Documenting the Vietnam Era Twin Study of Aging: Balancing Act

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Annual NADDI meeting at the University of Wisconsin,
April 10, 2015

VETSA
VIETNAM ERA TWIN STUDY OF AGING

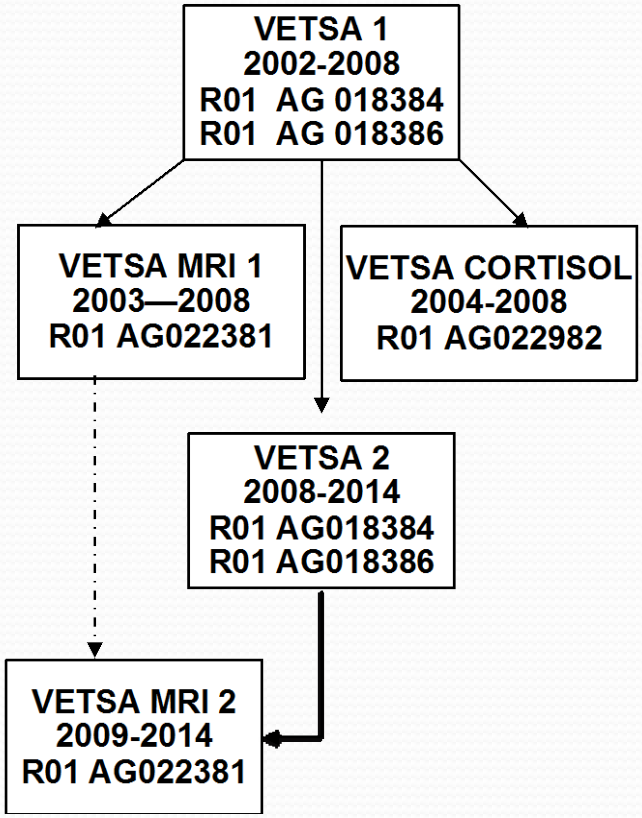
Supported by NIA R01s: AG018386, AG018384, AG022381, AG022982 , and R03 AG037985

- Time to think in a different way about “social sciences data.” It’s more than surveys and questionnaires.
- Many studies ideal for DDI are not in the planning stage or at the beginning. Most have already completed data collection or have years of longitudinal data.
- Many have multi-modal data (self-report, interviewer, biomedical tests, biospecimens, experimental data, in-person cognitive testing, imaging).
- Today: Perspective from the Vietnam Era Twin Study of Aging (VETSA). A longitudinal study of risk and preventive factors affecting cognitive decline, starting in mid-life.

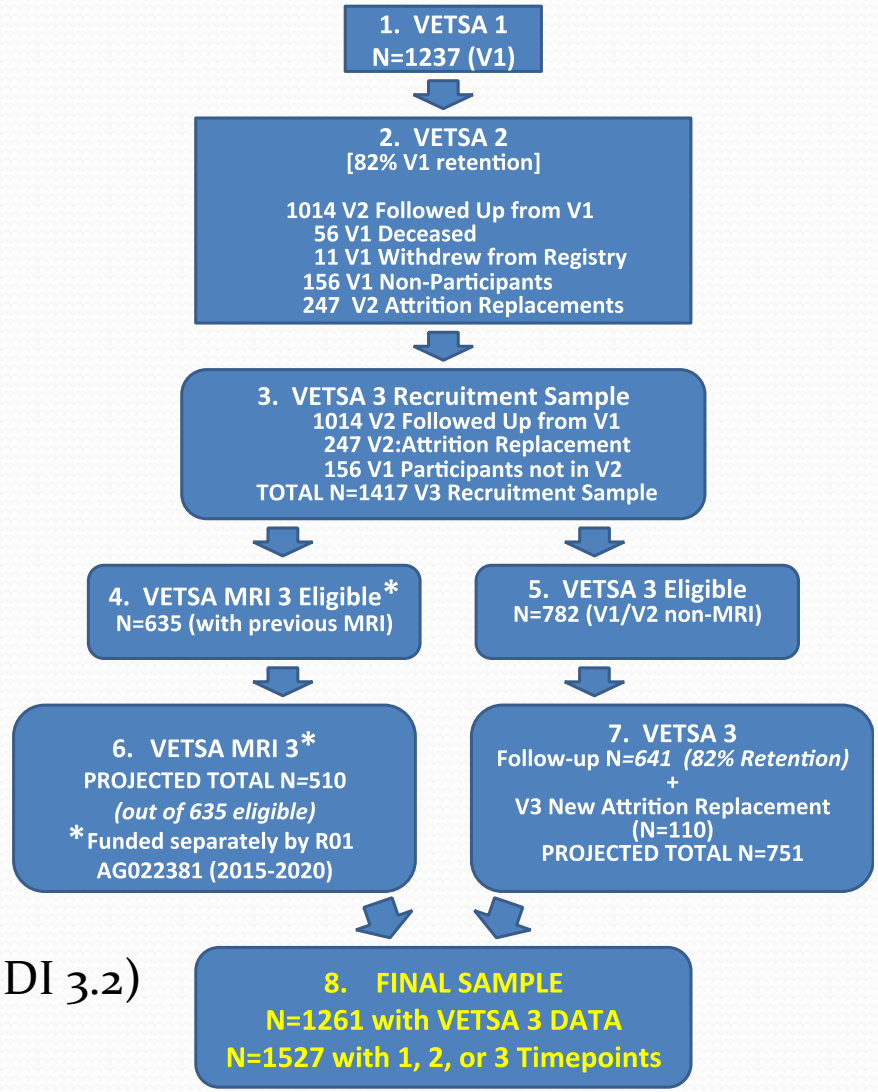
1237 individual male twins at VETSA 1

- Age at VETSA 1 assessment: 55.4 yrs(range 51-60)
- Community dwelling non-patient sample
- 10-12 hrs of assessment: SR questionnaires, in-person interviews and tests, screenings, imaging, biospecimens.
- Previous data available but not publicly accessible

HS Figure 1:
Completed VETSA Data Collections

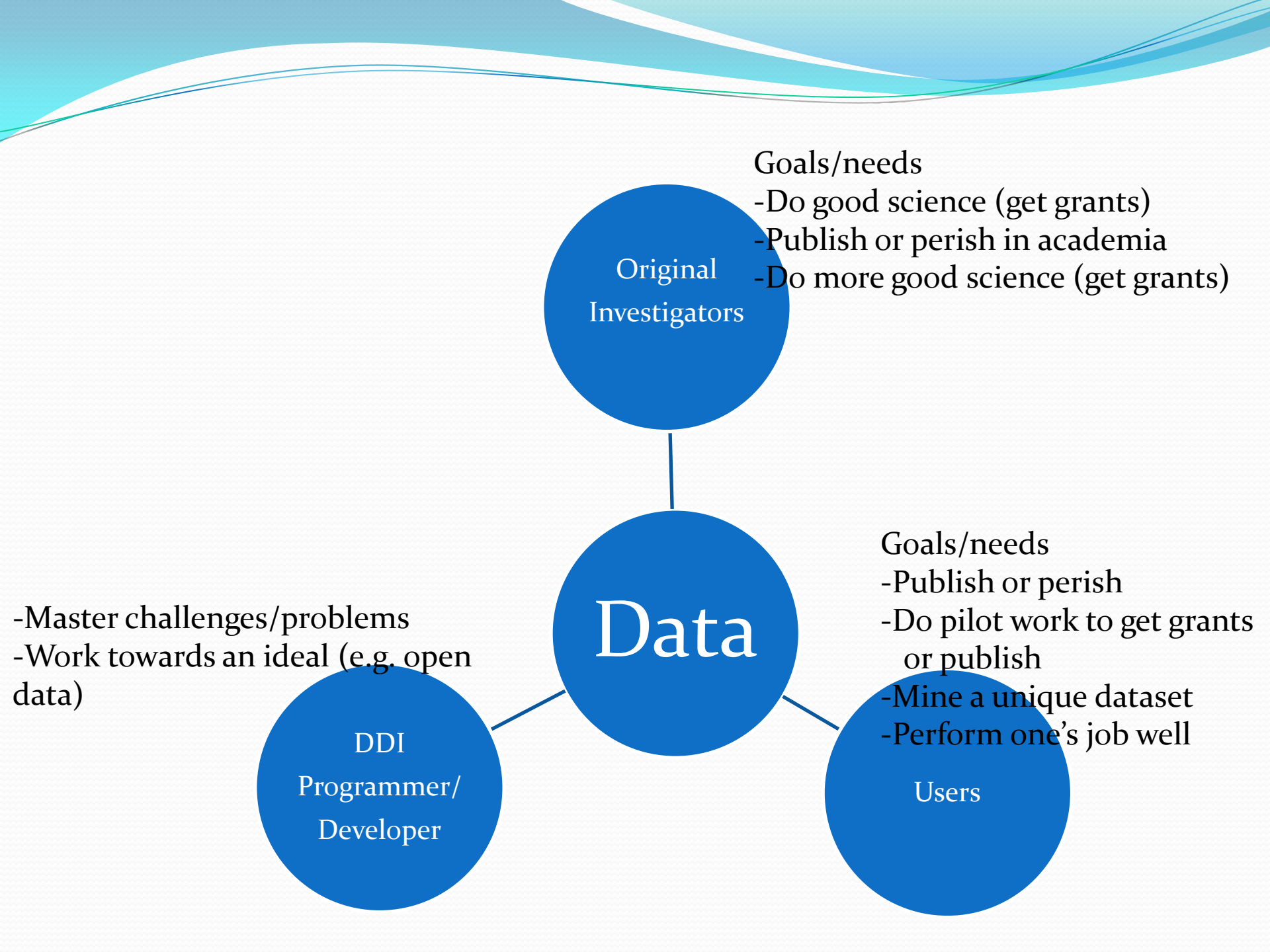


HS FIGURE 2. Recruitment Flow Chart



~4500 variables at baseline
(now documented in Colectica Designer/DDI 3.2)
~3500(+++) variables VETSA 2

Original Investigators
DDI
Programmer/
Software Developer
Users
e.g. Secondary data analysis
Archives
Research data services


Goals/needs
-Do good science (get grants)
-Publish or perish in academia
-Do more good science (get grants)
Original Investigators
Data
-Master challenges/problems
-Work towards an ideal (e.g. open data)
DDI Programmer/ Developer
Goals/needs
-Publish or perish
-Do pilot work to get grants or publish
-Mine a unique dataset
-Perform one's job well
Users

Good science/good publications need to know:

- Quality of research methods
- What measures
- How assessed
- How scored
- Any details essential to:
  - Understanding reliability and validity of the measures;
  - Interpreting results
  - Evaluating similarities and differences of results compared with other studies.
  - In some cases, enough detail to be able to replicate and extend that study through conducting a new study.

- **Can (or should) DDI meet the needs of current social science? (Walk a mile in my shoes……)**
- Dorothea:

  "DDI was built on things that fall naturally out of data"

~NOT~

VETSA COGNITIVE MEASURES	
General Cognitive Ability	Armed Forces Qualification Test Form 7a: Age 20, 55, 61
COGNITIVE DOMAINS	MEASURES (VETSA 1 & VETSA 2 unless noted)
Verbal Ability	WASI Vocabulary (55); WRAT (61)
Visual Spatial Ability	Gottschaldt Hidden Figures Card/Mental Rotation (Ekstrom, 1976)
Verbal Memory	Logical Memory (Immediate, delayed, delayed adjusted) CVLT (Short & Long Delay FR; Long Delay adjusted)
Visual Spatial Memory	Visual Reproduction Immediate, Delay, Delay adjusted
Short Term Memory	Spatial Span Forwards; Digit Span Forwards
Working Memory	Spatial Span Backwards Adjusted for SS Forward Digit Span Backwards Adjusted for DS Forward Letter Number Sequencing Adjusted for DS Forward Reading Span
Executive Functions (Switching/Interference)	Trails Switching Adjusted for Trails 2, 3 Stroop Color-Word Interference Adjusted for Stroop Word D-KEFS Verbal Fluency Switching Adj for Animal Fluency AX-CPT
Verbal Fluency	D-KEFS Letter Fluency D-KEFS Category Fluency
Abstract Reasoning	WASI Matrix Reasoning
Processing Speed	Trails Number Sequencing; Trails Letter Sequencing Stroop Word; Complex and simple reaction time

D-KEFS TRAILS: Condition 2

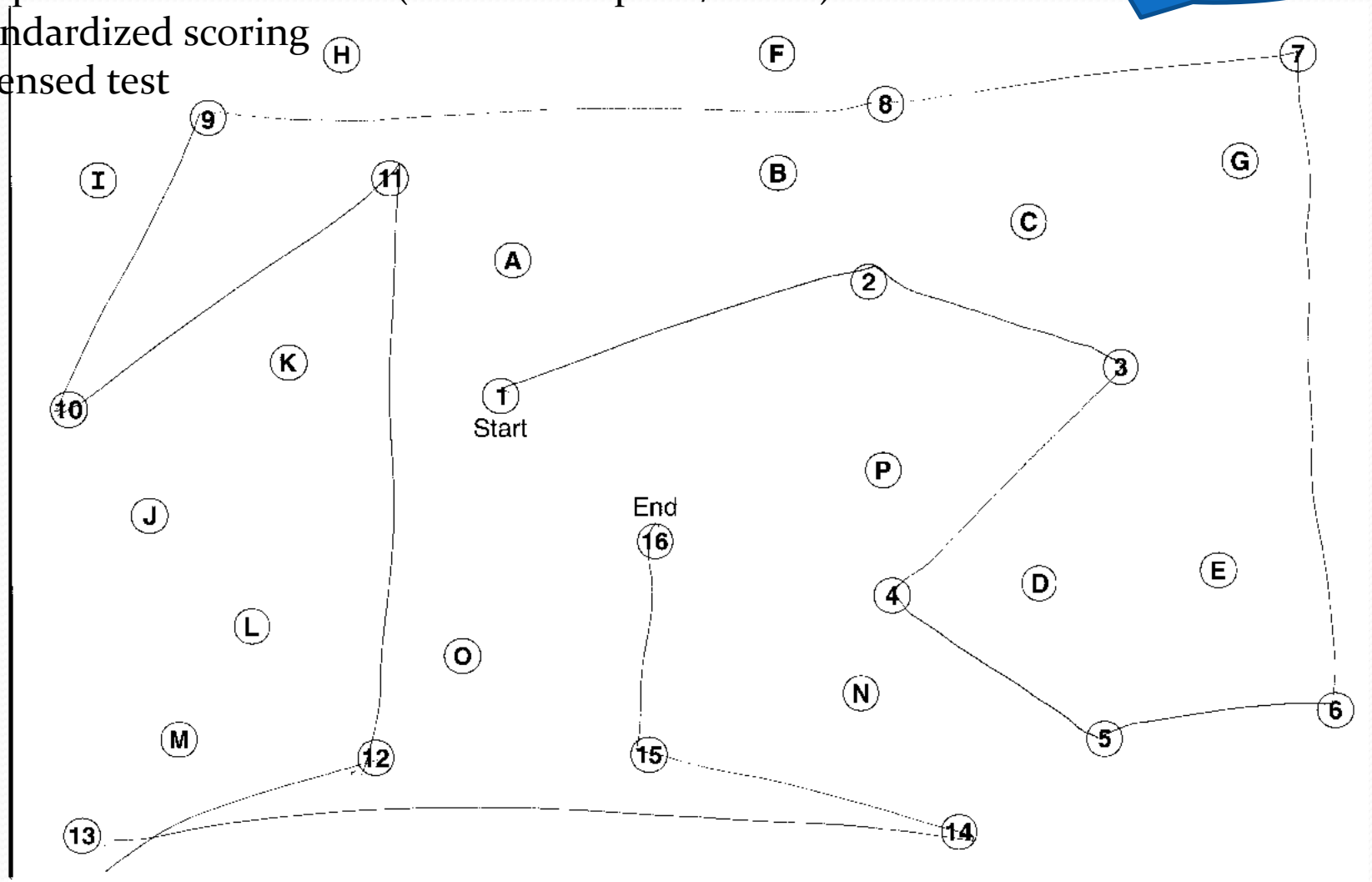
-Simple instructions

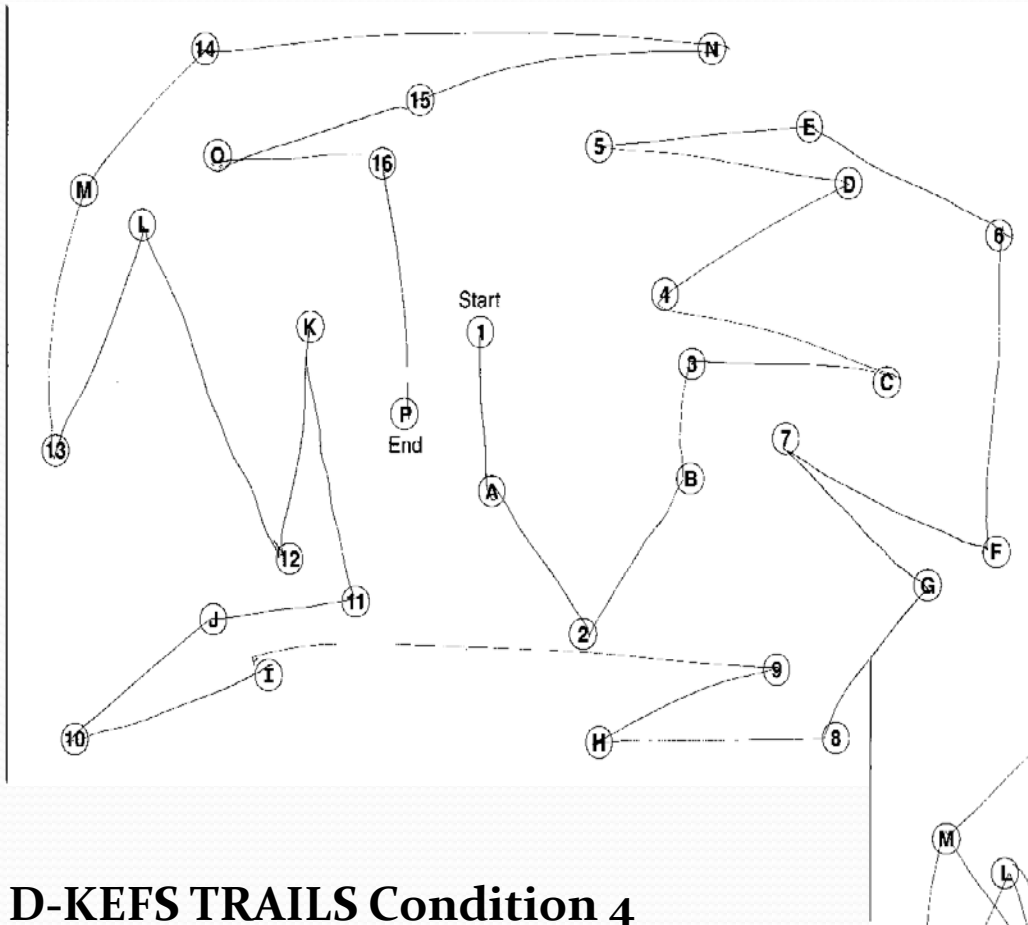
-Simple outcome variables (time to complete/errors)

-Standardized scoring

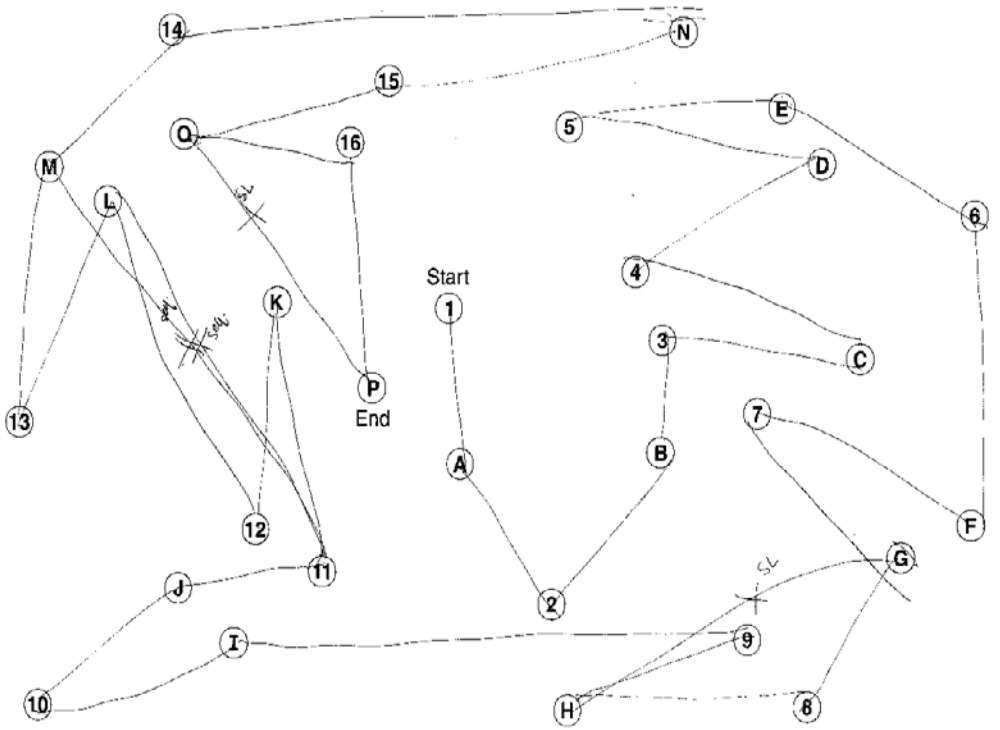
-Licensed test

Processing Speed





Executive Function (Set Shifting)



D-KEFS TRAILS Condition 4

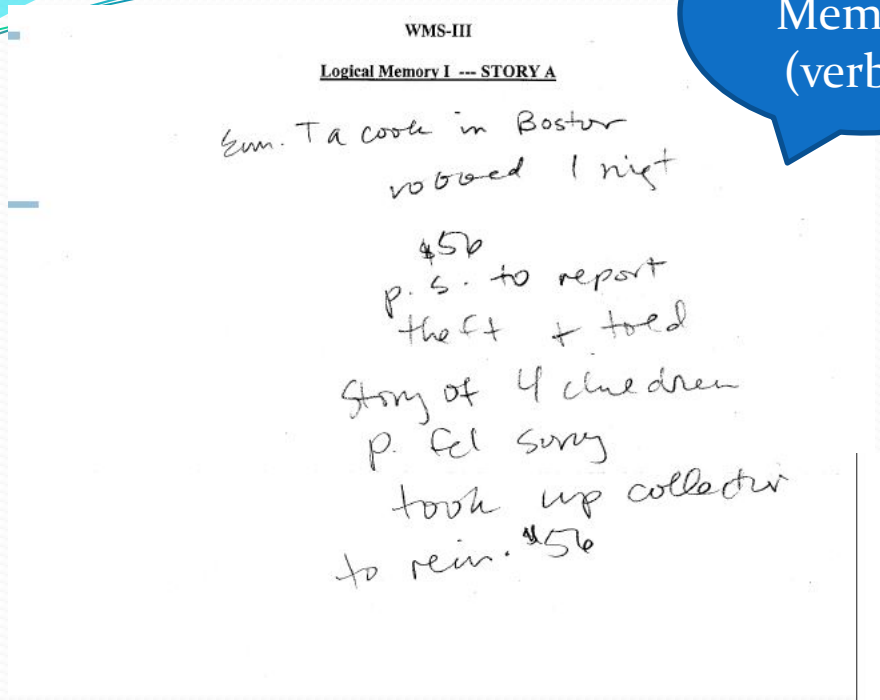
-Standard scoring system and rules;

-Yields few variables (time, # errors)

-Need to make conceptual distinctions

-Need to clarify creation of composite variables

Episodic Memory (verbal)


WMS-III

Logical Memory I --- STORY A

Em. T a cook in Boston
robbed 1 night
$56
P. S. to report
theft + told
story of 4 children
P. fel sorry
took up collection
to rein. $56

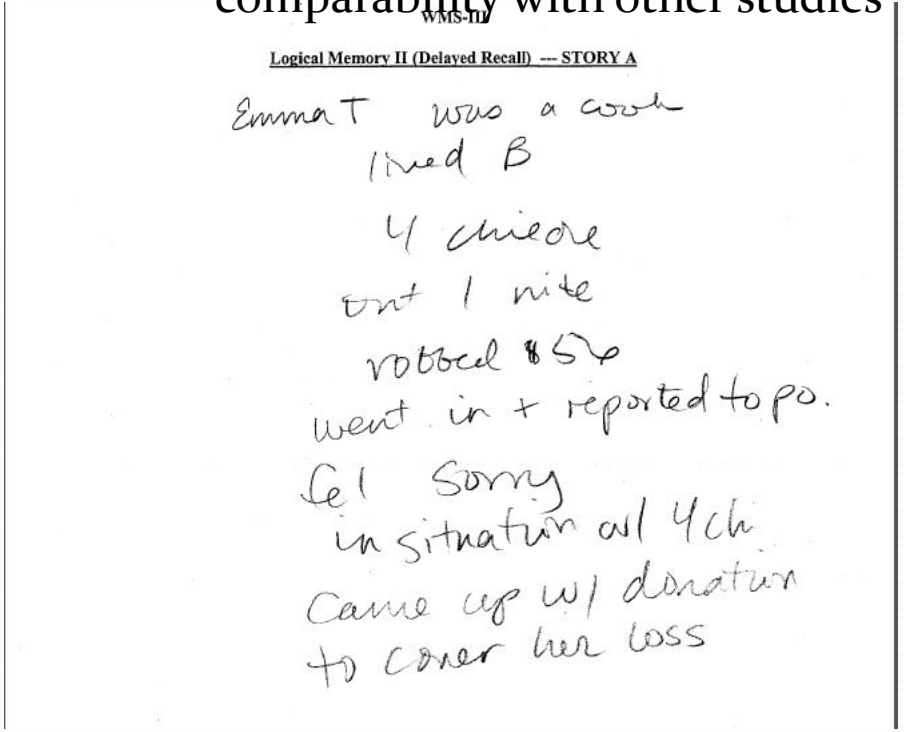
Logical Memory

-More complex instructions

-Complex scoring system (Proprietary—needs reference)

-Only a few variables/scores

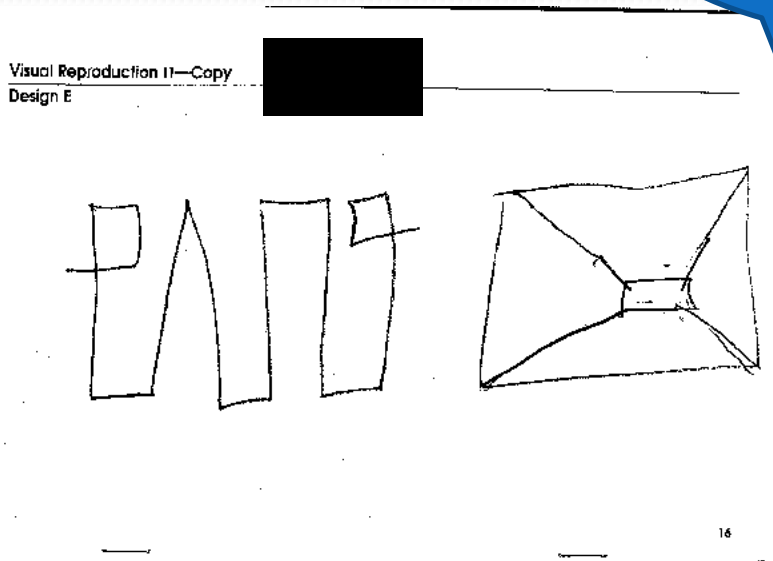
-Any deviations from standard instructions essential to know for comparability with other studies

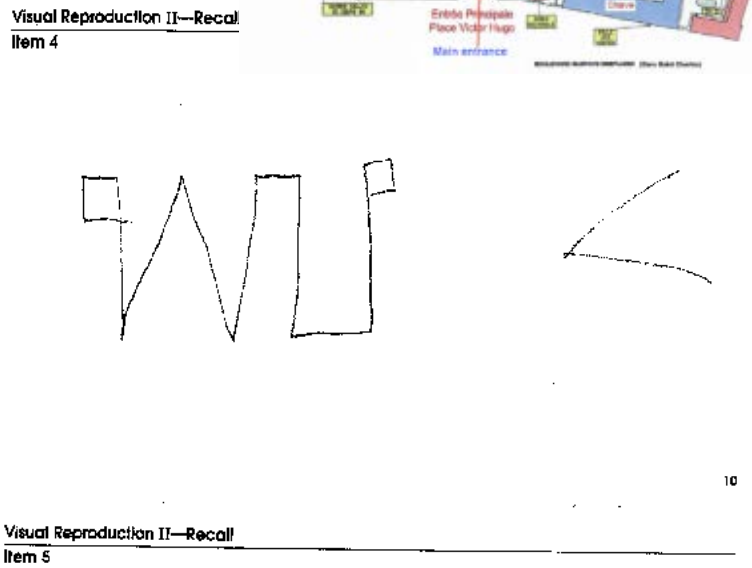

WMS-III

Logical Memory II (Delayed Recall) --- STORY A

Emma T was a cook
lived B
4 children
ont 1 nite
robbed $56
went in + reported to po.
fel sorry
in situation w/ 4 ch
Came up w/ donation
to cover her loss

Visuo-spatial
Episodic
Memory
(5 cues;
3 conditions)





Visual Reproductions:

-Proprietary test
-Relatively brief instructions and easy administration
-Difficult but well-documented scoring system (references)
-Relatively few outcome variables
-Related but different concept to Verbal Episodic Memory

Episodic Memory (Verbal)

List A Immediate Free Recall Trial 1
I'm going to read a list of words to you. Listen carefully, because when I'm through, I want you to tell me as many of the words as you can. You can say them in any order, just say as many of them as you can. Are you ready?

Read List A at an even pace, taking slightly longer than one second per word, so the entire list takes 18 to 20 seconds. Then say: **Go ahead.**

Trial 2
I'm going to read the same list again. Like before, tell me as many of the words as you can, in any order. Be sure to also say words from the list that you told me the first time.

Trials 3 and 4
I'm going to read the same list again. Like before, tell me as many of the words as you can, in any order, including words from the list you've said before.

Trial 5
I'm going to read the same list one more time. Like before, tell me as many of the words as you can, in any order, including words

Record all responses verbatim, in the order recalled. Prompt only once (e.g., Anything else cued recall trial (i.e., after 15 seconds with no response or when the examinee says he/she

List A
truck
spinach
giraffe
bookcase
onion
motorcycle
cabinet
zebra
subway
lamp
celery
cow
desk
boat
squirrel
cabbage

	Trial 1	Resp Type	Trial 2	Resp Type	Trial 3	Resp Type	Trial 4
1	truck		cabinet		truck		truck
2	spinach		motorcycle		spinach		spinach
3	boat		spinach		cabbage		cabinet
4	squirrel		truck		eel		celery
5	cabinet		cabinet		boat		onion
6			cow		bookcase		boat
7			desk		cow		desk
8			onion		onion		cabinet
9					cab		onion
10					desk		zebra
11					boat		desk
12							motorcycle
13							bookcase
14							giraffe
15							
16							
17							
18							
19							
20							
	Total Correct C		Total Correct C		Total Correct C		Total Correct
	Total Repetitions R		Total Repetitions R		Total Repetitions R		Total Repetitions
	Total Intrusions I		Total Intrusions I		Total Intrusions I		Total Intrusions

CVLT-II
Comprehensive Scoring System

Standard Form - Core Report

Name : 204248

Test Date : 10/09/2004

Level of Recall

Level of Immediate Recall	Number Correct Raw	Number Correct Standard Score	Level of Delayed Recall	Number Correct Raw	Number Correct Standard Score
Trial 1	5	-1	Short Delay Free Recall	10.0	0.5
Trial 5	12	0.5	Short Delay Cued Recall	13.0	1
Trials 1-5 Total	45	51 (T-Score)	Long Delay Free Recall	10.0	0
Trial B	4	-1	Long Delay Cued Recall	12.0	0.5

Learning Characteristics, Trials 1-5 Total

	Raw	Standard Score
Semantic Clustering (Chance Adjusted)	-0.8	-1.5
Serial Clustering Bidirectional (Chance Adjusted)	2	1.5
Subjective Clustering Bidirectional (Chance Adjusted)	0.2	-0.5
% Recall from Primacy	31%	0
% Recall from Middle	44%	0
% Recall from Recency	24%	-0.5
Total Learning Slope Trials 1-5	1.8	1
Across-Trial Recall Consistency	76	0

06/04/2007

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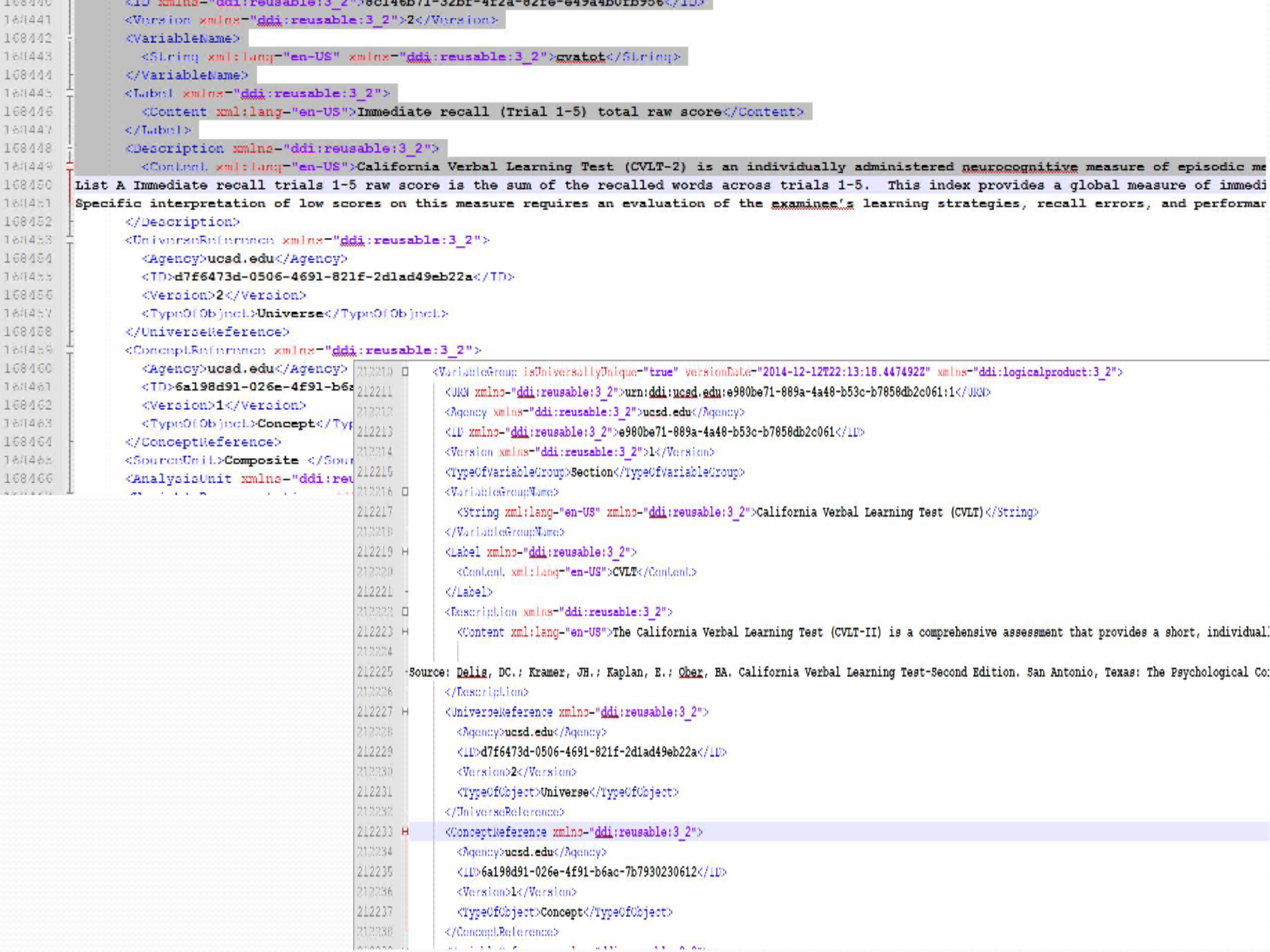
CVLT:

-Complex instructions
-Proprietary measure/need reference
-Scored by licensed software
-Complex output (~300 variables)
-Partial conceptual link with Logical Memory & Visual Reproduction



-Simple tests
-Simple instructions
-Simple scoring systems

Short –term memory

Working memory

Digits Forward

Discontinue: Complete 2 additional items (both trials for each item) after scor

SAY: *"I am going to say some numbers. Listen carefully, and when I am through, I want you to say them right after me. Just say what I say."*

Item	Trial A	Pass = 1 Fail = 0	# Correct	Trial B	Pass = 1 Fail = 0	# Correct
1	1-7			6-3		
	17	1	2	63	1	2
2	5-8-2			6-9-4		
	582	1	3	694	1	3
3	6-4-3-9			7-2-8-6		
	6439	1	4	7286	1	4
4	4-2-7-3-1			~~8-5-8-3-6~~		
	42731	1	5	75386	0	5
5	6-1-9-4-7-3			~~3-9-2-4-8-7~~		
	619473	1	6	349381	0	5
6	~~6-9-1-7-4-2-8~~			~~4-1-7-9-3-8-6~~		
	59478138	0	6	41973862	0	7
7	~~5-8-1-9-2-6-4-7~~			~~3-8-2-8-3-4-7-1~~		
	58942867	0	7	38295187	0	8
8	~~2-7-5-8-6-3-5-8-4~~			~~1-8-9-4-3-5-6-8~~		
	275823864	0	8	75432678	0	7
9	3-6-5-1-9-4-7-2-8-5			9-5-2-4-6-8-1-3-7-4		
10	5-2-8-6-9-1-7-4-8-3-9			2-5-1-9-6-4-8-3-7-1-6		

Scoring:
Pass = 1 / Fail = 0: 1 = correct, 0 = incorrect
# Correct: Enter the number of digits the subject got correct, even if all digits were not correct
(i.e. if subject said "5-8" for item 1, trial a; their # Correct is 2)

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Revised 4/28/03

Subject ID [redacted]
Date ___

Letter-Number Sequencing

Item	Trial	Sequence	trial score	# correct
1	A	**L-2** *(2-L)*		
		2L	1	2
	B	**6-P** *(6-P)*		
		6P	1	2
	C	**B-5** *(5-B)*		
		5B	1	2
2	A	**F-7-L** *(7-F-L)*		
		7FL	1	3
	B	**R-4-D** *(4-D-R)*		
		4DR	1	3
	C	**H-1-8** *(1-8-H)*		
		18H	1	3
3	A	**T-9-A-3** *(3-9-A-T)*		
		39AT	1	4
	B	**V-1-J-5** *(1-5-J-V)*		
		15JV	1	4
	C	**7-N-4-L** *(4-7-L-N)*		
		47LN	1	4
4	A	**8-D-6-G-1** *(1-6-8-D-G)*		
		168DG	1	5
	B	**K-2-C-7-S** *(2-7-C-K-S)*		
		17CKS	0	4
	C	**5-P-3-Y-9** *(3-5-9-P-Y)*		
		359Y	0	4
5	A	**M-4-E-7-Q-2** *(2-4-7-E-M-Q)*		
		247MQ	0	5
	B	**W-8-H-5-F-3** *(3-5-8-F-H-W)*		
		358HW	0	5
	C	**6-G-9-A-2-S** *(2-6-9-A-G-S)*		
		269GHS	0	5
6	A	**R-3-B-4-Z-1-C** *(1-3-4-B-C-R-Z)*		
	B	**5-T-9-J-2-X-7** *(2-5-7-9-J-T-X)*		
	C	**E-1-H-8-R-4-D** *(1-4-8-D-E-H-R)*		
7	A	**5-H-9-S-2-N-6-A** *(2-5-6-9-A-H-N-S)*		
	B	**D-1-R-9-B-4-K-3** *(1-3-4-9-B-D-K-R)*		
	C	**7-M-2-T-6-F-1-Z** *(1-2-6-7-F-M-T-Z)*		

Discontinue after scores of 0 on all 3 trials in an item.

Scoring:
Trial score
0 = incorrect
1 = correct

Correct
of digits and letters given correctly (regardless of whether subject passed trial)

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Revised 4/28/03

Cognitive Effort (Pupillometry)

-Complex

-Details of Digits Forward

-Parameters of light and timing settings on Pupillometer

-Details of instructions

-Define hundreds of variables

-How composite measures are created

-Not licensed (yeah!)

-Complex (and many) concepts

Digits Forward

Discontinue: Complete 2 additional items (both trials for each item) after scores of 0 on *both* trials of any item.

SAY: *"I am going to say some numbers. Listen carefully, and when I am through, I want you to say them right after me. Just say what I say."*

Item	Trial A	Pass = 1 Fail = 0	# Correct	Trial B	Pass = 1 Fail = 0	# Correct
1	1-7 17	1	2	6-3 63	1	2
2	5-8-2 582	1	3	6-9-4 694	1	3
3	6-4-3-9 6439	1	4	7-2-8-6	1	4
4	4-2-7-3-1 42731	1				
5	6-1-9-4-7-3 619473	1				
6	[illegible] 59478138	0				
7	[illegible] 58942867	0				
8	[illegible] 2758237864	0				
9	3-6-5-1-9-4-7-2-8-5					
10	5-2-8-6-9-1-7-4-8-3-9					

Scoring:
Pass = 1 / Fail = 0: 1 = correct, 0 = incorrect
# Correct: Enter the number of digits the subje
(i.e. if subject said "5-8" for item 1, trial a; their

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Revised 4/28/03

Before the subject arrives:

1) Assemble the Pupillome
   a. Clean the eye cu
   b. Attach the eye cu
2) Turn on the Pupillomete
   a. Hold the Up arr
      boot up.
   b. If the device doe
      the message "Ple
      complete the nex
3) Set ID number
   a. From the main s
   b. Select the bracel
   c. Press SELECT o
   d. Input the ID
      i. Use the a
      ii. Move the
      iii. Input the
      iv. Move the
   e. Press the RIGHT
4) Place the pupillometer i
5) Place a sticky-note on th
   and "# Correct" column

General Instructions:

- The charger should be k
- When putting the device
  you've done it correctly
  part of the main screen.
- When taking the device
  releases, and then pull it
- At the end of a testing da
  It should NOT be left in
- How to run a scan:
  - Position the instr
    and tilt it to the s
  - Press and hold th
    Targeting phase.
    and move the dev
  - When you see a g
- How to load a protocol:
  - From the main sc
  - Highlight the nut
  - Highlight the blu
    displayed (protoc
  - Press the RIGHT

Light Reflex Test:

1) Now we're going to use this device called a pupillometer. This is just something that measures the size of the pupil in your eye. To get the measurement, we just hold this circular piece up to your eye like this (demonstrate on yourself) so that we block out most of the light in the room.
2) Before we get started, I need to as
   Pupillometry Screening Form.
   - **[If OK to test]** Proceed.
   - **[If not OK to test]** Because y
     to get accurate readings, so we
   - If the subject says he sees bett
3) Ok, now I need to set things up qu
   Digit Span" Powerpoint file and p
4) Load **"Protocol 0"**
5) Now, we're going have the pupill
   pupil reacts. The pupillometer has
   records how small your pupil gets.
6) Now I want you to lean forward, p
   eye with your hand. I'm going to
   I'll ask you to blink as little as pos
   blink again.

   If the subject wears glasses, have
7) This first one will be practice, and
8) Prep the pupillometer for scanning
9) Tell the subject: Try not to blink,
   turn green to indicate that the reco
   message "Measurement Done!" ap
10) For the practice trial, just record th
    record the time *and* whether it's a
11) Show your subject the practice gra
    give them positive feedback. If th
12) Give them positive feedback throu
    keep it up!
13) Repeat steps 8 - 12 until you get 4
    The basic criteria for a good scan
    - The display is green.
    - There are no sudden dr

Digit Span Test:

1) Great! Now I have to set things up quickly before we continue.

to the next slide, which shows a sound-icon in the middle of the screen, and a "1"
r. Place the cursor over the icon so you will be able to start the span as soon as

t up to your eye and ask you to remember some numbers while I'm holding it
be for 15 seconds at a time. Four lights will be on during that time, but they're
ant you to look at the dark space right in the middle of them. Don't look directly
cause it will affect the recording. Again, I'll let you know when it's ok to blink.

it is through and says, "repeat",
he computer says. Do you have

At the same time you release
one simultaneously, because this

finishes early, do not move or
y: OK, you can blink now.

ther it's a "good" or "bad" scan

d if they had a good scan give
first good scan.

ard keeping your eye open for

ned over the sound icon.

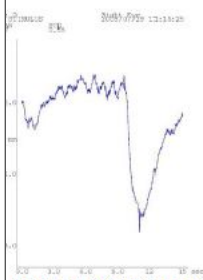
length, or until you've done all
ength, and make sure to advance

rn off before you're done
umbers you can remember.

nprehension sheet while you put

trial or not
digit span is
"good" trial.

t 2 seconds



Looked at light at 9 seconds
Good for 3 and 6-digit spans, **Bad** for 9

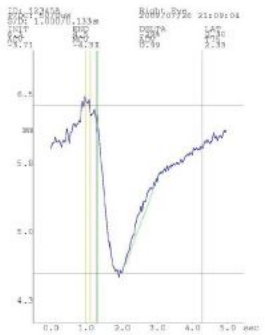
Good vs. Bad Scans – Light Reflex Test

A trial is "good" when the graph shows a smooth line that has no sudden drops or jumps (these indicate blinks or other problems with the scan).

In this recording mode, the device will automatically scan for these artifacts, and if it finds any it will turn the display red to show it's a "bad" trial.

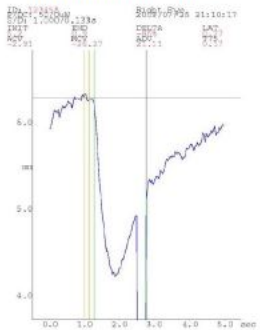
However, even if it's green, you must still check the graph. If a subject blinks late in the scan it can result in a green display, but it is still a bad trial.

Good Trial

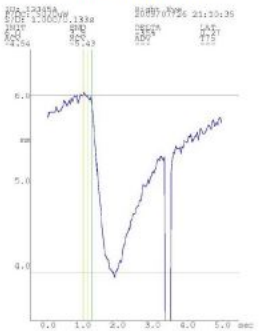


Bad Trials

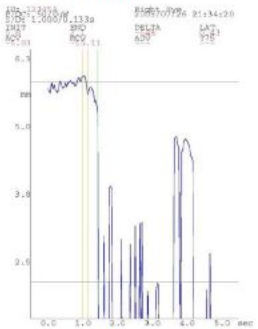
Early Blink (red display)



Late Blink (green display)



Droopy Eyelid



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Record ID = 2895
Subject ID = 89809B
Eye Measured = Left
Finite Measurement Duration = 1
Pulse Intensity = 50uW
DC Intensity = 50uW
Pulse Start Time = 0.000sec
Pulse Duration = 0.167sec
Measurement Duration = 15.000sec
Frames Tracked =

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DS3AvgBaselineDiameter	DS3AvgLastDigitAmplitude	DS3AvgPCA	DS3AvgDSWF0_1	DS3AvgDSWF1_2	DS3AvgDSWF2_3	DS3AvgDSWF3_4	DS3AvgDSWF4_5	DS3AvgDSWF5_6	DS
3.214413238	3.434116582	0.219703344	3.298453184	3.310254637	3.399816716	3.434116582	3.491993173	3.455063454	***
3.134572959	3.177285083	0.042712124	3.127670952	3.158218304	3.193486925	3.177285083	3.155793989	3.072570952	***
4.125994968	4.346074955	0.220079986	4.23921442	4.285251093	4.37412049	4.346074955	4.362097629	4.031925172	***
4.131109826	4.302378676	0.17126885	4.126865464	4.323980792	4.33204849	4.302378676	4.30329753	4.378891812	***
4.845345593	5.003525249	0.158179657	4.916409556	4.923354824	4.922651084	5.003525249	4.947623952	4.980178936	***
4.660802698	4.903143271	0.242340573	4.791911602	4.937756848	4.933432984	4.903143271	4.942477353	5.049830492	***
3.247219014	3.415365946	0.168146932	3.313471194	3.395847364	3.349812845	3.415365946	3.294703718	3.354109053	***
2.437107611	2.489487282	0.052379672	2.453766612	2.431611025	2.492877742	2.489487282	2.472320167	2.570194077	***
3.45519166	3.665763565	0.210571905	3.491397476	3.648295426	3.706627516	3.665763565	3.598062245	3.698437266	***
2.391780138	2.558233357	0.166453218	2.460776885	2.523757148	2.479111024	2.558233357	2.629217565	2.591449261	***
3.15313766	3.396869918	0.243732258	3.189037216	3.249499698	3.314209239	3.396869918	3.495451685	3.495162376	***
2.374392534	2.422427261	0.048034727	2.368581959	2.392206657	2.378556287	2.422427261	2.439782866	2.334562024	***
2.24746262	2.5012189069	0.152755429	2.29728265	2.516494775	2.482789142	2.5012189069	2.510429782	2.5082220067	***

Time Profile =

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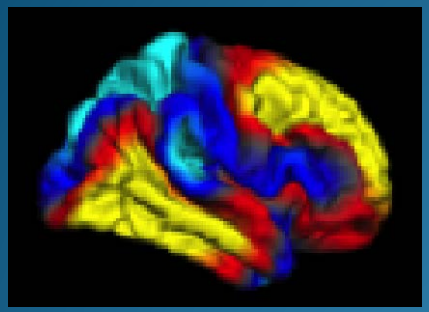
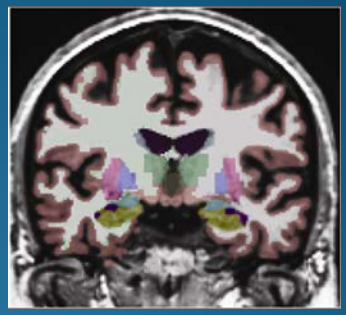
0.466666669	0.500000000	0.533333361	0.566666663	0.600000024	0.633333325	0.666666687
0.699999988	0.733333349	0.766666651	0.800000012	0.833333313	0.866666675	0.899999976
0.933333337	0.966666639	1.000000000	1.033333302	1.066666722	1.100000024	1.133333325
1.166666627	1.200000048	1.233333349	1.266666651	1.299999952	1.333333373	1.366666675
1.399999976	1.433333278	1.466666698	1.500000000	1.533333302	1.566666722	1.600000024

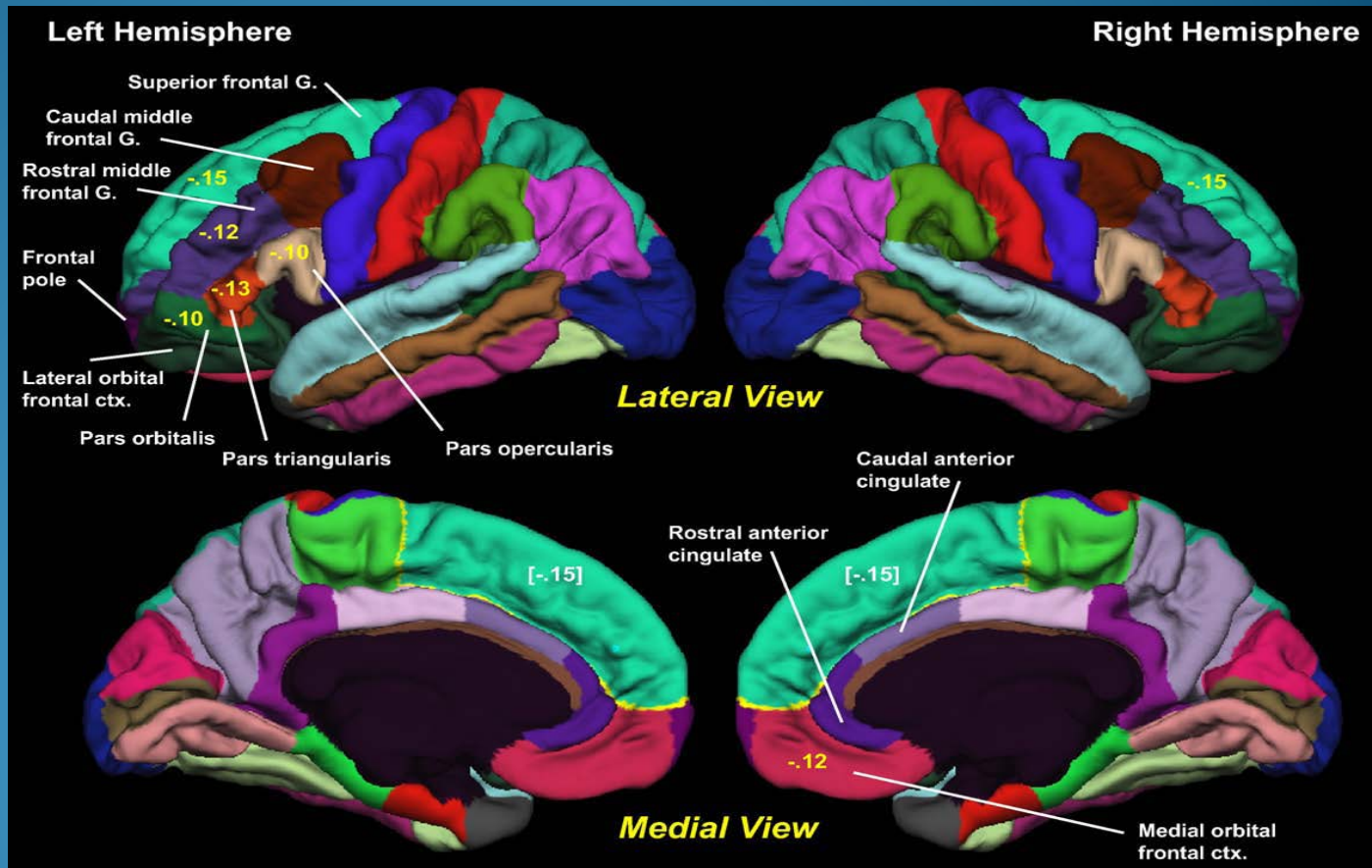
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
1	Subject ID	Time	Good or B	Profile No	Device ID	Record ID	Eye Measu	Pulse Inter	DC Intensi	Pulse Start	Pulse Dura	Measuren	Diameter	Diameter	Percent Cl	C. Lat	Mean C. Vel	Max C. Vel
2	19004A	13:15:33		1	P90004S	948	Right	50	0	1	0.133	5	5.9	4.4	24	300	-2.98	-3
3	19004A	13:16:09		1	P90004S	949	Right	50	0	1	0.133	5	5.3	4.2	21	300	-2.41	-2
4	19004A	13:16:28		1	P90004S	950	Right	50	0	1	0.133	5	5	3.9	21	300	-2.71	-
5	19004A	13:16:50		1	P90004S	951	Right	50	0	1	0.133	5	5.1	4	21	267	-2.6	-
6	19004A	13:17:14		1	P90004S	952	Right	50	0	1	0.133	5	4.9	3.8	23	300	-2.75	-3
7	19004B	13:44:48		1	P90003S	906	Right	50	0	1	0.133	5	6	4.9	19	300	-2.47	-3
8	19004B	13:45:27		1	P90003S	907	Right	50	0	1	0.133	5	5.9	4.7	21	300	-2.53	-3
9	19004B	13:45:58		1	P90003S	908	Right	50	0	1	0.133	5	5.8	4.7	20	267	-2.5	-3
10	19004B	13:46:45		1	P90003S	909	Right	50	0	1	0.133	5	5.9	4.6	22	333	-2.76	-3
11	19004B	13:47:28		1	P90003S	910	Right	50	0	1	0.133	5	5.6	4.2	24	300	-2.92	-3
12	19013A	9:14:15		1	P90004S	2936	Right	50	0	1	0.133	5	4.9	3.4	31	333	-2.64	-3
13	19013A	9:14:38		1	P90004S	2937	Right	50	0	1	0.133	5	4.5	3.1	32	267	-2.84	-4

Neuroimaging

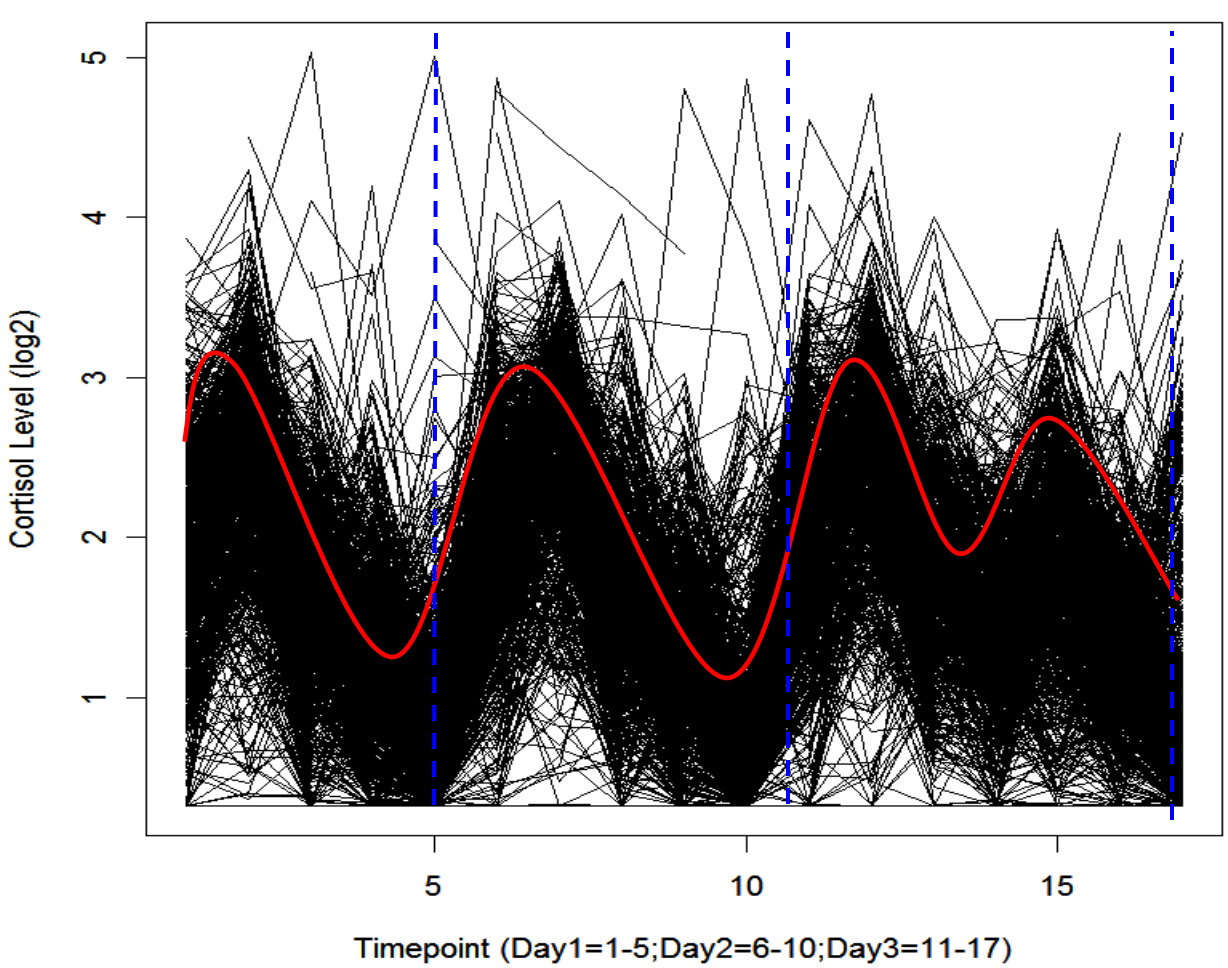
- ***VETSA 3-D Structural MRI (N=534):***







Cortisol levels across 3 nonconsecutive days in 783 VETSA participants



Challenges

- Longitudinal data
- Consortia/Harmonizing across complex studies
- Complex non-questionnaire/non-survey data
- Complicated instructions/scoring
- Large raw data sets from computerized tests, MRI,GWAS
- Syntax for computerized testing (i.e. parameters for timing, size of cues, speed of cue presentation)
- References
- Multiple concepts associated with tests
- Portions of Colectica/DDI seem disconnected that are essential to interconnect.

Closing

- When a variable—especially in a large study—is not based on a question what are the options for data capture in DDI?
  - "Shoehorning" information into the existing system
- Can DDI be all things to all people (researchers, users) or is there a breaking point where it becomes too big, too complex?
- Where do you draw the line in making data available for users?
- Spend more time with researchers…make data documentation easier and more in line with actual research.

PDF

CITATION

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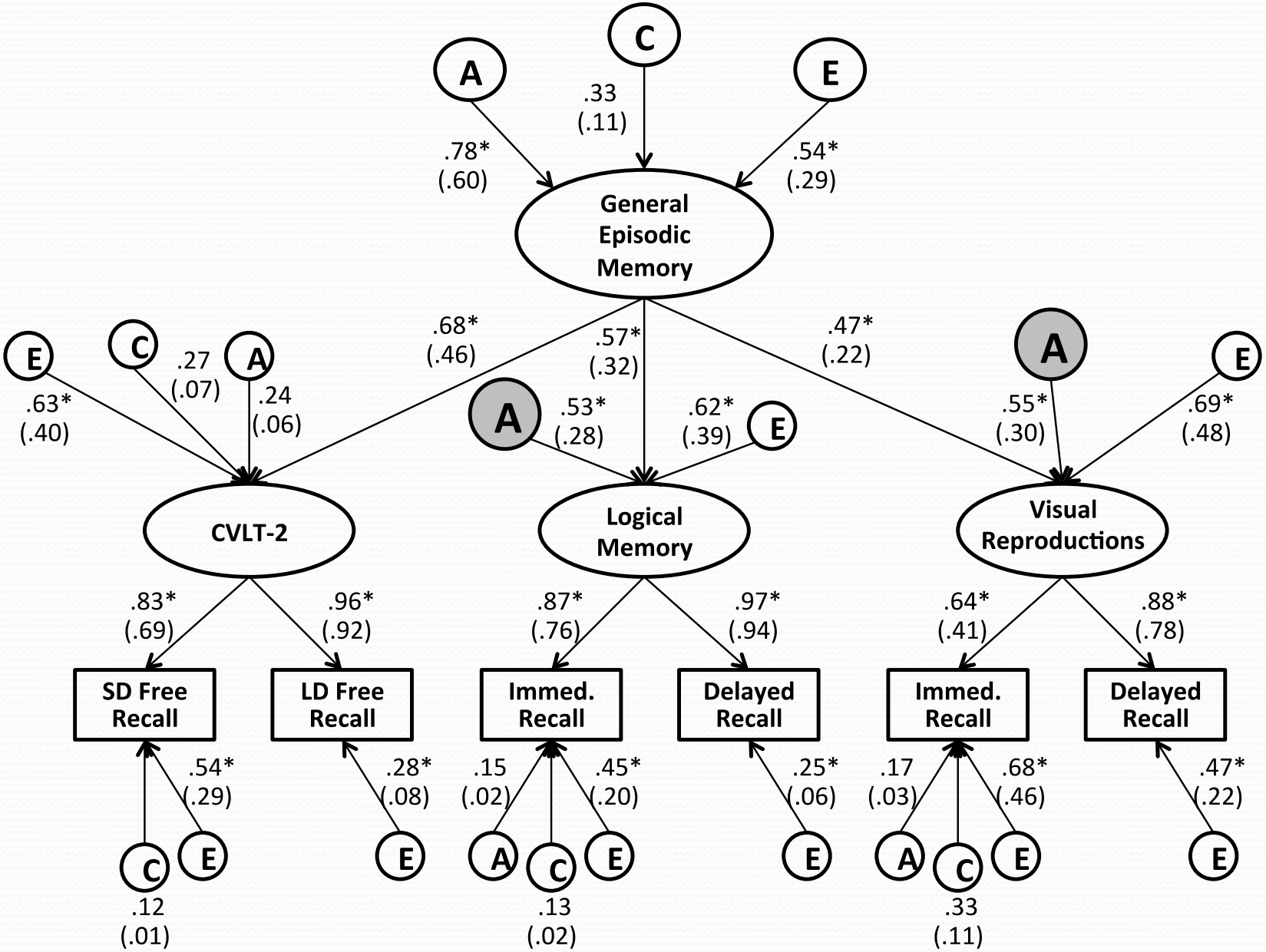
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