

Chapter 11

Cognitive Assessments

At the time of Visit 3, this chapter has been revised in three primary ways:

1. The chapter has been expanded to include all procedures related to the assessment of cognition. As such, assessments which were previously described in separate chapters including the **Clinical Dementia Rating Scale, the TICS and Dementia Questionnaire** (formerly in the Follow Up chapter), are now components of this chapter.
2. The chapter has been reorganized to improve usability. In particular, **detailed scoring criteria for clock drawing and logical memory are now in an Appendix** to this chapter rather than with their associated tests.
3. A Neuro-Motor Exam has been added to the Cognitive Assessment and is described herein.

Table of Contents

Certification and Quality Control	11-2
Validity Ratings	11-2
Missing Data Codes	11-2
General Assessment Issues	11-3
Digital Data Codes and Guidelines	11-5
Overview of In-Person Cognitive Testing	11-5
• MMSE	11-6
• HVLTL Immediate	11-9
• Clock Drawing Test	11-10
• Trail Making Test	11-11
• Logical Memory	11-14
• Number Span Test	11-15
• Digit Symbol Substitution Task	11-16
• Animal Fluency	11-17
• Verbal Fluency (FAS)	11-18
Scoring Criteria Appendix	11-19
Neuro-Motor Exam	11-28
Digital Data Procedures	11-31
Telephone Interview for Cognitive Status (TICS)	11-32
Dementia Questionnaire (DQ)	11-37
Clinical Dementia Rating Scale (CDR)	11-41

Certification and Quality Control

Certification to administer all cognitive tests is overseen by Dr. Stephanie Cosentino and Dr. Stacy Andersen. Certifications can take place in person or by skype. Once certified, examiners will send Drs. Cosentino and Andersen the first five test batteries that they have administered for review. After this, examiners will have one of every five batteries double scored by a second examiner at their site. Scoring discrepancies will be resolved by the two scorers and the final score will be entered into the database. Unresolved scoring issues should be discussed with Drs. Cosentino and Andersen. When an examiner's batteries are consistently error-free (5 in a row), 1 out of every 10 batteries can be double scored. To maintain certification, examiners must administer the cognitive battery at least twice per month. Examiners should be re-certified on an annual basis.

Validity Ratings

At the completion of cognitive testing, you will be asked to assign a validity code to **each of the cognitive tests** on the Factors Affecting Testing pages. Please indicate if any tests were not administered or discontinued, and the corresponding reasons in the “test was NOT completed” column. Do not enter anything in the “Test WAS completed” column. If a test was considered to be valid without any issues affecting performance, assign a code of 0 for the individual validity ratings in the “Test WAS completed” column. Do not enter anything in the “Test was NOT completed” column. The validity ratings regarding **establishing and maintaining mental set** should be used as indicated below. Additionally, please assign an **overall validity rating** to the test session as indicated on the validity rating page (last page of Panel 7 Cognitive Assessment).

	Use ‘Failure to Establish Set’ if:	Use ‘Failure to Maintain Set’ if:
Test was NOT administered or completed	Person could not understand instructions	NA
Test administered but NOT completed	NA	Person had difficulty remembering instructions
Test completed	NA	NA

Missing Data Codes in REDCap

When participants are unable to perform certain test items, or if certain questions are not administered, it may be appropriate to use one of the following missing data codes. Each test item in REDCap has specific missing data codes that are available, therefore the following codes are not applicable to all items. Examiners should use their best judgment to determine which code best describes the reason that data for an item is missing. When there are missing items within a test, do NOT calculate a total test score.

Code	Definition	When to Use
N	Not applicable	When the item was not administered and therefore no score is available. Also use for summary scores that cannot be computed because individual items are missing.
D	Don't know	When the examiner does not know why the data is missing. This is most applicable when questionnaires are returned via mail and data is missing.
P	Protocol	This is used when the procedure or question is not relevant to the participant. This may apply to DQ items if, for example, a person scores above the MMSE cut-off score for receiving the DQ.
H	Physical or sensory	When participants have a physical or sensory problem such as motor, hearing, or vision impairment that prevents them from completing the test item in a valid manner.
C	Cognitive or behavioral	When participants have a cognitive or behavioral problem that prevents them from engaging in the test in a valid manner. This code should not be used if the participant is simply unable to complete the item because they don't know the answer or the task is too difficult.
R	Refused	When participants refuse to respond.
O	Other	When none of the above situations apply.

General Issues Regarding Cognitive Assessment

- Each site will pursue IRB approval to audio record cognitive testing. Audio recordings can be used for later scoring if there is concern that responses were not recorded accurately.
- If a person responds, “I don't know”, please cue with, “*Would you like to take a guess?*”
- If a person becomes frustrated or appears to give up on a test, you should say, “*Just try your best*”. If additional encouragement is needed, you may also explain to the participant that “*These tests were designed to be challenging, so don't be discouraged if they are difficult.*”
- If a person asks how they are doing, please refrain from giving them specific feedback about accuracy (this would invalidate the test). Instead, depending on the situation, you can say: “*I'm sorry I can't give you specific feedback about your performance! I know that must be frustrating, but it is part of the testing rules.*”
- If the participant asks if they have said a word before on memory testing or fluency tests, you should say, “*I'm sorry, I'm not able to give you feedback on that*”.
- If the participant asks you to slow down presentation of stimuli on HVLT, Logical Memory, or Number Span, you should give a polite nonverbal response indicating that you cannot slow down. Once you have finished delivering the information and the person has provided their response, you should say, “*I'm sorry, I have to read the information at that speed*”.
- Self-corrections are accepted only if you have not moved onto the next test.
- Once the delay interval has passed for a memory test, examiners should determine whether it is appropriate to administer the delay. If necessary, examiners should extend administration of the delayed test beyond the recommended window, rather than administering the delay before the necessary time has elapsed. Examiners should never split up related tests to administer a delay condition. This includes:
 - CDT Command & Copy

- Trail Making A & B
- Number Span Forward and Backward
- Animal Fluency and FAS

Digital Data Codes and Guidelines

Sites will receive paper for digital tests from CUMC. All written data will be collected on the digital paper including: MMSE Pentagons, MMSE Sentence, Trail Making Practice and Test for A & B, and Digit Symbol. IDs and test codes (below) must be written on the bottom of each piece of paper **AFTER** the participant completes the test **USING the digital pen in the lower right corner**. Do not write over the participant's writing.

Pentagons	P
Sentence	S
Trails A Practice	PA
Trail Making Part A	TA
Trails B Practice	PB
Trail Making Part B	TB
Digit Symbol	DS

Order of In-person Cognitive Testing

The order of test administration is outlined in the table below. Examiners will encounter situations in which participants are unable to or not motivated to complete portions of the test battery. No specific tests should be prioritized in this situation; just administer the battery in the order below.

Completed By	Completed When	Measure	Digital Pen Required
Participant	In Person (~ 35 minutes) OR, if necessary, tests in bold can be administered by phone. See phone administration in Chapter 1.	Folstein Mini-Mental Status Exam (TICS for phone administration)	Yes
		HVLT Immediate	No
		Clock Drawing Test	Yes
		Trail Making Test	Yes
		Logical Memory 1A	No
		Number Span Test (Digit Span)	No
		Digit Symbol Substitution Task	Yes
		Animal Fluency	No
		Letter Fluency	No
		HVLT Delay**	No
		Logical Memory IIA***	No
CDR	No		
Examiner	Following testing	Cognitive Testing Validity Ratings	No

**Administer 20-25 minutes after the completion of the immediate condition of the test. If necessary, administer non-cognitive measures to fill the time and return to the delay condition after you have completed intervening measure(s) and 20 minutes has passed. If necessary, it is preferable to go beyond the delay period rather than to administer the delay portion of the test prior to 20 minutes.

*** Administer 30-40 minutes after the completion of the immediate condition of the test. If necessary, administer following tests to fill the time interval and return to the delay condition after you have completed intervening task(s) and 30 minutes have passed. If necessary, it is preferable to go beyond the delay period rather than to administer the delay portion of the test prior to 30 minutes.

Digital Voice Recorder

The entire cognitive assessment should be voice-recorded using the Zoom H4n Pro digital voice recorder. Before turning on the recorder, read the following script: **“This digital voice recorder will record your responses so that I can go back and make sure that I am correctly writing your responses and so that we can analyze voice features that may be related to health and brain function.”**

Instruction Sheet for MINI MENTAL STATE EXAMINATION (MMSE)

NOTE 1. Have three separate pieces of paper to be used for pentagons (digital paper), comprehension (regular paper), and sentence (digital paper).

NOTE 2. When you begin the MMSE, do not ask the person if they have problems with their memory, as is indicated on the form. Instead, begin the MMSE by saying:

“I’m going to ask you some questions about your memory. What is the year?”

Orientation to Time: Each question should be asked separately, as specified on the test form. Write the participant's response to each question in the space provided. Score one point for each correct response. No partial credit is given.

If the participant gives only the last two digits of the year, say "What is the full year?"

When a year or season is near transition (2 weeks on either side), say “Are you sure?”

If you have to clarify “day of week”, say “Is it Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, or Saturday?”.

If the participant gives the date when prompted for the day (or vice versa), give credit for date if the response is correct. Conversely, subtract credit for the date if response is incorrect. All other items require exact answers.

Orientation to Place: Each question should be asked separately, as indicated on the test form. Site specific and regionally specific queries are listed below in the table. Please consult this table to determine the appropriate question for your testing location **prior to beginning the test.**

Table A. County and City Questions

MMSE Item	If you are in a major city, query as follows...	If you are in a suburb, query as follows...	*Exceptions*
County (City/Town)	Query for City	Query for County	BU scores 2 points for city only and does not query county or part of city
City/town (or part of city/ neighborhood)	Query for Part of City / neighborhood	Query for City	

Table B. Building Questions

MMSE Item	House or Apartment Building	Nursing Home / Skilled Nursing Facility	Hotel	Exceptions
Building (name or type)	Query for type of building (my home, my sister’s home, the specific type of house (e.g., ranch), nursing home, hospital, hotel are all acceptable)			DK site queries for street name
Floor of Building (room number or address)	Query for address	Query for floor if multiple floors, or room # if single floor		DK site queries for house number

**For address, do not record the right or wrong answer verbatim. Just score as 1 or 0. But if it is wrong, record HOW it is wrong (e.g., wrong street number). If participants are seen at a family member's house and do not know the address, the item is scored as incorrect.*

Registration: "Listen carefully. I am going to say three words. You say them back after I stop. Ready? Here they are..APPLE [pause], PENNY [pause], TABLE [pause]. Now repeat those words back to me." Repeat all three words together until the person is able to accurately recall all three (but only up to 5 times). If the person answers incorrectly on the first trial, say, "The words were APPLE [pause], PENNY [pause], TABLE [pause]."

Write the participant's response to each question in the space provided. Score one point for each correct response. Score only the first trial. At the end of the trial, give the following instructions: "Now keep those words in mind. I am going to ask you to say them again in a few minutes."

Attention: "The word WORLD is spelled W-0-R-L-D. Spell WORLD backwards."

Repeat the instructions if the participant asks for a repetition or appears confused. As clarification, the examiner may say "Start from the end and go to the beginning." Allow additional trials if the participant requests them.

If the person spells WORLD forwards, say, "Good – and can you spell it backwards now?" Credit based on the final response.

Record the letters of the participant's final response. One point is given for each correct letter (for example, "D-L-0-W" would receive two points for the correct placement of the "D" and the "L").

Insert Pentagon task here along with the digital pen introduction. Then return to recall of the 3 items.

"This is the pen you'll be using. It's hooked up to our computer system so we can track how you draw and how you write. It has been known to give a little buzz or vibration at times, and it's usually when you draw like this [demonstrate horizontal angle]. If it happens, it's not a big deal, nothing to worry about. To stop the buzzing you can just hold it vertically [demonstrate this] or like a normal pen [demonstrate this] and you shouldn't have an issue." In the event that a participant questions why we're using a different pen, try to refrain from answering by saying, "It's just the pen we use for this test." As a last resort to maintain rapport, it is acceptable to tell the participant, "It's a digitized pen."

Drawing: The pentagon model should be presented flat on the desk in front of the person. Give the participant a pencil or pen and the paper and say: "Please copy this design." If a person traces the stimulus when asked to copy the pentagons, re-direct them to the appropriate space on the page. Do not allow erasures. If the participant appears dissatisfied with his/her drawing or requests a second attempt, allow the participant to re-draw the figures on the same page. Clearly label the first and second attempt. The best drawing should be scored. AFTER the participant completes the drawing, write the participant ID, as well as 'P' for pentagon at the bottom right of the digital page **USING the digital pen.**

One point is given if the participant draws two intersecting pentagons (5-sided figures), the intersection results in a 4-sided figure, and all ten angles are present, with two of them intersecting.

Recall: "What were those words I asked you to remember?" If needed, explain the source of the three objects by saying "I asked you to repeat three words earlier and to remember them. Can

you recall them now?" Write the participant's response to each question in the space provided. One point is given for each correct response. If the participant is unable to recall an item, the item should be scored as incorrect.

Naming: Show the participant a pencil or pen and say, "**What is this?**" If the participant gives a function (e.g., "You can write with it"), say "Yes, but what is this called?" No other clues should be provided. Repeat for wristwatch. Write the participant's response to each question in the space provided. One point is given for each correct response. If the person says "clock" for watch, this is scored as incorrect and is not cued. **You must use pen and watch. Please buy a watch for your test kit if you do not wear one, and place it on your wrist BEFORE testing.*

Repetition: Engage the participant's attention and clearly say, "**Now I am going to ask you to repeat what I say. Ready? 'No ifs, ands, or buts.' Now you say that.**" Score the first attempt. If the response is incorrect, write the participant's response in the space provided. One point is given for an exact repetition of the phrase. **If the participant requests that you repeat the phrase before they have begun to respond, you can repeat the entire command up to 5 times.** If a participant requests a repetition after they have begun to respond, encourage them to take their best guess and score their final attempt. If they still request a repetition, repeat the phrase to maintain rapport but the score should not change.

Comprehension: "**Listen carefully because I am going to ask you to do something.**" Present the blank paper at the participant's mid-line and say "**Take this paper in your right hand, fold it in half and put it on the floor.**" One repetition is permitted at the participant's request only if the person has not yet begun any of the steps, but the entire command must be repeated verbatim. The participant is allowed to fold the paper using both hands.

**If the person does not complete 3-step command and asks what comes next, please encourage them to take their best guess.*

**If the person takes the paper with their left hand but verbally acknowledges that he or she should have taken it with their right hand, credit can be awarded for that item.*

**If the person folds the paper more than once (i.e., in fourths), credit is not awarded for folding in half.*

Record the participant's performance for each of the three separate actions indicated on the form.

Reading: Show the stimulus card ("CLOSE YOUR EYES") to the participant and say: "**Read this and do what it says.**" If the participant just reads the sentence but does not close their eyes, you can say, "**And please do what it says**". If the participant is unable to read, read the sentence out loud. Record the participant's performance. One point is given if the instructions are completely and correctly followed.

Writing: Give the participant the digital pen and the blank piece of digital paper in landscape orientation and say: "**Please write a sentence.**" If needed, prompt the participant by saying "**Write about the weather.**" **AFTER** the participant completes the sentence, write the participant ID, as well as 'S' for sentence at the bottom right of the digital page **USING the digital pen.**

One point is given for any complete sentence (even if not about the weather). Grammar, spelling, and punctuation are not scored, but the participant must write a sensible sentence that contains a subject and a verb. A sentence with an implied subject (e.g., close the door) is acceptable. If the sentence is illegible, ask the participant to read it aloud for scoring.

HVLT-R

Refer to the record form for all instructions and procedures. Additional considerations are below:

Prior to reading the list of words, please stick to the script. Do not add, “The words are…” and do not ask the person if they have any more words once they are finished recalling the list.

Repetition of a word at the person’s request is provided only on Trial 1. Each word can be repeated up to two times. However, if this is necessary, please note that hearing impairment may have influenced performance on the test when completing the validity ratings. On Trials 2 and 3, please provide a nonverbal response by shaking your head to indicate that you cannot repeat the words any longer.

Responses are not timed and participants should be encouraged to take their time and keep trying if frustrated. Record responses in order and include any intrusions or perseverations.

The delayed memory trial should be administered after 20 minutes has elapsed. If you are in the middle of another test, complete the test before moving onto the HVLT delay.

Scoring Considerations:

Free Recall. For Trials 1-4, simply count the number of correct words recalled for each learning trial. Total Recall is the summed total for Trials 1, 2, and 3.

Rehearsing: If the person is clearly **rehearsing** words that they have already said, do not record or score as perseverations. If the person names a word not previously said while **rehearsing**, record and credit.

Delayed Memory: If a person does not freely recall any words, or doesn’t remember doing a word list but remembers the words once you begin the recognition trial, they do not receive credit for these words on the delay trial.

Scoring Intrusions and perseverations on the HVLT: An **intrusion** is a word that is provided by the participant but was not on the list. A **perseveration** is a word that is repeated by the participant; multiple repetitions of the same word are each counted as perseverations. If a person repeats an intrusion (e.g., “moon, lion, tiger, moon”), the first instance should be scored as an intrusion, and any further instances would be scored as perseverations. So, for this example, it would be 1 intrusion and 1 repetition. A participant may ask the examiner, “You didn’t say X, did you?”. The table below describes the procedures for responding to this question. Also, if the word is **not from the list**, then explicit rules for scoring are below.

		Examiner response	Previously Said	Previously Didn’t Say
Words from the List	“X” – I already said that.	-	Not Perseveration	Credit
	I already said “X”.	-	Not Perseveration	Credit
	Did I say “X”?	<i>“I’m sorry, I’m not able to give you feedback on that”</i>	Perseveration	Credit
	You didn’t say “X”, did you?		Perseveration	Credit
Words Not from the List	“X” – I already said that.	-	Not Perseveration	Intrusion
	I already said “X”.	-	Not Perseveration	Intrusion
	Did I say “X”?	<i>“I’m sorry, I’m not able to give you feedback on that”</i>	Perseveration	Intrusion
	You didn’t say “X”, did you?		Perseveration	Intrusion

FHS digital Clock Drawing Protocol

The examiner should fold the dCDT form, check *the right upper hand box* (carefully remaining inside of the box). The pen should vibrate to indicate that the pen has been activated. Present the command side of the clock form and the digital pen to the participant. Read the command instructions. The copy condition should be completed immediately following the command condition. When you take the paper back, record the ID on the command side below the dotted line and check the second box to complete the test.

The pen **should not** be capped between the command and copy condition. The lower right hand box **should not** be checked until after the test has been completed and the ID has been recorded **USING the digital pen**.

Command condition

Place folded paper, blank side up, and pen in front of participant. Say, **“I’d like you to draw a clock, put in all of the numbers, and set the hands to ten after eleven.”** Begin timing as soon as instructions are completed. Tests will be discontinued by the examiner after 5 minutes.

IMPORTANT ADMINISTRATION CONSIDERATIONS

Examinees should not be allowed to rotate the paper PRIOR to beginning their clock. However, if examinees rotate their paper once they have started their clock (for example, as they are writing the numbers), **do not stop them**. For the FHS question regarding rotation, there is an option to enter “NA”. This option is not relevant and should not be selected.

If the examinee asks if they can use roman numerals, you can tell them that Arabic numbers are preferred. But **do not stop them** if they spontaneously use roman numerals.

If the examinee finishes their drawing, and quickly fixes an aspect of the clock after you have finished timing, it is not necessary to record additional time.

You are allowed to repeat the time if the participant asks. However, prior to providing the time, pause to be sure the reminder is actually needed. Sometimes participants go onto state the time themselves WITHOUT asking for confirmation. For this task, NEVER help the participant unless they look you in the eye and ask for it! (Example: A participant keeps her head down and says, "Did you say 10 after 11? Hmmm, yeah that goes like this.") Under *'Did participant ask for a reminder of time,'* circle NO!

If the participant says the CORRECT time but asks you to confirm the time, score as “N/A”.

If the participant says the INCORRECT time, correct them and score as a request for reminder of time.

Copy Condition

Place pen and folded paper with prepared clock showing in front of participant. Say, **“Please copy this clock.”** If the participant asks, “does it have to be exact?” Respond by saying, **“Just do the best you can.”** Begin timing as soon as instructions are completed. Tests will be discontinued by the examiner after 5 minutes.

TRAILMAKING PART A

TRAIL MAKING A SAMPLE: Place paper in front of participant, give participant the digital pen, and say, **“On this page (point) are some numbers. Begin at number 1 (point to “1”) and draw a line from one to two, (point to “2”), two to three (point to “3”), three to four (point to “4”), and so on, in order, until you reach the end (point to the circle marked “END”). Draw the lines as fast as you can. Do not lift the pen from the paper. Ready, Begin!”**

If the participant makes a mistake on Sample A, point it out and use the relevant prompt below:

1. **“You started with the wrong circle. This is where you start”** (point to “1”).
2. **“You skipped this circle”** (point to the one omitted). **You should go from number one (point) to two (point), two to three (point) and so on until you reach the circle marked END (point)."** If it is clear that the participant intended to touch the circle but missed it, do not count it as an omission, but caution him/her to touch the circle.
3. **“You only went as far as this circle (point). You should have gone to this circle marked END (point)."**
4. **“Please keep the pen on the paper, and continue right on to the next circle.”**

After the mistake has been explained, mark out the wrong part with a regular pen and say, **“Go on from here”**, pointing to the last correct circle. If the participant succeeds, say, **“Good! Let’s try the next one.”** If the participant still cannot do it, discontinue the test. *Participants are not permitted to start over on a new “practice” sheet if they make errors on the sample.*

AFTER the participant completes the practice, write the participant ID, as well as ‘PA’ for Practice Trails A at the bottom right of the digital page USING the digital pen.

TEST: TRAILS A

“On this page are numbers from 1 to 25. Do this the same way. Begin at number 1 (point to “1”) and draw a line from one to two, (point to “2”), two to three (point to “3”), three to four (point to “4”), and so in, in order, until you reach the end (point to the circle marked “END”). Remember, work as fast as you can and do not lift the pen from the paper. Ready, Begin!”

1. Start timing. If the participant makes an error, call it to his or her attention immediately, by following the steps below, and have the participant proceed from the point where the mistake occurred. Do not stop timing. The assistance given when an error is made should proceed stepwise as follows:
 - a. Cross out line with a regular pen, point to last correct circle; say, **“This is a mistake. Start again here.”**
 - b. If participant does not start, ask, **“What should come next?”**
 - c. If unable to proceed, ask, **“Do you remember the sequence?”**
 - d. If participant still cannot proceed, go back three circles and say, **“You were at X [number] (point), what should come next?”**

When Part A is finished, stop timing, take the paper and say, **“That’s fine. Now we’ll try another one.”** Record the time with a regular pen. **Then use the DIGITAL PEN** to write the participant ID, as well as ‘TA’ for Test Trails A at the bottom right of the page.

TRAIL MAKING B SAMPLE: Place paper in front of participant. Say, “**On this page are some numbers and letters. Begin at number one** (point) **and draw a line from one to A** (point to “A”), **A to two** (point to “2”), **two to B** (point to “B”), **B to three** (point to “3”), **three to C** (point to “C”), **and so on, in order, until you reach the end** (point to the circle marked END). **Remember, first you have a number** (point to “1”), **then a letter** (point to “A”), **then a number** (point to “2”), **then a letter** (point to “B”), **and so on. Draw the lines as fast as you can and do not lift the pen from the paper. Begin!**”

If the participant succeeds, say, “**Good! Let’s try the next one.**” If the person makes an error, explain the error according to the error guidelines for the sample. Use additional instruction as necessary to explain the test instructions to the participant. If the person is clearly unable to get through the sample or understand the instructions, you do not need to administer the test. Record “inability to establish set” as the reason the test was not administered. However, if you are unsure of their ability, proceed to the test.

AFTER the participant completes the practice, USE THE DIGITAL PEN to write the participant ID, as well as ‘PB’ for Practice Trails B at the bottom right of the digital page.

TEST TRAILS B:

“**On this page are some numbers and letters. Do this one the same way. Begin at number one** (point) **and draw a line from one to A** (point to “A”), **A to two** (point to “2”), **two to B** (point to “B”), **B to three** (point to “3”), **three to C** (point to “C”), **and so on, in order, until you reach the end** (point to the circle marked END). **Remember, first you have a number** (point to “1”), **then a letter** (point to “A”), **and so on. Do not skip around, but go from one circle to the next in the proper order. Draw the lines as fast as you can and do not lift the pen from the paper. Ready, Begin!**”

Start timing. If the participant makes an error, immediately put a dash through the incorrect line USING A REGULAR PEN, and have the participant proceed from the point at which the mistake occurred. Follow error correction guidelines outlined on the record form in the Error Corrections for TEST. Do not stop timing. Each time you have to use an error correction, this is counted as a CUE. For each new error, administer all error corrections, one at a time, in order, without skipping any, until the person can continue.

AFTER the participant completes the test, write the participant ID, as well as ‘TB’ for Test Trails B at the bottom right of the digital page.

If the person stops at 'L' and thinks that's the end of the test, the prompt is, "what comes next". If they still think that they are at the end, continue to cue them until they catch on but do not count this as an error. Record the number of cues in the scoring section. If the participant cannot continue, mark that the test was not completed and make a note in the back of the battery documenting what happened.

Error and Cue Definitions:

Loss of Set Error = Person fails to alternate between numbers and letters.

Sequencing Error = Person alternates between numbers and letters but goes in wrong order.

Perceptual Errors = Confusion between I and 1 or B and 8.

Cue = any comment provided by the examiner as listed in the error correction box. Each error should be accompanied by at least 1 cue (unless the participant self-corrects).

If a participant makes the same error twice in a row (e.g., draws a line from 3 to 5 and repeats the error after it is pointed out by the examiner), this is counted as one error.

IMPORTANT ADMINISTRATION CONSIDERATIONS for TRAILS A and B

1. If the participant starts before the instructions are done in the sample, say, **“I’m sorry, but I have to read through all of the instructions.”**
2. If the participant starts before the instructions are done in the test, say, **“please don’t start until I say *begin*”**.
3. If the participant says the next number loud, questioning you regarding whether it is correct, say: **“I can’t say anything until you draw the line.”**
4. If the person **starts trails early**, stop them by providing the appropriate cue. This does not present a problem for the electronic pen. There should also be a place in the scoring section that says "Participant started test early?" - be sure to circle 'yes'!
5. General rule of thumb is to **give person the benefit of the doubt**. If they pass through an incorrect circle but it's clearly on their way to the correct circle, do not stop them. Similarly, if they nearly miss a correct circle but it is clear that they intended to pass through it, do not stop them.
6. If participants lose their place on either Trails A or B, they are **allowed to retrace lines**.

Data Collection: Record the time to completion. AND number of pen lifts/corrected errors. It is important to continue this test to the extent that the participant is willing and able. If the participant struggles, but is able to maintain set with some cuing, it is important to continue the test for as long as necessary. If you find that the participant loses set with each circle, it may be discontinued. If the tester has provided all allowable prompts and the person simply can't continue / doesn't know what to do, it is appropriate to discontinue. If they can continue with prompting, cycle through the prompts as necessary for each of the remaining errors until 5 minutes is reached. Trails A and B will each be discontinued at 5 minutes.

1. **“Check here if test NOT completed”:** Answer ‘YES’ if test was administered and participant completed all circles within 5 minutes. Answer ‘No’ if the test was not administered, or if the test was discontinued at any time, including if the participant “timed out” at the 5 minute mark.
2. **“Time to Completion”:** This value cannot be higher than 5 minutes. If the examiner discontinued the test at 5 minutes because the participant “timed out”, then enter 5’00 for time to completion, and enter ‘12’ (insufficient time) as the code in the validity section under “Test Not Completed”.
3. **Pen lifts:** Pen lifts should be counted throughout the test; however, pen lifts during error corrections are not counted.

LOGICAL MEMORY IMMEDIATE and DELAYED

*****Please see record form for all instructions and procedures.*****

Regarding administration of the Logical Memory Test, prior to reading the story provided, interviewers should emphasize to the participants that no repetitions will be permitted during the administration of this measurement. Following the instructions for Logical Memory I, please state, “*Please listen carefully, because I am not allowed to repeat any portions of the story*”.

The length of time to read the story should be approximately 30 seconds.

No credit is given for “employed” if the participant responds: “Anna Thompson, a cook in a school”.

On Logical Memory I, the cue is to say “Anything else?” after the person has recounted the story. In cases where a participant says “I don’t remember”, the tester can say: “Anything at all?”

The LM II form says: “If the 30-40 minute delay period has elapsed and another test is being administered, interrupt the other test and administer this test”. **Please disregard this and do NOT interrupt another test. LM II should be completed as soon as possible after finishing the ongoing test according to the rules in the “General Issues” section at the beginning of this chapter.**

Record time LMI is completed, or start a separate timer to begin the delay period.

Number Span Test

This is a test of working memory and it taps two different working memory constructs. The first, Forward Number Span, measures the capacity for holding information very briefly for the purpose of repeating it exactly. The second, Backward Number Span, measures the ability not only to hold the information but also to manipulate the numbers and reverse the sequence. This test is also referred to as Digit Span.

Numbers for both forward and backward span tests are presented, with sequences ranging from 2 to 9 numbers. Two trials are administered at each sequence length. There are two scores: total number of correct trials; longest sequence repeated correctly prior to failing two consecutive trials of the same length.

Source

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Administration and Scoring — Forward Number Span

[Say]: **“I am going to ask you to repeat some numbers for me. Wait until I finish saying the numbers and then repeat them in the same order. For example, if I say 1-8-7, you would say 1-8-7. If I say 2-9-8, what would you say? If the participant gives the wrong answer, say, “Actually you would say 2-9-8.”**

[Say]: **“Repeat only the numbers I say each time”**. Then start with the test items. Before each of the first two items, say, **“Ready?”** **If the participant is clearly attentive and ready for the next item, it is not necessary to continue to use this prompt beyond the second item. However, if you feel it is necessary to re-direct attention, this prompt may be used as often as necessary.**

Administer the items in the order indicated on form. Write participant's response on the answer sheet. Continue testing until two number strings at the same length are failed. Record total number of trials correct and longest number sequence repeated correctly.

Administration and Scoring — Backward Number Span

[Say]: **“I am now going to ask you to repeat some numbers for me but to reverse them from the way I say them. Wait until I finish saying the numbers and then repeat them in reverse order, or backward. For example, if I say 3-7-4, you would say 4-7-3. If I say 7-3-6, what would you say?”** If the participant gives the wrong answer, say, **“Actually, you would say 6-3-7.”**

[Say]: **“Repeat only the numbers I say each time, backward, in reverse order.”** Then start with the test items. Before each of the first two items, say, **“Ready?”**

If a participant repeats the numbers in the forward order on either of the first two test items, you may remind them to say the numbers in reverse order by saying, **“Remember, after I say the number sequence, repeat the sequence backwards. Ready? Do not give them the number sequence again. Score correct if the participant is able to give the correct reverse order after the prompt. This prompt can only be given once. If it is given please mark “prompt given”.** Write the participant's response on the answer sheet. Continue testing until two number strings at the same length are failed. Record total number of trials correct and longest number sequence repeated correctly prior to the two failed trials. Responses that are “chunked” (e.g., “18” “95” for 1895) are given credit.

No repetitions are allowed on this test.

WAIS-R DIGIT SYMBOL

Place the test form on table in front of participant. Read aloud the following instructions:

SAY: "Look at these boxes. Notice that each has a number in the upper part and a special mark in the lower part. Each number has its own mark. Now look down here where the boxes have numbers in the top part but the squares at the bottom are empty." [Point to sample items.]

SAY: "You are to put in each of the empty squares the mark that should go there, like this: Here is a 2; the 2 has this mark, so I put it in this square like this. Here is a 1; the 1 has this mark, so I put it in this square. This number is 3; the 3 has this mark, so I put it in this square." [Examiner fills in the first three boxes to demonstrate. The examiner should use both the sample items and the key at the top of the page during the instructions to clearly indicate how participants should use the key to find the appropriate numbers].

[SAY]: "Now you fill in the squares up to this heavy line." [if participant makes errors, continue to help until all sample items are correct.] "Yes, now you know how to do them."

[SAY]: "When I tell you to start, you do the rest of them. Begin here and fill in as many squares as you can, one after the other, without skipping any. Keep working until I tell you to stop. Work as quickly as you can without making any mistakes. When you finish this line, go on to this one. Ready? Begin." [Allow 90 seconds.]

- If the subject skips an item, immediately give a reminder to go in order and not skip any; point out skipped item and direct the participant to continue from the last item completed successfully in order.
- Do not intervene if the participant fills in a wrong symbol, but if the participant has clearly lost focus as to what to do (e.g., starts filling in something other than symbols), you may give the following reminder: **"Remember, you are to fill in the symbol that goes below each number, as indicated in the key up above."**
- If the participant pauses at the end of a row, say **"Good, keep going."** [Point to the beginning of the next row, if necessary.]
- If the participant starts at the right side of the row, redirect him or her to begin at the left side by pointing to the appropriate square and saying, **"Please continue over here"**. Any symbols filled in from the right side should receive credit.
- Participants should be given the benefit of the doubt if the symbols closely resemble the correct symbols (i.e., rounded edges). However, if the errors to the symbols clearly change the meaning of the symbol (i.e., changing the symbol for #2 to a 't' or changing the symbol for #5 to a 'u' with a tail) then credit should not be awarded.

AFTER the subject completes the test, write the participant ID, as well as 'DS' for Digit Symbol at the bottom right of the digital page **using the digital pen**. Do not write over the boxes

CATEGORY (ANIMAL) FLUENCY

[SAY]: "I am going to give you a category and I want you to name, as fast as you can, all of the things that belong in that category. For example, if I say 'articles of clothing', you could say 'shirt', 'tie', or 'hat'. Can you think of other articles of clothing?"

Allow up to 20 seconds for the participant to produce two responses. **Circle the response type (Correct, Partially Correct, Incorrect), and read the associated instruction from the table.**

Participant Response to Sample	Examiner Response
Correct ≥ 2 correct responses	<i>That's right.</i>
Partially Correct 1 correct response only ≥ 1 incorrect AND ≥ 1 correct responses	<i>That's right. You also could have said 'shoes' or 'coat'. _____ is (are) correct, but _____ is (are) not an article of clothing. You also could have said 'shoes' or 'coat'.</i>
Incorrect No response	<i>You could have said 'shoes' or 'coat' since they are articles of clothing.</i>
≥ 1 incorrect responses only	<i>No, (x) is (are) not an article (s) of clothing. You could have said 'shoes' or 'coat' since they are articles of clothing."</i>

Next, read the instructions for the Animals category: [SAY] "Now I want you to name things that belong to another category: **Animals**. You will have one minute. I want you to tell me all the animals you can think of in one minute. Ready? Begin."

Start timer as you say "Begin". Write actual responses as legibly as possible on the *Worksheet for Category Fluency-Animals*. Record each verbalization in the appropriate space depending on the time frame (15 second intervals) in which it was said. Stop the procedure at 60 seconds.

One prompt ("Tell me all the animals you can think of.") is permitted if the participant makes no response for 15 seconds or expresses incapacity (e.g., "I can't think of anymore."). It is also permissible to repeat the instruction or category if the participant specifically requests it.

To be consistent with baseline, we **will not** redirect people after set loss errors like we do on FAS.

If the person asks if something is an animal and is correct ("Are birds animals?"), say yes and credit.

Mythical/ fictional creatures (e.g., unicorns) do NOT receive credit and should be scored as OTHER errors. The one exception is "dragon" which receives credit because a Komodo dragon is an animal.

If a participant said mice after giving mouse as an answer, it is a perseveration.

In a "thinking aloud" response such as, "Fish are reptiles", both fish and reptiles would get credit.

Infant names of species are given credit, such as "cow, calf" (2 points) or "dog, puppy" (2 points).

	Said	Didn't Say
Did I say "x"?	<i>P</i>	<i>No credit</i>
"X" – I already said that.	<i>P, SC</i>	<i>No credit</i>
I already said X.	<i>P, SC</i>	<i>No credit</i>
Response said as if person was rehearsing previously said words	<i>Not a P</i>	<i>Credit</i>

VERBAL FLUENCY (FAS)

“I will say a letter of the alphabet. Then I want you to give me as many words that begin with that letter as quickly as you can. For instance, if I say *B*, you might give me bad, bottle, bed. However, I do not want you to use words that are proper names such as Boston or Brian. Also, I do not want you to use the same word again with a different ending, such as bake, baking, baked. Any questions?”

The first letter is *F*. Give me as many words as you can that begin with *F*.”

Begin timing. Record each verbalization in the appropriate space depending on the time frame (15 second intervals) in which it was said. Time for one minute. Record all responses in the cells provided for each 15 second time interval. Be sure that the words are written clearly and that the order in which the responses were given is obvious. If your writing is not neat enough for someone else to read, you need to go back after testing and write the ambiguous words clearly. The best strategy to represent order is to write the words in columns, with ample space separating the columns.

Never provide a word from a test category to the participant. If they have difficulty hearing the specific letter (for example differentiating ‘F’ from ‘S’, please say these letters as many times as necessary, slowly and clearly so that they can see the placement of your lips and teeth when saying these letters).

Say: **“The next letter is *A*. Begin.”** Record as above.

Say: **“The next letter is *S*. Begin.”** Record as above. It is often helpful to maintain the “sss” sound for 1 second, because it makes it more obvious that the letter is “S” not “F” or “X”).

If the person says, “that’s it!” or has a very long pause that indicates they are finished, you may say **“you have more time...”** or **“keep going!”**

If the person makes errors, **you can cue him/her back to set after the 2nd CONSECUTIVE ERROR OF THE SAME TYPE** as follows. If the 2 consecutive errors are:

- **Wrong first letter (same wrong letter):** “Remember we want words that start with the letter _”.
- **Proper nouns:** “Remember, no proper names”.
- **Different forms of same word:** “Remember, don’t use the same word with different endings.”

If the participant says a word unfamiliar to you, wait until after the test is completed, and ask about it (**“It sounded like you said (insert) – is that correct? I’m not familiar with that word. Can you spell it? What does it mean?”**) Have the participant spell the word and/or give a definition. This will allow you to later look in the dictionary to see whether the word was, in fact, a valid response. If it is in fact a word, the person does not need to have said the correct definition to receive credit for providing the word.

If a person provides an ambiguous word like “frank”, always give credit.

	<i>FAS</i>	
	<i>Said</i>	<i>Didn’t Say</i>
<i>Did I say “x”?</i>	<i>P</i>	<i>No credit</i>
<i>“X” – I already said that.</i>	<i>P, SC</i>	<i>No credit</i>
<i>I already said X.</i>	<i>P, SC</i>	<i>No credit</i>
<i>Response said as if person was rehearsing previously said words</i>	<i>Not a P</i>	<i>Credit</i>

P = Perseveration; SC = Self-Correction

SCORING FAS

In the box located within each cell, write the total number of words produced during that time interval that “pass.” A word “passes” if it meets the following conditions:

- a. It is a valid dictionary word
- b. It begins with the appropriate letter (e.g., “F”)
- c. It is NOT a proper noun (e.g., if a participant says, “France, oh, I can’t use that, it’s a proper noun,” it is counted as an error and a self-correction).
- d. It is NOT the same word that was given earlier in the trial with a different ending. Interpret this rule concretely.

Fill in all of the error boxes, with zeros if necessary. ALL of the variables MUST be filled in.

If a word applies to multiple scoring types, ONLY score it as one error type and the error should be applied in the following order: (1) Wrong 1st letter (2) Perseveration (3) Broken Rule (4) Other Error.

Wrong First Letter: For each letter condition, and following the guideline described above, count the total number of errors, produced during that allotted minute, that do NOT begin with the correct letter. Place this total in the column marked “Wrong First Letter.” If a participant gives consecutive errors of the same type (prior to being corrected after 2 errors), only the 1st error is scored.

*Example: If the participant says, “friend, foe, folly, **shop, stop** (examiner cue) furniture, **ship**...,” code 2 errors; “shop” is the 1st error (“stop” is NOT counted as a separate error) and “ship” is the 2nd error. However, if the participant says, “friend, foe, folly, **shop, clothes**, (no examiner cue because letters are different!) furniture, **ship**...,” code 3 errors.*

Perseverations: For each letter condition, count the total number of words, produced during the allotted minute, that are repetitions of a previously given word. If the same word is given several times during the allotted minutes, each repetition of the word should be counted. Perseverations, unlike the other two error types, are counted as errors, even if they are said consecutively. Place this total in the column marked “Perseverations.”

Example: During the A trial, the participant says: “apple, anteater, oath, found, did I say found?, fix ..[examiner cue].” “Oath” would be scored as a wrong first letter, “found” would be scored as a 2nd wrong first letter error, and the 2nd instance of “found” would be scored as a perseveration.

Broken Rule: For each letter condition, and following the guideline described above, count the total number of errors, produced during the allotted minute, which reflect a “broken rule” (i.e., proper noun or same word with a different ending). Any proper nouns are considered errors (e.g., names of months, days of week, etc.). In other words, any noun that is capitalized when spelled is an error. Place this total in the column marked “Broken Rules.” If a participant gives consecutive errors of the same type (prior to being corrected after 2 errors), only the 1st error is scored.

Example: If a participant says “run,” then “running” does NOT pass, but “ran” DOES pass. In contrast, if the words were “frustrates” and “frustrated,” the second word would be coded as a “broken rule”. However, “Frustration” and “frustrating” would both get credit because they are different words, rather than the same word with a different ending. Similarly, “South, southwest, southeast, southern” count as 4 points because the ending changes the meaning.

OTHER ADMINISTRATION AND SCORING CONSIDERATIONS

Neologisms (made-up words) and phonemic errors (e.g., “photo” for “F”) are “other” errors.

If the person makes an error and then self-corrects, it is counted as an error and a self-correction.

Foreign Words

Different numbers that begin with the same letter (six, seven, etc.) or “same number” (six, sixteen, sixty, etc.) are acceptable because the ending changes the meaning of the word.

Phrases given that begin with the appropriate letter should be counted as 1 point per phrase, no error, unless the first word of the phrase is given again, in which case the 2nd incidence of the word is scored a perseveration. (e.g. “stop sign” = 1 point. “stop sign, stop, sign” = 2 points, 1 perseveration. “an hour” = 1 point. “french fry” = 1 point.)

Abbreviations (ASAP, SOS, etc.) are fine.

If a participant **starts to say a word but stops in the middle** of saying it because they have already said the word, and if it is clear what that word was going to be, then score it as a *perseveration and self-correction*. For example, if on animals, the participant says “ze...”, it can be inferred that they were going to say zebra and if they previously said zebra it will be scored as perseveration and self-correction.

Self-correction/perseveration examples: "Frank," then, "no, can't do that... oh wait, okay," gets 1 pt., 1 broken rule error & 1 SC. “Frank,” then, "no, can't do that... oh wait, okay, frank:” the first mention gets a broken rule error and no SC, and the second gets 1 pt. & 1 SC. “Fair” and, then later, said “fair, I said that. Oh, different kind,” gets 1 pt. and no errors for the first ‘fair,’ and 1 pt., 1 SC and 1 psv. for the second ‘fair.’ “Fair”; and, then later said “fair, I said that. Oh, different kind, fare,” gets 1 pt and no errors or SCs for the first ‘fair,’ 1 psv and 1 SC for the second, and 1 pt and no errors for the third.

If a person says a word that has two different meanings (i.e., foul/fowl) and later says “the same” word again, assume person is offering the other meaning of the word. Other examples are (for/four, sun/son, ale/ail, etc.).

Clock Drawing Test (CDT) Scoring

There are three scoring sections for the Clock Drawing Test including:

- I. LLFS CDT panel
- II. Review of the Digital CDT Scoring assigned by Clocksketch
- III. Framingham CDT items scored as a drop down panel in the Clocksketch program

I. LLFS CDT panel

1. A “significant error” would be:

- Missing numbers
- Missing circle
- Duplicate numbers
- Wrong number of hands
- Hands in the wrong place
- It DOES NOT include errors in hand length

2. For “Time to Completion”:

This value cannot be higher than 5 minutes for either command or copy. If the examiner discontinued either test at 5 minutes because the participant “timed out”, then enter 5’00 for time to completion, and enter ‘12’ (insufficient time) as the code in the validity section under “Test Not Completed”.

II. Review of Clocksketch Scoring

The information here supplements the information contained in the MIT / Lahey Instructions and Manual available through the Clocksketch website. If any questions arise that are not covered in the Clocksketch manual or in the LLFS MOP, please use the group email address to circulate questions and comments: llfs@csail.mit.edu.

One helpful thing may be to establish a master clock scorer at each site, so there is a go-to person if individual scorers have questions. If any clocks are extremely difficult to score, you can upload them to Clocksketch unscored and Sandra Rizer at CUMC will be available to assist with scoring.

LLFS examiners will enter the following data into Clocksketch:

1. Demographic and clinical information
 - a. Participant ID
 - b. MMSE score: Enter ‘Unknown’ for this variable
 - c. Referring Doctor (Enter Cosentino)
 - d. Scorer (Enter RA name if not previously entered)
 - e. Site name (Default = LLFS)
 - f. Dementia Status (broad impression as to whether the person was Not demented, MCI (for questionable cases), or Mild - Moderate Dementia)
 - g. Confidence Level in dementia status (how confident the examiner is in his or her impression)

Some Scoring Notes for Digital Scoring on Clocksketch

Splitting Strokes: Splitting strokes is generally discouraged. One clock we came across contained a center dot drawn in the same stroke as a hand. This should not be split to create a center dot; simply place the stroke in the appropriate hand folder. Splitting strokes creates a problem in reliability as different testers tend to split the same stroke at different places. In the above example there will be no center dot registered by ClockSketch, however, it is rare and reliability is more essential. Another splitting strokes cautionary tale came up with one of the practice tests. The examinee drew a 3 in the 9 place, then self-corrected by placing a “c” on the top loop of the 3; essentially crossing out the 3, but using part of this numeral to create a 9. While it may seem logical to split the stroke to finish the 9 and designate part of the 3 as crossed out digit, this is in fact incorrect. Place the “c-shaped” stroke in the nine folder, and the 3 should go into the xoutdig folder. Splitting strokes is encouraged for dividing a stroke that makes up both clock hands. It’s important to indicate that there is both a minute hand and an hour hand by splitting in this case. It’s also encouraged when a participant corrects hand length by placing an arrowhead lower on the shaft. The portion above the arrowhead should be clipped and placed into xouthand folder.

Original versus Prime: Generally, if there is a significant amount of time between a participant drawing a hand and overwriting it, this should be categorized as a prime. If a participant overdraws the hour hand without changing the length or any element of it, this would be considered HH’. In other cases, participants will return to previously drawn clock elements and add a novel feature to the element. Not infrequently, participants add “hats” to the 11 on copy clock or will add a line segment to better connect a hand to the center dot. This should be classified as part of the original as it adds to the original without over-drawing.

Noise: When deciding if a stroke is noise or part of another clock component, the time and the order in which the stroke was made can be useful. If the stroke, no matter the size, was created very close in time (less than 0.5 seconds) and in consecutive order to a stroke that makes up the majority of e.g. the 2, then it would be considered part of the 2. If the stroke was created several seconds from the stroke composing the 2 or if there is another stroke in between that stroke, then this stroke is likely noise. A useful tool in making this determination has been created for the newest version of Clocksketch. If you press Ctrl-Y, the program will display the latency for each stroke i.e. the time from the end of the last stroke and the beginning of the one you’re examining. It’s important to remember that you must consider the pre- and post-stroke latency for each item. Location of the noise stroke is also important to consider. If a stroke does not lie on or very close to another stroke that composes a component of the clock, it likely belongs in the noise folder.

Clocks Drawn Under the Line: It sometimes happens that a cognitively impaired participant will draw under the line on command condition. In these situations, **DO NOT** re-direct the participant to draw above the line as this could affect their clock drawing and this is something we try our hardest to prevent. When this happens, the clock cannot be scored by Clocksketch because this space is purged from the file before being transmitted to Dana and Randall. Instead, this clock should be hand scored using our old CDT scoring forms. Mark the appropriate factor affecting testing, and make a note in the Clocksketch file that the participant drew below the line. Finally, email Dana and Randall the date and time of the participant who drew below the line.

A Third Hand Pointing to the 12: When a participant draws a third hand pointing to the 12, we give benefit of the doubt and assume this is a second hand. To classify consistently and without throwing off the clock computations, classify this as a MH or MH' depending on whether the MH or second hand was drawn first, and designate which hand should be used for the length comparison by right clocking on the appropriate MH folder.

Targeting the 11 or 2 without a Hand: If a participant targets the 11 or 2 without using a hand (e.g. by circling or underlining it), the strokes composing the targeting object should be placed in the Noise folder.

Hour hand vs. Minute Hand: If hand length is reversed (i.e. one hand points to the 11 and one to the 2, but the one pointing to the 11 is longer), you can assume the 11-targeting hand is the hour hand and the 2-targeting hand is the minute hand. If the hands do not point to 2, 11, or 10:

1. If a hand points to the upper left quadrant it is considered an “hour hand”
2. If a hand points to the upper right quadrant it is considered a “minute hand”
3. Otherwise, defer to hand length in determining hour hand versus minute hand. The longer hand then would be the minute hand.

Complex Numeral Self-Corrections: Recently a participant drew a 1 in the 12 location, then subsequently added a 2 to correct this so that a 12 was in the 12 location. After a bit more thinking, the participant drew a 1 over the 2 indicating that it should be a 1 at the top of the clock. This left two 1's on the page. Scoring these can be difficult as we want to capture as much as we can about what happened. In this case, we decided to score the 1's as 1 and 1', indicating that the participant left to 1's on the page. Then we placed the 2 in the xoutdigit folder to indicate that the participant made some attempt to self- correct despite eventually coming to the wrong decision.

Xoutpersevdig Clarification: If the person draws a 2 followed by another 2, then crosses out the first number the first 2 is still considered an xoutpersevdig rather than an xoutdig. Despite the strict definition of a perseverated digit which pops up when you try to save a stroke in the xoutpersevdig folder.

Tick Marks: A tick mark is a tick mark is a tick mark. Whether a person crosses out a tick mark as a correction or perseverates on a tick mark, each stroke should be placed in Tick Mark folder.

Center Dot Primes: Unless the center dot strokes are in different positions, all center dot strokes should be classified as the same center dot regardless of time or whether the participant overdraws this. This is simply to keep scoring consistent longitudinally.

Do-Overs: In Framingham, we always allow participants to start over no matter how much they have drawn. If a participant draws more than just an outline, place all of this data in the Not Clock Data folder. If a participant draws only an outline then starts over, the clock outline should be scored as CF and the actually outline as CF'.

Were Any Non-standardized Cues given (e.g. numerals, hands, etc.): This question is meant to capture whether the tester gave non-standardized cues to demented participants who can complete the CDT Command with prompting.

III. Scoring Framingham Variables in the Drop Down Panel in Clocksketch

Quick Definition - Extraneous Marks: any mark that does not represent a hand, number, numeral substitute, or outline of the clock. Extraneous marks include bisecting lines, crisscrossing, radiating lines, etc. Be careful not to confuse numeral substitutes with extraneous marks.

Variable	Scoring Instruction
Rotated paper while placing numbers	<p>No: The participant did not rotate the paper when placing numbers.</p> <p>Yes: The participant turned the paper while inserting numbers. If the examiner did not record this data, observe the numbers. Select yes if it appears that the angle of the hand or wrist would have been uncomfortable and would have caused the participant to either rotate the paper (or write upside down, which is highly unusual).</p> <p>N/A: Numbers were not placed along the circle, which may have precluded the impulse to rotate the paper.</p> <p>Unknown: Examiner did not record this data. Note: you should consult with the Clinical Supervisor, but it is typically assumed that the participant did NOT rotate the paper unless you can see otherwise.</p>
Attempt to self-correct any error	<p>No: Errors are made, but the participant makes no effort to correct them. Please note: this option should NOT be circled if the participant self-corrects incorrectly (in this case, circle “yes” to acknowledge the attempt)</p> <p>Yes (result is correct): participant makes a successful effort (crossing out, overwriting, etc) to correct his/her drawing. Clock must be error-free. .**** This is a revision to previous scoring rules on 8/5/15.</p> <p>Yes (result is incorrect): the participant makes any effort (crossing out, overwriting, etc) to correct his/her drawing. The “correction” itself need not be an improvement over what was initially drawn. This also includes a self-correction of an originally CORRECT variable. NOTE: this applies if a participant successfully corrects SOME BUT NOT ALL errors.**** This is a revision to previous scoring rules on 8/5/15.</p> <p>No errors/N/A: If there are NO errors present</p> <p>Unknown: Examiner did not record this data.</p>
Needed reminder of time for hand-setting (in clock to command only)	<p>No</p> <p>Yes: The participant asks, any time after beginning the drawing, that the time be repeated and the examiner provided the time again.</p> <p>N/A: Participant did not represent the time in any manner AND did not ask that the time be repeated. If a person writes time down as a way of remembering, this counts as “N/A”. If the participant asks for a time reminder but then says the CORRECT time and asks for a clarification, this is not scored as a reminder for time, this is scored as “N/A”.</p> <p>Unknown: Examiner did not record this data.</p>
Clock outline is <u>clearly</u> irregular, angular, lumpy, or has indentations	<p>No: the outline of the clock is neatly drawn and has no obvious lumps, indentations, or angles. Please note that the elongation of the outline as an oval should not be considered irregular.</p> <p>Yes: the circle is not symmetrical, and/or it has noticeable irregularities, lumps, indentations, angles, etc. Again, an oval outline is not irregular.</p> <p>Tremor N/A: if the participant has a marked tremor that has affected his/her ability to write neatly throughout the test, do not penalize them for having a “lumpy” or “irregularly shaped” clock. Mark N/A.</p> <p>Hint: If unsure, use Template #1 to evaluate how symmetrical the outline is. Compare the four quadrants of the outline, are they significantly different?</p>
Clock outline perseveratively overdrawn (more than two times around)	<p>No: the outline is drawn once or twice around, stopping short of beginning a third pass.</p> <p>Yes: participant continued to draw the same outline more than twice on top of previously drawn outline.</p> <p>NOTE: multiple circles drawn in different locations on the page are not coded here (see next variable; “perseveration of clock outline”)</p>

Numerals	
Numerals or numeral substitutes are: (circle all that apply) (If Absent: Leave the rest of <u>Numerals</u> section blank; skip ahead to <u>Time Setting</u>)	Absent: there are no numerals or numeral substitutes drawn. No numerals present; only substitutes: Participant produced marks (“numeral substitutes” such as ticks, lines, circles, etc.) in number locations to represent clock numerals. Written Out: One or more numbers is spelled out (e.g., “ONE” for ‘1’) Arabic: the participant used some/all Arabic numerals (1, 2, 3, 4, etc.) to number the clock. Roman: Some/all Roman numerals (I, II, III, IV(III), V, etc.) used to number the clock. Note: when Roman numerals are used on a standard clock, the 4 is represented by “IIII” rather than “IV” and numerals generally face center of the clock (VI will be upside down).
Dots, words, symbols, or other marks substituted for one or more numerals	No: Only numerals are used; if some numerals are missing, there is NO mark in the place of the missing numeral. If a mark is made as a place-maker, a number was subsequently written to replace it. Yes: Numeral substitutes are used in place of one or more numerals Unknown: A determination cannot be made if marks are meant to be numeral substitutions. NOTE: If a clock has BOTH marks substituted for numerals and missing numerals, BOTH variables should be scored as “yes”. If numerals or substitutes are present, but unintelligible, mark N/A.
Time Setting	
Is one <i>hand</i> correctly pointing to “11” AND the 11 is generally in the correct location	No: There is NOT a distinguishable line pointing purposefully to the “11,” OR the “11” is NOT approximately in the <i>correct</i> location on the clock. Yes: There IS a distinguishable line pointing purposefully to the “11,” AND the “11” is approximately in the <i>correct</i> location on the clock (NOTE: <i>both</i> conditions must be met).
If no, “11” location OR numeral “11” (not in correct location) indicated correctly?	No: Neither the eleven location NOR the number “11” is indicated by a hand or mark. Yes: The eleven location OR the number “11” is indicated in some manner (a hand, circling, marking, putting a line, placing an x next to or at the location, etc.) N/A: If the answer was “Yes” to the previous question (i.e., there is a hand pointing to the 11 and the 11 is in approximately the correct location), then this question is not applicable.
Is one hand correctly pointing to the “2” AND the 2 is approximately in the correct location?	No: There is NOT a distinguishable line pointing purposefully to the “2,” OR the “2” is NOT approximately in the correct location on the clock Yes: There is a distinguishable line pointing purposefully to the “2,” AND the “2” is approximately in the correct location on the clock (NOTE: <i>both</i> conditions must be met).
If no, is “2” location OR numeral “2” (not in correct location) indicated correctly?	No: NEITHER the two location NOR the number “2” is indicated by a hand or mark. Yes: The two location OR the number “2” is indicated in some manner (a hand, circling, marking, putting a line, placing an x next to or at the location, etc.) N/A: If the answer was “Yes” to the previous question (i.e., there is a hand pointing to the 2 and the 2 is in approximately the correct location), then this question is not applicable.
Other Observations	
Extraneous marks in clock	No: The clock is free from any <i>extraneous</i> marks (NOTE: this does NOT include marks that are clearly numeral substitutions or those that were used as place markers.) Yes: The clock has extraneous marks. Examples include: <ul style="list-style-type: none"> • Bisecting, crisscrossing, or radiating lines, or tick marks (<i>not</i> used as number place markers)
Other observations: (please describe below)	No: nothing to add Yes: Describe anything significant in interpreting/understanding data not captured by variables above. Avoid redundancy when using the “other observations” box. It is not necessary to use this box to state things that are reflected elsewhere in the scoring pages. Examples to avoid: <ul style="list-style-type: none"> • “one hand points to the 10” • “drew outline in a clockwise motion” Examples include: <ul style="list-style-type: none"> • Counterclockwise placement of numbers (i.e., “1” in “11” position; “2” in “10” position) • human hands are drawn • smiley face is drawn • blatant difference in size of numerals NOTE: “Other observations” box does not result in a point deduction in the algorithm. When appropriate, mark “yes” to “extraneous marks” instead, as this box does result in a point deduction.

Tester's clinical assessment of clock drawing	Enter "Cannot Determine"
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Logical Memory Scoring Criteria

Scoring is deferred until after the examination and is done from the written record, which must be written in a legible, decipherable manner. The story consists of 25 units. On the *Worksheet for Logical Memory IA-Immediate*, underline each unit that is successfully recalled. Then total the units recalled and enter that number (00-25) in the space provided. This is the number to be entered on NACC UDS Form CI, item 3c. Scoring criteria for each unit are given below.

Story A Scoring Criteria			
Text	General Rule	Examples of 1-point Responses	Examples of 0-point Responses
Anna	<i>“Anna” or variant of the name</i>	Ann; Annie; Annette	Angela; Allison
Thompson	<i>“Thompson” is required</i>	—	Thompkins; Thomas of
South	<i>“South” (in any context)</i>	from South; who lived in South; who came from South	—
Boston,	<i>“Boston” (in any context)</i>	who worked in Boston; on a trip to Boston	—
employed	<i>An indication that she held a job</i>	worked; had a job as; who was; who earned a living as	who wanted to be; employed a cook
as a cook	<i>“cook” or some form of the word is required</i>	who cooked	as a waitress; in the kitchen
in a school	<i>“school” is required</i>	at a high school; by a school	in a hospital; at a company
cafeteria,	<i>“cafeteria” is required</i>	—	lunchroom; dining hall; diner; restaurant; kitchen
reported	<i>Indication that a formal statement was made to someone in authority (in any context)</i>	filed a complaint; said to the police; made a statement; notified the police; called the police; told the police	said; told how
at the City Hall	<i>“City Hall” (in any context)</i>	went to City Hall; called City Hall	—
Station	<i>“Station” in any context, or word, or a word phrase denoting a police station</i>	police station; train station; station house; police headquarters; precinct house; police department	office; building
that she had been held up	<i>An indication that she had been held up (i.e., gun point or knife)</i>	that someone held her up; that she was in a stick-up	that she was beaten; she had been attacked; that she was robbed; she got mugged
on State Street	<i>“State Street” (in any context)</i>	she lived on State Street; on her way to State Street	on some street; State Avenue
the night before	<i>Indication that the holdup occurred the previous night</i>	last night; the previous night	at night; one night; yesterday; the day before

and robbed	<i>Indication that a robbery took place</i>	was robbed; her money was stolen; they took her money; someone took her purse	lost her money; somebody took her things
of fifty-six dollars.	<i>Indication that an amount of money greater than \$49 but less than \$60 was taken from her</i>	fifty-some dollars; fifty-five dollars; about fifty dollars	sixty-five dollars; a lot of money; the police collected fifty-six dollars for her
She had four	<i>“four” is required together with an indication that the children were hers</i>	she was the mother of four	she had two; she had some; there were some
small children,	<i>“children” or a synonym is required</i>	little children; kids; small kids; young children	babies; girls; sons; small boys
the rent was due,	<i>A phrase indicating that the rent was due</i>	she had not paid the rent; she owed for the rent; the landlord had to be paid; she needed money for the rent	she owed money; she needed money; there was no money
and they had not eaten	<i>Indication that her children, or the family, were without food</i>	they had gone without food; they were hungry; there was no food; her kids had nothing to eat; she couldn’t feed her family	there wasn’t much food; they had only a little food; she had not eaten; didn’t have money to buy food
for two days.	<i>“two days” is required, or a phrase meaning about two days</i>	for a couple of days; for one or two days; for two or three days	for days; for several days; for a day; for three days
The police,	<i>A word or phrase signifying one or more members of the police department (in any context)</i>	the cops; the policeman; the detectives; the police officer; they (where police is clearly meant)	they (unspecified); some people; her neighbors; somebody
touched by the woman’s story,	<i>An indication that her story evoked sympathy</i>	were touched; felt sorry for the woman; wanted to help her; were sympathetic; were impressed by her story; (implying emotional reaction)	listened to her story; helped her; believed in her
took up a collection	<i>A phrase indicating that money was collected</i>	chipped in; collected money; donated; collected some food	gave her some money; found some money
for her.	<i>An indication that the money collected was for her or her children</i>	and gave it to her for her children; for her family; for them; to help her out; gave her money	as a gift; to make things better; for food

Neuro-Motor Examination

BACKGROUND

The neuro-motor examination incorporates aspects of the MDS-UPDRS (Movement Disorder Society – Unified Parkinson’s Disease Rating Scale) in order to assess signs of stroke, Parkinson’s Disease, and other movement disorders. Findings from this examination panel will inform the differential diagnosis of dementia. The neuro-motor examination has three parts, all of which can be completed within approximately 5 minutes. The first section involves examiner observations. The second section requires the examiner to give instructions to the participant. The final section requires the examiner to manipulate the participant’s arms. Concurrent medical problems such as stroke, paralysis, arthritis, contracture, and orthopedic problems such as hip or knee replacement and scoliosis may interfere with individual items in the motor examination. When necessary, mark “cannot assess” for an item.

WHEN TO ADMINISTER

Generation	Administration Rule
Proband	Administer at Visit 3 In person
Offspring	Administer at Visit 3 In person
Grandchildren	Administer at Visit 3 In person IF one of the following criteria are present: <ul style="list-style-type: none"> • Evidence during LLFS evaluation of <i>any</i> symptom which would be measured by neuro-motor exam • Reported history of stroke, Parkinson’s disease, or another movement disorder (e.g., Lewy Body Disease, Progressive Supranuclear Palsy, Corticobasal Degeneration, Amyotrophic Lateral Sclerosis (ALS; “Lou Gehrig’s Disease), Primary Lateral Sclerosis • Concern by the examiner of Mild Cognitive Impairment or Dementia (e.g., difficulty on cognitive testing, report of cognitive difficulties by the participant or a family member)

SECTION I: EXAMINER OBSERVATIONS

For these items, the examiner should “rate what they see” throughout the entirety of the LLFS visit.

FACIAL ASYMMETRY

With regard to facial asymmetry, if the examiner suspects mild asymmetry, they can confirm this by asking the participant to squeeze their eyes tightly (“like you have soap in them”), puff out their cheeks, or smile.

REDUCED FACIAL EXPRESSION

Reduced facial expression refers to a reduction in spontaneous expressions of various emotions throughout the examination, accompanied perhaps by a reduced blinking and a “masked” appearance of the face.

GAIT

Testing gait is best performed by having the participant walk away from and towards the examiner so that both right and left sides of the body can be easily observed simultaneously. In the LLFS, this will be conducted **after the SPPB**. It cannot be incorporated directly into the gait speed assessment given that gait speed is timed, and the instructions differ slightly. Interviewer script to participant: ***“I would again like to observe how you normally walk. Please walk to the other end of the walking course, turn around, and walk back toward me.”***

Examiners will rate the presence of abnormal arm swing (one or both arms not swinging normally while walking), gait (magnetic, wide-based, or shuffling), turning (multiple steps needed to turn around), and circumduction (swinging one leg in a semi-circle while walking).

SECTION II: EXAMINATION REQUIRING SPECIFIC INSTRUCTIONS TO PARTICIPANT

TREMOR OF HANDS – RESTING

Resting tremor may be observed at any time during the examination, including when participants are sitting quietly, answering questions, or engaged in an activity with the opposing hand. If the rater is unsure about the presence of a resting tremor, he/or she can ask the participant to sit quietly in a chair with his or her hands placed on the arms of the chair, in their lap, or on a table in front of them (while their feet are comfortably supported on the floor) for 10 seconds with no other directives.

TREMOR OF HANDS – POSTURAL

The examiner should instruct the participant to stretch the arms out in front of their body at shoulder height with their palms down, while seated. The wrist should be straight and fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds. Each hand should be rated separately. Interviewer script: ***“Please extend your arms out in front of you, palms down. (ensure participant’s fingers are comfortably separated and observe for 10 seconds).”***

FINGER TAPS

Each hand is tested separately for ten seconds. Interviewer script: ***“I would like you to tap your index finger on your thumb as quickly AND as big as possible.”*** Demonstrate the task; continue to perform the task *if necessary* while the participant is being tested. Observe for 10 seconds. Evaluate for any interruptions (i.e., broken rhythm or slight slowing) in the tapping movement. Rate each hand separately.

SECTION III: EXAMINATION REQUIRING MANIPULATION OF PARTICIPANT'S BODY

Rigidity refers to increased resistance to passive range of motion and is rated for the neck and all four extremities separately. **Instruct the participant to go as limp as possible as you test.** Rigidity is tested in the limbs by supporting the joint with one hand; the examiner then uses the other hand to move the participant's limb through a full range of motion. Rigidity is judged on slow passive movement of major joints with the participant in a relaxed position and the examiner manipulating the arms. **If it seems difficult for the person to fully relax the body part under examination,** use an activation maneuver such as fist opening and closing or finger tapping in a limb *not being tested*.

Introductory script for Arms: *“With your permission, I would now like to gently move your arms in different ways. Please let the muscles in your limbs go as limp as possible.”*

RIGHT/LEFT UPPER LIMB

For arms, test the wrist and elbow joints simultaneously. This is tested at the wrist, elbow, and shoulders with the greatest amount of rigidity detected used as the rating for that limb. To do this, Hold the participant's hand with one had while cradling his/her elbow with your other hand. Then flex and extend the participant's forearm and feel for increased resistance to the movement. Add rotation of his/her wrist. Finally, rotate the upper arm gently around the shoulder joint.

Workflow of Data from Digital Pens

Field center computers to do this must be PCs (no Macs) and running Windows 7 or XP, not 8

Clock Drawing

- Administer test during home visit
- Return to field center and download data from epen
- Store this data locally
- Score test using ClockSketch software locally.
- Once a week upload anonymized clock files to clocksketch website, by uploading the “UploadMe.csk” file.
- Once a month Lahey/MIT will create and send to DMCC a csv file that contains the FHS clock variables for each test done by each site during the preceding month. This will be one csv file with the data for all clocks for all sites for that month. The data in the csv file will have in it the participant IDs assigned by each site. (The clock tests are anonymized while being uploaded to MIT, but the IDs can be decrypted and reinserted into the files before the csv file is created. This saves the step previously mentioned about creating a table matching MIT-generated patient IDs with LLFS-generated IDs.)
- When requested by the DMCC, Lahey/MIT will provide the full set of dCDT variables. This is easier and more efficient than sending this information on a regular basis, given the large number of variables (~2000) and the fact that there may be variables that are added or eliminated over the next couple of years as more dCDT data gets analyzed.
- Final analysis variables will be made available by DMCC as sas and csv files for investigators

MMSE, Trail Making and Digit Symbol with epen

Store raw pen data to Box and store locally at each field center.

TELEPHONE INTERVIEW FOR COGNITIVE STATUS (PANEL 7B)

General Guidelines

Although the TICS is simple to administer and score, examiners should be well practiced. Examiners should speak clearly and articulate distinctly. Prior to the TICS administration, examiners should:

1. Ensure that they have a TICS Panel 7b available.
2. Ascertain the examinee's ability to hear spoken language at a conversational volume.
3. Have information on the street address where he or she is located.
4. Have information on their expected level of cognitive functioning (normal, MCI, dementia).

In administering the TICS, the following guidelines should also be taken into consideration:

1. In general, the examinee's answers should precisely match the given scoring criteria. If a precise answer is not given, the examiner should probe for the correct response. For example, if the examinee's response to "What animal does wool come from?" (Item 7) is "a ram" or "ewe" the examiner should say, "Is there another name for that?"
2. Reasonable judgment should be exercised regarding allowing the examinee sufficient time to answer a question before proceeding on to the next question.
3. If an examinee changes an incorrect response to a correct response at any time during the TICS, credit should be given for the new correct response.
4. If an examinee changes a correct response to an incorrect response at any time during the TICS, the new response should be recorded and credit should not be given.
5. Almost all examinee responses should be recorded *verbatim* in the spaces provided on the Record Form. Exception: FOR CONFIDENTIALITY PURPOSES, do not record responses for items 1 and 3 (name and orientation to place), however, you should indicate the nature of the error (e.g., missed a digit on zip code).

Administration of TICS according to expected level of cognitive impairment:

- I. **When there is NO concern of significant cognitive impairment (MCI, dementia)**, the following script (an abridged version of the suggested script from the TICS manual) should be read to the **examinee** to introduce the test. Ideally, no one other than the examinee should be present in the room.

Interviewer: *"I am going to ask you some questions to test your memory. Some of these are likely to be easy for you, but some may be difficult. Please bear with me and try to answer all the questions as best you can. If you can't answer a question, don't worry. Just try your best. Please do not use any paper, pencils, or calendars to assist you in answering the following questions. Also, be sure that the room is quiet; there should be no television, radio, or music playing. Are you ready?"*

II. When there IS concern of cognitive impairment, it is essential that the examiner speak with someone other than the person being interviewed (the "examinee"). This may be the examinee's caregiver or a family member who is at the same location and who is able to comprehend and follow basic instructions. This person (the "proctor") must make sure that the environment is appropriate for testing. When the examiner has the **proctor** on the telephone, the following instructions should be given:

"In a couple of minutes, I am going to be asking [examinee's name] a number of different questions to test [his/her] thinking and memory. Before we start, I need to ask you whether the address I have for your current location is correct. Please don't repeat it out loud if [examinee's name] is in the room with you, since I will be asking [him/her] the same question in a few minutes. Is your current address [examinee's address]?" If the answer is "no", ask the proctor either to step into another room before giving you the correct address or to have the examinee leave the room briefly before giving you the address. Then go on to say, *"Please be sure that all papers, pencils, books, calendars, newspapers, and everything else that might provide distraction or visual cues are removed from [examinee's name] sight. Also, please be sure that the room is quiet; there should be no television, radio, or music playing.*

"Some of the questions may be difficult for [examinee's name] to answer. [He/She] may ask you for help. If [he/she] does, just encourage [him/her] to do as well as [he/she] can. [He/She] should guess if necessary. Please do not give [him/her] any answers or hints, okay? If you and [examinee's name] are ready, please put [him/her] on the phone."

Instructions to the Examinee: When the examiner has the examinee on the telephone, the following instructions should be given. Ideally, no one other than the proctor should be present in the room.

Interviewer Script: *"I am going to ask you some questions to test your memory. Some of these are likely to be easy for you, but some may be difficult. Please bear with me and try to answer all the questions as best you can. If you can't answer a question, don't worry. Just try your best. Are you ready?"* These instructions may be repeated verbatim or paraphrased, if necessary. For each of the actual TICS items, except for Item 5 and Item 8, single repetitions are permitted. When the examinee is ready, begin administering the TICS items according to the following instructions.

Administration of Individual Items

Item 1: Orientation to Name. Say to the examinee, *"Please tell me your full name."* Score 1 point for the correct first name (or nickname) and 1 point for the correct last name. The maximum score is 2 points. FOR CONFIDENTIALITY PURPOSES, DO NOT RECORD RESPONSE; only indicate accuracy and if incorrect, the nature of the error (e.g., gave daughter's name).

Item 2: Orientation to Time. Ask the examinee, *"What is today's date?"* Score 1 point each for

correct month, date, year, day of the week, and season. Probe for any of these that are not provided spontaneously (e.g., *"What day of the week is it?"* or *"What season is it?"*). Precisely correct answers are required (e.g. a hot day in early June is not summer). The maximum score is 5 points.

Item 3: Orientation to Place. Ask the examinee, *"Where are you right now?"* Score 1 point each for correct house number, street, city, state and zip code. If any of these are not given spontaneously, probe (e.g. *"What number is that?"* or *"What is your zip code?"* – 5-digit zip code is sufficient.) If the examinee is in a facility with no house number (e.g. a hospital or nursing home), the name of the facility may be substituted for the house number. The maximum score is 5 points. FOR CONFIDENTIALITY PURPOSES, DO NOT RECORD RESPONSE; only indicate accuracy and if incorrect, the nature of the error (e.g., omitted a digit on zip code).

Item 4: Counting Backward from 20 to 1. Say to the examinee, *"Please count backward from 20 to 1."* If the examinee makes an error on Trial 1, ask him or her to try again. *Note, this is the only item where examinees are cued to try again. Score 2 points if completely correct on first trial or 1 point if correct on second trial. Score 0 points if there are any errors on the second trial. The maximum score is 2 points.

Item 5: Remembering a Word List. Say to the examinee, *"I am going to read you a list of ten (10) words. Please listen carefully and try to remember them. When I am done, tell me as many of the words as you can, in any order. Ready? The words are (Pause): cabin, pipe, elephant, chest, silk, theater, watch, whip, pillow, giant. (Pause). Now tell me all the words you can remember."* The words should be read at approximately one word every 2 seconds. No repetitions of the word list are permitted by the examiner. Score 1 point for each correctly recalled word. Score 0 points for incorrect responses (e.g. repetitions of list words, intrusions of words not on the list). The maximum score is 10 points.

Item 6: Serial 7 Subtractions. Say to the examinee, *"100 minus 7 equals what." (Pause for a response.) "and 7 from that? And 7 from that? Etc.."* No further prompts or instructions are given, except to *"keep going"*. Stop the examinee after five serial subtractions. Score 1 point for each correct subtraction. Do not inform the examinee of incorrect responses, but allow subtractions to be made from the last response. That is, score 1 point for a correct subtraction, even if the subtraction was from a previously incorrect response. For example, "93, 85, 78, 71, 65" would be awarded 3 points. The maximum score is 5 points.

Item 7: Naming to Verbal Description. Ask the examinee:

- *"What do people usually use to cut paper?" (Pause for a response.)* Score 1 point for *"scissors"* or *"shears"*.
- *"How many things are in a dozen?" (Pause for a response.)* Score 1 point for *"12"*.
- *"What do you call the prickly green plant that lives in the desert?" (Pause for a response.)* Score 1 point for *"cactus"*. If the participant responds with a type of cactus such as "prickly pear", cue for the more general name.
- *"What animal does wool come from?" (Pause for a response.)* Score 1 point for *"lamb"*. If the participant responds with "fish", they most likely misheard "wool" as "oil". Repeat the question and spell "wool" if needed).

The maximum score is 4 points.

Item 8: Repetition. Say to the examinee, "*Say this: 'No ifs, ands, or buts.'*" (Pause for a response.) "**Now, say this: 'Methodist Episcopal.'**" No repetitions of the phrases by the examiner are permitted AFTER the examinee has begun to respond. However, a repetition is permitted if requested PRIOR to the response. Score 1 point for each correct repetition. The maximum score is 2 points.

Item 9: Recent Memory. Ask the examinee, "*Who is the President of the United States right now?*" (Pause for a response.) "*Who is the Vice-President?*" Score 1 point for current president's full (i.e., first and last) name. Score 1 point for current vice-president's full (i.e., first and last) name. If only the last name is given, probe for the full name. The examinee must provide both first and last name in order to receive credit for each question. The maximum score is 2 points. (*Note:* If the TICS is used in another country the examiner should modify this question using the correct titles for the head of state, Monarch and Prime Minister in Denmark).

Item 10: Praxis. NOTE CHANGE TO THIS ITEM BEGINNING at V3. Say to the examinee, "*With your finger, tap five times on the back of your phone.*" (This was changed from "on the part of the phone that you speak into" due to the use of cell phones and the fact that examinees may accidentally end the call when tapping the screen). Score 2 points if five taps are clearly heard, 1 point if either more than or fewer than 5 taps are heard, and 0 points if no taps are heard. The maximum score is 2 points.

Item 11. Opposites. Say to the examinee, "*I am going to say a word and I want you to give me its opposite. For example, the opposite of 'hot' is 'cold'.*"

- "*What is the opposite of west?*" (Pause for a response.) Score 1 point for "*east*". If the participant responds with "dry" they they most likely mishears "west" as "wet". Repeat the question and spell "west" (if needed).
- "*What is the opposite of generous?*" Score 1 point for "*cheap*", "*stingy*", "*tight*", "*selfish*", "*greedy*", "*mean*", "*meager*", or other correct antonym.

The maximum score is 2 points.

Item 12: "*Earlier I read you a long list of words that I asked you to remember. I would like you to try to tell me as many of the words as you can remember now.*" Maximum score is 10 points.

Items 13-14: To obtain the TICS Total score, sum the number of points obtained for each of the 11 items. A maximum of 41 points may be obtained. The examiner should exercise care to ensure that the appropriate number of points is awarded for each answer and that the addition is done correctly. The TICS Total score should be entered in the space provided on the first page of the TICS Record Form. **NOTE: We have 2 total scores, Q13** (maximum of 41 excluding Item 12) and **Q14** (maximum of 51 including Item 12).

Items 15a-15d: Interviewer needs to answer **Q15a** regarding the overall validity of the TICS test.

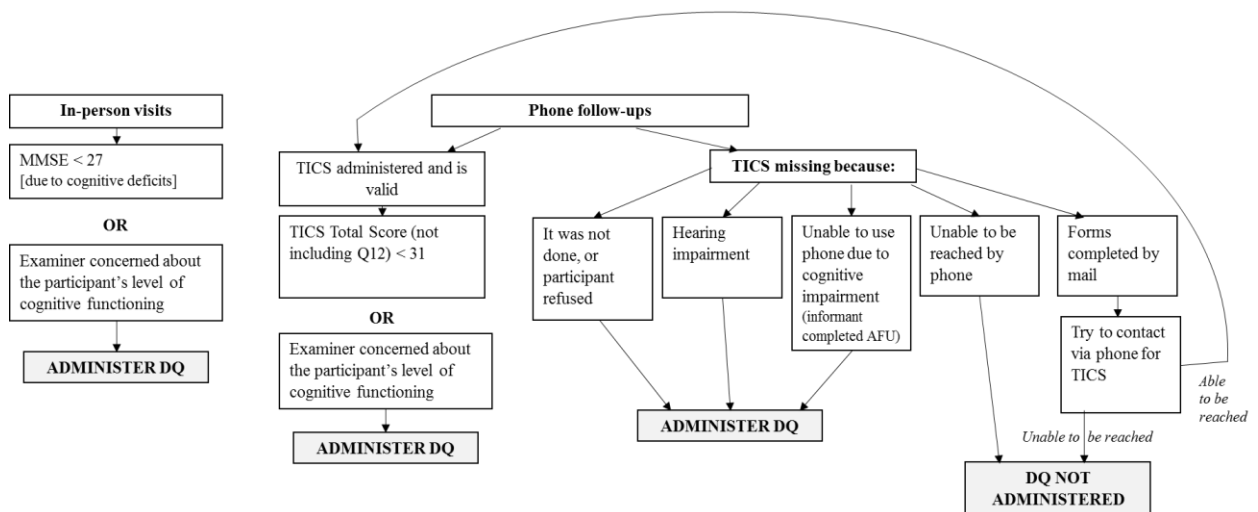
If the Interviewer deems the test invalid, please answer **Q15b-Q15d** regarding the reasons for the test to be considered invalid.

At the conclusion of the TICS, thank the examinee for his or her participation.

DEMENTIA QUESTIONNAIRE (DQ)

The Dementia Questionnaire (DQ) for LLFS is based on the original DQ (Kawas et al. 1994) with modifications from the Cardiovascular Health Study and WHICAP. The DQ is an interview that assesses the cognitive and functional status of the participant in the following domains: memory and cognition, expression (language), daily functioning, recognition of problems (insight), and other medical and psychiatric difficulties. While most DQ questions are answered in a multiple-choice format, notes are required to assist in the interpretation of responses.

1. The DQ should be given to an informant identified by the participant. Administration of the DQ varied to some extent by site prior to Visit 3 and were reconciled in March 2014 (detailed point by point in the Visit 2 MOP). The current MOP integrates all previous modifications. As of January 2019, the DQ is administered on a limited basis as follows:
2. The DQ will be **NOT** be administered to individuals considered to be cognitively normal. It will only be administered when participants score **< 27 on the MMSE (or TICS Total Score (not including Q12) < 31)** OR when the examiner is concerned about the participant's level of cognitive functioning. See Flowchart below.



Administer the DQ according to the flowchart above EXCEPT WHEN:

1. It was administered within the past 6 months

OR

2. Informant endorsed “Yes” to **≥ 3 of the first 6 DQ items on two consecutive DQs**. If this is the case, please ask the informant the following: “Since we last interviewed you (or other informant) in (Month, Year), has the participant’s condition improved, remained stable, or worsened?”

General Points for Administration

With each of the items in the first section the informant may report that the participant has always had difficulty. To probe for this ask, "*Do you think you/they could do it better a year ago?*"

If the informant reports that they never did or do not want to do the activity, ask "*Do you think they could do it if they had to?*" Handling money is an item to which informants often respond that the participant does not do it. In such cases ask about the informant's view of whether they have the ability to do it: "*Do you think /he/she could make change for purchases if/he/she had to?*"

Throughout the DQ, you will need to ask for specific examples of the ability or inability to perform a given activity, and include enough probes to help the informant determine the reason for the problem. Specific probes are provided on the form for this purpose. These probes should be followed up by restating the response (e.g., "*So you said that you always accompany your mother out of the apartment because she got lost a few times last month – would you say this interferes with her daily living?*")

Administration Guidelines

Before presenting Item 1 say: "*You have been identified by [participant's name] as someone who would be able to answer questions about his/her health and well-being. I would like to ask you some questions about [participant's name] memory and other health related items that may interfere with his/her daily living. The reason we are asking these questions is so we can get another perspective on [participant's name] health and well-being.*"

If this is a **follow-up, then add** that "we are interested in your perspective on [participant's name] changes since we last interviewed you on [insert date of last interview]". Follow-up DQ administrations should refer to **changes in cognitive function since the previous administration of the DQ.**

Item 1: Memory Problem.

Note: The date/age of onset for memory/cognition questions (Q1-7) and expression questions (Q10-12) should not be recorded if it has already been indicated on a previous DQ.

Ask: "***Does participant's name have any problems with his/her memory?***" Mark the informant's answer, Yes or No. If the informant reports Yes, ask about date of onset and the other details.

Ask: "***Around what time would you say this started?***" Record the date in the space provided - Month and Year. If the problems began after a stroke or other event or accident, the exact date may be able to be produced. However, informants rarely provide an exact date. Use your interviewing skills to help them; events or holidays may serve as helpful benchmarks. If they come up with a month, ask them beginning/middle/end? If an exact date is not possible to pin down, but you can get month and year, record the 15th of the month. If they come up with the year, try to narrow it down to the month or season. If the informant can only narrow it to a year, record June 15th of that year. If the informant narrows it to a couple of years, choose the midpoint. If needed, write in the margins to record details.

State: "***You said that their memory has not been the same since [date of onset]. Can you describe what kinds of problems they have been having with their memory?***" Obtain as many details and descriptions as possible about the nature of the memory problems, and the effect they have had on the participant's life.

Ask: "***Who first noticed their memory problem(s)?***" Record the relationship of the person to the participant and the circumstances surrounding this first notice of problems.

Continue with **Items 2-7**, asking: "***Does (participant's name) have any problems with _____ that interferes with daily living?***" Mark the informant's answer, Yes or No. Ask for an example for each item to which they respond "Yes". If the informant reports "Yes", proceed with inquiring about the date of onset or age of onset and other details and examples.

Item 8. Ask: "***Would you say that these problems started all of a sudden or gradually (slowly)?***" Circle the informant's answer and describe any details about the course of the problems that are provided. **This item should not be administered if already recorded on a previous DQ.**

Item 9: Ask: "***Would you say that there has been a steady decline in his/her memory since [date of onset]? Or has [his/her] memory been worse since [date of onset] and remained stable, or at the same level? Has there been further decline in memory since [date of onset] that is not gradual, but stepwise, like drops all of a sudden, then stable, then another drop...***" For each of these questions, try to probe the course of decline. Record the description that the informant agrees with and any details they provide you about the course of memory problems. Examples:

Ask: "***Would you say that the memory problems have been continuous or that there are some days when his/her memory is better than others?***" Record the informant's characterization of whether there is fluctuation in memory.

Ask: "***Did the memory problems begin around the same time as a medical, emotional or physical event in his/her life, like the death of a loved one, an accident, or an illness?***" Record the informant's view of whether the onset of the memory problems coincided with an event.

Ask: "***Did memory problems start before or after his/her _____ problems began?***" Record any details provided about the timing of the memory problems with a cerebrovascular event or onset of EPS.

Items 10-12 Verbal Expression. Ask for examples of each and date or age of onset.

Items 13-20 Daily Functioning. Ask the items as described and score not only those behaviors that are due to physical limitations, but also to cognitive problems. For example, a participant with Parkinson's Disease or severe arthritis may have difficulty with buttons and require complete assistance getting dressed. For someone who performs any aspects of their own dressing and who reports difficulty, this would also be a yes in item 17 (trouble in dressing or self-care). In other words, it is possible for someone to have some physical limitations but to also have problems with cognitive function that interfere with these basic activities of daily function, and the functional problems related to cognitive decline would also be scored a 1 or yes. Again, please provide as much information and probes as possible for the informant to make their own decision about whether the participant is able to perform these activities. **The cause of the daily functioning problem (e.g., participant is blind but knows how to dress him/herself), if known by the informant, should be noted in the "Notes and Examples" section after Item 20. Q16b (retired) may be omitted if it has already been recorded that the participant has. If retirement has been previously recorded, the interviewer skips to Q17.**

The informant should be read as much information as is needed from the anchor descriptions in order to answer the question as accurately as they can. Make sure it is clear that they need to think about the statements in terms of [participant's name] **ability to live on their own** (independence).

Item 21-25b: If the informant answered "YES" to any of Q1-12 above, OR "YES" to Q13-15 or 16c-20 above not due solely to sensory or physical impairment, ask Q21-25b below; otherwise, skip to Q26a." (Q21-25b should not be asked for participants who have a problem on Items 13-15 or 16c-20 that is due only to sensory or physical impairments, as the Recognition of Problem questions are not typically relevant to sensory- or physically-based impairments). If Recognition of Problem questions have been previously recorded, skip to Q26a.

Item 21-22. Ask: "*Who first noticed something wrong?*" Record the relationship of the person to the participant and the circumstances surrounding the problems being noticed for the first time.

Item 22. "Old Self" - please add "*when these problem(s) [was/were not] present*".

Item 23-25. These are self-explanatory; remember to record verbatim "*what cause was given*".

Items 26(a-1) Stroke Questions. These items should only be asked if there is both stroke (Q26a=Yes) and memory loss (Any of Q1-12=Yes or any of Q15 or 16c-20=Yes and is not due only to sensory or physical impairment). If Q1-12 are answered as "No" and Q13-15 or 16c-20 are answered "Yes" only due to sensory or physical impairment, these items are not relevant. If Q26k and Q26l have been previously recorded, the interviewer skips to Q27a.

Item 27: Alcohol problems. This question pertains to significant persistent alcohol use, such as 3 or more drinks per day OR if alcohol use ever affected ability to function in personal, family or professional life. In a repeat administration of the DQ, Q27a "Since [date of last interview] does [participant name] have a drinking problem or a history of alcoholism?" refers only to changes since the previous administration of the DQ. Therefore, the phrase "history of alcoholism" should be replaced with "alcoholism".

Items 28-29: Depression.

For the following questions, I would like you to answer Yes or No.

... you can also add , "*did [participant] feel sad, depressed, blue or down in the dumps?*"

During this interview, a participant may not answer a question with yes or no, but will describe their feelings in more detail or recall an event. Write down what the participant says. Then use your interviewing skills to encourage the participant to choose yes or no. Sometimes the participant will not narrow their answer to a yes or no after these types of prompts. In these cases, write down what the participant tells you in the margins of the page. This will allow discussion of "borderline" answers with the adjudication team. A general rule is that items will be marked as Yes even if the participant has the symptom only some of the time or if they tell you that they the symptom is mild in intensity.

Questions 30-35. Self-explanatory Q30 (drives) may be omitted if it has already been recorded that the participant has stopped driving. If driving cessation has been previously recorded, the interviewer skips to Q36.

Question 36-37. Self-explanatory. Omit Q37 "most frequent type of contact if "Live together" is endorsed for Q36 as it can be assumed that the most frequent type of contact is "Mostly In-Person for Q37.

Question 38. This question is not asked of the participant, but is to be answered by the Interviewer. This question is based on the judgment of the informant's responses to this questionnaire. Please rate the reliability of the responses as "very reliable", "fairly reliable", "not very reliable" or "don't know". Please try to give a response and limit the use of don't know.

Clinical Dementia Rating (CDR) Scale

When and to whom should a CDR score be assigned?

Visit Type	Participants	Include information from Informant to assign score WHEN:
Visit 3 (In person or Phone)	Assign everyone a CDR score regardless of age or generation	DQ is being collected <u>OR</u> You are concerned that the participant has cognitive impairment (e.g., difficulty on cognitive testing, report of cognitive difficulties by the participant or a family member, reported history of Alzheimer’s disease or another dementia).
Phone Follow Ups	<ul style="list-style-type: none"> • Proband Generation • Offspring ≥ 70 • Offspring and Grandchildren < 70 during expanded 3 yr FU 	When TICS Total < 31 OR You are concerned that the participant has cognitive impairment (e.g., difficulty on cognitive testing, report of cognitive difficulties by the participant or a family member, reported history of Alzheimer’s disease or another dementia)
Offspring < 70 Annual Brief Phone FU	No CDR	

Please note: The collection of informant data for the CDR is not dependent on whether a proxy is used for other LLFS instruments. If no informant data is available for CDR, or if informant is not necessary based on above table, please mark the appropriate box regarding the availability of informant data.

What is the CDR?

The CDR covers six different areas of functioning including Memory, Orientation, Judgment and Problem Solving, Community Affairs, Home and Hobbies, and Personal Care. Each area is scored on a scale from 0 – 3. For persons in the 0 to 3 range, the examiner assigns a score in each area based on information collected via participant and informant interview (e.g., Dementia Questionnaire), cognitive testing (e.g. memory and orientation), observation (e.g. cleanliness of house). Scores should be assigned on the basis of cognitive, **not physical**, difficulties. The range of CDR scores is:

0	Normal
0.5	Borderline impairment
1.0	Mild impairment
2.0	Moderate impairment
3.0	Severe impairment

For persons with profound impairment a CDR **global score of 4** is given.

For persons who appear to have terminal dementia (vegetative) a **global score of 5** is given.

How is the CDR Score Assigned?

Scores in each category should be derived based on the guidelines detailed in each section below. Use all information available and score each category as independently as possible.

CDR DOMAIN INTERVIEWING AND SCORING

I. Memory: Scores of zero should be reserved for individuals who have nothing more than occasional and **INCONSISTENT** minor short term or long term memory lapses. **CONSISTENT** (even mild) memory lapses qualify as a 0.5 rating. Note that memory for distant events (long term memory) can be “perfect” when short term memory is impaired. It should be ascertained whether the endorsed issue is out of the ordinary, or if this has always been the case (ex: trouble remembering a list of grocery items).

Score	Description of Functional Ability
0	Inconsistent forgetfulness occurring once in a while (e.g., forgetting where you put your keys / names sometimes); not significantly worse than past 6 months; normal performance on testing.
.5	Consistent and to some extent progressive forgetfulness: repetition of questions & conversations, rapid forgetting, may need reminders / strategies to remember things that they did not need previously. Informant may say they're noticing memory lapses more and more.
1	Forgetfulness with functional consequences: forgetting to pay bills, difficulty managing medications, difficulty on the job, getting lost, forgetting items at store. Memory problem is noticeable to others.
Notes	<p>If speaking with an informant, it is useful to start with general questions (does the participant have memory problems, yes or no?), and then go into more specific questions (does it happen every day, or just once in a while?). If there is normal performance on testing but reports of memory problems, we need to ask for specific examples of memory lapses.</p> <p>To move from a 0 to a 0.5 you need to distinguish between <i>consistent</i> and <i>inconsistent</i> memory lapses, and perhaps have some evidence of decline over time. Here it becomes important to ascertain whether the person's memory is different now than it was 6 months ago. It becomes a score of 1 when there is evidence of associated functional impairment (e.g., forgetting to pay bills).</p> <p>If memory testing is impaired but there are no reported memory problems, ask the informant (if available) about specific situations (e.g., does [participant] forget to buy items at the store?) to try to establish concordance.</p>

II. Orientation: This is addressed in the MMSE, but questions can also be asked by examiner if needed. Note. Examiners should be concerned about cognitive impairment in participants who suggest that they aren't oriented because they “don't need to know”, “don't care”, “don't read the newspaper,” “don't work”, etc. If participant can't be contacted, orientation can and should be probed via informant.

Score	Description of Functional Ability
0	Usually knows date, day of the week, and approximate time of day. Orientation on MMSE or TICS should be ≥ 7 without discordance (e.g., stating it is January and also summer) or major errors (e.g., year is 2004). Day of the week or date may be off by one day.
.5	Some confusion about the date evidenced by one or more minor errors, OR confusion about time, OR discordant responses OR difficulty with temporal order of events that have occurred (e.g., not sure if they saw movie then had dinner, or vice versa). No major errors (e.g., very incorrect year).
1	Clear disorientation evidenced by: significant discordances between responses, OR disoriented to time of day, OR markedly incorrect answers (e.g., year is 2004, or month is off [unless it is very near the beginning or end of month]). One major error OR multiple smaller errors.
Notes	This domain requires the experimenter to judge <i>how significant</i> any orientation errors are. For example, missing the date or day of the week by one day is a much smaller error than saying it is January 24 th when it is January 2 nd . Getting the year incorrect on January 1 st is a smaller error than getting the year incorrect in August. Getting the 'orientation to place' questions incorrect may require some additional questions

	from the experimenter, for example asking if they have recently moved and/or whether they are currently at home. If the person is at home and cannot remember the address, it is likely more significant than if they are at a family member's house and do not know the address.
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III. Judgment and Problem Solving: Here we are interested in how the participant handles issues such as financial affairs and household maintenance. It is important to distinguish problems *remembering* how something used to be done (a memory issue) from problems *grasping* how to approach a problem (a judgement issue). Informants will often struggle to make this distinction, so specificity and caution are required on the part of the interviewer. For example, if an informant endorses trouble with judgment and provides the example that the participant “asks about her deceased siblings”, this should be interpreted as an impairment in memory rather than judgment.

Score	Description of Functional Ability
0	Able to solve problems and handle finances (e.g., make change, pay bills, balance checkbook).
.5	Able to handle finances but may make small mistakes.
1	Has shown poor judgment or would have difficulty handling new problems . Unable to handle finances due to cognitive impairment (i.e., not due to visual impairment).
Notes	If speaking with participant, you can give a concrete problem to solve to ascertain their judgment & problem solving. If speaking with informant, ask about things that could feasibly happen (e.g. small fire).

IV. Community Affairs: The focus for this domain should be on the extent to which individuals can carry out independent activities *outside of the home*. In the event that a participant seems to be slightly physically impaired (i.e., 1-2 mobility problems endorsed on either Physical Measures or Annual Follow-Up Questionnaire), it may be beneficial to inquire whether the participant *would* engage in social activities if it weren't for their physical issues, to separate cognitive from physical problems.

Score	Description of Functional Ability
0	Person engaged in community as usual; no change in the degree of engaging in community activities.
.5	May need reminders to do or finish activities: e.g., may need reminders to go to church, despite having gone to church every week for years. Still able to work/drive but starting to have difficulties due to memory or thinking problems. May consistently show up late to events without reminders. Needs assistance but this is not obvious to an observer
1	Needs to be brought or accompanied to activities because they are unable to or would no longer initiate on their own (e.g., someone would need to turn up to their house to accompany them to church). Unable to work/drive due to memory or thinking problems. Appear normal to a casual observer but would be determined to be cognitively impaired if engaged in a conversation.
Notes	Need to ensure that depression is not the primary reason for withdrawal from community affairs. Informant information is particularly valuable here. Try to ascertain the degree of disengagement from activities – active role CDR=0, passive role CDR=0.5, no longer engaged CDR>=1.

V. Home and Hobbies: Here the examiner should focus on what individuals do in comparison to what they used to be able to do with regard to *interest* in engaging in hobbies and activities, as well as *ability*. As with other domains, it must be determined whether the participant never performed these duties, or if this deficit is a new development.

Score	Description of Functional Ability
0	No difficulty with household tasks (e.g., cooking, laundry, yard work, taking out garbage) and hobbies (e.g., gardening, reading, crafts, sports).
.5	May abandon household activity midway through (e.g. get distracted and forget), or forget to add soap to laundry every so often, perhaps some trouble multitasking, but otherwise no clear and consistent difficulty or errors. Unusual to give a 0.5 score in this domain.
1	Difficulty executing activities correctly: for example, they no longer cook for themselves, forget to do laundry or housework, they require a sign above the washing machine reminding them to add soap.
Notes	Difficult to ascertain “questionable” impairment - the person is either having difficulty (e.g. forgets to do laundry / dishes; requires a sign above washing machine reminding them to put soap in <input type="checkbox"/> in which case you would give a 1) or not (in which case they get a 0). Valuable to compare past and present in this domain (e.g., did they ever cook for themselves?)

VI. Personal Care: Here it is important not to accept excuses for disorganization in the home or clothing or personal appearance. Questioning informants may be useful, but the examiner should observe surroundings including the person and home (when possible). In the event that participants have been recently placed into an assisted living facility or nursing home, it may also be useful to ask what their personal care routine looks like (in most of these cases, home health aides come by to initiate and assist with bathing and showering).

Score	Description of Functional Ability
0/0.5	No problems with personal care; participant showers / bathes and changes clothes as often as they always did. Able to wash, dress, and groom without help. Able to eat cleanly with proper utensils.
1	Needs reminding to do personal care activities: participant will not initiate taking a shower or changing clothes as regularly as they should (e.g., they are able to take a shower, but will not do so for several days, or until someone reminds them to). If they go to shower but cannot remember how to turn the water on, OR need help dressing, washing, or grooming due to cognitive ability then CDR > 1.
Notes	This may not be clear from speaking with the participant only. If the participant has no problems in any other domains, it is unlikely that they will receive CDR>0 in personal care.

How can other LLFS data help you score the CDR?

When interviewing the participant and/or informant, use the following information and tables to see how to integrate other LLFS data to help assign your CDR score. The additional questions are intended to probe deeper into the specifics of an endorsed problem, or to gain insight into a domain not covered by other formal questioning. The questions are not mandatory; if you are able to confidently assign a domain score, and justify this assignment, based on other data from the interview, then there is no need to pursue the domain further via these questions.

If you decide you need more information on a specific domain, try to incorporate the additional questions as naturally as possible, preferably in conversation with the participant or directly after the domain-relevant interview questions. For example, if in the administration of the Rest and Activity Questionnaire (AFU form questions 10c1-5) the participant mentions they are more sedentary than they used to be, you could ask which activities they have stopped doing, and whether this was due to a physical impairment or other causes. If the opportunity does not present itself during the questionnaire, it would be convenient to

ask “how do you spend your time” or a similar question at the end of the formal questions, rather than trying to circle back around to the topic later in the follow-up.

If you come to the end of the interview and realize you do not have enough information to make a confident judgment in any particular domain, these tailored questions can also be asked at the very end. Try to refer back to anchor points in the interview (ex: “a little earlier you said your mother’s memory wasn’t what it used to be, I was wondering if you could tell me a little more about his/her [domain]...”) and continue to probe until you feel you have all you need to properly assign a score in each domain.

In-Person Assessments	Telephone Assessments
Physical Function and Activity	Annual Follow-Up (AFU) Telephone Contact Questionnaire
MMSE, HVLTL, Logical Memory	TICS
Dementia Questionnaire	Dementia Questionnaire
IADLs	

Information from *Participants*

Category	Physical Function and Activity or AFU	Cognitive Test (in person/over the phone)	IADL Items (in person)	Additional questions <i>(“Now I would like to ask you a few questions about your [domain]”)</i>
Memory		MMSE: 3-item recall HVLTL Logical Memory TICS: delayed recall		<i>Are you able to shop for a few items without a written list?</i> <i>Is your memory any worse than it was 6 months ago?</i> <i>Who is the current President, Governor, Mayor, and previous President to current one?</i> <i>What is/was your spouse’s birthday? What are your children’s names, and birthdays?</i>
Orientation		MMSE/TICS Time/Place items		<i>If you had to guess the time right now, what would it be?</i> (If answer is way off, e.g. saying 5pm when it is 10am, this would indicate a score of 1).
Judgment and Problem Solving (often requires additional questions, esp. on phone)			Ability to handle finances	<i>Upon arriving in a strange city, how would you locate a friend that you wished to see?</i> (answers might include “use phone book/directory”, “call a mutual friend”, etc)
Community Affairs	Rest & Activity Questionnaire		Ability to shop, ability to travel	<i>How do you spend your time?</i> (red flag would be “I stay home all the time”) <i>Do you still do as many activities outside the home as you used to?</i> <i>Are there any activities that you don’t do anymore?</i>

Home and Hobbies	Rest & Activity Questionnaire		Ability to prepare food, ability to keep house, ability to do laundry	<p><i>How do you spend your time?</i> (example of a red flag would be “I watch the same TV show over and over”)</p> <p><i>Do you have any hobbies?</i></p> <p><i>Are there any hobbies that you used to do that you don't do anymore?</i></p> <p><i>Do you do laundry / dishes yourself?</i></p> <p><i>Do you cook for yourself?</i></p>
Personal Care	Difficulty bathing/showering			

Information from Informants

Category	Physical Function or AFU	DQ Items	Additional questions for Informant (“Now I would like to ask you a few questions about [name’s] [domain]”)
Memory		Memory problems, trouble with names, trouble remembering family members, trouble recalling short lists	<p><i>Does [name] repeat themselves in conversation?</i></p> <p><i>Is [name’s] memory worse now than 6 months ago?</i></p> <p><i>Does [name] ask the same question / tell the same story over and over?</i></p> <p><i>Does [name] ask about things that you just said a few minutes ago (e.g. what time are we leaving)?</i></p> <p><i>Would you say that the memory problems have been continuous, or are there some days when his/her memory is better than others?</i></p>
Orientation (DQ questions refer only to place; need additional questioning regarding time)		Trouble finding way on familiar streets, trouble finding way indoors	<p><i>Does [name] usually know what day of the week it is?</i></p> <p><i>Would [name] be able to tell you the date off the top of their head?</i></p> <p><i>Does [name] know when it is time to eat (e.g., would they know to eat lunch without a reminder)?</i></p> <p><i>How often does [name] forget the day of the week/ time of the month/ time of the day?</i></p> <p><i>Does [name] get lost indoors?</i></p>
Judgment and Problem Solving (need DQ examples to judge severity of impairment)		Trouble handling money, trouble grasping situations	<p><i>If there were a small fire / burst water pipe at home, how would [name] deal with it? Would they be able to handle it?</i></p> <p><i>Does [name] do their own bills? Does / did [name] have trouble with this?</i></p> <p><i>Does [name] understand when a plan or new concept is explained to them, or do they need it repeated?</i></p>
Community Affairs (modify questions as needed if participant in nursing home)	Rest & Activity Questionnaire	Trouble at work *only applies if participant is still working – if retired, can ask if retirement was voluntary/not due to any other impairments	<p><i>Do you have to remind [name] about activities that s/he was previously involved in?</i></p> <p><i>Does [name] engage in meaningful activities outside the home (e.g., social functions, seeing friends, clubs)?</i></p> <p><i>If in nursing home, does [name] engage in any social activities held there?</i></p> <p><i>Does [name] go out on their own shopping, to social engagements, sports events, etc.?</i></p> <p><i>Is [name] still working/ driving? If not, why?</i></p>

			<i>Does [name] participate in events hosted by nursing/assisted living facility?</i>
Home and Hobbies (modify questions as needed if participant in nursing home)	Rest & Activity Questionnaire	Trouble with household tasks	<i>How does [name] spend their time? Does the person engage in prior hobbies (gardening, reading, etc.)? Does [name] do household chores such as doing the dishes / using kitchen appliances? Is [name] able to cook reliably / independently? Is [name] active in the household (e.g. involved in decisions about what to buy at store, etc.?) If in nursing home, are all of their meals prepared for them at structured times?</i>
Personal Care	Difficulty bathing/showering	Trouble with dressing/self-care, trouble feeding self, trouble controlling bladder/bowels	<i>Are there food stains on clothing / counter / table? Are household items put away properly? Is there odor or stains suggesting incontinence? Does [name] require assistance to take care of the above items?</i>

How can I check the accuracy of my CDR Score?

Ultimately, the CDR score is a subjective, clinically based rating assigned by integrating all available data, which will be different for each participant. As such, it can be useful to check your scores against other available data as outlined below.

General Association between CDR Domain Scores and MMSE/DQ Items

Category	Notes
Memory	If DQ items = 0, CDR should be $\leq .5$. If any DQ items are = 1, the CDR score should be at least 1.
Orientation	If orientation score on MMSE = 10, CDR score should be $\leq .5$. If time is < 5 and place = 5, the CDR score should be either .5 or 1. If the person is disoriented to place, the CDR score should be ≥ 2 .
Judgment and Problem Solving	If DQ item is = 1 or IADL item ≥ 2 , the CDR score should be $\geq .5$.
Community Affairs	If DQ item #2 is = 1 or IADL item ≥ 2 , the CDR score should be $\geq .5$.
Home and Hobbies	If DQ item is = 1 or any IADL item ≥ 2 , the CDR score should be $\geq .5$.
Personal Care	If DQ item 17 or 18 is = 1, the CDR score should be at least .5. If DQ item 19 is = 1, the CDR score should be at least 3 (except if due to a known physical condition).

General Association between Overall CDR Scores and MMSE

Dementia Stage	Overall CDR Score	Typical MMSE Score Range	Appearance
Borderline	0.5	27 - 30	Appears normal, and may or may not have cognitive complaints.
Mild Dementia	1	20 – 26	Appearance is normal and general observer may not notice any dementia.
Moderate Dementia	2	12 - 19	Appearance is normal but cognitive problems apparent when in conversation
Severe, Dementia	3	3 – 11	Marked cognitive difficulty obvious to all.
Profound Dementia	4	0 – 2	Severe speech and comprehension problems, problems feeding self.
Terminal Dementia	5	0	Mute, bedridden, incontinent.