

NACC Uniform Data Set (UDS) — FTLD Module

Follow-up Visit Packet FORMS

Version 2.0, January 2012

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NOTE: Version 2 is NOT the most current version of the FTLD Module forms and is no longer used for data submission. For the most current version, please visit <http://www.alz.washington.edu>.

This packet last modified October 28, 2013.

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
FVP	Follow-up Visit Packet, the set of forms completed for submission to NACC at evaluations following the subject's initial visit
IVP	Initial Visit Packet, the set of forms completed for submission to NACC at a subject's initial evaluation
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). For forms that are part of the FTLD Module to the UDS, the **last character is 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: Neuropsychologic 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

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: This form is to be completed by clinic staff.

Visit #: ____

Examiner's initials: ____

NACC expects and intends that all FTLD forms will be attempted on all subjects being evaluated for the FTLD 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 FTLD Module of the UDS database, even though these forms may include some 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		
A3aF	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
A3F	Family History: Affected Family Members	<input type="checkbox"/> 1	<input type="checkbox"/> 0	____	
B3F	Supplemental UPDRS	Required			
B9F	Clinical PPA and bvFTD Features	Required			
C1F	Neuropsychological Battery Summary Scores	Required			
C2F	Social Norms Questionnaire	Required			
C3F	Social Behavior Observer Checklist	Required			
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	Required			
E3F	Imaging in Diagnosis	Required			

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

Form A3aF: Record of Consent for Biologic Specimen Use

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: 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 Follow-up Visit Packet, Form A3aF.

Visit #: _____
Examiner's initials: _____

One of these forms will be completed for each relative who provides a specimen. If the information below was previously submitted for the relative but there has been a change in consent, fill out the form in its entirety. If information recorded previously is found to be incorrect (e.g. sibling's or child's birth date), edit the original form; do not create a new entry on this form.

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 and FTLD Module Initial Visit or FTLD Follow-up Visit Form A3F (if applicable).

- ☐ 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.

1a.	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
1b.	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
1c.	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 would 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 A3F: Family History: Affected Family Members

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: This form is to be completed by a clinician with experience in evaluating patients with frontotemporal lobar degeneration. For additional clarification and examples, see FTLD Coding Guidebook for Follow-up Visit Packet, Form A3F.

Visit #: _____
Examiner's initials: _____

INSTRUCTIONS: Review all data collected on Form A3F at all previous FTLD module visit(s), if applicable, with the subject or informant. For family members who were denoted as being affected at a previous FTLD module visit, any corrections to their data should be made to that previous A3F form. Any newly obtained diagnoses for a family member, including family members previously reported as being affected at a past FTLD module visit, should be indicated on this form and should not be submitted as a correction to the previous A3F.

If this is the first time you are providing A3F information for this subject's family, fill out this form in its entirety.

"AFFECTED FAMILY MEMBERS" — Please consider blood relatives only. For the purposes of Form A3F, "affected" means affected by dementia **OR** by any of the non-normal clinical diagnoses listed in Appendix 1 on page 6 of this form.

1. AFFECTED FAMILY MEMBERS			
<p>Since the last FTLD Module visit, is new information available concerning data collected by items 1a through 1g, below?</p> <p>If 1 (Yes), COMPLETE SECTION 1 and then go on to Section 2.</p> <p>If 0 (No), SKIP TO SECTION 2.</p>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	
<p>1a. Are there affected family members? (See box above for definition of "affected.") If the answer is "No" or "Unknown," please skip the rest of this form.</p>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown
<p>1b. In this family, is there a known mutation in a gene associated with FTLD? If the answer is "No" or "Unknown," please SKIP TO SECTION 2.</p>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown
<p>1c. What is the predominant mutation?</p>	<input type="checkbox"/> 1 MAPT <input type="checkbox"/> 2 PGRN <input type="checkbox"/> 3 C9ORF72 <input type="checkbox"/> 4 FUS <input type="checkbox"/> 8 Other (SPECIFY: _____) <input type="checkbox"/> 9 Unknown		
<p>1d. Is there evidence for this mutation in the form of commercial lab test documentation?</p>	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown

1e. Is there evidence for this mutation in the form of research lab test documentation?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown
1f. Is there evidence for this mutation in the form of family report?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 9 Unknown
1g. Is there other evidence for this mutation?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SPECIFY: _____) <input type="checkbox"/> 9 Unknown		

AFFECTED PARENTS — Use the form below to provide information on affected parents only (see definition of “affected” in the box above). **Provide all information below if it has not been submitted previously. If you are updating previously submitted A3F data for one or more relatives, please enter all data in the row for that relative and also correct any previously submitted A3F form data for this relative, if applicable. Otherwise, check the box for 0 (No) in the first line below to indicate no affected parent or no change since data were previously submitted on affected parents.**

2. AFFECTED PARENTS					
Since the last FTLD Module visit, is new information available concerning the status of the subject's mother or father?				<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
If 1 (Yes), please COMPLETE ITEM 2a and/or ITEM 2b, below. If 0 (No), SKIP SECTION 2 and go on to Section 3.					
		a. Neurological problem*	b. Primary DX**	c. Method of evaluation***	d. Age of onset
2a.	Mother	_____	_____	_____	_____
2b.	Father	_____	_____	_____	_____

***Codes for neurological problems and psychiatric conditions**

- 1 Cognitive impairment/behavior change
- 2 Parkinsonism
- 3 ALS
- 4 Other neurologic condition such as multiple sclerosis or stroke
- 5 Psychiatric condition such as schizophrenia, bipolar disorder, or alcoholism
- 9 Unknown

****Codes for primary diagnosis**

See Appendix 1 on page 6 of this form

*****Codes for method of evaluation**

For descriptions, see Appendix 2 on page 6 of this form

- 1 Autopsy
- 2 Examination
- 3 Medical record review from formal dementia evaluation
- 4 Review of general medical records AND informant and/or subject telephone interview
- 5 Review of general medical records only
- 6 Subject and/or informant telephone interview
- 7 Family report

AFFECTED SIBLINGS — Use the form below to provide information on affected siblings only (see definition of “affected” in the box on page 1 of this form). **Provide all information below if it has not been submitted previously. If you are updating previously submitted A3F data for one or more relatives, please enter all data in the row for that relative and also correct any previously submitted A3F form data for this relative, if applicable. Otherwise, check the box for 0 (No) in the first line below to indicate no affected sibling or no change since data were previously submitted on affected siblings.**

“Sibling’s birth year” on this form MUST agree with the birth year listed for that sibling on UDS Initial Visit or UDS Follow-up Visit Form A3 and FTLD Module Initial Visit or FTLD Follow-up Visit Form A3F (if applicable).

“Unknown” (9999) is not a permissible value. If birth year is unknown, please provide an approximate year on UDS Initial Visit or UDS Follow-up Visit Form A3 so that the sibling with unknown birth year ends up in correct birth order relative to the other siblings.

(EXAMPLE: Suppose a subject is the oldest of three children. The subject was born in 1930 and the middle sibling in 1933; the youngest sibling’s birth year is unknown. An approximate birth year of 1934 or later should be assigned to the youngest sibling.) **Use that same birth year on FTLD Module Forms A3F and A3aF.**

If an affected sibling has already been listed on UDS Initial Visit or UDS Follow-up Visit Form A3 with a birth year of 9999, then UDS Initial Visit or UDS Follow-up Visit Form A3 must be edited so that an approximate birth year is entered, as described in the paragraph above. That same birth year should be entered below.

“Sibling’s birth month” should be filled out if known; otherwise, please enter “99”. Only full siblings should be listed.

3. AFFECTED SIBLINGS					
Since the last FTLD Module visit, is new information available concerning the status of any of the subject's siblings?				<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
If 1 (Yes), please COMPLETE SECTION 3, below. If 0 (No), SKIP SECTION 3 and go on to Section 4.					
	a. Sibling's birth mo / yr	b. Neurological problem*	c. Primary DX**	d. Method of evaluation***	e. Age of onset
3a.	___ / ____	___	_____	___	_____
3b.	___ / ____	___	_____	___	_____
3c.	___ / ____	___	_____	___	_____
3d.	___ / ____	___	_____	___	_____
3e.	___ / ____	___	_____	___	_____
3f.	___ / ____	___	_____	___	_____
3g.	___ / ____	___	_____	___	_____
3h.	___ / ____	___	_____	___	_____
3i.	___ / ____	___	_____	___	_____
3j.	___ / ____	___	_____	___	_____
3k.	___ / ____	___	_____	___	_____
3l.	___ / ____	___	_____	___	_____
3m.	___ / ____	___	_____	___	_____

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- 7 Family report

AFFECTED CHILDREN — Use the form below to provide information on affected children only (see definition of “affected” in the box on page 1 of this form). **Provide all information below if it has not been submitted previously. If you are updating previously submitted A3F data for one or more relatives, please enter all data in the row for that relative and also correct any previously submitted A3F form data for this relative, if applicable. Otherwise, check the box for 0 (No) in the first line below to indicate no affected child or no change since data were previously submitted on affected children.**

“Child’s birth year” on this form **MUST** agree with the birth year listed for that child on UDS Initial Visit or UDS Follow-up Visit Form A3 and FTLN Module Initial Visit or FTLN Follow-up Visit Form A3F (if applicable).

“Unknown” (9999) is not a permissible value. If birth year is unknown, please provide an approximate year on UDS Initial Visit or UDS Follow-up Visit Form A3 so that the child with unknown birth year ends up in correct birth order relative to the other children. (EXAMPLE: Suppose a subject has three children. The oldest is a son born in 1960, the youngest a son born in 1964, and the middle child a girl whose birth year is unknown. The girl should be assigned an approximate birth year of 1962 or 1963.) **Use that same birth year from UDS Initial Visit or UDS Follow-up Visit Form A3 on FTLN Module Forms A3F and A3aF.**

If an affected child has already been listed on UDS Initial Visit or UDS Follow-up Visit Form A3 with a birth year of 9999, then UDS Initial Visit or UDS Follow-up Visit Form A3 must be edited so that an approximate birth year is entered, as described in the paragraph above. That same birth year should be entered below.

“Child’s birth month” should be filled out if known; otherwise, please enter “99”.

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4. AFFECTED CHILDREN					
Since the last FTLN Module visit, is new information available concerning the status of any of the subject's children?				<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
If 1 (Yes), please COMPLETE SECTION 4, below. If 0 (No), then END FORM HERE.					
	a. Child's birth mo / yr	b. Neurological problem*	c. Primary DX**	d. Method of evaluation***	e. Age of onset
4a.	___ / ___	___	___	___	___
4b.	___ / ___	___	___	___	___
4c.	___ / ___	___	___	___	___
4d.	___ / ___	___	___	___	___
4e.	___ / ___	___	___	___	___
4f.	___ / ___	___	___	___	___
4g.	___ / ___	___	___	___	___
4h.	___ / ___	___	___	___	___
4i.	___ / ___	___	___	___	___

Center: _____ Subject ID: _____ Form Date: ____/____/____

Visit #: ____

4j.	____ / ____	____	____	____	____
	a. Child's birth mo / yr	b. Neurological problem*	c. Primary DX**	d. Method of evaluation***	e. Age of onset
4k.	____ / ____	____	____	____	____
4l.	____ / ____	____	____	____	____
4m.	____ / ____	____	____	____	____

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****APPENDIX 1: PRIMARY DIAGNOSIS CODES**

CODE	DIAGNOSIS	CODE	DIAGNOSIS
040	Mild cognitive impairment (MCI), not otherwise specified	140	Progressive supranuclear palsy
041	MCI — amnesic	150	Corticobasal syndrome/corticobasal degeneration
042	MCI — multiple domain with amnesia	160	Huntington's disease
043	MCI — single domain nonamnesic	170	Prion disease
044	MCI — multiple domain nonamnesic	180	Cognitive dysfunction from medications
045	Impaired, but not MCI	190	Cognitive dysfunction from medical illness
050	Alzheimer's disease	200	Depression
070	Dementia with Lewy bodies	210	Other major psychiatric illness
080	Vascular dementia	220	Down syndrome
100	Alcohol-related dementia	230	Parkinson disease
110	Dementia of undetermined etiology	240	Stroke
120	Behavioral variant frontotemporal dementia	250	Hydrocephalus
130	Primary progressive aphasia, semantic variant	260	Traumatic brain injury
131	Primary progressive aphasia, nonfluent/agrammatic variant	270	CNS neoplasm
132	Primary progressive aphasia, logopenic variant	280	Other
133	Primary progressive aphasia, not otherwise specified	310	Amyotrophic lateral sclerosis
		320	Multiple sclerosis

*****APPENDIX 2: METHOD OF EVALUATION**

- Autopsy** — If the autopsy was performed at an outside institution, **you must have the report** to code as diagnosis by autopsy.
- Examination** — The subject must have been examined in person at your ADC/institution or by genetic studies staff associated with your ADC/institution to code as diagnosis by examination. Medical records may or may not have been used when assigning diagnosis.
- Medical record review from formal dementia evaluation** — Medical records should be from an examination that focused specifically on dementia; that was performed by a neurologist, geriatrician, or psychiatrist; that includes a neurologic examination, an imaging study, and cognitive testing (e.g., MMSE, Blessed, or more formal tests). A telephone interview may also be used to collect additional information.
- Review of general medical records AND informant and/or subject telephone interview** — **General medical records** can be of various types, including those from a primary-care physician's office, hospitalization records, nursing home records, etc. They may include a neurologic exam and a cognitive test such as the MMSE along with a medical history. **The telephone interview** with the subject and/or the informant should include a medical history to capture the nature and presentation of cognitive deficits, if present, and age of onset if symptomatic. If the subject is normal or is in the early stages of dementia, brief formal cognitive testing should be included in the interview. Unless an affected subject is in the early stages of dementia, the interview should be conducted with an informant.
- Review of general medical records ONLY** — See definition No. 4 above. If general medical records are used to diagnose a subject as demented or not demented, they should include a medical history, neurologic exam, and a cognitive test such as an MMSE. In most cases, general medical records alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTLD spectrum subtypes, or of parkinsonian disorders other than Parkinson disease.
- Subject and/or informant telephone interview** — See definition No. 4 above.
- Family report** — Family report should be coded when the informant for the family reports a subject as having been diagnosed with a particular disorder. In most cases, family report alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTLD spectrum subtypes, or of parkinsonian disorders other than Parkinson disease.

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

Form B3F: Supplemental UPDRS

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: 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.

Visit #: ____

Examiner's initials: ____

		Not to a degree that would justify such a diagnosis	Yes — with asymmetry		Yes — without major asymmetry	Untestable
			L>R	R>L		
SECTION A						
A1.	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	
A2.	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	
A3.	Does the subject have bulbar weakness and/or fasciculations consistent with a diagnosis of ALS*?	<input type="checkbox"/> 0			<input type="checkbox"/> 3	
A4.	Does the subject have eye movement abnormalities consistent with a diagnosis of progressive supranuclear palsy (PSP)*?	<input type="checkbox"/> 0			<input type="checkbox"/> 3	
A5.	Does the subject have dystonia* or rigidity consistent with a diagnosis of corticobasal degeneration (CBD)*?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
A6.	Is there ideomotor apraxia* consistent with a diagnosis of CBD?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8
A7.	Is the alien limb phenomenon* present consistent with a diagnosis of CBD?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2		<input type="checkbox"/> 8
A8.	Is there myoclonus* consistent with a diagnosis of CBD?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
A9.	Is there a cortical sensory deficit* consistent with a diagnosis of CBD?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 8

***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.**

SECTION B		Gait disturbances
B1.	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): _____
B2.	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): _____

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

Form B9F: Clinical PPA and bvFTD Features

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: 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.

Visit #: _____
Examiner's initials: _____

Gateway question for primary progressive aphasia (PPA)		
	No	Yes
1. Does the subject have an acquired and progressive difficulty with language* consistent with PPA of a neurodegenerative type? *DIFFICULTY WITH LANGUAGE: Other than simple dysarthria, are there difficulties with retrieving, using, repeating, sequencing, or understanding words? If answer is "No", check "0 (Absent)" for Questions 2–11 and "0 (No)" for Question 12.	<input type="checkbox"/> 0	<input type="checkbox"/> 1

Characterizing speech and language symptoms / assigning PPA subtype				
Are these features present on the current examination? 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.	Absent	Questionably present	Definitely present	Not evaluated
2. Poor object naming (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. Impoverished word selection / retrieval in spontaneous speech or writing (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. Impaired word comprehension (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. Poor object/person knowledge (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. Grammatical simplification or grammatical errors in speech or writing (Core diagnostic feature of nonfluent/agrammatic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9
7. Effortful, halting speech (Core diagnostic feature of nonfluent/agrammatic variant)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Characterizing speech and language symptoms / assigning PPA subtype (continued)

	Absent	Questionably present	Definitely present	Not evaluated
8. Circumlocutory, empty speech (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. Speech sound/word errors (paraphasias) (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. Impaired speech repetition (inability to repeat verbatim sentence-length material) (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
11. Surface dyslexia and dysgraphia — <i>also refer to Word Reading Test from 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. ROOT DIAGNOSIS OF PPA 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 Proceed to Question 14		<input type="checkbox"/> 1 Yes — Meets root diagnosis of PPA Proceed to Question 13	
13. Consensus diagnosis of dominant PPA subtype based on clinician and neuropsychologist judgment <i>NOTE: The diagnostic criteria in this module do not match the criteria in UDS V2.0 (Form D1). While Version 2.0 of the UDS is still in use, keep the two sets of diagnostic criteria separate.</i>	<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)

	No	Yes
14. Does the subject have acquired, clinically important alterations in behavior, personality, or comportment consistent with bvFTD of a neurodegenerative type? If answer is "No", check "0 (Absent)" for Questions 15–21 and "0 (Meets <3 of the features described in Questions 15–21: does not meet criteria for bvFTD; or an exclusionary feature is present.)" for Question 22.	<input type="checkbox"/> 0	<input type="checkbox"/> 1

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. Disinhibition 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. Apathy or inertia 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. Loss of sympathy/empathy 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. Ritualistic / compulsive behavior 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. Hyperorality and appetite changes 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. Changes on neuropsychological testing consistent with bvFTD (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. Impaired daily functioning Are these alterations in behavior, personality, or comportment 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. Does the subject meet the criteria for clinical probable* or possible** bvFTD syndrome?</p> <p>*PROBABLE: Meets three of the above criteria and has impaired daily functioning and has imaging consistent with bvFTD.</p> <p>**POSSIBLE: Meets three of the above criteria but is not functionally impaired or does not have imaging consistent with bvFTD.</p> <p><i>NOTE: The diagnostic criteria in this module do not match the criteria in UDS V2.0 (Form D1). While Version 2.0 of the UDS is still in use, keep the two sets of diagnostic criteria separate.</i></p>	<p><input type="checkbox"/> 0 Meets <3 of the features described in Questions 15–21: does not meet criteria for bvFTD; or an exclusionary feature is present.</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. Was an electromyogram (EMG) performed at this visit? If answer is "1 (Yes)", SKIP TO QUESTION 25.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
24. Has an EMG been performed in the past year? If answer is "0 (No)", SKIP TO QUESTION 26.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
25. If an EMG was performed, did it show evidence of motor neuron disease?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9

<i>If subject has only one diagnosis (either PPA or bvFTD), then END FORM HERE.</i>	
<p>26. For subjects with a diagnosis of both PPA and bvFTD, which diagnosis appeared first?</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>

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

Form C1F: Neuropsychological Battery Summary Scores

Center: _____ Subject ID: _____ Form Date: ____/____/____

NOTE: 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.

Visit #: _____
Examiner's initials: _____

KEY: If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes in the first data element and skip the rest of the data elements for that test:

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

1. Benson Complex Figure Copy

1a. Total score for copy of Benson figure (0–17) _____

2. Verbal Fluency: Phonemic Test

2a. Number of correct **F-words** generated in 1 minute (0–40) _____

2b. Number of **F-words** repeated in 1 minute (0–15) _____

2c. Number of **non-F-words** and rule violation errors in 1 minute (0–15) _____

2d. Number of correct **L-words** generated in 1 minute (0–40) _____

2e. Number of **L-words** repeated in one minute (0–15) _____

2f. Number of **non-L-words** and rule violation errors in 1 minute (0–15) _____

2g. TOTAL number of correct **F-words and L-words** (0–80) _____

2h. TOTAL number of **F-word and L-word** repetition errors (0–30) _____

2i. TOTAL number of **non-F/L words** and rule violation errors (0–30) _____

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

3. Word Reading Test — Regular and Irregular Words

REGULAR

3a. Total completely accurate words (0–15) _____

3b. Total semantically related inaccurate words (0–15) _____

3c. Total other phonologically related words or nonword errors (0–15) _____

IRREGULAR

3d. Total completely accurate words (0–15) _____

3e. Total semantically related inaccurate words (0–15) _____

3f. Total words that are “regularized” (read using “phonics,” e.g., *sew* read as *sue*) (0–15) _____

3g. Total other phonologically related words or nonword errors (0–15) _____

4. Benson Complex Figure Delay (Recall)

4a. Total score for 10- to 15-minute delayed drawing of Benson figure (0–17) _____

4b. Recognized original stimulus from among four options? ☐ 0 No☐ 1 Yes**5. Semantic Word-picture Matching Test**

5a. Total correct word-picture matches (0–20) _____

6. Semantic Associates Test

6a. Total correct animal associations (0–8) _____

6b. Total correct tool associations (0–8) _____

6c. Sum of all correct associations (Semantic Associates Test total score) (0–16) _____

7. Northwestern Anagram Test — Short Form

7a. Correct subject who-questions (0–5) _____

7b. Correct object who-questions (0–5) _____

7c. Total score: sum of all correct questions (0–10) _____

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

8. Sentence Repetition Test

- 8a. Number of completely accurate sentences (0–5) ____
- 8b. Total number of words omitted from sentences (0–37) ____
- 8c. Total number of semantically related or unrelated incorrect real words (0–20) ____
- 8d. Total number of phonologically related words or nonword errors (0–20) ____

9. Noun and Verb Naming Subtests

- 9a. Total nouns correct (0–16) ____
- 9b. Total verbs correct (0–16) ____
- 9c. Noun-to-verb ratio (total nouns correct / total verbs correct) ____

10. Sentence Reading Test

- 10a. Number of completely accurate sentences (0–5) ____
- 10b. Total number of words omitted from sentence (0–37) ____
- 10c. Total number of semantically related or unrelated incorrect real words (0–20) ____
- 10d. 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 Questionnaire¹

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 Questionnaire¹

FOR CLINIC USE ONLY:

Center: _____ Subject ID: _____ Form Date: ____/____/____

Reason code:

Visit #: _____

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

Examiner's initials: _____

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

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13.	Keep money you find on the sidewalk?	<input type="checkbox"/> ₀ NO	<input type="checkbox"/> ₁ YES
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): _____

24. Break Score (0–12): _____

25. Overadhere Score (0–10): _____

26. Yes-No Ratio Score (0–22): _____ . _____

Form C3F: Social Behavior Observer Checklist¹

Center: _____ Subject ID: _____ Form Date: ____/____/____

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

Visit #: ____

Examiner's initials: ____

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.

1.	Was overly self-conscious / embarrassed for self:	<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+
2.	Showed too little self-consciousness / embarrassment for self:	<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+
3.	Insensitive to others' embarrassment or privacy:	<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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4. Failed to adapt / defer to structure of testing situation established by examiner:	<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+
5. Was preoccupied with time or kept a strict timetable:	<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+
6. Acted overly dependent:	<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+
7. Was anxious:	<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+
8. Was stimulus-bound:	<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+
9. Was perseverative:	<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+

10.	Showed decreased initiation:	<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+
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):	<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+
12.	Was overly disclosing or inappropriately familiar:	<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+
13.	Showed diminished social / emotional engagement:	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely
14.	Showed exaggerated / labile emotional reactivity:	<input type="checkbox"/> 0 Not at all	<input type="checkbox"/> 1 A little bit	<input type="checkbox"/> 2 Moderately	<input type="checkbox"/> 3 Severely

15.	DESCRIPTOR TOTAL SCORE (0-42):	___
16.	CHECKLIST (BEHAVIOR) SCORE (0-105):	___

17.	LENGTH OF THE ENTIRE FTLD NEUROPSYCHOLOGICAL TESTING SESSION: 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.	___
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FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) — FTL D MODULE

Form C4F: Behavioral Inhibition Scale¹ — Informant Questionnaire

INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the informant**, who will be describing the subject's current typical behavior. This form may be handed to the informant 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 informant 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 informant 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 informant leaves, clinic staff should make sure that all questions were completed by the informant (i.e., none was left blank) by discussing the missing item with the informant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the informant, clinic staff should call the informant 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 informant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of informant 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) — FTL D MODULE

Form C4F: Behavioral Inhibition Scale¹ INFORMANT QUESTIONNAIRE

FOR CLINIC USE ONLY:

Center: _____ Subject ID: _____ Form Date: ____/____/____

Visit #: _____

THIS QUESTIONNAIRE WAS COMPLETED:

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

Examiner's initials: _____

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

Copyright © 1994 by the American Psychological Association. Adapted with permission. The official citation that should be used in referencing this material is Table 1 (adapted), p. 323, from Carver C. S., & White, T. L. (1994). Behavioral inhibition, behavioral activation, and affective responses to impending reward and punishment: The BIS/BAS Scales. Journal of Personality and Social Psychology, 67(2), 319-333. doi:10.1037/0022-3514.67.2.319. No further reproduction or distribution is permitted without written permission from the American Psychological Association.

FOR CLINIC USE ONLY:

8. BIS Total Score (7–28): _____

Form C5F: Interpersonal Reactivity Index¹ INFORMANT QUESTIONNAIRE

INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the informant**, who will be describing the subject's current typical behavior. This form may be handed to the informant for completion by him- or herself at any time during the study visit. If the informant 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 informant 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 informant leaves, clinic staff should make sure that all questions were completed by the informant (i.e., none was left blank) by discussing the missing item with the informant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the informant, clinic staff should call the informant 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 informant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of informant 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 Perspective-taking (PT) Score.

Form C5F: Interpersonal Reactivity Index¹ INFORMANT QUESTIONNAIRE

FOR CLINIC USE ONLY:

Center: _____ Subject ID: _____ Form Date: ____/____/____ Visit #: _____ Examiner's initials: _____

THIS QUESTIONNAIRE WAS COMPLETED:

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

PLEASE GIVE US SOME INFORMATION ABOUT YOURSELF:

Your sex: ☐ 1 Male ☐ 2 Female Your date of birth (mm/yyyy): ____/____/____

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

	Does NOT describe well	←-----→	Describes VERY well
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
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

¹Davis 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): ____

16. Perspective-taking Score (PT) (7–35): ____

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Form C6F: Revised Self-Monitoring Scale¹ INFORMANT QUESTIONNAIRE

INSTRUCTIONS FOR THE CENTER

This questionnaire is designed to be completed **independently by the informant**, who will be describing the subject's current typical behavior. This form may be handed to the informant for completion by him- or herself at any time during the study visit. If the informant 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 informant 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 informant leaves, clinic staff should make sure that all questions were completed by the informant (i.e., none was left blank) by discussing the missing item with the informant and encouraging them to provide a response. If this is not done and it is later noticed that some items were missed by the informant, clinic staff should call the informant 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 informant. In the shaded area at the top of the form, the appropriate response would therefore be, "This questionnaire was completed via telephone interview of informant 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.

¹ 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.

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

Form C6F: Revised Self-Monitoring Scale¹ INFORMANT QUESTIONNAIRE

FOR CLINIC USE ONLY:

Center: _____ Subject ID: _____ Form Date: ____/____/____ Visit #: _____ Examiner's initials: _____

THIS QUESTIONNAIRE WAS COMPLETED:

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

¹ 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.

	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)
8. 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
9. 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
10. 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
11. 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
12. 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
13. 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

¹ 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.

FOR CLINIC USE ONLY:

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

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

Form E2F: Imaging Available

Center: _____ Subject ID: _____ Form Date: ____ / ____ / ____

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

Visit #: _____
Examiner's initials: _____

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)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
IF YES, complete 1a – 1f; if no, go to Question 2.	
1a. Date of scan (MM / DD / YYYY): <i>NOTE: A value of 99 (unknown) is permissible for day only.</i>	____ / ____ / ____
1b. 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
1c. Was ADNI protocol used?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes ADNI version: _____ <input type="checkbox"/> 9 Unknown
1d. 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
1d1. Scan model:	_____

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
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)	
<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes	
IF YES, complete 2a – 2e; if no, go to Question 3.	
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
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)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
IF YES, complete 3a – 3f; if no, go to Question 4.	
3a. Date of scan (MM / DD / YYYY): <i>NOTE: A value of 99 (unknown) is permissible for day only.</i>	____/____/____
3b. 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
3c. Ligand used:	<input type="checkbox"/> 1 11C-PIB <input type="checkbox"/> 2 18F-AV45 <input type="checkbox"/> 3 Other (SPECIFY): _____ <input type="checkbox"/> 9 Unknown
3d. Was ADNI protocol used?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <i>ADNI version:</i> _____ <input type="checkbox"/> 9 Unknown
3e. 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

3e1. Scan model:	_____
3f. Are results of quantitative image analysis available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
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)	
	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (If yes, identify type(s) below)
IF YES, complete 4a – 4d; if no, end form here.	
4a. Is a dopaminergic scan available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
4b. Is a serotonergic scan available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
4c. Is a cholinergic scan available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
4d. Is another kind of scan available?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SPECIFY): _____

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

Form E3F: Imaging in Diagnosis

Center: _____ Subject ID: _____ Form Date: ____/____/____

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

Visit #: _____
Examiner's initials: _____

	No	Yes	Unknown
1. Was imaging obtained <u>as part of this visit for use in diagnosis</u>? If the answer is "0 (No)", SKIP THE REST OF THIS FORM.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
STRUCTURAL MRI			
2. Was structural MRI done? If "No", SKIP TO QUESTION 3.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
2a. Was focal atrophy (beyond what would be expected for age) appreciated by visual inspection? If "No" or "Unknown", SKIP TO QUESTION 3.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
Where was focal atrophy appreciated?			
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
FDG-PET			
3. Was FDG-PET done? If "No", SKIP TO QUESTION 4.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
3a. Was focal hypometabolism appreciated by visual inspection? If "No" or "Unknown", SKIP TO QUESTION 4.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
Where was focal hypometabolism appreciated?			
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
AMYLOID PET			
4. Was amyloid PET done? If "No", SKIP TO QUESTION 5.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
4a. Was amyloid deposition appreciated by visual inspection? If "No" or "Unknown", SKIP TO QUESTION 5.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
Where was amyloid deposition noted?			
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
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
CBF SPECT			
5. Was CBF SPECT done? If "No", SKIP TO QUESTION 6.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
5a. Were abnormalities appreciated by visual inspection? If "No" or "Unknown", SKIP TO QUESTION 6.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9
Where were abnormalities noted?			
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
OTHER IMAGING			
6. Was other imaging done?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	
If yes, specify: _____			