject? (I.e., at least one of the characteristics described in Questions 2–11 is “Definitely present”).	<input type="checkbox"/> 0 No (SKIP TO QUESTION 14) <input type="checkbox"/> 1 Yes			
Characterizing speech and language symptoms / assigning PPA subtype				
<i>Are these features present on the current examination?</i> <i>Note: Many of these items are also evaluated in the neuropsychological assessment. The responses recorded here should represent the consensus of the clinical and neuropsychological evaluation.</i>				
	<b>Absent</b>	<b>Questionably present</b>	<b>Definitely present</b>	<b>Not evaluated</b>
2. <b>Poor object naming</b> (Core diagnostic feature of semantic variant; abnormal in all variants)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
3. <b>Impoverished word selection / retrieval in spontaneous speech or writing</b> (Core diagnostic feature of logopenic variant; abnormal in all variants)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
4. <b>Impaired word comprehension</b> (Core diagnostic feature of semantic variant; absent in other variants)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
5. <b>Poor object/person knowledge</b> (Secondary diagnostic feature of semantic variant; absent in other variants)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
6. <b>Grammatical simplification or grammatical errors in speech or writing</b> (Core diagnostic feature of nonfluent/agrammatic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7. <b>Effortful, halting speech</b> (Core diagnostic feature of nonfluent/agrammatic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
8. <b>Circumlocutory, empty speech</b> (Secondary diagnostic feature of logopenic variant; also present in semantic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
9. <b>Speech sound/word errors (paraphasias)</b> (Secondary diagnostic feature of logopenic variant; abnormal in nonfluent/agrammatic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
10. <b>Impaired speech repetition (inability to repeat verbatim sentence-length material)</b> (Core diagnostic feature of logopenic variant; present in nonfluent/agrammatic type; absent in semantic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9



	Absent	Questionably present	Definitely present	Not evaluated
11. <b>Surface dyslexia and dysgraphia</b> — also refer to <i>Word Reading Test</i> from <i>FTLD Neuropsychological Battery</i> (Secondary feature of semantic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
12. <b>ROOT DIAGNOSIS OF PPA</b> Does the subject have an acquired and progressive difficulty with language consistent with PPA of a neurodegenerative type AND is the language disorder the most prominent deficit at symptom outset and for the initial phase (1–2 years) of the disorder?	<input type="checkbox"/> 0 No <b>(SKIP TO QUESTION 14)</b>		<input type="checkbox"/> 1 Yes — Meets root diagnosis of PPA <b>(PROCEED TO QUESTION 13)</b>	
13. <b>Consensus diagnosis of dominant PPA subtype based on clinician and neuropsychologist judgment</b>	<input type="checkbox"/> 1 PPA, semantic variant (semPPA) <input type="checkbox"/> 2 PPA, nonfluent/agrammatic variant (nf/gPPA) <input type="checkbox"/> 3 PPA, logopenic variant <input type="checkbox"/> 4 PPA not otherwise specified			

### Gateway question for behavioral variant frontotemporal dementia (bvFTD)

14. **Are acquired alterations in behavior, personality, or comporment important elements in the clinical presentation of the subject? (I.e., at least one of the characteristics described in Questions 15–21 is “Definitely present”).**
- 0 No **(SKIP TO QUESTION 23)**  
 1 Yes

### Characterizing symptoms of bvFTD

<i>Have the following symptoms/behaviors been prominent, persistent, and recurrent in (approximately) the past three years?</i>	Absent	Questionably present	Definitely present	Not evaluated
15. <b>Disinhibition</b> Socially inappropriate behavior; loss of manners or decorum; impulsive, rash, or careless actions	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
16. <b>Apathy or inertia</b> Loss of interest, drive, and motivation; decreased initiation of behavior	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
17. <b>Loss of sympathy / empathy</b> Diminished response to other people’s needs or feelings; diminished social interest, interrelatedness, or personal warmth	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
18. <b>Ritualistic / compulsive behavior</b> Simple repetitive movements or complex compulsive or ritualistic behaviors	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
19. <b>Hyperorality and appetite changes</b> Altered food preferences, binge eating, increased consumption of alcohol or cigarettes, oral exploration or consumption of inedible objects	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
20. <b>Changes on neuropsychological testing consistent with bvFTD</b> (refer to neuropsychological evaluation and neuropsychologist’s impression)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
21. <b>Impaired daily functioning</b> Are these alterations in behavior, personality, or comporment the principal cause of impaired daily living activities?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

<p>22. <b>Does the subject meet the criteria for clinical probable* or possible** bvFTD syndrome — in other words, are features described in Questions 15–20 the most prominent parts of the clinical picture now or initially?”</b></p> <p>*PROBABLE: Meets three of the above criteria in Questions 15–20 and: (1) has impaired daily functioning (Question 21 = Definitely Present); and (2) has imaging consistent with bvFTD.</p> <p>**POSSIBLE: Meets three of the above criteria in Questions 15–20 and either: (1) is not functionally impaired (i.e., Question 21 = Absent) <u>or</u> (2) does not have imaging consistent with bvFTD.</p>	<p><input type="checkbox"/> 0 0 = Does not meet criteria for bvFTD: either subject meets &lt;3 of the features described in Questions 15–20, OR another diagnosis is suggested by prominent features not covered by Questions 15–20</p> <p><input type="checkbox"/> 1 Probable bvFTD</p> <p><input type="checkbox"/> 2 Meets criteria for possible bvFTD and has impaired daily functioning but without evidence of diagnostic imaging</p> <p><input type="checkbox"/> 3 Meets criteria for possible bvFTD (with or without evidence of diagnostic imaging), but daily functioning is not significantly impaired</p>
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	No	Yes	Uncertain
23. <b>Was an electromyogram (EMG) performed at this visit?</b> If answer is “1 (Yes)”, SKIP TO QUESTION 25.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
24. <b>Has an EMG been performed in the past year?</b> If answer is “0 (No)”, SKIP TO QUESTION 26.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
25. <b>If an EMG was performed, did it show evidence of motor neuron disease?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

*If subject has only one diagnosis (either PPA or bvFTD), then END FORM HERE.*

<p>26. <b>For subjects with a diagnosis of both PPA and bvFTD, which diagnosis appeared first?</b></p>	<p><input type="checkbox"/> 1 bvFTD</p> <p><input type="checkbox"/> 2 PPA, semantic variant</p> <p><input type="checkbox"/> 3 PPA, nonfluent/agrammatic variant</p> <p><input type="checkbox"/> 4 PPA, logopenic variant</p> <p><input type="checkbox"/> 5 PPA not otherwise specified</p> <p><input type="checkbox"/> 9 Unknown</p>
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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) FTLD MODULE

# Form C1F: Neuropsychological Battery Summary Scores

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by ADC or clinic staff. For test administration and scoring, see FTLD Module Coding Guidebook for Follow-up Visit Packet, Form C1F. Time to completion of C1F and C2F tests should be reported at the end of Form C3F.*

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:  
**95 = Physical problem    96 = Cognitive/behavior problem    97 = Other problem    98 = Verbal refusal**

1. Word Reading Test — Regular and Irregular Words		
REGULAR		
1a. Total completely accurate words <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 2a)</i>	(0–15, 95–98)	___ ___
1b. Total semantically related inaccurate words	(0–15)	___ ___
1c. Total other phonologically related words or nonword errors	(0–15)	___ ___
IRREGULAR		
1d. Total completely accurate words	(0–15)	___ ___
1e. Total semantically related inaccurate words	(0–15)	___ ___
1f. Total words that are “regularized” (read using “phonics,” e.g., <i>sew</i> read as <i>sue</i> )	(0–15)	___ ___
1g. Total other phonologically related words or nonword errors	(0–15)	___ ___
2. Semantic Word-picture Matching Test		
2a. Total correct word-picture matches <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 3a)</i>	(0–20, 95–98)	___ ___
3. Semantic Associates Test		
3a. Total correct animal associations <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 4a)</i>	(0–8, 95–98)	___ ___
3b. Total correct tool associations	(0–8)	___ ___
3c. Sum of all correct associations (Semantic Associates Test total score)	(0–16)	___ ___
4. Northwestern Anagram Test — Short Form		
4a. Correct subject who-questions <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 5a)</i>	(0–5, 95–98)	___ ___
4b. Correct object who-questions	(0–5)	___ ___
4c. Total score: sum of all correct questions	(0–10)	___ ___

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:

**95 = Physical problem    96 = Cognitive/behavior problem    97 = Other problem    98 = Verbal refusal**

5. Sentence Repetition Test		
5a. Number of completely accurate sentences <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 6a)</i>	(0–5, 95–98)	____ ____
5b. Total number of words omitted from sentences	(0–37)	____ ____
5c. Total number of semantically related or unrelated incorrect real words	(0–20)	____ ____
5d. Total number of phonologically related words or nonword errors	(0–20)	____ ____
6. Noun and Verb Naming Subtests		
6a. Total nouns correct <i>(If test not completed, enter reason code, 95–98, and SKIP TO QUESTION 7a)</i>	(0–16, 95–98)	____ ____
6b. Total verbs correct	(0–16)	____ ____
6c. Noun-to-verb ratio (total nouns correct / total verbs correct)	(88.88 = Cannot be calculated)	____ . ____
7. Sentence Reading Test		
7a. Number of completely accurate sentences <i>(If test not completed, enter reason code, 95–98, and END FORM HERE)</i>	(0–5, 95–98)	____ ____
7b. Total number of words omitted from sentence	(0–37)	____ ____
7c. Total number of semantically related or unrelated incorrect real words	(0–20)	____ ____
7d. Total number of phonologically related words or nonword errors	(0–20)	____ ____

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) — FTLD MODULE

## Form C2F: Social Norms Questionnaire<sup>1</sup>

### INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **by the subject in the presence of a qualified psychologist or psychometrist** as part of a face-to-face battery of tests. The examiner should read and explain the instructions to the subject, then ask the subject to complete the questionnaire. If the subject asks for clarification of the procedure or questions, it is acceptable for the examiner to discuss the questionnaire with him or her. Tell the subject that “Don’t know” and “Not applicable” are not allowable responses for any item. While it is permissible to help a cognitively impaired subject understand and complete the questionnaire (e.g., by reading the questions out loud, or marking their response for them), the examiner should ensure that they merely help the subject understand a question (e.g., by saying, “Do you think it’s OK to cut in line if you are in a hurry?”), but not help them formulate their response. In this way, if the subject asks what they should answer, it would be permissible to respond with prompts such as, “It’s up to you. Answer whatever you think is best. It’s OK to guess if you’re not sure.”

**KEY:** If the subject is so impaired as to make administration of this questionnaire impossible, please give the reason by checking one of the following reason codes in the “FOR CLINIC USE ONLY” section and skip the remaining data elements.

**95 = Physical problem    96 = Cognitive/behavior problem    97 = Other problem    98 = Verbal refusal**

If the subject completes some but not all of the questionnaire, items that are missing should be left blank, and all affected summary scores should be entered as “88” or “88.88”, as appropriate.

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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

# Form C2F: Social Norms Questionnaire<sup>1</sup>

**FOR CLINIC USE ONLY:**

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

95=Physical problem     96=Cognitive/behavior problem     97=Other problem     98=Verbal refusal

**Instructions:** Following is a list of behaviors that a person might engage in. Please decide whether or not it would be socially acceptable and appropriate to do these things in the mainstream culture of the United States and answer yes or no to each. Think about these questions as if they were occurring in front of or with a stranger or acquaintance, NOT a close friend or family member.

**WOULD IT BE SOCIALLY ACCEPTABLE TO:**

1. Tell a stranger you don't like their hairstyle?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
2. Spit on the floor?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
3. Blow your nose in public?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
4. Ask a coworker their age?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
5. Cry during a movie at the theater?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
6. Cut in line if you are in a hurry?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
7. Laugh when you yourself trip and fall?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
8. Eat pasta with your fingers?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
9. Tell a coworker your age?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
10. Tell someone your opinion of a movie they haven't seen?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
11. Laugh when someone else trips and falls?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
12. Wear the same shirt every day?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
13. Keep money you find on the sidewalk?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES

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14. Pick your nose in public?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
15. Tell a coworker you think they are overweight?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
16. Eat ribs with your fingers?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
17. Tell a stranger you like their hairstyle?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
18. Wear the same shirt twice in two weeks?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
19. Tell someone the ending of a movie they haven't seen?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
20. Hug a stranger without asking first?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
21. Talk out loud during a movie at the theater?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES
22. Tell a coworker you think they have lost weight?	<input type="checkbox"/> 0 NO	<input type="checkbox"/> 1 YES

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**FOR CLINIC USE ONLY. Note: Calculation of the four summary scores below is OPTIONAL.**

23. SNQ22 Total Score (0–22, 88=Unknown):	___ ___
24. Break Score (0–12, 88=Unknown):	___ ___
25. Overadhere Score (0–10, 88=Unknown):	___ ___
26. Yes-No Ratio Score (0–22, 88.88=Unknown):	___ ___ . ___ ___

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

# Form C3F: Social Behavior Observer Checklist<sup>1</sup>

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by the examiner who administered the neuro-psychological battery to the subject. For additional clarification and examples, see FTL D Module — Instructions for Neuropsychological Questionnaires (Forms C2F – C6F) and Tests Reported on Form C1F. Check only one box per question.*

**Directions:** Immediately after the end of your evaluation of the subject, please rate his/her behavior during the time he/she was with you. Use the scales for both the main descriptors (i.e., 1, 2, 3 ...) and the behavior counts (a, b, c ...) and complete all items.

Your descriptor ratings and behavior counts for the same item can be independent. You may describe the subject as having a particular characteristic on a main descriptor, even if you endorse “never” for all of the behavior counts for that item, or vice versa.

<b>1. Was overly self-conscious / embarrassed for self:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Spontaneously mentioned that he/she was performing badly	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Made other self-depreciatory comments	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Showed emotional distress over his/her performance / cognitive abilities	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>2. Showed too little self-consciousness / embarrassment for self:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Disrobed immodestly (took off shoes, belt, pants, etc.; lifted shirt, etc.)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Engaged in belching or flatulence, or picked nose without apology	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Giggled or otherwise made silly, childish comment or noise	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>3. Insensitive to others' embarrassment or privacy:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Insulted or made a negative comment about examiner	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Made an embarrassing comment about examiner	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Made an inappropriate or embarrassing joke	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+

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<b>4. Failed to adapt / defer to structure of testing situation established by examiner:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Resisted redirection while engaging in a verbal monologue	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Interrupted examiner	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Verbalized a desire to leave the evaluation prematurely	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
d. Physically attempted to leave the evaluation prematurely	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
e. Failed to maintain topic of discussion, initiated tangent	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
f. Demanded that test protocol be broken for him/her (e.g., insisted on completing an item after being told to stop, tried to cheat, tried to turn page to advance to next item against examiner's expressed wishes, etc.)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>5. Was preoccupied with time or kept a strict timetable:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Reminded examiner what time evaluation had to be finished	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>6. Acted overly dependent:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Mentioned caregiver's absence or asked when caregiver would return	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Asked for feedback on performance	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Showed frustration when examiner would not provide explicit feedback	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>7. Was anxious:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Mentioned being nervous about testing / performance anxiety	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Mentioned being nervous about diagnosis or prognosis	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>8. Was stimulus-bound:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Made stimulus-bound error on testing	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Picked up object on desk unnecessarily	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Circumstantial speech; overly focused on details, overly lengthy	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+

<b>9. Was perseverative:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Repeated previous answer on testing	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Repeated an anecdote	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>10. Showed decreased initiation:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Began response in a notably delayed manner (not due to general slowing)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Required additional verbal prompting to initiate task	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>11. Showed fluctuating level of cognitive ability through sessions regardless of complexity of material (e.g., was coherent at times and had notable difficulty understanding at other times):</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Lost task set / forgot instructions after performing task correctly	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Repeated rules to self multiple times during task	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Lost train of thought during conversation or response (demonstrated thought blocking)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>12. Was overly disclosing or inappropriately familiar:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
a. Spontaneously revealed inappropriately personal information concerning self (only)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
b. Spontaneously revealed inappropriately personal information concerning a relative or friend (can also involve self)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
c. Stood or leaned too close to examiner (noticeably entered examiner's personal space)	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
d. Touched examiner	<input type="checkbox"/> 0 Never	<input type="checkbox"/> 1 Once	<input type="checkbox"/> 2 2-3x	<input type="checkbox"/> 3 4+
<b>13. Showed diminished social / emotional engagement:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
<b>14. Showed exaggerated / labile emotional reactivity:</b>	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely

Rankin (2010)

<b>15. DESCRIPTOR TOTAL SCORE (0-42):</b>	_____
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<b>16. CHECKLIST (BEHAVIOR) SCORE (0-105):</b>	_____
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<p><b>17. LENGTH OF THE ENTIRE FTLD NEUROPSYCHOLOGICAL TESTING SESSION:</b>                  Record in minutes the approximate length of the testing session upon which these checklist responses were based. This should include, at minimum, time spent on all tests in the FTLD neuropsychological battery (all tests recorded on Form C1F, plus Form C2F), as well as time spent administering any other neuropsychological tests.</p>	_____
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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) — FTLD MODULE

## Form C4F: Behavioral Inhibition Scale<sup>1</sup> CO-PARTICIPANT QUESTIONNAIRE

### INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the co-participant**, who will be describing the subject's current typical behavior. This form may be handed to the co-participant for completion by him- or herself at any time during the study visit. Tell the subject that "Don't know" and "Not applicable" are not allowable responses for any item. If the co-participant asks for clarification of questions, it is acceptable for a qualified psychologist or psychometrist to discuss the questionnaire with him or her. However, if the co-participant completes this questionnaire collaboratively with the clinician, either face-to-face or via telephone, **you must inform NACC of this change in protocol** by checking the appropriate box in the gray "FOR CLINIC USE ONLY" area at the top of the questionnaire.

Before the co-participant leaves, clinic staff should make sure that all questions were completed by the co-participant (i.e., none was left blank) by discussing the missing item with the co-participant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the co-participant, clinic staff should call the co-participant as soon as possible so that the missing items can be completed by phone. In this case, the questionnaire is not considered to have been completed independently by the co-participant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of co-participant by clinic staff."

If there are still missing items, these items should be left blank, and "88" should be entered for the total score.

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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) — FTLD MODULE

# Form C4F: Behavioral Inhibition Scale<sup>1</sup>

FOR CLINIC USE ONLY:

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**THIS QUESTIONNAIRE WAS COMPLETED:**

- 0 Independently by co-participant, as described in "Instructions to the Center"
- 1 Via in-person interview of co-participant by clinic staff
- 2 Via telephone interview of co-participant by clinic staff

**INSTRUCTIONS:** Indicate how well each statement describes the subject's **CURRENT** behavior. There are no right or wrong answers; we just want to get your impression of how you think the subject typically behaves.

If you have questions about how to complete this questionnaire, please ask a staff member, and they will be happy to help you.

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
1. If the subject thinks something unpleasant is going to happen, he/she usually gets pretty "worked up."	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. The subject worries about making mistakes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Criticism or scolding hurts the subject quite a bit.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. The subject feels pretty worried or upset when he/she thinks somebody is angry at him/her.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Even if something bad is about to happen to the subject, he/she rarely experiences fear or nervousness.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. The subject feels worried when he/she thinks he/she has done poorly at something.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. The subject has very few fears compared to his/her friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

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FOR CLINIC USE ONLY:

8. BIS Total Score (7–28, 88=Unknown): \_\_\_\_\_

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) FTL D MODULE

## Form C5F: Interpersonal Reactivity Index<sup>1</sup> co-PARTICIPANT QUESTIONNAIRE

### INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the co-participant**, who will be describing the subject's current typical behavior. This form may be handed to the co-participant for completion by him- or herself at any time during the study visit. If the co-participant asks for clarification of questions, it is acceptable for a qualified psychologist or psychometrist to discuss the questionnaire with him or her. However, if the co-participant completes this questionnaire collaboratively with the clinician, either face-to-face or via telephone, **you must inform NACC of this change in protocol** by checking the appropriate box in the gray "FOR CLINIC USE ONLY" area at the top of the questionnaire.

Before the co-participant leaves, clinic staff should make sure that all questions were completed by the co-participant (i.e., none was left blank) by discussing the missing item with the co-participant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the co-participant, clinic staff should call the co-participant as soon as possible so that the missing items can be completed by phone. In this case, the questionnaire is not considered to have been completed independently by the co-participant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of co-participant by clinic staff."

If there are still missing items, these items should be left blank, and "88" should be entered for the Empathic Concern (EC) Score and

## Form C5F: Interpersonal Reactivity Index co-PARTICIPANT QUESTIONNAIRE

FOR CLINIC USE ONLY:

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**THIS QUESTIONNAIRE WAS COMPLETED:**

- 0 Independently by co-participant, as described in "Instructions to the Center"     1 Via in-person interview of co-participant by clinic staff     2 Via telephone interview of co-participant by clinic

Please give us some information about yourself:

**Your sex:**

- 1 Male  
 2 Female

**Your date of birth (mm/yyyy):**

\_\_\_\_/\_\_\_\_

**Your relationship to subject:**

- 1 Spouse or spouse equivalent  
 2 Child  
 3 Daughter- or son-in-law  
 4 Parent  
 5 Sibling  
 6 Other (other relative, friend, neighbor, paid caregiver)

**DIRECTIONS:** Indicate how well each statement describes the subject's **CURRENT** behavior. There are no right or wrong answers; we just want to get your impression of how you think the subject typically behaves.

If you have questions about how to complete this questionnaire, please ask a staff member, and they will be happy to help you.

	Does NOT describe well	←-----→			Describes VERY well
1. The subject shows tender, concerned feelings for people less fortunate than him/her.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. The subject sometimes finds it difficult to see things from the "other guy's" point of view.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Sometimes the subject does NOT feel very sorry for other people when they are having problems.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. The subject tries to look at everybody's side of a disagreement before he/she makes a decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. If the subject sees somebody being taken advantage of, the subject feels kind of protective towards him/her.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. The subject is likely to try to understand others better by imagining how things look from their perspective.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Other people's misfortunes do NOT usually disturb the subject a great deal.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Does NOT describe well	←-----→			Describes VERY well
8. If the subject is sure he/she is right about something, he/she doesn't waste much time listening to other people's arguments.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. If the subject sees someone being treated unfairly, the subject doesn't feel much pity for him/her.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. The subject is often quite touched by things he/she sees happen.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. The subject believes that there are two sides to every question and tries to look at both of them.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12. I would describe the subject as a pretty soft-hearted person.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13. If the subject is upset at someone, the subject usually tries to put him/herself "in the other person's shoes" for a while.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. Before criticizing me, the subject is likely to imagine how he/she would feel if he/she were in my place.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<sup>1</sup>Davis MH. *Measuring individual differences in empathy: evidence for a multidimensional approach.* J Pers Soc Psychol 1983; 44(1):113-126.

**FOR CLINIC USE ONLY:**

15. Empathic Concern Score (EC) (7–35, 88=Unknown):	___ ___
16. Perspective-taking Score (PT) (7–35, 88=Unknown):	___ ___

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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

## Form C6F: Revised Self-monitoring Scale<sup>1</sup> **co-PARTICIPANT QUESTIONNAIRE**

### INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the co-participant**, who will be describing the subject's current typical behavior. This form may be handed to the co-participant for completion by him- or herself at any time during the study visit. If the co-participant asks for clarification of questions, it is acceptable for a qualified psychologist or psychometrist to discuss the questionnaire with him or her. However, if the co-participant completes this questionnaire collaboratively with the clinician, either face-to-face or via telephone, **you must inform NACC of this change in protocol** by checking the appropriate box in the gray "FOR CLINIC USE ONLY" area at the top of the questionnaire.

Before the co-participant leaves, clinic staff should make sure that all questions were completed by the co-participant (i.e., none was left blank) by discussing the missing item with the co-participant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the co-participant, clinic staff should call the co-participant as soon as possible so that the missing items can be completed by phone. In this case, the questionnaire is not considered to have been completed independently by the co-participant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of co-participant by clinic staff."

If there are still missing items, these items should be left blank, and "88" should be entered for the Sensitivity to Socio-emotional Expressiveness (EX) Score, the Ability to Modify Self-presentation (SP) Score and the RSMS Total Score.

<sup>1</sup> Copyright © 1984 by the American Psychological Association. Adapted with permission. The official citation that should be used in referencing this material is Table 9 (adapted), p. 1361, from Revision of the Self-Monitoring Scale. Lennox, Richard D.; Wolfe, Raymond N. *Journal of Personality and Social Psychology*, Vol 46(6), Jun 1984, 1349-1364. doi: 10.1037/0022-3514.46.6.1349. No further reproduction or distribution is permitted without written permission from the American Psychological Association.



## Form C6F: Revised Self-monitoring Scale<sup>1</sup> CO-PARTICIPANT QUESTIONNAIRE

FOR CLINIC USE ONLY:

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**THIS QUESTIONNAIRE WAS COMPLETED:**

0 Independently by co-participant, as described in "Instructions to the Center"     1 Via in-person interview of co-participant by clinic staff     2 Via telephone interview of co-participant by clinic staff

**DIRECTIONS:** Indicate how well each statement describes the subject's **CURRENT** behavior. There are no right or wrong answers; we just want to get your impression of how you think the subject typically behaves. If you have questions about how to complete this questionnaire, please ask a staff member, and they will be happy to help you.

	Certainly, always false (0)	Generally false (1)	Somewhat false, but with exceptions (2)	Somewhat true, but with exceptions (3)	Generally true (4)	Certainly, always true (5)
1. In social situations, the subject has the ability to alter his/her behavior if he/she feels that something else is called for.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. The subject is often able to correctly read people's true emotions through their eyes.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. The subject has the ability to control the way he/she comes across to people, depending on the impression he/she wants to give them.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. In conversations, the subject is sensitive to even the slightest change in the facial expression of the person he/she is conversing with.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. The subject's powers of intuition are quite good when it comes to understanding others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. The subject can usually tell when others consider a joke in bad taste, even though they may laugh convincingly.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. When the subject feels that the image he/she is projecting isn't working, he/she can readily change to something that does.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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	Certainly, always false (0)	Generally false (1)	Somewhat false, but with exceptions (2)	Somewhat true, but with exceptions (3)	Generally true (4)	Certainly, always true (5)
<b>8.</b> The subject can usually tell when he/she said something inappropriate by reading it in the listener's eyes.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>9.</b> The subject has trouble changing his/her behavior to suit different people and different situations.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>10.</b> The subject can adjust his/her behavior to meet the requirements of any situation he/she is in.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>11.</b> If someone is lying to the subject, he/she usually knows it at once from that person's manner or expression.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>12.</b> Even when it might be to his/her advantage, the subject has difficulty putting up a good front.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>13.</b> Once the subject knows what the situation calls for, it's easy for him/her to regulate his/her actions accordingly.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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14. Sensitivity to Socio-emotional Expressiveness Score (EX) (0–30, 88=Unknown):	___
15. Ability to Modify Self-presentation Score (SP) (0–35, 88=Unknown):	___
16. RSMS Total Score (0–65, 88=Unknown):	___

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

## Form E2F: Imaging Available

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by the clinician or imaging specialist involved in interpreting the scan. For additional clarification and examples, see FTL D Module Coding Guidebook for Follow-up Visit Packet, Form E2F. Check only one box per question.*

<p><b>1. Is a structural MRI scan, obtained as part of the current evaluation or a previous evaluation and not yet recorded, available for data sharing? (REPORT MOST RECENT)</b></p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p><b>IF YES, complete 1a – 1f; if no, go to Question 2.</b></p>	
<p>1a. Date of scan (MM / DD / YYYY): <i>NOTE: A value of 99 (unknown) is permissible for day only.</i></p>	<p>____ / ____ / _____</p>
<p>1b. Is it in DICOM format or other electronic format?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (specify format): _____ <input type="checkbox"/> 9 Unknown</p>
<p>1c. Was ADNI protocol used?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <i>ADNI version:</i> _____ <input type="checkbox"/> 9 Unknown</p>
<p>1d. Scan manufacturer:</p>	<p><input type="checkbox"/> 1 GE <input type="checkbox"/> 2 Siemens <input type="checkbox"/> 3 Philips <input type="checkbox"/> 4 Other: _____ <input type="checkbox"/> 9 Unknown</p>
<p>1d1. Scan model:</p>	<p>_____</p>

1e. Field strength:	<input type="checkbox"/> 1 1.5T <input type="checkbox"/> 2 3T <input type="checkbox"/> 3 7T <input type="checkbox"/> 4 Other: _____ <input type="checkbox"/> 9 Unknown
1f. Are results of quantitative image analysis available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
<b>2. Is an FDG-PET scan, obtained as part of the current evaluation or a previous evaluation and not yet recorded, available for data sharing? (REPORT MOST RECENT)</b>	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
<b>IF YES, complete 2a – 2e; if no, go to Question 3.</b>	
2a. Date of scan (MM / DD / YYYY): <i>NOTE: A value of 99 (unknown) is permissible for day only.</i>	____ / ____ / _____
2b. Is it in DICOM format or other electronic format?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (specify format): _____ <input type="checkbox"/> 9 Unknown
2c. Was ADNI protocol used?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <i>ADNI version:</i> _____ <input type="checkbox"/> 9 Unknown
2d. Scan manufacturer:	<input type="checkbox"/> 1 GE <input type="checkbox"/> 2 Siemens <input type="checkbox"/> 3 Philips <input type="checkbox"/> 4 Other: _____ <input type="checkbox"/> 9 Unknown
2d1. Scan model:	_____
2e. Are results of quantitative image analysis available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

<p><b>3. Is an amyloid PET scan, obtained as part of the current evaluation or a previous evaluation and not yet recorded, available for data sharing? (REPORT MOST RECENT)</b></p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p><b>IF YES, complete 3a – 3f; if no, go to Question 4.</b></p>	
<p>3a. Date of scan (MM / DD / YYYY): <i>NOTE: A value of 99 (unknown) is permissible for day only.</i></p>	<p>____ / ____ / _____</p>
<p>3b. Is it in DICOM format or other electronic format?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (specify format): _____ <input type="checkbox"/> 9 Unknown</p>
<p>3c. Ligand used:</p>	<p><input type="checkbox"/> 1 11C-PIB <input type="checkbox"/> 2 18F-AV45 <input type="checkbox"/> 3 Other (specify): _____ <input type="checkbox"/> 9 Unknown</p>
<p>3d. Was ADNI protocol used?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <i>ADNI version:</i> _____ <input type="checkbox"/> 9 Unknown</p>
<p>3e. Scan manufacturer:</p>	<p><input type="checkbox"/> 1 GE <input type="checkbox"/> 2 Siemens <input type="checkbox"/> 3 Philips <input type="checkbox"/> 4 Other: _____ <input type="checkbox"/> 9 Unknown</p>
<p>3e1. Scan model:</p>	<p>_____</p>
<p>3f. Are results of quantitative image analysis available?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>

<p><b>4. Are other PET or SPECT scans, obtained as part of the current evaluation or a previous evaluation and not yet recorded, available for data sharing? (REPORT MOST RECENT)</b></p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes <i>(If yes, identify type(s) below)</i></p>
<p><b>IF YES, complete 4a – 4d; if no, end form here.</b></p>	
<p>4a. Is a dopaminergic scan available?</p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 9 Unknown</p>
<p>4b. Is a serotonergic scan available?</p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 9 Unknown</p>
<p>4c. Is a cholinergic scan available?</p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 9 Unknown</p>
<p>4d. Is another kind of scan available?</p>	<p><input type="checkbox"/> 0 No</p> <p><input type="checkbox"/> 1 Yes (SPECIFY):</p> <p>_____</p>

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) **FTLD MODULE**

## Form E3F: Imaging in Diagnosis

ADC name: \_\_\_\_\_ Subject ID: \_\_\_\_\_ Form date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by the clinician or imaging specialist involved in interpreting the scan. For additional clarification and examples, see FTL D Module Coding Guidebook for Follow-up Visit Packet, Form E3F. Check only one box per question.*

	No	Yes	Unknown
<b>1. Was imaging obtained as part of this visit for use in diagnosis?</b> If the answer is "0 (No)", SKIP THE REST OF THIS FORM.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
<b>STRUCTURAL MRI</b>			
<b>2. Was structural MRI done?</b> If "No", SKIP TO QUESTION 3.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
<b>2a. Was focal atrophy (beyond what would be expected for age) appreciated by visual inspection?</b> If "No" or "Unknown", SKIP TO QUESTION 3.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>Where was focal atrophy appreciated?</b>			
2a1. Right frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a2. Left frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a3. Right temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a4. Left temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a5. Right medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a6. Left medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a7. Right parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a8. Left parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a9. Right basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a10. Left basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
2a11. Other area of the brain (specify below): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

	No	Yes	Unknown
<b>FDG-PET</b>			
<b>3. Was FDG-PET done?</b> If "No", SKIP TO QUESTION 4.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
<b>3a. Was focal hypometabolism appreciated by visual inspection?</b> If "No" or "Unknown", SKIP TO QUESTION 4.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>Where was focal hypometabolism appreciated?</b>			
3a1. Right frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a2. Left frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a3. Right temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a4. Left temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a5. Right medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a6. Left medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a7. Right parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a8. Left parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a9. Right basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a10. Left basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
3a11. Other area of the brain (specify below): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

	No	Yes	Unknown
<b>AMYLOID PET</b>			
<b>4. Was amyloid PET done?</b> If "No", SKIP TO QUESTION 5.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
<b>4a. Was amyloid deposition appreciated by visual inspection?</b> If "No" or "Unknown", SKIP TO QUESTION 5.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>Where was amyloid deposition noted?</b>			
4a1. Right frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a2. Left frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a3. Right temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a4. Left temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a5. Right medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9



	No	Yes	Unknown
4a6. Left medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a7. Right parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a8. Left parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a9. Right basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a10. Left basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
4a11. Other area of the brain (specify below): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

	No	Yes	Unknown
<b>CBF SPECT</b>			
<b>5. Was CBF SPECT done?</b> If "No", SKIP TO QUESTION 6.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
<b>5a. Were abnormalities appreciated by visual inspection?</b> If "No" or "Unknown", SKIP TO QUESTION 6.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
<b>Where were abnormalities noted?</b>			
5a1. Right frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a2. Left frontal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a3. Right temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a4. Left temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a5. Right medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a6. Left medial temporal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a7. Right parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a8. Left parietal lobe	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a9. Right basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a10. Left basal ganglia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
5a11. Other area of the brain (specify below): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

	No	Yes	Unknown
<b>OTHER IMAGING</b>			
<b>6. Was other imaging done?</b> If "Yes", specify: _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	