PPMI
Cognitive Assessments

Overview and Introduction to Administration & Scoring

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Background and Rationale for the PPMI Cognitive/Behavioral Assessment

- Sensitive to cognitive and non-cognitive behavioral aspects

- Relatively brief

- Repeatable

- Not require extensive formal training

PPMI is a biomarker study!!

Review of Behavioral and Psychophysical Tests

- UPSIT
- Epworth Sleepiness Scale
- REM Sleep Disorder Questionnaire
- Geriatric Depression Scale (GDS-15)
- State-Trait Anxiety
- Impulse control (QUIP)
- SCOPA-AUT

University of Pennsylvania Smell Identification Test (UPSIT)

- 40 forced-choice items
- Odorants like "pizza", "lilac" and "motor oil"
- Higher scores indicate better olfaction
- Score of 18 indicates anosmia
- Administered at <u>Baseline Visit only</u>
- Booklets and score keys supplied by the CTCC

From Doty et al, Physiology and Behavior 1984.

Administration of the UPSIT

- Do not need to fill in ID information on booklets
- Keep booklets as source documents
- Capture score for each booklet on the UPSIT source document worksheet
- A well-ventilated room is best
- Make sure subject does test without help
- Check to make sure that all questions are answered

Sleep Scales

- Sleep disturbances are common in PD

- REM sleep behavior disorder is (RBD) is a major risk factor for PD

- Up to 25% of PD patients have daytime drowsiness

From Schenk et al, Sleep, 2002

Epworth Sleepiness Scale

- 8 items, very brief

- Patient should choose best answer

- Score of 8-10 indicates significant daytime drowsiness

Epworth Sleepiness Scale

How likely are you to doze off or fall asleep in the following situations?
Answer considering how you have felt over the past week or so.

0 = Would never doze
1 = Slight chance of dozing
2 = Moderate chance of dozing
3 = High chance of dozing

1. Sitting and reading

2. Watching TV

3. Sitting inactive in a public place (e.g., theater or meeting)

4. As a passenger in a car for an hour without a break

5. Lying down to rest in the afternoon when able

6. Sitting and talking to someone

7. Sitting quietly after a lunch without alcohol

8. In a car while stopped for a few minutes in traffic

Johns MW. A new method for measuring daytime sleepiness: the Epworth sleepiness scale. Sleep 1991;14:540–5.

REM Sleep Disorder Questionnaire

A.   Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver

1.   I sometimes have very vivid dreams. (0 = No, 1 = Yes)

2.   My dreams frequently have an aggressive or action-packed content.
(0 = No, 1 = Yes)

3.   The dream contents mostly match my nocturnal behaviour. (0 = No, 1 = Yes)

4.   I know that my arms or legs move when I sleep. (0 = No, 1 = Yes)

5.   It thereby happened that I (almost) hurt my bed partner or myself. (0 = No, 1 = Yes)

From Staisny-Kolster, Movement Disorders, 2007

REM Sleep Questionnaire

- The bed partner's (caregiver) input is encouraged, but not required.

- Record who completed questionnaire

- Subjects/partners should respond to each question. If they are not certain, they should choose the response (either yes or no) that is most likely.

REM Questionnaire

- Questions 6.1 to 6.4 should be marked "yes" if any of the phenomena described in the appropriate line is present.

- Scoring will be performed centrally.

6.   I have or had the following phenomena during my dreams:

6.1   speaking, shouting, swearing, laughing loudly (0 = No, 1 = Yes)   6.1 ☐

6.2   sudden limb movements, "fights" (0 = No, 1 = Yes)   6.2 ☐

6.3   gestures, complex movements, that are useless during sleep, e.g., to wave, to salute, to frighten mosquitoes, falls off the bed (0 = No, 1 = Yes)   6.3 ☐

6.4   things that fell down around the bed, e.g., bedside lamp, book, glasses (0 = No, 1 = Yes)   6.4 ☐

REM Sleep Questionnaire

- For question 10, more than one nervous system disease may be recorded.
- Mark yes/no then choose all diagnoses that apply
- All PD subjects should record "parkinsonism".

10.   I have/had a disease of the nervous system: (0 = No, 1 = Yes)

    10a.   stroke

    10b.   head trauma

    10c.   parkinsonism

    10d.   RLS

    10e.   narcolepsy

    10f.   depression

    10g.   epilepsy

    10h.   inflammatory disease of the brain

    10i.   other, specify: _____

Geriatric Depression Scale (GDS-15)

GERIATRIC DEPRESSION SCALE (Short Version)

| 1 | 3 | 2 | | 4 | 8 |

SUBJECT ID [ ][ ][ ]   VISIT NO [ ][ ]

INITIALS [ ][ ][ ]   SITE NO [ ][ ][ ]   VISIT DATE [ ][ ] [ ][ ] [ ][ ][ ][ ]
                                                        MM   DD   YYYY

Choose the best answer for how you have felt over the **past week**. (0 = No, 1 = Yes)

1. Are you basically satisfied with your life?   1. [ ]

2. Have you dropped many of your activities and interests?   2. [ ]

3. Do you feel that your life is empty?   3. [ ]

4. Do you often get bored?   4. [ ]

5. Are you in good spirits most of the time?   5. [ ]

6. Are you afraid that something bad is going to happen to you?   6. [ ]

7. Do you feel happy most of the time?   7. [ ]

8. Do you often feel helpless?   8. [ ]

9. Do you prefer to stay at home, rather than going out and doing new things?   9. [ ]

10. Do you feel you have more problems with memory than most?   10. [ ]

11. Do you think it is wonderful to be alive now?   11. [ ]

12. Do you feel pretty worthless the way you are now?   12. [ ]

13. Do you feel full of energy?   13. [ ]

14. Do you feel that your situation is hopeless?   14. [ ]

15. Do you think that most people are better off than you are?   15. [ ]

Geriatric Depression Scale

- 15 items, 5-10 minutes

- Self-administered

- Developed for geriatrics, but works well for PD

- Score of 5 or higher indicates depression (Weintraub)

Brink TL, Yesavage JA, Lum O, Heersema P, Adey MB, Rose TL: Screening tests for geriatric depression. *Clinical Gerontologist 1:* 37-44, 1982.

Geriatric Depression Scale

- An answer of 0= NO for questions 1, 5, 7, 11, and 13 indicate depression.

- A score of 1=YES on the rest of the questions (2,3,4,6,8,9,10,12,14,15) indicate depression.

- Add up the answers that indicate depression and give them a value of 1.

- Only raw scores are captured in the database.

- But, it is recommended that you total the score locally. If the GDS-15 score indicates at least moderate depression (score of 8 or higher), the PPMI site investigator should be notified, and clinical assessment for significant depression should be considered.

GDS Score
Categories of Depression

- 0 – 4   Normal depending on age education, complaints
- 5 – 8   Mild depression
- 8 – 11   Moderate depression
- 12-15   Severe depression

State-Trait Anxiety

Charles D. Spielberger, Ph.D

- 40 item scale
  (20 state/20 trait)
- Some questions reverse response order—need to check
- Scores range from 20-80 for both scales
- Scores above 40 on the state scale indicates significant anxiety

A number of statements which people have used to describe themselves are given below. Read each statement and then mark the appropriate choice to the right of the statement to indicate how you feel *right now*, that is, *at this moment*. There are no right or wrong answers, but give the answer which seems to describe your present feelings best.

	Not at All	Somewhat	Moderately So	Very Much So
1. I feel calm	☐	☐	☐	☐
2. I feel secure	☐	☐	☐	☐
3. I am tense	☐	☐	☐	☐
4. I feel strained	☐	☐	☐	☐
5. I feel at ease	☐	☐	☐	☐
6. I feel upset	☐	☐	☐	☐
7. I am presently worrying over possible misfortunes	☐	☐	☐	☐
8. I feel satisfied	☐	☐	☐	☐
9. I feel frightened	☐	☐	☐	☐
10. I feel comfortable	☐	☐	☐	☐

Spielberger, C. D et al . (1970). *Manual for the State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press

Impulse Control Disorders (QUIP)

- 8 item QUIP screening questionnaire (2 questions each for eating, buying, sex and gambling)

- 5 minutes to complete

- Score of 1 or higher on any item indicates presence of ICD

Weintraub et al, Movement Disorders, 2009

QUIP Items

_____

A. GAMBLING

1. Do you or others think you have an issue with too much gambling behaviors (such as casinos, internet gambling, lotteries, scratch tickets, betting, or slot or poker machines)?   __Yes __No

2. Do you have difficulty controlling your gambling behaviors (such as increasing them over time, or having trouble cutting down or stopping them)?   __Yes __No

E. OTHER BEHAVIORS

Do you or others think that you spend too much time....

1. On specific tasks, hobbies or other organized activities (such as writing, painting, gardening, repairing or dismantling things, collecting, computer use, working on projects, etc.)?   __Yes __No

2. Repeating certain simple motor activities (such as cleaning, tidying, handling, examining, sorting, ordering, or arranging objects, etc.)?   __Yes __No

3. Walking or driving with no intended goal or specific purpose?   __Yes __No

Instructions and Scoring

Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease
(QUIP-Current-Short)

Reported :   _____ Patient   _____ Informant*   _____ Patient and Informant

Patient name: _____

Date: _____

- The QUIP is a self-report instrument. It may be completed by a patient, informant or both. Record who completed the scale at the top of the page.

- The QUIP will be scored centrally. The scoring rule is provided in the Operations Manual for your reference.

Reporting Clinically Significant ICDs

- Reinforce that the subject should answer all items, including those (like sexual function) that are potentially sensitive.

- Responses to these questions will not be disclosed without first informing the subject. However, if the QUIP responses indicate the presence of a significant ICD, the study staff should inform the PPMI site investigator and clinical follow-up should be considered.

- Contact PPMI Project Manager or Clinical Monitor if you are not sure how to proceed if the QUIP suggests an ICD.

SCOPA-AUT

- 21 questions, about 10 minutes

- Domains: gastrointestinal, urinary, cardiovascular, thermoregulatory, pupillomotor, skin, respiratory, and sexual

- All but sexual dysfunction correlate with disease severity

SCOPA

SCOPA-AUT

By means of this questionnaire, we would like to find out to what extent <u>in the past month</u> you have had problems with various bodily functions, such as difficulty passing urine, or excessive sweating. Answer the questions by placing a cross in the box which best reflects your situation. If you wish to change an answer, fill in the 'wrong' box and place a cross in the correct one. If you have used medication in the past month in relation to one or more of the problems mentioned, then the question refers to how you were while taking this medication. You can note the use of medication on the last page.

1. In the past month have you had difficulty swallowing or have you choked?

    never   sometimes   regularly   often

2. In the past month, has saliva dribbled out of your mouth?

    never   sometimes   regularly   often

3. In the past month, has food ever become stuck in your throat?

    never   sometimes   regularly   often

4. In the past month, did you ever have the feeling during a meal that you were full <u>very quickly</u>?

    never   sometimes   regularly   often

Visser et al, Movement Disorders 2004

SCOPA-AUT

- For subjects receiving treatment for autonomic disturbance (e.g. anticholinergics), they should answer the questions based on whether they had the problem even while being treated.

- Any medications used to treat autonomic problems should be recorded on the last page.

- The coordinator should check this question against the medication list.

SCOPA-AUT

- It is permissible to have input from a spouse or other knowledgeable informant when completing the SCOPA-AUT (record source of information on the source worksheet)

  A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver

- If appropriate, reinforce that the subject should answer all items, including those (like sexual function) that are potentially sensitive. Responses to these questions will not be disclosed without permission from the subject.

. Questions?

PPMI
Neuropsychological Battery

Overview and Introduction to Administration & Scoring

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Neuropsychological Battery

Baseline and then annual assessments, in this order:

- Hopkins Verbal Learning Test-Revised (HVLT-R) Learning Trials

- Benton Line Orientation (ODD only or EVEN only)

- Semantic Fluency
  - ANIMALS
  - VEGETABLES
  - FRUITS

- WAIS-III Letter-Number Sequencing Test

- Symbol-Digit

- HVLT-R delayed recall

- HVLT-R recognition trial

- Montreal Cognitive Assessment (MoCA)

Testing Materials

- CTCC will provide you with test stimuli.
- Operations Manual provides:
  - General testing guidelines
  - Detailed instructions for each test
- Source document worksheet (SDW) package includes administration notes, examiner cues.
- SDW packages exist for each visit (e.g., baseline, 12 month, 24 month etc.)
- Certification quiz to be completed prior to testing a subject.

Hopkins Verbal Learning Test-Revised

- 12 word list

- 3 learning trials

- Delayed recall trial

- Recognition trial

Hopkins: Key Instructions Learning Trials

- Instruct subject per the manual/test forms.

- Read list at 1 word per 2 seconds pace.

- Read very clearly & at good volume.

  - you cannot repeat a trial or words

- Record responses verbatim if possible.

  - consider taping for checking later

- <u>Do not</u> warn about the delayed recall trial.

Benton Line Orientation
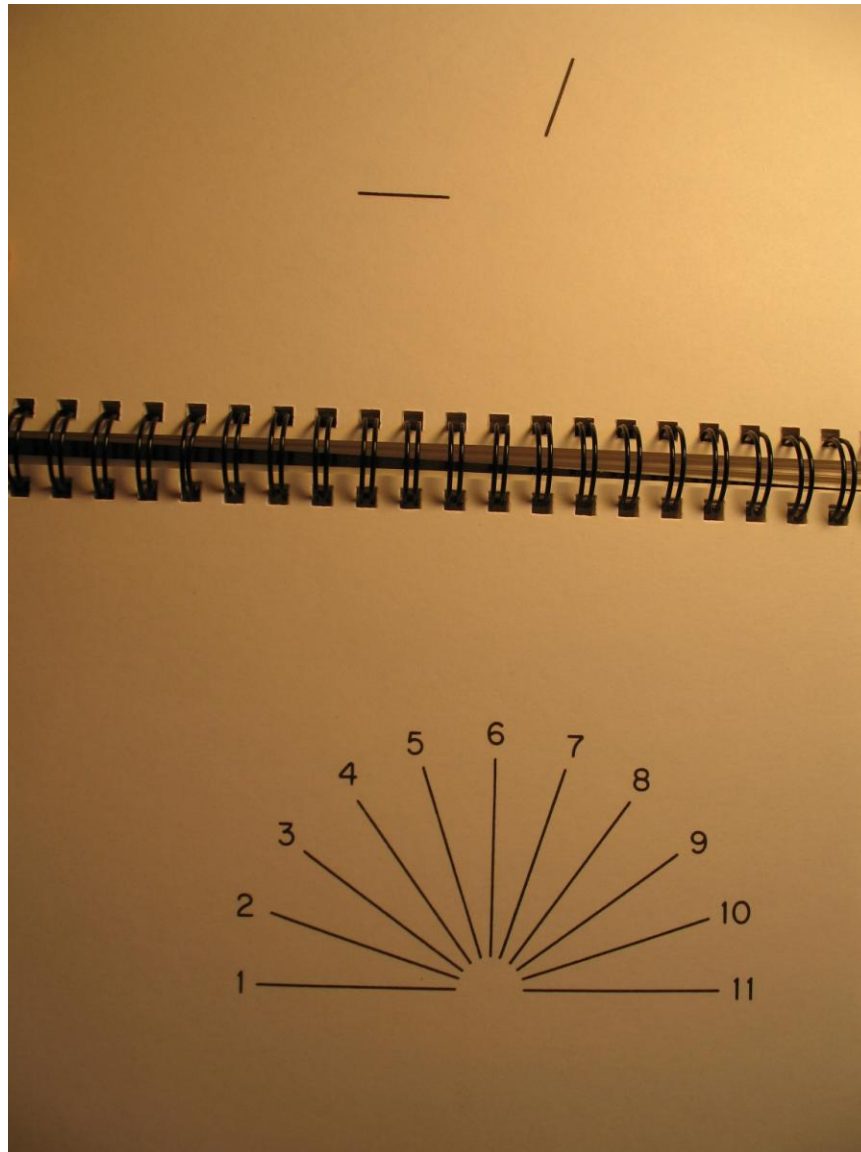
Benton Line Orientation

- Split half: 15 even items; 15 odd items.

  – Sites will be provided with an EVEN book and an ODD book

- Practice trials are important - want to be sure subject understands the task (if they're capable; most will be).

- Practice section provides opportunity for training, as necessary.

  – Follow the Operations Manual

  – If they don't succeed initially during Practice, teach them the task line by line (with the items marked A', B' etc.)

- All practice items are administered to all subjects.

Benton Line Orientation: Starting the Test

- The transition to the actual test requires additional instruction. With the book open at test items section:

- "Now we are going to do more of these, except now the lines up here (point to upper page) are shorter because part of the line has been erased"

- Complete all items regardless of performance.

Benton Line Orientation: What if they fail the Practice Section?

- Traditionally, the test is not administered if the subject does not get two practice items correct.

  - Two correct means correct responses for <u>both lines</u> on <u>2 items</u>, e.g., B & C

- *In this study, administer the test regardless of how the subject does on the Practice Items (with the one exception, below)*

- Subjects who show that they do <u>understand the task</u> should be administered the entire test (even if they fail all practice items)

  - Close misses, &/or can explain to you the test requirements

- <u>One exception</u>: If the subject, via their responses, shows no understanding of the task, don't administer the test.

  - Record reason on the CRF

  - This should be <u>very rare</u>

  - Requirement: despite training, responses are persistently way off & subject cannot verbalize requirements.

Benton Line Orientation: Loss of Set During the Test

- Occasionally a subject will forget what they're meant to be doing during the test.

  - evidence: OK performance, then responses that are not close

    - e.g., correct is 3 & 8; they respond 1 & 5

- Stop and ask them to explain how they arrived at those responses (e.g. "show me…").

- If the explanation shows a loss of understanding of task requirements, reinstruct

  - Use the practice items, not the actual test item(s)

  - Help them understand what the test requires them to do, but don't cross the line into helping them do better

- Rationale: We're testing spatial orientation, not intelligence or the ability to remember instructions.

- This should occur rarely (if at all).

Semantic Fluency: 3 Categories

- Animals

- Vegetables

- Fruits

    – Administration & scoring is consistent with the Alzheimers Disease Neuroimaging Initiative (ADNI) rules.

    – In turn based on CERAD

Semantic Fluency

- 60 second trials

- Try to write down verbatim
  - at least a syllable or so to help you catch repetitions (perseverations)

- Never ask them to slow down
  - consider taping for scoring check

- Can prompt once during the trial

Semantic Fluency Scoring

- 1 point per unique correct response

- Liberal scoring: See the Operations Manual

- Examples of liberal approach:

  - Animals: Count both "dog" and "spaniel"; birds, insects, fish ….

  - Vegetables: Count "peppers" and "green peppers"; grains; herbs…

WAIS-III Letter Number Sequencing

- Examiner reads mixed numbers & letters:
  - f 8 a 4
  - Subject recites in numerical & alphabetical order:
    - ➤4 8 a f

- Task increases in difficulty (like digit span)

- Challenge is helping older or declining subjects understand task requirements (what they need to do) sufficiently well during the practice section

WAIS-III Letter Number Sequencing

- Practice items include reinstruction as necessary

- Test is administered even if subject fails the practice items

- Read stimuli loudly & clearly

- Don't repeat a sequence

- Discontinue the test if a subject fails all 3 trials at a given level (e.g., trials 3a, 3b, 3c are all failed)

- <u>Word to the wise</u>:

    Despite instruction that the numbers should be recited before the letters, count a trial as correct if the letters are recited first.

    – obviously both letters & numbers must be in correct sequence

Symbol Digit Modalities Test

- Assesses information processing speed

- Rapid (trial is 90 seconds)

    - WAIS EXAMINERS: DRILL THIS IN!

- Easily administered and scored

Hopkins Verbal Learning Test Delayed Recall

- AKA "Trial 4"

- Insert in the SDW package cues you to administer this after Symbol Digit.

- Administer irrespective of how much time has passed since the completion of the learning trials

  - the intervening tests are constant & provide "interference"

- <u>Must be</u> done before the MoCA

Hopkins Verbal Learning Test Recognition Trial

- Insert in the SDW package cues you to administer this <u>after</u> Hopkins Delayed Recall trial.

- We are recording just 3 scores:

    – Total # true positives

        - Subject responded "yes" when you read a word that was on the list

    – Total # <u>related</u> false positives

        - Subject responded "yes" when you read a word that was <u>not</u> on the list, but is related to words on the list (e.g., a gem)

    – Total # <u>unrelated</u> false positives

        - Subject responded "yes" when you read a word that was <u>not</u> on the list, and is unrelated to words on the list (doesn't belong to 1 of the 4 categories represented on the list, e.g. is not a gem ….)

- Form has shading to help you to do this

MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME:
Education: Date of birth:
Sex: DATE:

VISUOSPATIAL / EXECUTIVE

Copy cube

Draw CLOCK (Ten past eleven) (3 points)   POINTS

[ ]   [ ]   [ ]   [ ]   [ ]   __/5
Contour   Numbers   Hands

NAMING

[ ]   [ ]   [ ]   __/3

MEMORY — Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED	
1st trial						No points
2nd trial						

ATTENTION

Read list of digits (1 digit/ sec.).
Subject has to repeat them in the forward order   [ ] 2 1 8 5 4
Subject has to repeat them in the backward order   [ ] 7 4 2   __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B   __/1

Serial 7 subtraction starting at 100   [ ] 93   [ ] 86   [ ] 79   [ ] 72   [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**   __/3

LANGUAGE

Repeat: I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ]   __/2

Fluency / Name maximum number of words in one minute that begin with the letter F   [ ] _____ (N ≥ 11 words)   __/1

ABSTRACTION

Similarity between e.g. banana - orange = fruit   [ ] train – bicycle   [ ] watch - ruler   __/2

DELAYED RECALL

Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional Category cue						
Multiple choice cue						

__/5

ORIENTATION   [ ] Date   [ ] Month   [ ] Year   [ ] Day   [ ] Place   [ ] City   __/6

© Z.Nasreddine MD   Version 7.1   www.mocatest.org   Normal ≥ 26 / 30   TOTAL __/30
Administered by: _____   Add 1 point if ≤ 12 yr edu

- Operations manual has <u>detailed</u> administration instructions.
- Abbreviated instructions are provided in the SDW package.
- Adhere closely to the cube copy and clock scoring instructions.
  - The clock scoring criteria are quite tough.
- Word list learning trials are not scored.
- Serial 7's maximum score is 3 (not 5)
- *Fluency (words beginning with "F") is to be recorded on a separate sheet (inserted with the MoCA form).*
  - Enter 1 if total is 11+ on the MoCA form; 0 if 10 or less
  - Enter total "F" raw score as a separate score on the applicable CRF
- Delayed word list recall is scored 0 to 5; 1 point per word
  - This is free uncued recall
  - No need to conduct the optional cued recall trials - they're not scored.
- Orientation responses have to be exact

Maximizing Data Validity

Minimizing Error Variance:

- Setting risk factors for error variance

- Testing materials risk factors

- Examiner risk factors

- Subject risk factors

- <u>Practice</u> administering the tests (e.g., with co-workers) prior to testing a real subject.

- Become fully familiar with the test instructions (try to memorize them).

- Have the test administration instructions with you and open at the relevant page during testing.

General Testing Guidelines

Rapport is important

- Adherence to standardized procedures does not mean that you must test in an unnatural or mechanical manner.

- Use a natural conversational tone, encourage interest in the activity, and reinforce good effort.

- Providing an idea of the reason for the testing, and how long it will take, often helps put subjects at ease.

- Stress the importance of good effort, and reassure examinees that all subjects find testing quite difficult at times – it is just part of the process.

General Testing Guidelines

Ensure Understanding

- Examinees should understand what a specific test requires them to do **before you start the actual test**.

- The administration instructions and practice items are designed to achieve this.

- You may need to supplement or reword these instructions to ensure the subject fully understands the test.

- If in doubt, re-instruct <u>before beginning</u>.

General Testing Guidelines

Prevent disruption

- Memory Tests: you cannot repeat the material (e.g. words, numbers or letters to be remembered).

- Do your best to ensure that distractions do not occur (e.g., turn off phones and put a Do not Disturb notice on the door).

- Read information loudly and clearly from the outset.

- If, in extreme circumstances, a specific trial is unambiguously undermined by an external event (e.g., your reading of a letter-number sequence is suddenly made inaudible by a jack-hammer), it may be permissible to repeat the sequence.

- This must truly be the exception rather than the rule, and should rarely if ever happen. When it does you must note this on the CRF.

- Do not continue with the testing until you have made certain that the distraction will not reoccur.

Error Risk Factors: Setting

- Noisy testing settings.

- Pulling tests together case by case.

    – organized materials and dedicated space are best.

- Interruptions during testing.

Error Risk Factors: Examiners

- Ineffective or incomplete training of examiners.

- Failure to follow data checking procedures:

  - double scoring, arithmetic checking.

  - double data entry.

Positive Examiner Attributes

- <u>Understands</u> the rationale for the testing

- <u>Accepts</u> the rationale, and is fully committed to gathering valid data
  - not going through the motions

- Understands the intent behind <u>specific tests</u>
  - facilitates sound decision making in the face of subject variability, unexpected events

Positive Examiner Attributes

- Able to establish good rapport

  – Can walk the line between putting <u>subjects at ease</u>,

  and

  – Maintaining a <u>business-like demeanor</u>

    - <u>respect</u> for the subject, & respect for the process

    - maintain the <u>professional expectation</u> that subjects will do their best.

    - <u>keeps things moving along</u> and the subject focused on the testing

Examiner Error Risk Factors

- Use of different examiners for the same subject over time.

- Frequent examiner turn-over.

- Use of examiners who test infrequently.

- Having new examiners certified by departing examiners (rather than via a core process).

  – charge of the light brigade…..

Examiner Error Risk Factors ...

- Examiners who don't communicate about novel situations or scoring dilemmas.

  - Each such circumstance allows for refinement of the rules and improves standardization.

- Examiners who know better than the manual.

- Examiners who think an administration or scoring rule is unfair.

  - bend the rules ("I know she can do this")

  - lean on the side of lenient scoring in misplaced kindness

Subject risk factors (for error variance)

- Needs glasses, hearing aid & doesn't have them.

- Failure to put forth good effort.

Mitigate by:

- Helping subject understand of the purpose of the testing.

- Explaining the costs of invalid data:

  - cozy little chats

  - redux: rapport/professional attitude balancing act

- <u>Examiners should record any concerns at time of testing</u>