NACC Uniform Data Set (UDS) — FTLD Module

Instructions

FOR NEUROPSYCHOLOGICAL QUESTIONNAIRES (FORMS C2F–C6F) AND TESTS REPORTED ON FORM C1F

Version 2.0, January 2012

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

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

These instructions last modified October 29, 2013.

NACC
National Alzheimer's Coordinating Center

Introduction

The neuropsychological testing module is estimated to take approximately 30 minutes to administer. This includes the testing of the subject and simultaneous completion of questionnaires by the informant.

It is intended that the tests be administered in the order in which they appear, even if they were previously administered at a recent clinic screening. This is necessary in order to standardize test administration among Centers. It is therefore suggested that the FTLD Neuropsychological Battery be administered in its entirety after the Uniform Data Set (UDS) neuropsychological battery and either before or after the administration of other tests commonly used by the Center.

The instructions provided within *FTLD Module — Instructions for Neuropsychological Questionnaires (Forms C2F-C6F) and Tests Reported on Form C1F* should be closely followed at all times, since these instructions may be different from Center-specific protocols that may already be in place.

Videotaping is recommended if the examiner is not familiar with language disorders. The tapes can then be viewed by clinicians who are experienced in language disorders, and these clinicians can assist with scoring. Alternatively, examiners should write the subject's response verbatim and seek the help of a clinician at their Center who is familiar with language disorders. If the answer is still unclear after these steps are taken, please contact NACC, which will forward your questions to the FTLD Neuropsychology work group.

Some participants may self-correct during the course of performance after an initial erroneous response. If this occurs, count the self-corrected response only if it occurs immediately after the error has been made. Thus, if a participant notices an error after drawing the complete Benson complex figure, for example, do not allow the correction. However, if when the participant starts to draw an erroneous line and immediately self-corrects, permit the correction.

Benson Complex Figure Copy

SCORE TO BE REPORTED ON FORM C1F, SECTION 1

Description

This test is a simplified form of the Rey-Osterrieth Complex Figure. The purpose of the test is to assess a subject's visuoconstructional and visual memory functions.

Source

Possin, KL, Laluz VR, Alcantar OZ, Miller BL, Kramer JH. *Distinct neuroanatomical substrates and cognitive mechanisms of figure copy performance in Alzheimer's disease and behavioral variant frontotemporal dementia.* Neuropsychologia. 2011 Jan; 49(1):43-8.

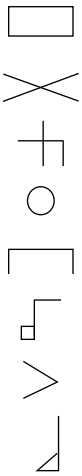
Administration

Give subject a pen, place sheet with figure in front of subject, and say, "Please copy this design as best you can." Please do not use colored pencils for each element because this can be disruptive and will not be consistent with other ADCs. Instead, please write notes to track progress. Have subject make his or her copy in the lower half of the page below the figure. When design is completed, leave the figure in front of the subject for 5 seconds and say "Be sure to remember this design, because I'll ask you to draw it again later from memory." Subjects should be given as much time as needed to complete the tests. Do not administer other figure-copy tests during the delay, and do not administer the Rey-Osterrieth before the Benson on the same day.

Scoring

Follow the scoring instructions as closely as possible and use your best judgment when scoring the Benson Complex Figure Copy.

The scoring system for the Benson Figure is modeled after Taylor's widely used scoring system for the Rey-Osterrieth Figure. Eight major figural elements have been identified. Each figural element is scored as 2 points if the element is drawn accurately and placed correctly in the figure (1 point for accuracy, 1 point for placement). Score 1 point if the element is poorly drawn but placed correctly or is correctly drawn but misplaced, and 0 points if the element is neither accurately drawn nor correctly placed. Detailed scoring rules are on the following page.



1.	Four-sided, 90° angles, width > height, any gaps or overlaps < 8mm	☐ 0	☐ 1	☐ 2
2.	Reasonably straight lines; any gaps or overlaps < 8mm	☐ 0	☐ 1	☐ 2
3.	Connects at middle third, no overlap with diagonals	☐ 0	☐ 1	☐ 2
4.	Reasonably round, doesn't touch sides	☐ 0	☐ 1	☐ 2
5.	Vertical lines > 1, 2 distance to diagonals, width > height, 90° angles	☐ 0	☐ 1	☐ 2
6.	Connects below #3, top of square above bottom	☐ 0	☐ 1	☐ 2
7.	Vertex corresponds to middle third; any gaps or overlaps < 8mm	☐ 0	☐ 1	☐ 2
8.	Gap b, w #7 < 5mm, angle at end of stem = 90°	☐ 0	☐ 1	☐ 2
	BONUS	☐ 0	☐ 1	

Time of day design completed: ___ ___ : ___ ___ ☐ AM ☐ PM

Total score (circle one): 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17

Always score leniently for borderline responses. If a response is borderline for accuracy and borderline for placement, give 1 point. Self-corrected responses are acceptable. Multiple attempts are acceptable at the subject's request either on an empty area of the page or, if more room is needed, on a fresh page. Ask the subject which drawing he or she would like you to score. If the subject copies directly on top of the stimulus instead of drawing below, the subject should be directed one more time to draw below the figure. If a subject draws close to the edge of the paper, that subject can start again. Instances may occur where test administrators should consider the test invalid (e.g., if the subject did not bring his or her glasses and can't see well enough to take the test). In these instances, enter the appropriate code listed on Form C1F. If a subject has motor problems and cannot complete the Benson Figure Complex Copy, a code of 95 (Physical problem) should be entered for the score on Form C1F, Question 1a.

For accuracy (A), element drawn must be recognizable as the target element and meet the additional criteria listed below. Leniency is given for wavy lines or rounded angles (e.g., due to tremor). A protractor and ruler should be used for making angle and distance judgments. Extraneous lines do not impact scoring.

For placement (P), element need not be accurate, it must only bear some slight resemblance to the target element (with leniency), be placed correctly, and meet the additional placement criteria below. Major rotation of an element is not acceptable for placement credit.

ELEMENT 1

Accuracy: Four reasonably straight sides must be present with 90º angles (±10º); width > height; corners do not have to touch and lines can be broken, but gaps or overlaps cannot exceed 8mm.

Placement: Any square-like or rectangular figure is present with at least 3 sides but no more than 4 sides. Less precise angles are acceptable. Rotation of the entire figure should not exceed 30°. If height is greater than width, this is considered an accuracy failure rather than a rotation-related placement failure.

2-point examples:

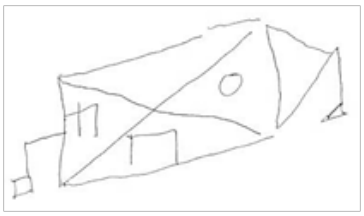
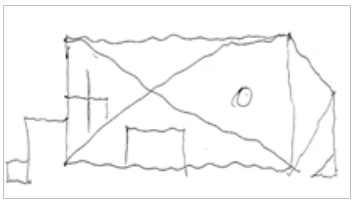
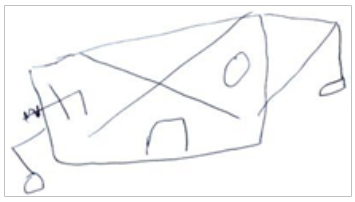


Figure is not rotated more than 30°, and gaps at corners and at broken lines do not exceed 8mm.

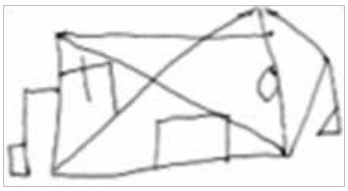


Leniency is given for wavy lines.

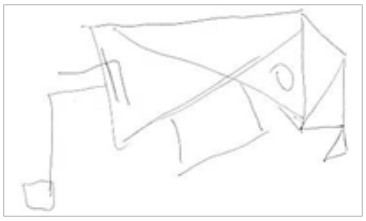
1-point examples:



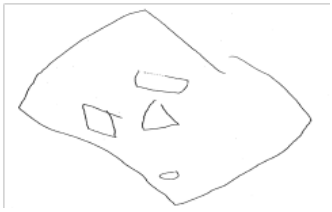
Accuracy: 0 Placement: 1
Bottom left angle is not precise.



Accuracy: 0 Placement: 1



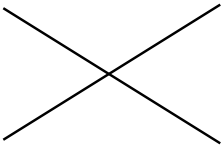
Accuracy: 0 Placement: 1
Three sides of the rectangle are present, and element bears enough of a resemblance to the target element to receive placement credit.



Accuracy: 1 Placement: 0
Placement credit is lost due to rotation.

0-point examples: pentagon, circle, triangle

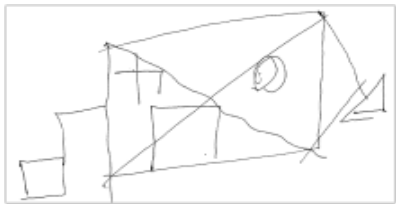
ELEMENT 2



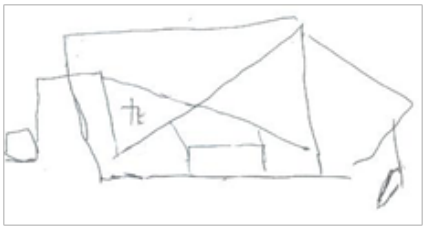
Accuracy: Two reasonably straight intersecting lines are recognizable as the target figure. Rotation is acceptable for accuracy and lines need not be diagonal.

Placement: Gap or overlap at the corners of the large rectangle must not exceed 8mm. If only one line is present but placement is correct, credit is given.

2-point examples:

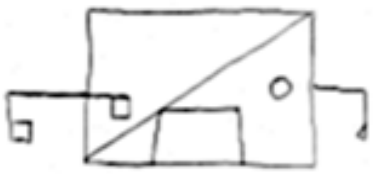


1-point examples:



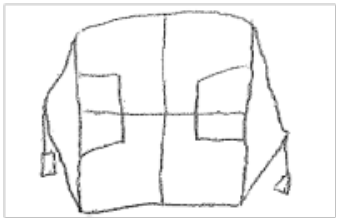
Accuracy: 1 Placement: 0

These lines are recognizable as the target figure (A), but the gaps at corners exceed 8mm (P).



Accuracy: 0 Placement: 1

Element loses accuracy point because one line is missing, but it is placed correctly.



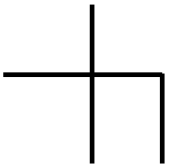
Accuracy: 1 Placement: 0

Lines are recognizable (A) but rotated (P).

Accuracy: 1 Placement: 0

Lines are recognizable but not correctly placed.

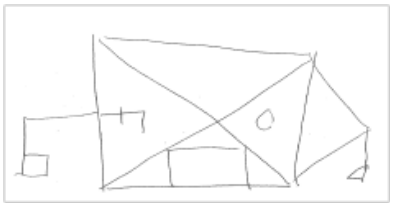
ELEMENT 3



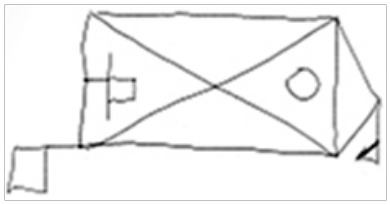
Accuracy: Figure is correctly shaped.

Placement: Figure is connected at the middle third of the large rectangle but does not need to be above element 6. Any gap with the large rectangle does not exceed 8mm. Lines may cross the large rectangle but not the diagonal lines.

2-point examples:

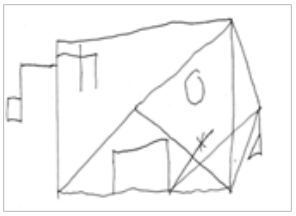


Placement credit is given because it connects at the middle third.



Do not deduct accuracy because of the extraneous line.

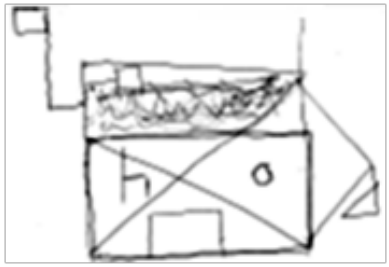
1-point examples:



Accuracy: 1 Placement: 0
Connects at upper third.

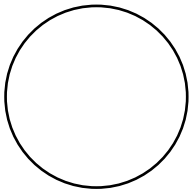
Accuracy: 1 Placement: 0
Element is correctly shaped (A), but the gap between the element and large rectangle exceeds 8mm (P).

Accuracy: 0 Placement: 1
Element bears some slight resemblance to the target element (with leniency) and is placed correctly, at the middle third (P). This is an example of the least resemblance an element might have to receive credit for placement.



Accuracy: 1 Placement: 0
Placement credit is lost due to overlap with diagonals. This element barely receives accuracy credit.

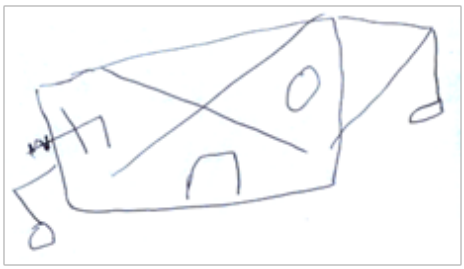
ELEMENT 4



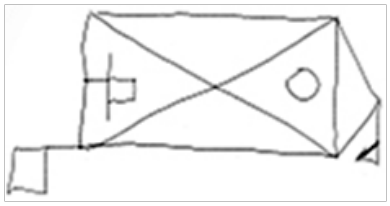
Accuracy: Reasonably round (longest diameter to shortest ratio < 2:1).

Placement: The circle is inside the right quadrant of the rectangle, which is defined by the diagonal lines. If the diagonal lines are not present or are misplaced, score based on their correct placement, with leniency. The circle cannot touch the large rectangle.

2-point examples:

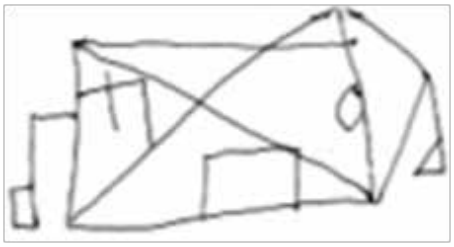


The ratio for this circle is 1.8:1, and so it barely receives accuracy credit.



Placement is scored based on where the diagonal lines should have been placed.

1-point example:

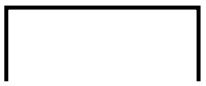


Accuracy: 1 Placement: 0

0-point example:

Exceeds ratio requirement (A). Circle touches the rectangle (P).

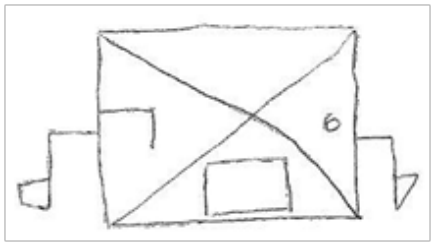
ELEMENT 5



Accuracy: The width must be > the height, and the angles are 90º (±10º). The vertical sides of the rectangle are > ½ of the vertical measurement between the bottom of the large rectangle and the closest part of diagonal lines. If the diagonal lines are not present, calculate based on where the lines should be placed (see 1st 2-point example). Extraneous lines are acceptable.

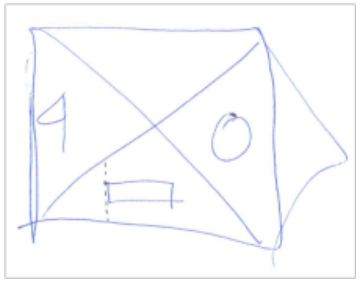
Placement: Figure is located in bottom quadrant of the large rectangle as defined by the diagonal lines. The gap or overlap with the bottom of the large rectangle does not exceed 8mm, and any overlap with the diagonal lines does not exceed 8mm.

2-point examples:

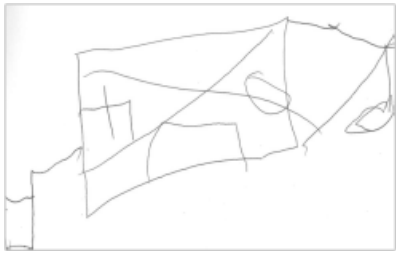


Extraneous lines are acceptable.

1-point examples:

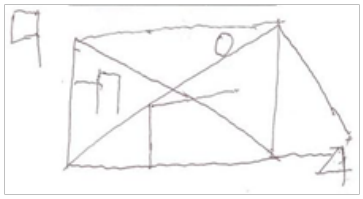


Accuracy: 0 Placement: 1
Vertical sides are < ½ vertical measurement. Dotted lines were added to illustrate vertical measurement.



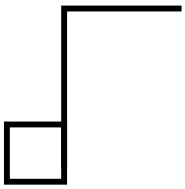
Accuracy: 0 Placement: 1
Top left angle is not precise.

0-point example:



This response would have received placement credit if the overlap with the diagonal lines did not exceed 8mm.

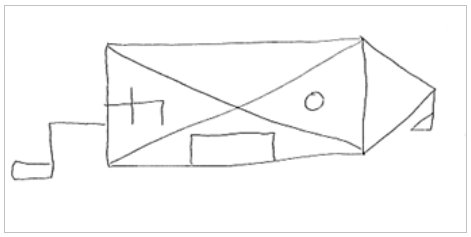
ELEMENT 6

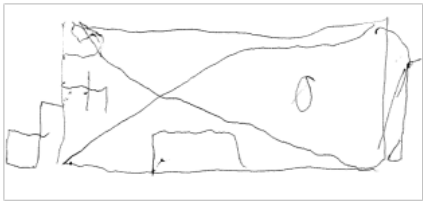


Accuracy: Flag points in the correct direction and shares a side with its staff. Flag may resemble a rectangle or a square.

Placement: Element must be outside the large rectangle and below the left internal element (#3). If left internal element is not present, score placement leniently based on where left internal element should have been placed. The top of the flag must be above the bottom of the large rectangle.

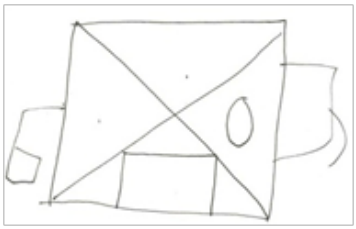
2-point examples:





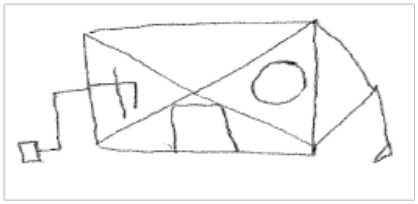
Extraneous lines are acceptable.

1-point examples:



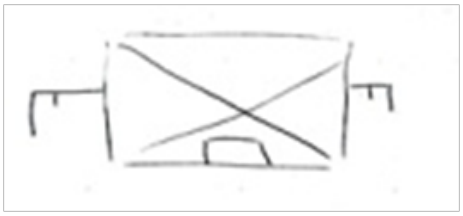
Accuracy: 0 Placement: 1

Flag does not point in the correct direction (A). Placement is scored based on where element 3 should have been placed.



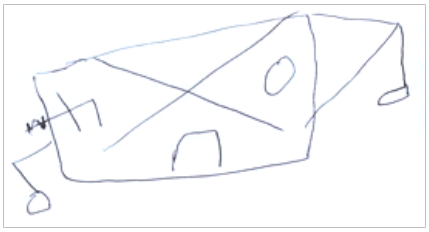
Accuracy: 0 Placement: 1

Element is just below element 3 (P), but flag does not share a side with the staff (A).



Accuracy: 0 Placement: 1

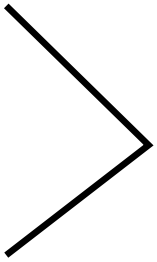
In this example, the element bears some slight resemblance to the target element and is placed correctly.



Accuracy: 1 Placement: 0

Top of the flag is below the bottom of the large rectangle (P).

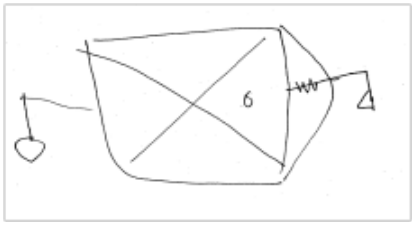
ELEMENT 7



Accuracy: Element is composed of two lines that form a triangle that is roughly the correct size, relative to element 1. The vertex of the angle must correspond to the middle third of the rectangle.

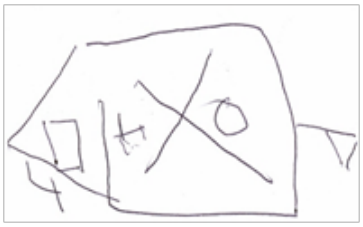
Placement: External lines must be outside the large rectangle on the right. Gap or overlap with the large rectangle should not exceed 8mm. Lines do not need to connect at corners for accuracy or placement credit.

2-point example:

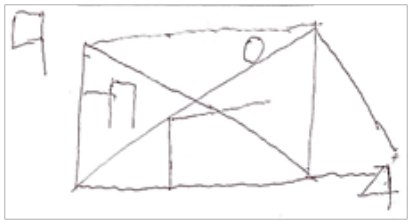


The lines to the right form a triangle-like shape, but if they were more rounded than this (i.e., if they formed a semi-circle), accuracy credit would be lost.

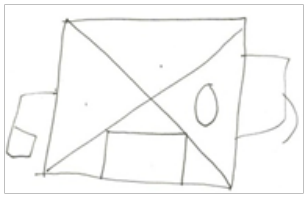
1-point examples:



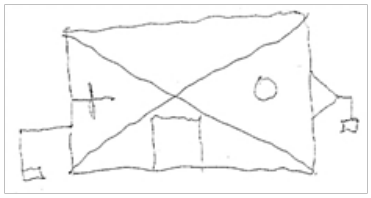
Accuracy: 1 Placement: 0
The vertex of the angle corresponds to the middle third of the large rectangle (A) but is on the wrong side (P).



Accuracy: 0 Placement: 1
The vertex corresponds to the bottom third of the large rectangle (A).

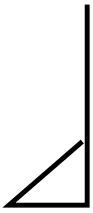


Accuracy: 0 Placement: 1
This element is considered to bear enough slight resemblance to target element to receive placement credit, although it is a borderline response.



Accuracy: 0 Placement: 1
Element is too small to receive accuracy credit

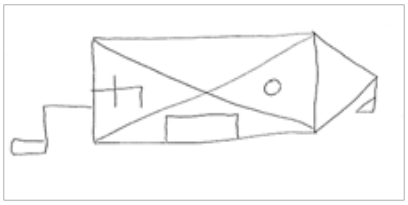
ELEMENT 8



Accuracy: There must be a triangle and a stem. The angle of the triangle at the furthest end of the stem must approximate 90° (± 15°). The flag and stem are in correct relationship to each other.

Placement: Either a stem or flag must be present and placed to the right of the rectangle. The flag need not be a triangle. The element must connect directly to element 7 or be within 8mm of either element 7 or element 1. No credit is lost for an additional stem. The top of the flag must be above bottom of large rectangle. Rotation > 45° is not allowed.

2-point example:

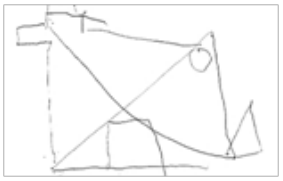


1-point examples:

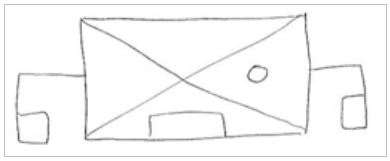
Accuracy: 0 Placement: 1
Stem is present and placed correctly (P). This is an example of the minimal amount of resemblance required to be eligible for placement credit.

Accuracy: 1 Placement: 0
The entire element is rotated > 45° (P), but the relationship between the triangle and stem is preserved (A).

Accuracy: 0 Placement: 1
The angle does not approximate 90° (A).



Accuracy: 0 Placement: 1
Accurate but not placed correctly.



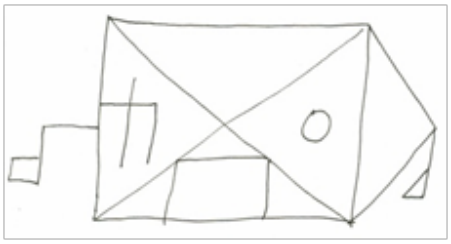
Accuracy: 0 Placement: 1
Element bears resemblance and is placed correctly.

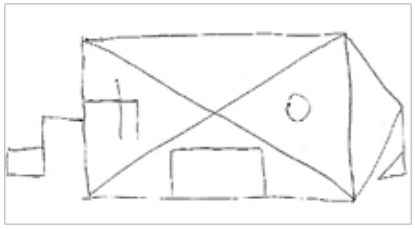
Accuracy: 1 Placement: 0
Accurate but not placed correctly.

BONUS POINT

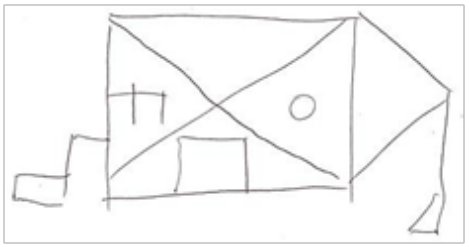
Each element must be accurately drawn, all elements must be properly placed, all elements must be drawn in proper proportions, all connections between elements must be clean, and no extraneous lines may be present.

1-point examples:





0-point example:



Verbal Fluency: Phonemic Test

SCORE TO BE REPORTED ON FORM C1F, SECTION 2

Description

This is a widely used measure of word generation that may be sensitive to dysfunction in the dominant frontal lobe. In this version, the subject is asked to say as many words as possible that begin with the letter "F" in 60 seconds, and then as many words that begin with the letter "L" in 60 seconds.

Source

MATERIALS: 1-minute timer

[Examiner]: "I'm going to say a letter of the alphabet. When I ask you to start, tell me as many words as you can that begin with that letter. You will have 1 minute before I tell you to stop. None of the words can be numbers or names of people, or places.

"For example, if I gave you the letter B, you could say brown, bottle or bake, but you wouldn't say Barbara, Boston or billion. Also, please try not to give me the same word with different endings, so if you said bake, you wouldn't also say baked or bakes, and if you said big, you wouldn't also say bigger and biggest.

"Let's begin. Tell me all the words you can, as quickly as you can, that begin with the letter 'F'. Ready? Begin."

ADMINISTRATION:

Start timer after completing instructions. Write actual responses as legibly as possible. Stop the procedure at 60 seconds.

PROMPTS:

1. If the participant pauses for 15 seconds:

   Keep going.
   What other words beginning with 'F' can you think of?

2. If the participant gives three consecutive words that do not start with the designated letter (provide this prompt only once during this condition):

   We are now using the letter 'F'.

MATERIALS: 1-minute timer

[Examiner]: "Now I want you to do the same for another letter. The next letter is L. Ready? Begin."

ADMINISTRATION:
Start timer after completing instructions. Write actual responses as legibly as possible. Stop the procedure at 60 seconds.

PROMPTS:

1. If the participant pauses for 15 seconds:

   Keep going.

   What other words beginning with 'L' can you think of?

2. If the participant gives three consecutive words that do not start with the designated letter (provide this prompt only once during this condition):

   We are now using the letter 'L'.

Guidelines

Record all responses, including repeated words and rule violations. When a rule violation (e.g., proper nouns, words beginning with the wrong letter) occurs on three consecutive responses, examiners should remind the participant of the correct rule. Each rule can be repeated only once per trial.

Scoring

CORRECT RESPONSES

Any word that begins with the specified letter, can be found in a dictionary, is not a proper noun or a number, and is not a repetition within that trial, should be scored as a correct response.

Although scoring of most responses is straightforward, many responses are ambiguous. For example, "frank" can refer to a man's name, a food item, or an adjective. The scoring principle with these sorts of responses is to give the benefit of the doubt and score the item as correct for the first instance of the response in a trial. In some instances, the context in which the response is given can provide clues as to the participant's meaning. For example, the sound "fôr" is ambiguous, and could be a preposition (for), golf term (fore), or number (four). If the word is given along with other numbers (e.g., "four, five"), the response can be interpreted as a number and be scored as a rule violation. If the response is at all ambiguous, however, apply the general principle of giving the benefit of the doubt. If a person self-corrects a rule violation or repetition during the trial, the response should not be counted as an error.

Other types of responses that should be scored as correct include:

- Contractions
- Compound words or conjoined words that convey a single meaning (e.g., ferris wheel)
- Slang words if they can be found in a dictionary
- Proper nouns that are not the names of people or places (e.g., days of the week, months of the year, brand names)

REPETITIONS

Any response that is repeated verbatim within the 60-second trial should be scored as a repetition.

If a repeated word has more than one meaning (e.g., "still" can be an adjective and a noun) or is a homophone (e.g., "flue" and "flew"), score the second response as a repetition error unless the participant explicitly or implicitly (e.g., with intonation or gesture) indicates that the second response has a different meaning or spelling, or if the context strongly suggests that it is a different word. For example, for the string of responses "felt, feeling, fresh, fabric, felt," the second occurrence of "felt" can be scored as correct since the context implies a different meaning than the first occurrence of "felt".

Grammatical variants should be scored as rule violations, not repetitions (see below).

RULE VIOLATIONS

Any response that reflects a deviation from the rules provided to the participant should be scored as a rule violation.

Several types of responses are potentially rule violations and include:

- Words beginning with letters other than the designated letter. This includes words that have the same initial sound but begin with a different letter (e.g., "phone" for f-words).
- Non-words
- Proper nouns that are names of people or places
- Numbers
- Grammatical variants of a previous response. These include words that are exactly the same as a previous response but with a different ending that represents a plural, altered tense, or other grammatical variant (e.g., present participle; comparatives). It is important to note that the examples in the instructions only explicitly prohibit plurals (e.g., bake, bakes), alteration in tense (bake, baking), and comparatives (big, bigger), and thus only these types of variants should be scored as rule violations.

Responses that are at all ambiguous should not be scored as rule violations. This particularly applies to responses that use the same root word as a previous response, but the addition is not a plural or change in tense. For example, give credit for 'bakery', even if 'bake' was a previous response.

Repeated rule violations count as repetitions, not rule violations.

Word Reading Test — Regular and Irregular Words

SCORE TO BE REPORTED ON FORM C1F, SECTION 3

Description

This is a test of word reading that includes regularly spelled and irregularly spelled words. Difficulties with reading words whose pronunciation cannot be immediately deduced from canonical spelling-sound rules is a phenomenon often seen in semantic variant of primary progressive aphasia.

Source

Argye E. Hillis, Johns Hopkins

Administration

For each word, there is a time limit of 10 seconds. No cues or prompting are to be provided. If the word is not read in 10 seconds, then move on to the next item. Give the stimulus sheet to the subject.

[Examiner] "Please read these words out loud."

If the subject reads the word perfectly, place a checkmark in the "correct" box. If the subject does NOT read the word perfectly, transcribe his or her response verbatim in the space below, and check the box that describes the kind of error the subject made. If you are unsure of the type of error, you should check the response with a member of your research team who has experience with aphasia. Examples of error types are presented in the following tables.

Sometimes the subject may generate a string of erroneous attempts. Only count the first word produced to code the error type for entry into NACC. If the subject initially says a word wrong and then immediately self-corrects, count the self-correction as correct.

If the subject does not respond, encourage them to do their best, or to take a guess. If they still don't respond, count the item as wrong.

	EXAMPLES: TYPES OF LANGUAGE ERRORS ON REGULAR WORDS			
		Semantic errors**		
	Phonemic errors*	Direct semantic errors	Related items	Dysarthric errors***
BALL	boss, bahk, bull	toy, throw		baw
BOOK	took, buht, back	paper, read	story	
ROAD	roll, pode, raid	street, drive	car	wllode
DOOR	doe, dure, dare	gate, open	lock	
LEAF	leap, keef, loaf	grass, grow	fall	wheeff
CANE	cake, tane, cone	crutch, walk		
DEER	deep, steer, theer	horse, santa	antlers	
ROPE	rote, roke, ripe	string, climb		

SPEAK	speech, speam, spike	talk, mouth		zhpeak
CUT	cup, shut, cat	slice, knife		ncut
KICK	kit, kuck, kip	boot, tootball		
SHAVE	shove, save, shape	scrape, razor, soap		zhave
PRAY	cray, prow	bless, church		
HANG	hat, bang	swing, clothes		
SHOOT	soup, shoe	kill, gun		zjoot

*__Phonemic errors__ are defined as errors in the sounds within a word. These sound omissions or substitutions can result in the production of another real word (e.g., "boss" for "ball") or a non-word "bauhk" for "ball," but in both instances the word sounds similar to the target word. Phonemic errors should be written out as they sound to the examiner.

**__Semantic errors__ are words that are related to the target item in meaning. Direct semantic errors are substitutions for the target (e.g., "gate" for "door," "slice" for "cut"); other types of semantic errors are words that are related to the target but not a substitute for it (e.g., "kneel" or "church" for "pray;" "open" or "knob" for "door").

***__Dysarthria__ is a motor disorder, not a language disorder. If you have had a novocaine injection and could not normally move your tongue or mouth, you can imagine what it is like to be dysarthric: you can produce a normal word, but the sounds are distorted. You can also imagine trying to talk with your mouth full or when you have a cold and your nose is stuffed. It is difficult to provide samples of all possible types of dysarthric errors, but this column shows a few. For blank boxes, the examiner will need to transcribe the production or record it for an expert to decide.

	EXAMPLES: TYPES OF LANGUAGE ERRORS ON IRREGULAR WORDS	
	Semantic error*	**Regularizing error****
SEW	needle, thread	sue
EARTH	globe, world, global	eerth
GHOST	phantom, casper	guh-host, jost
SWORD	stab, knife	sooward, ess-word
TONGUE	mouth, swallow	ton-gew
HEIR	will	here, hire
LIMB	foot, arm	lim-buh
AISLE	walk, bride	ay-zle
CHOIR	church, hymn	ch-ore, cho-ear
LAUGH	joke, funny	log
SIGH	worry	sig
GAUGE	meter, measure	gog
SEIZE	grab, arrest	size, see-zee
SIEVE	funnel, strainer	seeve, seevie
KNOCK	door	kuh-nock

***Semantic error**: Produces a word that is a substitute for or related to the target word in meaning.

****Regularizing error**: Tries to pronounce the sounds of the word as they are written — that is, phonetically.

Scoring

Credit is given for spontaneous self-correction. Sum the columns to derive a total score for the correct responses and for each category of error.

Do not count distorted phonemes (speech sounds) as errors if a word is understood as the correct word with all of the correct phonemes in the correct order. For example, if the subject is dysarthric, the dysarthric errors are not considered errors; score them as correct. Words with omitted, inserted, or transposed phonemes are counted as phonological related errors (whether they are words or nonwords; examples include the word bear read as "dare" or [blart]). An example of a semantically related word would be bear read as "tiger."

Benson Complex Figure Delay (Recall)

SCORE TO BE REPORTED ON FORM C1F, SECTION 4

Source

Possin, KL, Laluz VR, Alcantar OZ, Miller BL, Kramer JH. *Distinct neuroanatomical substrates and cognitive mechanisms of figure copy performance in Alzheimer's disease and behavioral variant frontotemporal dementia.* Neuropsychologia. 2011 Jan; 49(1):43-8.

Recall instructions

10–15 minutes after completion of the copy trial, subjects should be given a blank piece of paper and pen and asked:

> **[Examiner]: "Remember that figure that I asked you to copy a while ago? I want you to draw as much of it as you can remember."**

The same scoring guidelines as used for figure copy should be used to score recall performance.

Recognition

After the completion of figure recall, place the recognition page in front of the participant and ask:

> **[Examiner] "Which of these figures was the one you copied before?"**

Semantic Word-picture Matching Test

SCORE TO BE REPORTED ON FORM C1F, SECTION 5

Description

This test evaluates spoken word recognition and assesses the frequency of semantic errors in word comprehension. The stimuli consist of five four-picture displays, each of which includes pictures of four objects that are semantically related. These five displays are each presented four times (once for each picture as the target), for a total of 20 trials. The location of the target picture is counterbalanced across all of the trials. The order of presentation of the displays is pseudo-randomized, so that no four-picture display appears in sequential trials.

Source

Rogalsky C, Love T, Driscoll D, Anderson SW, and Hickok G. *Are mirror neurons the basis of speech perception? Evidence from five cases with damage to the purported human mirror system.* Neurocase. 2011;17(2):178-87. Reproduced by permission.

Instructions for the subject:

> **[Examiner] "You are going to see four pictures, while you hear a word. With your finger, please point to the picture that matches the word. If you need to hear the word again, I will repeat it for you."**

Administration

Ensure that all pictures presented to the subject are in color. Use the score sheet to record which picture the subject points to throughout the experiment. Circle the number that corresponds to the location to which the subject pointed. The location of the correct answer (the matching picture) is indicated by the number that is in **bold**. If the subject would like to hear the auditory stimulus again, first ask them to answer, and record this initial response. Then, repeat the word, and make a note of their second response, if different from the initial response.

For each word-picture item, there is a time limit of 10 seconds. No cues or prompting are to be provided. If the answer is not given within 10 seconds, then move on to the next item.

Scoring

One point is given for each correct response given on the first attempt. An "I don't know" response is considered incorrect. However, if the subject was distracted or unable to hear the first stimulus presentation (e.g., the subject was coughing, experienced a hearing-aid malfunction, etc.), then 1 point should be given if the correct response is made after the second presentation of the word.

Semantic Associates Test

SCORE TO BE REPORTED ON FORM C1F, SECTION 6

Description

This is a test of knowledge of the meaning of objects. Subjects are asked to pick one of two pairs of objects that "go together." The object pairs are made up of a stimulus object paired with another object to which it is related by context, function or category membership, next to the same stimulus object paired with an object that is entirely unrelated. Persons with semantic variant PPA and others with impaired lexical knowledge fail to grasp shared associations. Standard American English dialect is used, with accommodations for the subject's regional variations.

Source

From the Northwestern Naming Battery (Cynthia K. Thompson, PhD and Sandra Weintraub, PhD, experimental edition — 2011); further copying or distribution is forbidden without authors' permission. Form created as part of the FTLD Module to the Uniform Data Set of the National Alzheimer's Coordinating Center.

Administration

There are three practice items. For the practice items, please follow the directions exactly as given below. Plan to continue to administer the actual test even if a subject picks the wrong pair for each of the practice items. When you are finished with the practice items and begin the actual test, do not name the items that are shown in the pictures, as done during the practice items. Instead, during the actual test, simply show the two pairs of pictures and have the subject point to the pair that "goes together."

During the actual test, if a subject picks the wrong pair, do not correct the subject. Instead, count this as an error and move on to the next item. During the actual test, if a subject says they cannot respond or that they "don't know," and this is not a more general approach the subject has taken to the testing, then the examiner can ask the subject to guess. If the subject does not want to guess, then count the item as incorrect.

PRESENTING THE PRACTICE ITEMS

> **[Examiner]: "You will see two pairs of pictures. The objects in one pair have a relationship to each other — that is, they go together. The objects in the other pair do not go together. Pick the pair that goes together. You don't have to say your choice or why you have picked it. You just need to point to your choice. Let's start with these practice items."**

PRESENT THE FIRST PRACTICE ITEM, which demonstrates a functional relationship. Point to the left picture pair and say:

"This pair shows a sweater and a blanket."

Then point to the other picture pair and say:

"This pair shows a sweater and a pillow. Which pair goes together?"

If the subject points to the correct answer (sweater, blanket), say:

"Yes, the sweater and blanket go together because both are used to keep us warm."

If the subject picks the wrong pair, say:

"A sweater and pillow don't go together because they are not used for the same purpose."

Point to the correct pair and say:

"The sweater and blanket go together because they can both be used to keep you warm."

TURN TO THE NEXT PRACTICE ITEM, which demonstrates an association that is contextual, and say:

"Let's look at another example."

Point to the picture pair on the left and say:

"This pair shows a sweater and a chest."

Point to the picture pair on the right and say:

"This pair shows a sweater and a work bench. Which pair goes together?"

If the subject points to the correct answer (sweater, chest), say:

"Yes, the sweater and chest go together because a sweater is usually kept in a chest of drawers but not on a work bench."

If the subject points to the incorrect pair, say:

"No, a sweater and work bench do not go together."

Point to the correct pair and say:

"The sweater and the chest go together because a sweater is usually kept in a chest of drawers and not on a work bench."

TURN TO THE THIRD PRACTICE EXAMPLE, one of categorical relations. Point to the picture pair on the left and say:

"This pair shows a sweater and a magnet."

Then point to the picture pair on the right and say:

"This pair shows a sweater and a dress. Which pair goes together?"

If the subject points to the correct answer, say:

"Yes, a sweater and a dress go together because they are both articles of clothing, things you wear."

If the subject points to the incorrect pair, say:

"No, the sweater and magnet do not go together."

Point to the correct pair and say:

"The sweater and the dress go together because they are both articles of clothing, things you wear."

Scoring

One point is given for each correct item. Tally the number correct for each category (Animals and Tools), and calculate the total correct. Total possible points for this subtest = 16.

Northwestern Anagram Test SHORT FORM[1]

SCORE TO BE REPORTED ON FORM C1F, SECTION 7

Description

This is a test of grammatical knowledge for constructing sentences.

Source

Northwestern Anagram Test (NAT) (Short Form, 2012), Cynthia K. Thompson, Sandra Weintraub, and Marsel Mesulam (https://flintbox.com/public/project/19927). Further copying or distribution is forbidden without authors' permission. Form created as part of the FTLD Module to the Uniform Data Set of the National Alzheimer's Coordinating Center.

Administration

Construction of stimuli for NAT:

MATERIALS NEEDED:

1. Sheet with word stimuli
2. Stimulus pictures, one per test item
3. Thin cardboard sheets (8.5 x 11 inches) on which to copy the word stimuli and each of the picture stimulus cards
4. Plastic protector sleeves (matte surface, not shiny), with three holes for insertion into three-ring binder
5. Three-ring binder

STEPS: Photocopy the word stimuli onto a thin cardboard sheet, and then cut them out following the lines around each word to make a small card for each word. (Note: The words for each stimulus sentence can be paper-clipped together to each stimulus card, ready for administration, and for storage when the test is not in use. Alternatively, an ice cube tray can be used to store the word cards for each test item.)

Photocopy each sample picture and each stimulus picture onto a thin cardboard sheet. Insert each of the resulting picture stimulus cards into a plastic protector. Next, insert these into the three-ring binder in sequence of administration. Insert the stimulus cards in such a way that they are visible on the back of each plastic sleeve. Thus, when the binder is open, the first page will be blank because it is the reverse side of the first stimulus sheet (practice item). By inserting stimulus sheets in this manner, the word cards can be placed on the blank sheet facing each stimulus page (the part of the binder resting on the desk on the subject's side) and the subject can use that surface to manipulate the word cards.

TEST ADMINISTRATION INSTRUCTIONS

Use a thick book or other means to elevate the front cover of the binder so that the stimulus pictures resting against the cover as the pages are turned are elevated for the subjects' viewing. Administer practice item 1 according to the instructions below. If the subject fails the item, demonstrate the correct response.

[1] Weintraub S, Mesulam MM, Wieneke C, Rademaker A, Rogalski EJ, Thompson CK. The Northwestern Anagram Test: Measuring sentence production in primary progressive aphasia. *American Journal of Alzheimer's Disease & Other Dementias.* 2009 Oct–Nov;24(5):408-16.

Then present the remaining items. If the subject completes an item, looks at it and then self-corrects, count the self-corrected response. Do not provide feedback as to whether an item is right or wrong.

(All text in **bold** is read aloud.)

Present the stimulus picture.

> **[Examiner] "This picture shows a** *(using subject's left and right for orientation, point to and name entity on the left side of the picture)* **and a** *(point to and name the entity on the right side of the picture)***. The action is** *(name the printed action).***"**

Present corresponding word cards, providing the first word of the target sentence, "Who" (underlined on the response form), in the upper left corner of the work space and distributing the remaining words in random array in the work space below "Who." Say,

> **[Examiner] "Use these other word(s) to make a sentence to go with the picture. Be sure to use all of the words to make your sentence. Start the sentence with this word, 'Who.' "**

Allow 30 seconds for subject to respond.

Practice item only: If the subject does not respond within 30 seconds or responds incorrectly, place the cards in the correct order.

Test items: Repeat instructions as given above. If a response is incorrect, enter the card order generated by the subject in the space provided on the score sheet. Gather up the cards and move on to the next item. Score as correct only if ALL words are in the order of the target sentence.

If the subject does not begin moving the cards by the time 15 seconds have elapsed, you may encourage them to try to do the best they can. If this behavior is repeated on subsequent items, continue to administer all items.

Scoring

Give one point for each correct item. The only acceptable answers are indicated on the response form, and there is only one point per item. Partial credit is not given for any pairs of words in the correct sequence. Total the number of correct responses to WH-Object and WH-SUBJ questions and then add those two numbers for the total NAT score.

Sentence Repetition Test

SCORE TO BE REPORTED ON FORM C1F, SECTION 8

Description

This is a test of oral repetition of sentence-length utterances.

Source

Argye E. Hillis, Johns Hopkins

Administration

This test should always be given BEFORE the Sentence Reading Test, and the two tests must be separated by other tests in the battery, not given in direct succession.

> **[Examiner]: "I'm going to read some sentences to you. Please repeat this back to me, exactly the way I say it."**

Read each sentence out loud to the subject. One repetition of the sentence is allowed in cases where the subject did not hear the sentence, but only if the subject explicitly requests it.

If the subject does not repeat the sentence perfectly, transcribe his or her response verbatim in the space below the sentence. Score each response to the right.

Scoring

Give 1 point for each sentence read completely correctly. Sentences that contain one or more words with omitted, inserted, or transposed phonemes are errors. Do not count distorted phonemes (speech sounds) as errors if a word is understood as the correct word with all of the correct phonemes in the correct order. Count the number of omitted words, semantically related words, and phonologically related words. Omitted words are words that are not spoken. Phonologically-related errors are words or non-words that are related in sound to the target word. Words with omitted, inserted, or transposed phonemes are counted as phonological related errors (whether they are words or nonwords; examples include the word bear repeated as "dare" or [blart]). Semantically related errors are words or responses that are related in meaning to the target. An example of a semantically related word would be bear repeated as "tiger."

Noun and Verb Naming Subtests

SCORE TO BE REPORTED ON FORM C1F, SECTION 9

Description

This is a test of confrontation naming of objects and actions.

Source

From the Northwestern Naming Battery (Cynthia K. Thompson, PhD and Sandra Weintraub, PhD, experimental edition — 2011); further copying or distribution is forbidden without authors' permission. Form created as part of the FTLD Module to the Uniform Data Set of the National Alzheimer's Coordinating Center.

Administration

Items are presented one at a time for the subject to name. For each item, there is a time limit of 10 seconds. No cues or prompting are to be provided. If the item is not named in 10 seconds, then move on to the next item. Before beginning this subtest, say:

> **[Examiner]: "I am going to show you some pictures. Some of them will be objects or things, and others will show people doing various actions. I want you to name each picture as quickly and accurately as you can."**

Show practice example (item p1, shoe), followed by action example (item p2, laugh).

> **[Examiner]: "For example, this picture shows a shoe, so you would say 'shoe'. This picture shows a man laughing. So you would say 'laugh' or 'laughing'."**

Any verb form (morphological inflection) is accepted as correct (e.g., for laugh, correct responses are laughs, laughed, and laughing). If the subject tends to confuse objects and actions (e.g., spoon for stirring), provide a reminder to name the action and not the object (e.g., say "Yes, but tell me what is happening."). If the subject again names the object, it is counted as an error. If the subject provides a different answer to describe the stimulus presented (e.g., "putting on his coat" instead of "zip,") then prompt the subject further (e.g., say, "Yes, but can you tell me a more specific name for the action or the verb?"). If the subject again provides the incorrect response, it is counted as an error.

Errors can be categorized, but for purposes of the FTLD Module, only accuracy will be noted.

Failures are not prompted by either semantic or phonemic cues.

Alternative responses for each picture are not permitted. For example, for item p2, the correct response is "laugh" in any of its verb forms (i.e., laughs, laughing, laughed). A response such as "man rubbing belly" is not considered a valid response.

Scoring

One point is given for each item named exactly, within 10 seconds. Any other response is an error. Errors can consist of phonemic paraphasias, semantic paraphasias, circumlocution, neologism. Minor phonemic distortions due to dysarthria are not considered errors, e.g., "zhou" for "shoe".

Calculate the total number of nouns and verbs correctly named and add these numbers together for the total naming score. A ratio of noun-to-verb naming can also be calculated if desired by dividing correct nouns by correct verbs. Scores less than 1 indicate less nouns than verbs while scores greater than 1 indicate more nouns than verbs. If either the noun or verb score is 0, a ratio cannot be calculated, and a code or "88.88" should be entered on Form C1F, item 9C.

Sentence Reading Test

SCORE TO BE REPORTED ON FORM C1F, SECTION 10

Description

This is a test of sentence reading.

Source

Argye E. Hillis MD, Johns Hopkins

Administration

This test should always be given AFTER the Sentence Repetition Test, and the two tests must be separated by other tests in the battery, not given in direct succession.

Give the stimulus sheet to the subject.

[Examiner] "Please read these sentences out loud."

If the subject does not read the sentence perfectly, transcribe his or her response verbatim in the space below. Score the response to the right.

Scoring

Give 1 point for each sentence read completely correctly. Do not count distorted phonemes (speech sounds) as errors if a word is understood as the correct word with all of the correct phonemes in the correct order. Sentences that contain one or more words with omitted, inserted, or transposed phonemes are errors. Count the number of omitted words, semantically related words, and phonologically related words. Omitted words are words that are not spoken. Phonologically related errors are words or non-words that are related in sound to the target word. Words with omitted, inserted, or transposed phonemes are counted as phonological related errors (whether they are words or nonwords; examples include the word bear read as "dare" or [blart]). Semantically related errors are words or responses that are related in meaning to the target. An example of a semantically related word would be bear read as "tiger."

FORM C2F
Social Norms Questionnaire

Description

This is a yes-no questionnaire to determine the degree to which subjects understand and can accurately identify implicit but widely accepted social boundaries in the dominant U.S. culture.

Source

Katherine Rankin, University of California, San Francisco

Administration

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 to 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.").

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

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.

> **[Examiner]: "The 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."**

Scoring

Social Norms Questionnaire (SNQ22) Scoring Key

	CORRECT RESPONSE
1. Tell a stranger you don't like their hairstyle?	NO
2. Spit on the floor?	NO
3. Blow your nose in public?	YES
4. Ask a coworker their age?	NO
5. Cry during a movie at the theater?	YES
6. Cut in line if you are in a hurry?	NO
7. Laugh when you yourself trip and fall?	YES
8. Eat pasta with your fingers?	NO
9. Tell a coworker your age?	YES
10. Tell someone your opinion of a movie they haven't seen?	YES
11. Laugh when someone else trips and falls?	NO
12. Wear the same shirt every day?	NO
13. Keep money you find on the sidewalk?	YES
14. Pick your nose in public?	NO
15. Tell a coworker you think they are overweight?	NO
16. Eat ribs with your fingers?	YES
17. Tell a stranger you like their hairstyle?	YES
18. Wear the same shirt twice in two weeks?	YES
19. Tell someone the ending of a movie they haven't seen?	NO
20. Hug a stranger without asking first?	NO
21. Talk out loud during a movie at the theater?	NO
22. Tell a coworker you think they have lost weight?	YES

Scoring

The instructions below are for deriving the summary scores (items 23–25) and Yes/No Ratio Score (item 26). **However, calculation of these scores is OPTIONAL, as they are automatically calculated upon submission of the form.**

Note that the coding scheme shown on the form (No=0 and Yes=1) is used only for recording item-level data and does not play a role in deriving the summary scores. Instead, item responses are scored as correct or incorrect based on the scoring key (see previous page), and a coding scheme of **Correct=0** and **Incorrect=1** is applied. Following are the formulas for the summary scores:

SNQ22 Total Score (optional) is calculated as [22 minus (the sum of items 1 to 22], ranging from 0 to 22 (higher scores reflecting better performance). If an item is missing, the total score should not be calculated. In this case, enter "88".

Break Score (optional) is the total number of errors made in the direction of breaking a social norm, and is calculated as (Sum of items 1, 2, 4, 6, 8, 11, 12, 14, 15, 19, 20, 21), ranging from 0 to 12 (higher scores reflecting more errors). If an item is missing, the total score should not be calculated. In this case, enter "88".

Overadhere Score (optional) is the total number of errors made in the direction of overadherence to a perceived social norm, and is calculated as (Sum of items 3, 5, 7, 9, 10, 13, 16, 17, 18, 22), ranging from 0 to 10 (higher scores reflecting more errors). If an item is missing, the total score should not be calculated. In this case, enter "88".

Yes/No Ratio Score (optional). In cases where it is unclear whether the subject's cognitive or behavioral deficits have caused them to answer in a stimulus-bound or otherwise meaningless manner, the validity of subject performance can also be measured by determining the ratio of Yes to No responses. The Yes/No Ratio Score, ranging from 0 to 22, can be calculated by counting the number of items to which the subject responded "Yes" and dividing by the number of items to which the subject responded "No." If this score is greater than or equal to 5, or is less than 0.3, please consider whether the subject was too impaired to fill out the form or answered the questions in a meaningless way. If the subject's answers are deemed valid, then please submit the data as is. However, if there is reason to suspect that the values are not valid, please select the appropriate reason code in the "For clinic use only" section and leave the rest of the form blank.

If the subject answered the C2F questions all yes or all no, then these answers are considered invalid. Please select the most appropriate reason code in the "For clinic use only" section and leave the rest of the form blank.

General administration guidelines for informant questionnaires C4F – C6F

If the informant feels that he or she will have a hard time completing this questionnaire, the examiner should reassure the informant that there are no right or wrong answers and that the informant should choose the response that he or she thinks is most accurate.

Encourage the informant by:

- Emphasizing that this is a subjective test, and that we only want their opinion about it
- Encouraging them to just put whatever seems best
- Telling them it's OK if they are not sure.

If the informant does not want to complete the questionnaire alone and asks for your help:

This is OK; just make sure to check the correct box in the gray "FOR CLINIC USE ONLY" area at the top of the page. Following are some guidelines as to what kind of help is appropriate:

Acceptable ways to help the informant	Unacceptable ways to help
Reading questions out loud — OK	Telling the informant what *you've* observed about the subject — NO
Marking their response for them — OK	
Repeating or closely rephrasing the question — OK	
Reiterating anchor points — OK	
Telling them what you think they should answer based on how they are describing the behavior to you — OK	

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."

FORM C3F
Social Behavior Observer Checklist

Description

This is a structured behavior rating that provides objective information about observed frequencies of spontaneous behaviors during the face-to-face clinical evaluation, including odd or inappropriate social behavior and dysexecutive behavior.

Source

Katherine Rankin, University of California, San Francisco

Administration

This form is to be completed by the examiner who administered the neuropsychological battery to the subject. Check only one box per question.

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.

Length of 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.

Scoring

Each descriptor and checklist item represents a separate score, ranging from 0 to 3, which can be analyzed to provide independently meaningful data. Also, scores for all descriptors 1–14 can be summed to derive the **Descriptor Total Score** (range 0–42), and all 35 checklist (behavior) items can be summed to derive the **Checklist (Behavior) Total Score** (range 0–105). Higher scores are interpreted as reflecting a greater degree of behavioral disturbance.

FORM C4F
Behavioral Inhibition Scale INFORMANT QUESTIONNAIRE

Description

This informant-based questionnaire is designed to measure the tendency towards behavioral inhibition, in the form of withdrawal-related behavior traits such as self-criticism, sensitivity to punishment cues, introversion, and general social anxiety.

Source

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.

Administration

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 informant 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.

> **[EXAMINER]: "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."**

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.

Scoring

Each item yields a score from 1 to 4.

The **BIS Total Score** is calculated as follows; please note that the formula below performs the required *reverse scoring* of items 5 and 7:

BIS1 + BIS2 + BIS3 + BIS4 + (5 – BIS5) + BIS6 + (5 – BIS7)

If an item is missing, the total score should not be calculated. In this case, enter "88". Higher scores are interpreted as reflecting higher levels of behavioral inhibition.

FORM C5F
Interpersonal Reactivity Index INFORMANT QUESTIONNAIRE

Description

These questions represent two subscales from a four-scale questionnaire measuring empathy in everyday social interactions. The seven-item **Empathic Concern (EC)** scale measures the other-centered emotional response resulting from the perception of another's emotional state. The seven-item **Perspective-taking (PT)** subscale measures subjects' tendency to spontaneously think of the perspective of others.

Source

Davis, M.H. (1980). JSAS Catalog of Selected Documents in Psychology, 10, 85. Reproduced by permission of the author, Mark H. Davis, Ph.D.; further copying or distribution without author's permission is prohibited. Form created as part of the National Alzheimer's Coordinating Center's FTLD Module to the Uniform Data Set, copyright 2013 University of Washington.

Administration

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.

> **[EXAMINER]: "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."**

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 items with them 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 the Perspective-taking (PT) Score.

Scoring

- Each item yields a score from 1 to 5.
- The **Empathic Concern Score (EC)**, ranging from 7 to 35, is calculated by summing items 1, 3, 5, 7, 9, 10, and 12, as follows; note that the formula below performs the required *reverse scoring* of items 3, 7, and 9:

  IRI1 + (6 – IRI3) + IRI5 + (6 – IRI7) + (6 – IRI9) + IRI10 + IRI12

  If an item is missing, the total score should not be calculated. In this case, enter "88".
- The **Perspective-taking Score (PT)**, ranging from 7 to 35, is calculated by summing items 2, 4, 6, 8, 11, 13, and 14, as follows; note that the formula below performs the required *reverse scoring* of items 2 and 8:

  (6 – IRI2) + IRI4 + IRI6 + (6 – IRI8) + IRI11 + IRI13 + IRI14

  If an item is missing, the total score should not be calculated. In this case, enter "88".
- Higher scores are interpreted as reflecting a greater degree of empathy.

FORM C6F
Revised Self-Monitoring Scale INFORMANT QUESTIONNAIRE

Description

This questionnaire is designed to assess the degree to which subjects attend to others' socioemotional signals and allow those signals to influence their behavior. The two subscales measure the subject's sensitivity to the expressive behavior of others (EX), and their tendency to monitor their self-presentation (SP).

Source

Administration

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 hiim 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.

> **[Examiner]: "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."**

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 Socioemotional Expressiveness (EX) Score, the Ability to Modify Self-presentation (SP) Score, and the RSMS Total Score.

Scoring

Each item yields a score from 0 to 5.

The **Sensitivity to Socioemotional Expressiveness Score (EX)**, ranging from 0 to 30, is the sum of items 2, 4, 5, 6, 8, and 11. The EX score may be calculated with the following formula:

RSMS2 + RSMS4 + RSMS5 + RSMS6 + RSMS8 + RSMS11

If an item is missing, the total score should not be calculated. In this case, enter "88".

The **Ability to Modify Self-Presentation Score (SP)**, ranging from 0 to 35, is calculated by summing items 1, 3, 7, 9, 10, 12, and 13, as follows; note that the formula below performs the required *reverse scoring* of items 9 and 12:

RSMS1 + RSMS3 + RSMS7 + (5 – RSMS9) + RSMS10 + (5 – RSMS12) + RSMS13

If an item is missing, the total score should not be calculated. In this case, enter "88".

The **RSMS Total Score**, ranging from 0 to 65, is the sum of all 13 items, as follows; note that the formula below performs the required *reverse scoring* of items 9 and 12:

RSMS1 + RSMS2 + RSMS3 + RSMS4 + RSMS5 + RSMS6 + RSMS7 + RSMS8 + (5 – RSMS9) + RSMS10 + RSMS11 + (5 – RSMS12) + RSMS13

If an item is missing, the total score should not be calculated. In this case, enter "88".

Higher scores are interpreted as reflecting a greater degree of interpersonal sensitivity and responsiveness.