LIFE-DSR

Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR)

ASSESSMENT PACKET

Participant ID

Date of Test

Rater Name

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LIFE-DSR Cognitive and Caregiver Assessments

Provided in this individual participant packet are all of the assessments needed for participants and their caregivers for the LIFE-DSR study visits.

How can I prepare for the study visits?

Before your scheduled visit with the subject and their caregiver, please review the assessments and associated manuals.

What is the timing and order of the assessments?

Every effort should be made to conduct phlebotomy or any invasive study related procedure **after** these assessments are administered. These assessments can be administered at any time during the conduct of the study visit, however, there is a unique order in which the assessments are to be given. Conduct the assessments in the proper order (as follows), beginning with the cognitive assessments and concluding with the caregiver assessments:

Cognitive Assessments (administered to Participant):

1. **Severe Impairment Battery** (SIB)
2. **Shoebox Memory Test**: The Shoebox Memory Test is integrated into the SIB. When conducting the SIB, please read the instructions carefully to know when to turn to the Shoebox Memory Test.
3. **Down Syndrome Mental Status Examination** (DS-MSE): The DS-MSE is given or not given based on the score of the SIB.

Caregiver Assessments:

4. **Vineland-3**
5. **Neuropsychiatric Inventory (NPI)**
6. **Dementia Questionnaire for People with Learning Disabilities (DLD)**

What materials do I need for the assessments?

The rater should take the following to the clinic room:

1. The assessment packet (this document)
2. The materials for the SIB and Integrated Shoebox assessments.
3. The materials for the DS-MSE assessment.
4. The iPad or device to access the Vineland-3.

SIB SUPPLIES

- ☐ Pen and Plain Unlined Paper
- ☐ Cup, Plate, Bowl, Measuring Cup
- ☐ Spoon, Fork, Knife, Measuring Spoons
- ☐ Plastic Container with Lid
- ☐ Plastic Scoop
- ☐ (1) Red square block
- ☐ (2) Blue square blocks
- ☐ (1) Green square block
- ☐ (2) Black square blocks
- ☐ (1) Black triangle block
- ☐ (1) Black circle block
- ☐ Stopwatch
- ☐ Cue Card: "Give me your hand"
- ☐ Cue Card: Picture of a Cup
- ☐ Cue Card: Picture of a Spoon

SHOEBOX SUPPLIES

- ☐ Small bar of soap
- ☐ Cup
- ☐ Glue
- ☐ Sponge
- ☐ Watch
- ☐ Fork
- ☐ Doll
- ☐ Tire
- ☐ Ring
- ☐ Opaque small box with top

DS-MSE SUPPLIES

- ☐ Ball
- ☐ Key
- ☐ Yellow toy truck
- ☐ (20) 1" wooden cubes
- ☐ White collared button-down shirt
- ☐ Cue Card: Picture of a Spoon

VINELAND-3 SUPPLIES

- ☐ iPad (issued by Sponsor)
- ☐ Clipboard
- ☐ Black pen

Who Administers Which Assessments?

If there are two raters on site, the Cognitive Measures and Caregiver Measures can be done simultaneously by different raters.

If the assessments are being done by a single rater, the Cognitive Measures are to be done first with the participant, followed by the Caregiver Assessments to be done with the caregiver, all in the abovementioned order. The same rater should conduct each study visit if possible.

How Are The Rater Assessments Administered?

All assessments (with the exception of the Vineland-3) are to be completed on the forms provided in this packet. **You will need an iPad, clipboard, and a black pen.**

The Vineland-3 is to be completed on the iPad provided to you. In case of any technical errors with the iPad or administration of the Vineland-3 with the iPad, the Vineland 3 can also be administered on another device with access to the internet like a laptop. There is also a paper version of the Vineland-3. The paper version provided can be used as a tool to review the Vineland-3 prior to administration or as a backup in case of technical error.

Source Documentation

This packet is the source documentation for your administration of these assessments. It is critical to document the participant responses verbatim. This gives you the opportunity to verify scoring if a question arises post administration.

Acknowledgments

- **Severe Impairment Battery** (SIB)**,** developed by Thames Valley Test Company, © University of Pittsburgh
- **Shoebox Memory Test**, developed by Burt, D.B. and Aylward, E.H. (1998)
- **Down Syndrome Mental Status Examination** (DS-MSE), developed by Haxby, J. V. (1989)
- **Vineland Adaptive Behavior Scales, Third Edition** (Vineland -3), developed by Sparrow, S., Cicchetti, D., and Saulnier, C., © Pearson
- **Neuropsychiatric Inventory** (NPI), developed and copyright held by Jeffrey L. Cummings, MD
- **Dementia Questionnaire for People with Learning Disabilities** (DLD), developed by Evenhuis, Kengen, and Eurlings, © Pearson

Participant ID | Site Number | Rater Initials | Date of Test | Visit Number

The Severe Impairment Battery (SIB)

Please follow the instructions provided when using this Scoring Sheet.

Start outside of the room that you will be testing in and greet the participant with #1a, #1b, and #1c will be walking towards the testing table (c directing participant to their seat).

1 (SI) a **"Hello, my name is________."** [Give your name]

2 points: spontaneously shakes hands
1 point: raises right hand towards examiner's but doesn't take examiner's hand

(SI) Score 2, 1 or 0

b **"I want you to answer some questions for me."**
"Come with me (to my office/over here)."
Prompt by taking the subject's arm: **"Come with me."**
Alternative: **"I want you to answer some questions for me – can you sit up/back/forward?"**
Prompt by taking the subject's arm: **"Sit up/back/forward."**

2 points: spontaneously moves in direction indicated or spontaneously sits up/back/forward
1 point: after prompt

(SI) Score 2, 1 or 0

c **"Please sit here."**
Prompt by taking the subject's arm: **"Sit here."**

Alternative: If the subject is in a wheelchair: **"Come and sit by this table."**
Prompt by pressing your arm gently on the subject's shoulder. **"Come and sit over here."**

Alternative: If the subject is sitting in a stationary chair; **'Pull your chair towards the table."**
Prompt by touching the table while repeating the instructions

2 points: spontaneously sits in chair or (alternative) spontaneously wheels chair to table or (alternative) spontaneously pulls table towards chair
1 point: after prompt

(SI) Score 2, 1 or 0

---

2 (M) **"My name is_________."** [Give your name]
"I want you to remember my name because I'm going to ask what it is." (pause)
"What's my name?" **"(Yes) My name is_______."** [Give your name]

2 points: spontaneously correct
1 point: close approximation e.g. Julie for Judy

(M) Score 2, 1 or 0

---

3 (O) **"What's your name?"**
If the subject gives first or last name only, prompt: e.g. **"John who?"**

2 Point: full name, one prompt allowed
1 Point: first, last name or previous name only

(O) Score 2, 1 or 0

---

4 (L) a **"Please write your name here."**

2 points: spontaneously correct (some degree of carelessness is allowed , especially if the subject signs usual signature)
1 point: partially correct i.e. first or last name only or previous name

(L) Score 2, 1 or 0

b **"Can you copy this?"**

2 points: spontaneously correct (printed name or signature), or 4a correct
1 point: partially correct

(L) Score 2, 1 or 0

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Shoebox Memory Test - integrated with SIB

Shoebox Memory Test: Immediate Memory

General Instructions: Verbal instructions and allowable follow-up prompts are indicated in bold. Record all gestures and responses. For object naming, give credit only for recognizable responses (i.e., so for soap). For recall, give credit for name and appropriate gestures or nonverbal vocalization, if they specify object.

1. Immediate Memory (3 items)

Place objects in single line from participant's left to right
Soap Cup Ring

a. "What is this called?" ☐ Soap ☐ Cup ☐ Ring

Check objects correctly named. If participant incorrectly names object, write their response below the object (e.g., mug for cup)

Prompts: **"This is a…."** See how participant describes item, and use their language to create a prompt. If they say, "*It's what you wash your hands with*," affirm and say, "**Yes, you wash your hands with it, but what is it called?**"

Provide correct name for each item not named and have them repeat it.

b. "Put the _____ in the box.". ☐ **Soap** ☐ **Cup** ☐ **Ring**

Check objects correctly placed in box.
Place the objects in the box if the person does not.

Put the lid on the box.

c. "What is in the box?" ☐ Soap ☐ Cup ☐ Ring

Prompts: ***"There's a…." "What else is in the box?"*** *or* ***"and a…"***

Check off each object correctly recalled.

If they incorrectly named object in 1a, they can still receive credit for memory of item if they use the same name.

Once you move on to next grouping, there is no credit (no score adjustment) given for delayed recall from previous grouping.

Score
1 pt. each word

/3

**************If participant does not recall all 3 objects discontinue immediate memory*********************

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

Shoebox Memory Test: Immediate Memory

2. Immediate Memory (6 items)

Place objects in single line from participant's left to right

soap cup ring glue sponge watch

Take the 3 previous items out of box the and and place in front of participant. Then, show the person each NEW object as you place it on the table and ask,: **"What is this called?"** Prompt as above. Provide correct name for each object not named and have them repeat it.

a. "What is this called?" ☐ Soap ☐ Cup ☐ Ring ☐ Glue ☐ Sponge ☐ Watch

Prompts: ***"This is a...."***

Check objects correctly named. If participant incorrectly names object, write their response below the object (e.g., clock for watch)

b. "Put the____ in the box." ☐ **Soap** ☐ **Cup** ☐ **Ring** ☐ **Glue** ☐ **Sponge** ☐ **Watch**

Check objects correctly placed in box. Place the objects in the box if the person does not.

Put the lid on the box.

c. "What is in the box?" ☐ Soap ☐ Cup ☐ Ring ☐ Glue ☐ Sponge ☐ Watch

Prompts: ***"There's a...." "What else is in the box?"*** **or** ***"and a..."***

Check objects correctly recalled.

Score

1 pt. each word

/ 6

***************If participant does not recall all 6 objects discontinue immediate memory**********************

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

Shoebox Memory Test: Immediate Memory

3. Immediate Memory (9 items)

Place objects in single line from participant's left to right

soap cup ring glue sponge watch fork doll tire

Take the 6 previous items out of box and and place in front of participant. Then, show the person each NEW object as you place it on the table, and ask "**What is this called?**". Prompt as above. Provide the correct name for each object not named and have them repeat it.

a. "What is this called?" *Prompts: **"This is a...."***

☐ Soap ☐ Cup ☐ Ring ☐ Glue ☐ Sponge ☐ Watch ☐ Fork ☐ Doll ☐ Tire

check each object correctly named. if participant incorrectly names object, write their response below the item (e.g., clock for watch)

b. "Put the____ in the box."

Check objects correctly placed in box.
Place the objects in the box if the person does not.

☐ **Soap** ☐ **Cup** ☐ **Ring**
☐ **Glue** ☐ **Sponge** ☐ **Watch**
☐ **Fork** ☐ **Doll** ☐ **Tire**

Put the lid on the box.

c. "What is in the box?"

☐ Soap ☐ Cup ☐ Ring
☐ Glue ☐ Sponge ☐ Watch
☐ Fork ☐ Doll ☐ Tire

Score
1 pt. each word

/ 9

*Prompts: **"There's a...." "What else is in the box?" or "and a..."***

Check objects correctly recalled.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

5 (O) **"What month is it now?"**

Prompt: **"Is it _________, _________ or ________?"**

(Six months prior to present month, present month, preceding month)

2 points: spontaneously correct
1 point: correct with multiple choice prompt

(O) Score 2, 1 or 0

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6 (L) **"Tell me the months of the year"**

Prompt: **"Begin with – January, February, March... go on...?"**

2 points: spontaneously correct
1 point: if correct following prompt, or misses only one or two month (Up to 2 prompts are allowed)

(L) Score 2, 1 or 0

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7 (0) **"What's the name of this city?"**

Prompt: **"Is it ____________, _____________ or ______________ ?"**

(Give target city and two alternatives)

2 points: spontaneously correct
1 point: correct following prompt

(O) Score 2, 1 or 0

---

8 (L) a **"What do you call the thing you drink coffee from?"**

Prompt: **"What's the (china/thing) you drink coffee/tea/cocoa out of?"**

2 points: 'cup' or 'mug'
1 point: related alternative, e.g. 'glass' or 'coffee pot', or if correct following prompt
0 points: unrelated item, e.g. 'plate'

(L) Score 2, 1 or 0

b **"What do you call the thing you eat soup with?"**

Prompt: **"What do you call the (utensil/piece of silverware/cutlery) used for soup?"**

2 points: "spoon"
1 point: related alternative, e.g. "soup bowl", or if correct after prompt
0 points: unrelated item, e.g. "knife"

(L) Score 2, 1 or 0

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

9 (L) a **Present the "Give me your hand" card**: **"Read this card and do what it says." without extending your hand to the participant**

First prompt: repeat the instructions, **"Read this card and do what it says." without extending your hand to the participant**

Second prompt: read the card aloud: **"Give me your hand."** and **lay your hand in front of the participant**

2 points: spontaneously offers hand
1 point: close approximation, e.g. holding up hand, or correct after first prompt
0 points: if examiner reads card

☐ (L) Score 2, 1 or 0

b **"Now give me your other hand." without extending your hand to the participant**

Prompt: repeat the instructions and **gesture with outstretched open hand**

2 points: spontaneously offers hand
1 point: close approximation, e.g. raising hand but not moving hand towards examiner, giving same hand or correct after prompt

☐ (L) Score 2, 1 or 0

c "**What does this say?"**

Prompt: **"Read this card aloud."**

☐

2 points: spontaneously reads card
1 point: partially correct, e.g. misreads card of reads only part of the sentence or correct after prompt

☐ (L) Score 2, 1 or 0

---

10 (M) **"Pardon me, what did you say?"**

Prompt**: "What did you say?"**

☐

2 points: spontaneously correct repetition of what was said in 9c
1 point: partially correct, i.e. repeats only parts of the sentence or correct after prompt

☐ (M) Score 2, 1 or 0

---

11 (L) **"Now say this: "**

a **"People spend money."**

☐

2 points: item repeated correctly
1 point: partially correct repetition or a comment using the word, e.g. "There's never enough money"

☐ (L) Score 2, 1 or 0

b **"Baby."**

☐

2 points: item repeated correctly
1 point: partially correct repetition or a comment using the word, e.g. "I love babies"

☐ (L) Score 2, 1 or 0

Participant ID | Site Number | Rater Initials | Date of Test | Visit Number

12 (ATT)

You are assessing attention. Do not repeat the number sequences, but encourage with "try to remember."

"2" **"5"** **"8-7"** **"4-1"**

"5-8-2" **"6-9-4"** **"6-4-3-9"** **"7-2-8-6"** **"4-2-7-3-1"** **"7-5-8-3-6"**

Write the numbers the participant says for each series.
Discontinue after failure on both series of a given length.

(ATT)

2 points: correct repetition of a three, four or five digit series
1 point: correct repetition of either a one or two digit series

Score 2, 1 or 0

Shoebox Memory Test: Delayed Memory

Administer in full, regardless of performance in previous section.

Score
1 pt. each word

a. "What is in the box?"

Prompts: ***"There's a...." "What else is in the box?"*** **or** ***"and a..."***

☐ Soap	☐ Cup	☐ Ring
☐ Glue	☐ Sponge	☐ Watch
☐ Fork	☐ Doll	☐ Tire

/ 9

13 (L) **"Tell me all the things you like to eat..."**
and/or "Tell me all the things you like to cook/eat for breakfast/dinner/lunch."
Record all the items named in one minute

Time for full 60 seconds and record everything said

2 points: four or more items named
1 point: one, two or three items named

(L)
Score 2, 1 or 0

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14 (M) **"Do you remember my name?"**
"(Yes) My name is ___________"

2 points: spontaneously correct
1 point: close approximation, e.g. "Carol" for "Karen", or "Ms/Dr Schmitt" for "Smith"

(M)
Score 2, 1 or 0

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

15 (L) **Show photograph of cup: "What's this?"**

2 points: "cup"
1 point: alternative, e.g. "mug" or "glass"

(L) Score 2, 1 or 0

---

16 (PR) **"Show me how you would use it"**

2 points: a clear demonstration
1 point: approximation, e.g. hand moves in upward motion but not clearly towards the mouth

(PR) Score 2, 1 or 0

---

17 (L) **"Take hold of this..." (give cup) "What is it (again)?"**

If the subject received 2 point for Q15 give full credit for this question (2points) but always complete the task

2 points: "cup," spontaneously correct, or if Q15 was correct
1 point: an approximation, or alternative, "mug" or "glass"

(L) Score 2, 1 or 0

---

18 (PR) **Allow the participant to keep hold of the cup: "Show me (again) how you would use it"**

2 points: a clear demonstration
1 point: an approximation, e.g. hand moves in upward motion but not clearly towards mouth

(PR) Score 2, 1 or 0

---

19 (L) Omit this question if either Q15 or Q17 was correct and give full credit (1 point)

"Is this a hat or a cup?"

1 point: "cup", or if Q15 or Q17 was correct
0 point: 'hat'

(L) Score 2, 1 or 0

---

* **"I want you to remember this cup..." (hold up cup) "...because I'm going to ask you about it in a few minutes, so try to remember it"**

***Be sure to say this part even if question 19 is omitted!**

Participant ID | Site Number | Rater Initials | Date of Test | Visit Number

20 (L) **Show photograph of spoon: "What's this?"**

2 points: "spoon"
1 point: approximation, e.g. "silverware/cutlery"

(L) Score 2, 1 or 0

---

21 (PR) **"Show me how you would use it"**

2 points: a clear demonstration
1 point: close approximation, e.g. hand is raised upwards to the mouth but there is no mouth movement towards the hand

(PR) Score 2, 1 or 0

---

22 (L) If the subject received 2 points for Q20 give full credit for this question (2 points) but always complete the task: **"Take hold of this..." (give spoon) "...what is it (again)?"**

2 points: spontaneously correct, or of Q20 was correct
1 point: approximation, e.g. "silverware/cutlery"

(L) Score 2, 1 or 0

---

23 (PR) **Allow the subject to keep hold of the spoon: "Show me (again) how you would use it"**

2 points: a clear demonstration
1 point: close approximation, e.g. hand is raised upwards to the mouth but there is no mouth movement towards the hand

(PR) Score 2, 1 or 0

---

24 (L) Omit this question if either Q20 or Q22 was correct and give full credit (1 point)
"Is this a boot or a spoon?"

1 point: "spoon" or if Q20 or Q22 correct
0 point: 'boot'

(L) Score 1 or 0

Show the subject the cup and spoon again

"I want you to remember this spoon..." (hold up spoon)" ...and also this cup..." (hold up cup)

*** "...because I'm going to ask you about these items later. Take a good look at them, and try to remember them."**

***Be sure to say this part even if question 24 is omitted!**

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

25 (M)

Examiner's left	*Center*	*Examiner's right*
plastic container	plate	**cup**

"Which one of these (items/objects/things) did I ask you to remember?"

Examiner's left	*Center*	*Examiner's right*
spoon	scoop	fork

"I also asked you to remember one of these (items/objects/things), which one was it?"

2 points: "cup" and "spoon" named
1 point: either "cup" or 'spoon' named

(M) Score 2, 1 or 0

Show the subject the cup and spoon again

"I want you to remember this spoon…"(hold up spoon) "…and also this cup…" (hold up cup) "…because I'm going to ask you about these items later. Take a good look at them and try to remember them"

* **Remember to say these lines!**

26 (L) **Show the subject a blue block: "What color is this?"**

Prompt: "**Is it blue or red?"**

2 points: spontaneously correct
1 point: color or shade near to the original (e.g. "purple" or navy?"), or if correct after forced choice

(L) Score 2, 1 or 0

* **Keep this blue block for yourself.**

27 (VS)

Examiner's left	*Center*	*Examiner's right*
blue	green	red

"Which of these blocks… (gesture to the blocks) … is the same color as this one?"
Prompt: **"This is my blue block, show me your blue block."**
If incorrect or no response: **"This is it-this is the blue block."**

2 points: spontaneously correct
1 point: if correct after prompt
0 points: if examiner identifies block

(VS) Score 2, 1 or 0

* **Remember to re-arrange order of the blocks here**

28 (M)

Examiner's left	*Center*	*Examiner's right*
green	**blue**	red

"Give that block back to me - the same one you just showed me."
Prompt: **"Which block did you just give me (did I just show you) - was is this one, this one, or this one?" (point to the blocks on the board)**
If incorrect or no response: **"This is it - this is the one."**

2 points: spontaneously correct
1 point: correct after prompt
0 points: incorrect or identified by examiner

(M) Score 2, 1 or 0

29 (VS) **"Now give me a different block, not the one I just showed you - a different one"**
Prompt: **"This is a blue block…" (hold up blue block) "…give me a different colored block"**

2 points: spontaneously correct
1 point: if correct after prompt

(VS) Score 2, 1 or 0

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30 (L) a **Show red block: "What color is this?"**
Prompt: **"Is it blue or red?"**

2 points: spontaneously correct
1 point: color near to the original ("pink" or "orange"), or if the subject is correct after forced choice

Score 2, 1 or 0 (L)

b **Show green block: "What color is this?"**
Prompt: **"Is it green or blue?"**

2 points: spontaneously correct
1 point: color or shade near to the original (e.g. "olive" or "lemon"), or if the subject is correct after forced choice

Score 2, 1 or 0 (L)

c **Show black square block: "What shape is this?"**
Prompt: **"Is it a square or a circle?"**

2 points: spontaneously correct
1 point: if correct after prompt

Score 2, 1 or 0 (L)

31 (VS)

Examiner's left	***Center***	***Examiner's right***
triangle	circle	square

"Which of these blocks... (gesture to the whiteboard) is the same shape as this one?"
Prompt: **"This is my square block, show me your square block"**
If incorrect or no response: **"This is it-this is the square block"**

2 points: spontaneously correct , 1 point: if correct after prompt, 0 points: if examiner identifies block

Score 2, 1 or 0 (VS)

* **Remember to re-arrange order of the blocks here**

32 (M)

Examiner's left	***Center***	***Examiner's right***
circle	**square**	triangle

"Give that block back to me- the same one you just gave me (I showed you)"
Prompt: **"Which block did you just give me (I did I just show you) - was it this one, this one, or this one?" (point to the blocks on the board)**
If incorrect or no response: **"This is it-this is the one"**

2 points: spontaneously correct
1 point: correct after prompt
0 points: incorrect or examiner identifies block

Score 2, 1 or 0 (M)

33 (VS) **"Now show me a different shape, not the one I just showed you - a different one."**
Prompt: **"This is a square... (hold up square block) show me a different shape."**

2 points: spontaneously correct
1 point: if correct after prompt

Score 2, 1 or 0 (VS)

34 (L) a **Show round block: "What shape is this?"**
Prompt: **"Is this a square or a circle?"**

2 points: spontaneously correct (either "circle" or "round" is acceptable)
1 point: if correct after prompt

Score 2, 1 or 0 (L)

b **Show triangular block: "What shape is this?"**
Prompt: **"Is this a triangle or a square?"**

2 points: spontaneously correct
1 point: if correct after prompt, or "pyramid"

Score 2, 1 or 0 (L)

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35 (C) a **"Draw a circle."**

Prompt by presenting a drawing of a circle: "Copy this."

2 points: circle, oval or ellipse drawn spontaneously
1 point: an approximation e.g. a shape that forms at least half a circle or if the subject draws a circular shape after the prompt or if the subject attempts to trace the circle
0 points: a straight line, dot etc.

(C) Score 2, 1 or 0

b **"Draw a square."**

Prompt by presenting a drawing of a square: "Copy this."

2 points: a square, rectangle or oblong (the figure must have 4 sides)
1 point: an approximation e.g. a shape that is open at one end but if closed would form a square, or if the subject draws a square shape after the prompt or if the subject attempts to trace the square
0 points: a straight line, dot etc.

(C) Score 2, 1 or 0

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36 (ATT) **"I'm going to tap the table and count the number of times I tap-listen."**

Tap the table three times, and count out loud, "1-2-3" as you tap

Use knuckles to knock on table. Avoid non-verbal cues like nodding your head while counting.

"Now you count when I tap, remember to keep counting, don't stop"

Tap five times, only one prompt allowed

2 points: if the subject counts to five without prompting
1 point: if the subject counts to five with one prompt
0 points: if the subject requires more than one prompt or doesn't count to five

(ATT) Score 2, 1 or 0

Be sure to demonstrate **ALL** the examples, ***before*** starting the scoring portion

37 (ATT)

Hold up 1st, 2nd and 3rd fingers: "Look at my fingers, see I'm holding up three fingers"
Then hold up 1st finger: "Now I'm holding up one finger"
Then hold up 1st and 4th: "Now you count my fingers…" "…(yes) two fingers"
Then hold up 1st finger only

Ask all five samples, even if answered incorrectly, BEFORE starting the scoring portion.

If the subject doesn't spontaneously count your fingers: **"I want you to count my fingers, keep counting, don't stop"**

Only one prompt allowed throughout the presentations (scoring begins here)

1st & 4th	1st	1st, 2nd & 3rd	4th finger	all 4 fingers
2	1	3	1	4

2 points: if the subject counts to five presentations without stopping
1 point: if the subject counts all five presentations but stops once and received one prompt
0 points: if incorrect or if the subject requires more than 1 prompt to continue counting

(ATT) Score 2, 1 or 0

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38 (M)

Examiner's left	***Center***	***Examiner's right***
measuring cup (jug)	cup	bowl

"Which one of these (items/objects/things) did I ask you to remember?"

Examiner's left	***Center***	***Examiner's right***
knife	measuring spoon(s)	spoon

"I also asked you to remember one of these (items/objects/things), which one was it?"

2 points: "cup" and "spoon" named
1 point: either "cup" or "spoon" named
Indicate that you should now prepare to leave

(M) Score 2, 1 or 0

Say, "I'm just going to grab something over here, I'll be right back" and walk behind the participant before doing #39…

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

39 (ON) **While walking back to the waiting room or preparing to leave, stand directly behind the subject and call his/her name**

2 points: a spontaneous response i.e. the subject turns around
1 point: some reaction (verbal or non-verbal but appears to be unsure of the direction of the sound)
0 points: no response

Score 2, 1 or 0

Now return to your seat and engage participant in #40

---

40 (L) **If the subject responds to Q39, engage the subject in conversation: "How have you been?"**

Prompt: **"Got any plans for the weekend?" or "Had any visitors today?"**
Alternative: If the subject did not respond to Q39 simply ask this question (or these questions) prior to the point of departure.

Score 2, 1 or 0

2 points: a coherent and appropriate answer to one of the question, it must be one complete sentence
1 point: an appropriate answer but not a complete sentence, e.g. "ok" or only two or three words, e.g. "I'm alright" or "Yes, I have"

SIB Scoring Summary Chart

Social interaction (SI)

Item	Score	
1a Shake hands	2,1,0	___
1b Follow directions	2,1,0	___
1c Sit/move to table/pull tray	2,1,0	___
Total (Maximum 6)		___

Memory (M)

Item	Score	
2 Examiner's name immediate	2,1,0	___
14 Examiner's name delayed	2,1,0	___
10 Sentence	2,1,0	___
25 Object immediate	2,1,0	___
38 Object delayed	2,1,0	___
28 Colored block	2,1,0	___
32 Shape	2,1,0	___
Total (Maximum 14)		___

Orientation (O)

Item	Score	
3 Subject's name	2,1,0	___
5 Month	2,1,0	___
7 City	2,1,0	___
Total (Maximum 6)		___

Language (L)

Item	Score	
4a Write name	2,1,0	___
4b Copy name	2,1,0	___
6 Months of year	2,1,0	___
8a Responsive naming-cup	2,1,0	___
8b Responsive naming-spoon	2,1,0	___
9a Reading comprehension	2,1,0	___
9b Verbal comprehension	2,1,0	___
9c Reading	2,1,0	___
11a Repetition-spend money	2,1,0	___
11b Repetition-baby	2,1,0	___
13 Fluency	2,1,0	___
15 Confrontational naming-cup	2,1,0	___
17 Object naming-cup	2,1,0	___
19 Forced-choice naming-cup	1,0	___
20 Confrontational naming-spoon	2,1,0	___
22 Object naming-spoon	2,1,0	___
24 Forced-choice naming-spoon	1,0	___
26 Color naming-blue	2,1,0	___
30a Color naming-red	2,1,0	___
30b Color naming-green	2,1,0	___
30c Shape identification-square	2,1,0	___
34a Shape identification-circle	2,1,0	___
34b Shape identification-triangle	2,1,0	___
40 Free discourse	2,1,0	___
Total (Maximum 46)		___

Attention (ATT)

Item	Score	
12 Digit span	2,1,0	___
36 Auditory span	2,1,0	___
37 Visual span	2,1,0	___
Total (Maximum 6)		___

Praxis (PR)

Item	Score	
16 Using cup-photograph	2,1,0	___
18 Using cup-cup	2,1,0	___
21 Using spoon-photograph	2,1,0	___
23 Using spoon-spoon	2,1,0	___
Total (Maximum 8)		___

Visuospatial ability (VS)

Item	Score	
27 Color matching	2,1,0	___
29 Color discrimination	2,1,0	___
31 Shape matching	2,1,0	___
33 Shape discrimination	2,1,0	___
Total (Maximum 8)		___

Construction (C)

Item	Score	
35a Drawing-circle	2,1,0	___
35b Drawing-square	2,1,0	___
Total (Maximum 4)		___

Orienting to name (ON)

Item	Score	
39 Orienting to name	2,1,0	___
Total (Maximum 2)		___

Total Score
Maximum Total = 100

If score is <60, STOP. Do not administer DS-MSE. Skip to page 27.

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Down Syndrome Mental Status Examination (DS-MSE)

Please Note: The Down Syndrome Mental Status Examination (DS-MSE) should be completed for those individuals who have achieved a score of > 60 on the Severe Impairment Battery (SIB).

If a participant has not achieved > 60 on the SIB, skip the DSMSE and proceed to the next study assessment.

Was the assessment performed?

____ Yes

____ No

____ N/A (participant did not score > 60 on the SIB)

If yes, please check the best description of behavior during test administration:

____ Participant was cooperative and engaged

____ Participant was cooperative but distracted

____ Participant was uncooperative

Please explain behavior during test administration:

If no, reason not done:

____ Participant unable for cognitive reasons

____ Participant unable for other reasons (physical, auditory, etc.)

____ Participant or study partner refused

____ Oversight

____ Other reason

____ Unknown

If other, please explain:

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

I. Introduction

A. "**What is your name?"** ________________________________(2)

Score: 1 point for the correct first name and 1 point for the correct last name.

Prompt: Say "**Hello, my name is [state your name].**
Alternative Prompt: **"You already know this, but my name is [state your name].**

If the participant offers only first or last name, ask for the other. **Repeat this question and all others as often as necessary.** Remember to make sure they state their first AND last name. Prompt for their last name if they do not say their last name.

"My name is…" and have the participant repeat it.
Prompt: "**And my name is?"**, and have the participant repeat it.

Participants Response: ________________________________

II. Orientation

A. **"How old are you?"** ________________________________(2)

Score: 2 points for correct answer, 1 point if within 5 years.

B. **"When is your birthday?"** ________________________________(3)

Score: 1 point each for correct month, date, and year.

Correct Month? _____ Correct Day? _____ Correct Year? ______

C. **"What season is it?"** ________________________________(2)

Prompt: **"Is it summer, fall, winter, or spring?"**

Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.
Remember: Dates of the seasons change.

D. **"What day of the week is it?"** ________________________________(2)

Ask as a multiple choice question if participant cannot state day of week spontaneously.

Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.

E. **"What is my name?"** ________________________________(1)

Score: 1 point for correct name.

F. "What kind of work do I do?" ________________________________(2)

Note: For this item, examples of acceptable responses include: doctor, psychologist, counselor, teacher, social worker, researcher, and scientist. Accept anything that is close to correct. **If a correct answer is not given ask, "Am I a waiter, a doctor, or a policeman?"**
(Substitute correct profession for doctor if necessary and say policewoman if female.)
Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

III. Verbal Repetition

"Say exactly what I say."

Score as correct if all words are in the correct order and recognizable, despite articulation errors.
Score: 1 point per item (Give no credit if you have to repeat the phrase, OR the words are out of order.
Reminder: **Administer ALL items.**

A.	**Record Response Verbatim:**
Ball	______________________
House	______________________
Apple Juice	______________________
Come with me	______________________
(The) cat ran home.	______________________
I bought cookies at (the) store.	______________________
There is (a) vegetable garden in (the) backyard.	______________________

____

(The) car broke down before we even left (the) city limits. ______________________

____

Scoring: Two methods will be used to score response on this item.

Method 1: One point (1) for each completely correct response with the single exception that for the response "I bought cookies at the store," the participant will be given credit if she/he substitutes "in" for "at". With this method, the highest possible score for this item is 8.

Method 2: provides alternate scoring that allows partial credit for partial completion of a response. Rather than only one point for a completely stated response, the participant receives one point for each correctly stated word. They may receive a score from one to nine, depending on the length of the response. Articles (a, an, the) receive no credit and if omitted no credit is deducted. No substitutions are permitted. With this method the highest possible score for this item is 30.

Note: For ease of scoring, words that do not count for scoring Method 2 are circled.

Score:

Method 1: ____/8

Method 2: ____/30

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

IV. Naming for Identity of 3 Objects (ball, key, truck)

Show the participant each object and ask, "What is this called?"

Prompt: **If no response is given, ask, "This is a ....?"**

Record all gestures and responses using phonetic alphabet.

A. Responses: ball _______ key _______ truck______

____________________(3)

Provide name for each object not named by participant and have participant repeat it.
Score: 1 point per correct word. Give credit only for recognizable responses (e.g., /ba/ for ball).

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

V. Verbal Comprehension

Place the ball, key, and truck in front of the participant, spaced about 1 foot apart.
Repeat all commands after incorrect response or nonresponse.
Record all responses.

Discontinue after 3 consecutive failures to respond correctly or to correct wrong response. i.e., if participant responds correctly to the 2nd presentation of command, a score of 0 is given, but it does not count towards discontinuation.

On items 4, 11, and 12, when making the request "Give me..." the **examiner must not offer his/her hand to receive the object** before the participant has moved the object toward the examiner.

		Trial 1	Trial 2	Score
1	"Touch the ball"			1, 1/2, or 0
2	"Touch the truck"			1, 1/2, or 0
3	"Touch the key"			1, 1/2, or 0
4	"Give me the truck"			1, 1/2, or 0
5	"Touch the key then the ball"			1, 1/2, or 0
6	"Touch the truck then the key"			1, 1/2, or 0
7	"Put the ball in the truck"			1, 1/2, or 0
8	"Put the key next to the ball"			1, 1/2, or 0
9	"Touch the truck with the key"			1, 1/2, or 0
10	"Touch the ball, then the truck, then the ball again"			1, 1/2, or 0
11	"Put the key in the truck and give me the ball"			1, 1/2, or 0
12	"Touch the truck then give me the key and the ball"			1, 1/2, or 0

TOTAL SCORE ____________________(12)

Score: 1 point if correct on first command; ½ point if correct after repetition for nonresponse;
0 points if correct after repetition for incorrect response.

For items 1, 2, and 3, no credit is deducted for picking up the object.

On item 5, no credit is deducted for carrying the key over to the ball or, on item 6, for carrying the truck over to the key.

On item 9, no credit is deducted for putting the key in the truck. All other responses must be made exactly as requested, e.g., when told "Put the key next to the ball", credit is not given for putting the ball next to the key, even though by doing so that participant gets the key next to the ball.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

VI. Immediate Memory for Location

"I'm going to put the key in my pocket (or lap), like this... and the truck under my chair, like this... And the ball behind the box, like this...."

"Where is the truck?"

Remember: If incorrect, show participant the truck again. Remind participant of the location of each object if he or she cannot indicate it to you.

"Where is the key?"
"Where is the ball?"

Repeat this procedure up to 3 times or until the participant correctly indicates location of all 3 objects.

A. Trial: **Truck** **Key** **Ball**

1. ____________ ____________ ____________

2. ____________ ____________ ____________

3. ____________ ____________ ____________ ____________________(3)

Score: 1 point for either naming or pointing to location. **Give credit only for 1st trial.** Credit is given if the participant locates the object either verbally or nonverbally, e.g., by pointing.

VII. Naming

A. Record response using phonetic alphabet.

Watch________________________________ ____________________

Pencil________________________________ ____________________

Finger________________________________ ____________________

Elbow________________________________ ____________________

Shirt________________________________ ____________________

Collar________________________________ ____________________

Sleeve________________________________ ____________________

Cuff________________________________ ____________________ ____________________(8)

Scoring: 1 point each if utterance is recognizable (e.g., /bo/ for elbow or /sli/ for sleeve). Note: If the participant had made an incorrect response or no response to sleeve, but then responds to cuff with "sleeve", give credit for the previously incorrect response, but give no credit for cuff. Give credit for identifying collar as "neckline."

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

VIII. Visuospatial Construction

A. Item 1 – Stacking Blocks

Put a block on the table in front of the participant and hand the participant another block.

Say, **"Put this on top of this one here."**

After participant has stacked first block, give him or her another block and indicate that he or she should put that on top of the other two. Then give the participant a fourth block.

Score: 1 point for each block stacked by participant. ____________________(3)

B. Items 2-6 – Constructing 3-D patterns to model

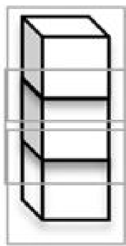
Give participant the correct number of blocks for each design. Construct design in front of participant and indicate that he or she should make one just like it.

Time limit: 1 minute per design.

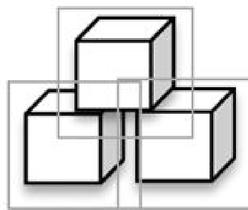
Discontinue after 2 consecutive failures.

Say, "Make yours look just like mine"

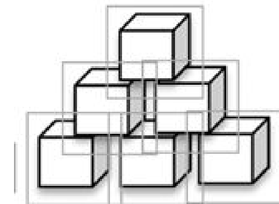
Score: 1 point for each design. (Give half credit on designs 3-6 if participant doesn't leave gaps in between blocks and correct participant's construction.)



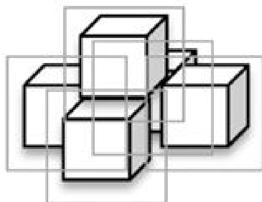
2.______



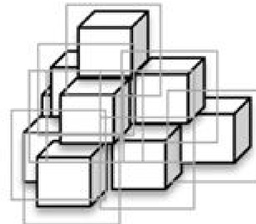
3.______



4.______



5.______



6.______

____________________(5)

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

IX. Delayed Memory for Location

A.

_____ **"Where is the truck?"**

_____ **"Where is the key?"**

_____ **"Where is the ball?"**

Score: 1 point for each location correctly indicated. (Credit is given if the participant locates the object either verbally or nonverbally, e.g., by pointing).

_____________________(3)

X. Apraxia

A. Intransitive

"Show me how you wave goodbye." ____________

"Show me how you salute." ____________

B. Transitive:

"Show me how you throw a ball." ____________
If fails: give them ball and say, "**Show me how you use this."** Give half credit if correct.

"Show me how you lock a door with a key." ____________
If fails: give them key and say, "Show me how you use this." Give half credit if correct.

Score: 1 point for each item (ideomotor apraxia) _____________________(4)

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DS-MSE

FINAL SCORE: ______________________________

NOTES:

NEXT STEPS:

1. **Water break***

Because the participant will have a blood draw at the conclusion of the assessments, it is important they hydrate regularly throughout the day. Please plan to break for water at the conclusion of the participant section.

2. **Proceed with Vineland on tablet**

3. **At conclusion of the Vineland, carry on with NPI, on next page.**

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

Neuropsychiatric Inventory (NPI):

Instructions for Use and Administration

I. Purpose of the NPI

The purpose of the Neuropsychiatric Inventory (NPI) is to obtain information on the presence of psychopathology in patients with brain disorders. The NPI was developed for application to patients with Alzheimer's disease and other dementias, but it may be useful in the assessment of behavioral changes in other conditions. Ten behavioral and two neurovegetative areas are included in the NPI:

A. Delusions
B. Hallucinations
C. Agitation/Aggression
D. Depression
E. Anxiety
F. Elation/Euphoria
G. Apathy/Indifference
H. Disinhibition
I. Irritability
J. Aberrant motor behavior
K. Sleep and Nightime Behavior Disorders
L. Appetite and Eating Disorders

II. Administration of the NPI

A. NPI Interview

The NPI is based on responses from an informed caregiver, preferably one living with the patient. If an informed observer is not available, this instrument cannot be used or must be modified. The interview is best conducted with the caregiver in the absence of the patient to facilitate an open discussion of behaviors that may be difficult to describe with the patient present. Several points should be made when you introduce the NPI interview to the caregiver:

- Purpose of the interview
- Ratings - frequency, severity, distress (described below)
- Answers apply to behaviors that are new since the onset of the disease and have been present for the past four weeks or other defined period
- Questions can usually be answered with "yes" or "no" and responses should be brief

When beginning the inventory, say to the caregiver **"These questions are designed to evaluate [your loved one's] behavior. They can usually be answered 'yes' or 'no' so please try to be brief in your responses."** If the caregiver lapses into elaborate responses that provide little useful information, he/she may be reminded of the need to be brief. Some of the issues raised with this are very emotionally disturbing to caregivers and the interviewer should reassure the caregiver that they will discuss the problems in more detail after completion of the inventory.

Questions should be asked exactly as written. Clarification should be provided if the caregiver does not understand the question. Acceptable clarifications are restatements of the questions in alternate terms.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

B. Changes in Behavior

The questions pertain to changes in the patient's behavior that have appeared since the onset of the illness. Behaviors that have been present throughout the patient's life and have not changed in the course of the illness are not scored even if they are abnormal (e.g., anxiety, depression). Behaviors that have been present throughout life but have changed since the illness are scored (e.g., the patient has always been apathetic but there has been a notable increase in apathy during the period of inquiry).

The NPI is typically used to assess changes in the patient's behavior that have appeared in a defined period of time (e.g., in the past four weeks or other defined interval). In some studies, the NPI may be used to address changes occurring in response to treatment or that have changed since the last clinic visit. The time frame of the question would then be revised to reflect this interest in recent changes. For example, the questions might be phrased "Since he/she began treatment with the new medications..." or "Since the dosage of ______________ was increased ...."

C. Screening Questions

The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, mark NO and proceed to the next screening question without asking the subquestions. If the answer to the screening question is positive or if there are any uncertainties in the caregiver's response or any inconsistencies between the response and other information known by the clinician (e.g., the caregiver responds negatively to the euphoria screening question but the patient appears euphoric to the clinician), the category is marked YES and is explored in more depth with the subquestions. If the subquestions confirm the screening question, the severity and frequency of the behavior are determined according to the criteria provided with each behavior.

In some cases, the caregiver will provide a positive response to the screening question and a negative reply to all subquestions. If this happens, ask the caregiver to expand on why he/she responded affirmatively to the screen. If he/she provides information relevant to the behavioral domain but in different terms, the behavior should be scored for severity and frequency as usual. If the original affirmative response was erroneous, leading to a failure to endorse any subquestions, then the behavior is changed to "NO" on the screen.

Some sections such as the questions pertaining to appetite are framed so as to capture whether there is an increase or decrease in the behavior (increased or decreased appetite or weight). If the caregiver answers "yes" to the first member of the paired questions (such as has the patient's weight decreased?), do not ask the second question (has the patient's weight increased?) since the answer to the second question is contained in the answer to the first. If the caregiver answers "no" to the first member of the pair of questions, then the second question must be asked.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

D. Frequency and Severity Ratings

When determining frequency and severity, use the behaviors identified by the subquestions as most aberrant. For example, if the caregiver indicates that resistive behavior is particularly problematic when you are asking the subquestions of the agitation section, then use resistive behavior to prompt judgments regarding the frequency and severity of agitation. If two behaviors are very problematic, use the frequency and severity of both behaviors to score the item. For example, if the patient has two or more types of delusions, then use the severity and the frequency of all delusional behaviors to phrase the questions regarding severity and frequency.

When determining frequency, say to the person being interviewed: "**Now I want to find out how often these things [define using the description of the behaviors noted as most problematic on the subquestions] occur. Would you say that they occur less than once per week, about once per week, several times per week but not every day, or every day?**" Some behaviors such as apathy eventually become continuously present, and then "are constantly present" can be substituted for "every day."

When determining severity, tell the person being interviewed "**Now I would like to find out how severe these behaviors are. By severity, I mean how disturbing or disabling they are for the patient. Would you say that [the behaviors] are mild, moderate, or severe?**" Additional descriptors are provided in each section that may be used to help the interviewer clarify each grade of severity.

In each case, be sure that the caregiver provides you with a definite answer as to the frequency and severity of the behaviors. Do not guess what you think the caregiver would say based on your discussion.

We have found it helpful to provide the caregiver with a piece of paper on which is written the frequency and severity descriptions (less than once per week, about once per week, several times per week and daily or continuously for frequency; and mild, moderate, and severe for severity) to allow him her to visualize the response alternatives. This also saves the examiner from reiterating the alternatives with each question.

E. Not Applicable Designations

In very impaired patients or in patients with special medical circumstances, a set of questions may not be applicable. For example, bed-bound patients may exhibit hallucinations or agitation but are unable to exhibit aberrant motor behavior. If the clinician or the caregiver believes that the questions are inappropriate, then the section should be marked NA (upper right corner of each section), and no further data are recorded for that section. Likewise, if the clinician feels that the responses are invalid (e.g., the caregiver did not seem to understand the particular set of questions asked), NA should also be marked.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

F. Neurovegetative Changes

Items 11 (sleep) and 12 (appetite) were added after the original publication of the NPI (Cummings et al, 1994). They were included because they are common problem areas in Alzheimer's disease and other dementias. They form part of the depression syndrome in some patients and were specifically excluded from the dysphoria subscale of the NPI in order to allow that subscale to focus on mood symptoms. These two symptoms are usually not included in the total NPI score and may not be included in all protocols.

G. Caregiver Distress (NPI-D)

When each domain is completed and the caregiver has completed the frequency and severity rating, you may want to ask the associated caregiver distress question if your protocol includes the distress assessment. To do this, ask the caregiver how much, if any, "emotional or psychological" distress the behavior he or she just discussed causes him or her (the caregiver). The caregiver must rate his or her own distress on a five point scale from 0 - no distress, 1- minimal, 2 - mild, 3 - moderate, 4 - moderately severe, 5 - very severe or extreme.

II. Scoring the NPI

FREQUENCY is rated as:

1 - Occasionally - less than once per week
2 - Often - about once per week
3 - Frequently - several times per week but less than every day
4 - Very frequently - daily or essentially continuously present

SEVERITY is rated as:

1 - Mild - produces little distress in the patient
2 - Moderate - more disturbing to the patient but can be redirected by the caregiver
3 - Severe - very disturbing to the patient and difficult to redirect

The score for each domain = FREQUENCY x SEVERITY.

DISTRESS is scored as:

0 - no distress
1 - minimal
2 - mild
3 - moderate
4 - moderately severe
5 - very severe or extreme.

A total NPI score can be calculated by adding the scores of the first 10 domain scores together.

In most cases, the two neurovegetative items are not included in the NPI total score. If they are included, specify that the 12 item score is being used rather than the 10 item score.

The distress score is not included in the total NPI score. The total distress score is generated by adding together the scores of the first 10 or all 12 items of the NPI distress questions; specify specifically whether the 10 or 12 item score is being used.

Thus, for each behavioral domain there are four scores:

- Frequency
- Severity
- Total (frequency x severity)
- Caregiver distress

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

A. Delusions (NA)

Does the patient have beliefs that you know are not true (for example, insisting that people are trying to harm him/her or steal from him/her)? Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I am interested if the patient is convinced that these things are happening to him/her.

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient believe that he/she is in danger - that others are planning to hurt him/her? ______
2. Does the patient believe that others are stealing from him/her? ______
3. Does the patient believe that his/her spouse is having an affair? ______
4. Does the patient believe that unwelcome guests are living in his/her house? ______
5. Does the patient believe that his/her spouse or others are not who they claim to be? ______
6. Does the patient believe that his/her house is not his/her home? ______
7. Does the patient believe that family members plan to abandon him/her? ______
8. Does the patient believe that television or magazine figures are actually present in the home? ______
   [Does he/she try to talk or interact with them?] ______
9. Does the patient believe any other unusual things that I haven't asked about? ______

If the screening question is confirmed, determine the frequency and severity of the delusions.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - once or more per day.

Severity:
1. Mild - delusions present but seem harmless and produce little distress in the patient.
2. Moderate - delusions are distressing and disruptive.
3. Marked - delusions are very disruptive and are a major source of behavioral disruption. [If PRN medications are prescribed, their use signals that the delusions are of marked severity.]

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

B. Hallucinations (NA)

Does the patient have hallucinations such as seeing false visions or hearing imaginary voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds or visions.

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient describe hearing voices or act as if he/she hears voices? ______
2. Does the patient talk to people who are not there? ______
3. Does the patient describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc)? ______
4. Does the patient report smelling odors not smelled by others? ______
5. Does the patient describe feeling things on his/her skin or otherwise appear tobe feeling things crawling or touching him/her? ______
6. Does the patient describe tastes that are without any known cause? ______
7. Does the patient describe any other unusual sensory experiences? ______

If the screening question is confirmed, determine the frequency and severity of the hallucinations.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - once or more per day.

Severity:
1. Mild - hallucinations are present but harmless and cause little distress for the patient.
2. Moderate - hallucinations are distressing and are disruptive to the patient.
3. Marked - hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

C. Agitation/Aggression (NA)

Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes? ______
2. Is the patient stubborn, having to have things his/her way? ______
3. Is the patient uncooperative, resistive to help from others? ______
4. Does the patient have any other behaviors that make him hard to handle? ______
5. Does the patient shout or curse angrily? ______
6. Does the patient slam doors, kick furniture, throw things? ______
7. Does the patient attempt to hurt or hit others? ______
8. Does the patient have any other aggressive or agitated behaviors? ______

If the screening question is confirmed, determine the frequency and severity of the agitation.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than daily.
4. Very frequently - once or more per day.

Severity:
1. Mild - behavior is disruptive but can be managed with redirection or reassurance.
2. Moderate - behaviors are disruptive and difficult to redirect or control.
3. Marked - agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm. Medications are often required.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

D. Depression/Dysphoria (NA)

Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient have periods of tearfulness or sobbing that seem to indicate sadness? ______
2. Does the patient say or act as if he/she is sad or in low spirits? ______
3. Does the patient put him/herself down or say that he/she feels like a failure? ______
4. Does the patient say that he/she is a bad person or deserves to be punished? ______
5. Does the patient seem very discouraged or say that he/she has no future? ______
6. Does the patient say he/she is a burden to the family or that the family would be better off without him/her? ______
7. Does the patient express a wish for death or talk about killing him/herself? ______
8. Does the patient show any other signs of depression or sadness? ______

If the screening question is confirmed, determine the frequency and severity of the depression.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - essentially continuously present.

Severity:
1. Mild - depression is distressing but usually responds to redirection or reassurance.
2. Moderate - depression is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate.
3. Marked - depression is very distressing and a major source of suffering for the patient.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

E. Anxiety (NA)

Is the patient very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the patient afraid to be apart from you?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient say that he/she is worried about planned events? ______
2. Does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense? ______
3. Does the patient have periods of [or complain of] shortness of breath, gasping, or sighing for no apparent reason other than nervousness? ______
4. Does the patient complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? [Symptoms not explained by ill health] ______
5. Does the patient avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds? ______
6. Does the patient become nervous and upset when separated from you [or his/her caregiver]? [Does he/she cling to you to keep from being separated?] ______
7. Does the patient show any other signs of anxiety? ______

If the screening question is confirmed, determine the frequency and severity of the anxiety.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - once or more per day.

Severity:
1. Mild - anxiety is distressing but usually responds to redirection or reassurance.
2. Moderate - anxiety is distressing, anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate.
3. Marked - anxiety is very distressing and a major source of suffering for the patient.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

F. Elation/Euphoria (NA)

Does the patient seem too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or finds humor where others do not.

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient appear to feel too good or to be too happy, different from his/her usual self? ______
2. Does the patient find humor and laugh at things that others do not find funny? ______
3. Does the patient seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others)? ______
4. Does the patient tell jokes or make remarks that have little humor for others but seem funny to him/her? ______
5. Does he/she play childish pranks such as pinching or playing "keep away" for the fun of it? ______
6. Does the patient "talk big" or claim to have more abilities or wealth than is true? ______
7. Does the patient show any other signs of feeling too good or being too happy? ______

If the screening question is confirmed, determine the frequency and severity of the elation/euphoria.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - essentially continuously present.

Severity:
1. Mild - elation is notable to friends and family but is not disruptive.
2. Moderate - elation is notably abnormal.
3. Marked - elation is very pronounced; patient is euphoric and finds nearly everything to be humorous.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

G. Apathy/Indifference (NA)

Has the patient lost interest in the world around him/her? Has he/she lost interest in doing things or does he/she lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient seem less spontaneous and less active than usual? ______
2. Is the patient less likely to initiate a conversation? ______
3. Is the patient less affectionate or lacking in emotions when compared to his/her usual self? ______
4. Does the patient contribute less to household chores? ______
5. Does the patient seem less interested in the activities and plans of others? ______
6. Has the patient lost interest in friends and family members? ______
7. Is the patient less enthusiastic about his/her usual interests? ______
8. Does the patient show any other signs that he/she doesn't care about doing new things? ______

If the screening question is confirmed, determine the frequency and severity of the apathy/indifference.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - nearly always present.

Severity:
1. Mild - apathy is notable but produces little interference with daily routines; only mildly different from patient's usual behavior; patient responds to suggestions to engage in activities.
2. Moderate - apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members.
3. Marked - apathy is very evident and usually fails to respond to any encouragement or external events.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

H. Disinhibition (NA)

Does the patient seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient act impulsively without appearing to consider the consequences? ______
2. Does the patient talk to total strangers as if he/she knew them? ______
3. Does the patient say things to people that are insensitive or hurt their feelings? ______
4. Does the patient say crude things or make sexual remarks that he/she would not usually have said? ______
5. Does the patient talk openly about very personal or private matters not usually discussed in public? ______
6. Does the patient take liberties or touch or hug others in way that is out of character for him/her? ______
7. Does the patient show any other signs of loss of control of his/her impulses? ______

If the screening question is confirmed, determine the frequency and severity of the disinhibition.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - essentially continuously present.

Severity:
1. Mild - disinhibition is notable but usually responds to redirection and guidance.
2. Moderate - disinhibition is very evident and difficult to overcome by the caregiver.
3. Marked - disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

I. Irritability/Lability (NA)

Does the patient get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the patient has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient have a bad temper, flying "off the handle" easily over little things? ______
2. Does the patient rapidly change moods from one to another, being fine one minute and angry the next? ______
3. Does the patient have sudden flashes of anger? ______
4. Is the patient impatient, having trouble coping with delays or waiting for planned activities? ______
5. Is the patient cranky and irritable? ______
6. Is the patient argumentative and difficult to get along with? ______
7. Does the patient show any other signs of irritability? ______

If the screening question is confirmed, determine the frequency and severity of the irritability/lability.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - essentially continuously present.

Severity:
1. Mild - irritability or lability is notable but usually responds to redirection and reassurance.
2. Moderate - irritability and lability are very evident and difficult to overcome by the caregiver.
3. Marked - irritability and lability are very evident, they usually fail to respond to any intervention by the caregiver, and they are a major source of distress.

Distress: How emotionally distressing do you find this behavior?
0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely

5. Very severely or extremely

J. Aberrant Motor Behavior (NA)

Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient pace around the house without apparent purpose? ______
2. Does the patient rummage around opening and unpacking drawers or closets? ______
3. Does the patient repeatedly put on and take off clothing? ______
4. Does the patient have repetitive activities or "habits" that he/she performs over and over? ______
5. Does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc? ______
6. Does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot? ______
7. Does the patient do any other activities over and over? ______

If the screening question is confirmed, determine the frequency and severity of the aberrant motor activity:

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - essentially continuously present.

Severity:
1. Mild - abnormal motor activity is notable but produces little interference with daily routines.
2. Moderate - abnormal motor activity is very evident; can be overcome by the caregiver.
3. Marked - abnormal motor activity is very evident, usually fails to respond to any intervention by the caregiver, and is a major source of distress.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

K. Sleep (NA)

Does the patient have difficulty sleeping (do not count as present if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed, or disturb your sleep?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Does the patient have difficulty falling asleep? ______
2. Does the patient get up during the night (do not count if the patient gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? ______
3. Does the patient wander, pace, or get involved in inappropriate activities at night? ______
4. Does the patient awaken you during the night? ______
5. Does the patient awaken at night, dress, and plan to go out thinking that it is morning and time to start the day? ______
6. Does the patient awaken too early in the morning (earlier that was his/her habit)? ______
7. Does the patient sleep excessively during the day? ______
8. Does the patient have any other nighttime behaviors that bother you that we haven't talked about? ______

If the screening question is confirmed, determine the frequency and severity of the nighttime behavior.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - once or more per day (every night)

Severity:
1. Mild - nighttime behaviors occur but they are not particularly disruptive.
2. Moderate - nighttime behaviors occur and disturb the patient and the sleep of the caregiver; more than one type of nighttime behavior may be present.
3. Marked - nighttime behaviors occur; several types of nighttime behavior may be present; the patient is very distressed during the night and the caregiver's sleep is markedly disturbed.

Distress: How emotionally distressing do you find this behavior?

0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

L. Appetite and eating disorders (NA)

Has he/she had any change in appetite, weight, or eating habits (count as NA if the patient is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

NO (If no, proceed to next screening question). **YES** (If yes, proceed to subquestions).

1. Has he/she had a loss of appetite? ______
2. Has he/she had an increase in appetite? ______
3. Has he/she had a loss of weight? ______
4. Has he/she gained weight? ______
5. Has he/she had a change in eating behavior such as putting too much food in his/her mouth at once? ______
6. Has he/she had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food? ______
7. Has he/she developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order? ______
8. Have there been any other changes in appetite or eating that I haven't asked about? ______

If the screening question is confirmed, determine the frequency and severity of the changes in eating habits or appetite.

Frequency:
1. Occasionally - less than once per week.
2. Often - about once per week.
3. Frequently - several times per week but less than every day.
4. Very frequently - once or more per day or continuously

Severity:
1. Mild - changes in appetite or eating are present but have not led to changes in weight and are not disturbing.
2. Moderate - changes in appetite or eating are present and cause minor fluctuations in weight.
3. Marked - obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the patient.

Distress: How emotionally distressing do you find this behavior?
0. Not at all
1. Minimally
2. Mildly
3. Moderately
4. Severely
5. Very severely or extremely

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

NPI

TOTAL SCORE: ______________ CAREGIVER DISTRESS SCORE: ____________

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

DLD

Screening Instrument for Diagnosis of Dementia in People with Learning Disabilites

H.M. Evenhuis, M.M.F. Kengen, H.A.L. Eurlings

Name: **Gender: M/F**

Birth Date:

Completed by:

Date of completion:

Address:

Other information:

Instructions: The questionnaire has to be completed by a caregiver who is familiar with the observed person. Behavior during approximately the last two months has to be observed and scored. Score the behaviour carefully, by circling '0', '1' or '2'.

Some of the items (e.g.those about the past or family members) are probably not spoken about regularly. It is advised to ask them incidentally, before completion of the DLD.

If the observed person is not able to move independently, items about 'where to go' (nos. 15 and 46) are to be scored '0' if he/she clearly know where to go (e.g by pointing).

Some items require verbal skills. If he/she is not able to engage in verbal tasks, e.g. due to a low functional level of hearing impairment, the item is scored as '2'.

The scores of the subscales (last page) are to be completed and added up afterwards by the psychologist or physician.

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

DLD

Record score in gray box

	Category	1	2	3	4	5	6	7	8
1. Understands what you want to communicate to him/her (by means of speaking, writing or gesticulation): 0 = normally yes 1 = sometimes 2 = normally no									
2. Remembers where he/she put something away as short time ago (no longer than half an hour ago): 0 = normally yes 1 = sometimes 2 = normally no									
3. Remembers an important event that took place during the last few weeks (talks about it or recognition is apparent from behaviour when it is spoken about): 0 = normally yes 1 = sometimes 2 = normally no									
4. Know which month it is (if it is the first week of the month you can accept the previous month as the correct answer): 0 = yes 1 = sometimes 2 = no									
5. Remembers family members or friends whom he/she has not seen for a long time or who are deceased: 0 = yes 1 = sometimes 2 = no									
Total Page 2									

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

Item	Category 1	2	3	4	5	6	7	8
6. Know whether it is spring, summer, autumn or winter: 0 = yes 1 = sometimes 2 = no			■					
7. Knows what year it is (a mistake of one year is permitted): 0 = yes 1 = sometimes 2 = no			■					
8. Is interested in outdoor activities *e.g. clubs, family parties, trips): 0 = normally yes 1 = sometimes 2 = normally no							■	
9. Hits or kicks other people or shows aggression in any other way: 0 = never 1 = sometimes 2 = often								■
10. Remembers events from his/her youth: 0 = remembers a lot 1 = remembers a little 2 = remembers nothing		■						
11. Is able to undress (can be with some help or stimulus): 0 = never 1 = sometimes 2 = often					■			
Total Page 3		■	■		■		■	■

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

	Category 1	2	3	4	5	6	7	8
12. During the day is: 0 = continent 1 = only continent with the help of others 2 = incontinent (always or several times a day)					▇			
13. Speaks (to an unknown person) integlligibly and sensibly (for individuals who only speak some stereotyped words, score 'no'): 0 = normally yes 1 = sometimes 2 = normally no				▇				
14. Remembers an instruction given just a moment ago (up to five minutes ago): 0 = normally yes 1 = sometimes 2 = normally no	▇							
15. Can find his/her way to familiar places in his/her residential environment: 0 = normally yes 1 = sometimes 2 = normally no			▇					
16. Keeps his/her cothes and belongings tidy: 0 = normally yes 1 = sometimes 2 = normally no							▇	▇
17. Is able to wash him/herself under the shower or at the sink (may require some help): 0 = always 1 = sometimes 2 = never								
Total Page 4	▇		▇	▇	▇		▇	▇

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

Category	1	2	3	4	5	6	7	8
18. Can talk about a holiday or trip (by words and gestures) to those who stayed at home: 0 = normally yes 1 = sometimes 2 = normally no	■							
19. Is able to dress (can be with some help or equipment): 0 = always 1 = sometimes 2 = never					■			
20. Is interested in what is going on in the home: 0 = normally yes 1 = sometimes 2 = normally no							■	
21. Is interested in papers and /or TV: 0 = normally yes 1 = sometimes 2 = normally no							■	
22. Speaks: 0 = yes 1 = only some stereotyped words 2 = no				■				
23. Recognises persons whom he/she came to know during the last few weeks (calls them by name of recognition is apparent from behaviour): 0 = normally yes 1 = sometimes 2 = normally no	■							
Total Page 5	■			■	■		■	

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

Item	Category 1	2	3	4	5	6	7	8
24. Is on familiar terms with one or more persons living in the home: 0 = often 1 = sometimes 2 = never							▇	
25. Understands simple instructions: 0 = normally yes 1 = sometimes 2 = normally no				▇				
26. Recognizes staff members whom he/she has known for more than a year (calls them by name or recognition is apparent from behaviour): 0 = normally yes 1 = sometimes 2 = normally no		▇						
27. Gets angry easily: 0 = never 1 = sometimes 2 = often								▇
28. Knows that today is a weekend or a week day: 0 = normally yes 1 = sometimes 2 = normally no			▇					
29. Can talk about what he/she has been doing today: 0 = normally yes 1 = sometimes 2 = normally no	▇							
Total Page 6	▇	▇	▇	▇			▇	▇

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

Category	1	2	3	4	5	6	7	8
30. Keeps him/herself busy at home on his/her own initiative (e.g. with hobbies, playing games, reading or talking with others): 0 = always 1 = sometimes 2 = never							▒	
31. Threatens others by words or gestures (without a clear motive): 0 = never 1 = sometimes 2 = often								▒
32. Accuses other people of harming him/her in any way (e.g. hitting or stealing), when this is not true: 0 = never 1 = sometimes 2 = often								▒
33. Remembers something that has been said (or communicated in any other way) recently (no longer than an hour ago): 0 = normally yes 1 = sometimes 2 = normally no	▒							
34. Cries at the slightest provocation: 0 = never 1 = sometimes 2 = often						▒		
Total Page 7	▒					▒	▒	▒

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

	Category	1	2	3	4	5	6	7	8
35. Knows which week day it is today: 0 = normally yes 1 = sometimes 2 = normally no				■					
36. Is able to get into and out of his/her bed: 0 = always 1 = sometimes 2 = never						■			
37. Is spontaneously helpful (e.g. washing the dishes or setting the table): 0 = often 1 = sometimes 2 = never							■		
38. Is restless or awake during the night: 0 = never 1 = sometimes 2 = always							■		■
39. Is gloomy or sad: 0 = never 1 = sometimes 2 = always							■		
40. Knows what was the profession of his/her father or mother: 0 = yes 1 = sometimes 2 = no			■						
41. Is incontinent during the night: 0 = never 1 = sometimes 2 = always						■			
	Total Page 8		■	■		■	■		■

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

	Category	1	2	3	4	5	6	7	8
42. Knows his/her age (a mistake up to five years is permitted): 0 = yes 1 = sometimes 2 = no			▒						
43. Knows name of his/her residence, or street address: 0 = yes 1 = sometimes 2 = no			▒						
44. Is readily upset: 0 = never 1 = sometimes 2 = often							▒		
45. Remembers where he/she was born or lived: 0 = yes 1 = sometimes 2 = no			▒						
46. Can find his/her way around the home (e.g. to the bedroom, toilet or his/her place at the table): 0 = normally yes 1 = sometimes 2 = normally no				▒					
47. Knows the name of the president (the preceding prime minister is permitted): 0 = yes 1 = sometimes 2 = no			▒						
	Total Page 9		▒	▒			▒		

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Record score in gray box

Category	1	2	3	4	5	6	7	8
48. Makes comments about physical complaints (excessive attention to phycical complaints is meant here): 0 = never 1 = sometimes 2 = often						▒		
49. Uses familiar objects in the correct manner (e.g. comb, scissors or toothbrush): 0 = normally yes 1 = sometimes 2 = normally no					▒			
50. Performs acts that are necessary in the toilet reasonably well (can be with some help): 0 = always 1 = sometimes 2 = never					▒			
Total Page 10					▒	▒		

Participant ID	Site Number	Rater Initials	Date of Test	Visit Number

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES

Category	1	2	3	4	5	6	7	8
	Short-term memory	Long-term Memory	Spatial & temporal orientation	Speech	Practical Skills	Mood	Activity & Interest	Behavioural disturbance
Total Page 2:								
Total Page 3:								
Total Page 4:								
Total Page 5:								
Total Page 6:								
Total Page 7:								
Total Page 8:								
Total Page 9:								
Total Page 10:								
Category Total								

SCS = Sum of Cognitive Score (1-3):

SOS = Sum of Social Scores (4-8):

Comments:

Print this page - Research Testing in progress, do not disturb

SIB/Shoebox Quick Set-up Guide

Months of the year
Cities