

# The BIOCARD Study

Biomarkers of Cognitive Decline Among Normal Individuals

## Functional Evaluation Limited Dataset

## Glossary of Terms

Term	Description
Allowable Codes	codes (and their meanings) allowed to be values for that variable
Audit Findings	error rates based on BIOCARD or NIH phase audits error rates are calculated as number of errors / total number of variables examined
Baseline visit	date admitted to NIH phase of BIOCARD study [Note: some data may have been collected prior to this date]
Collection	when the variable information was collected (i.e., Baseline, Follow-up)
Comments	further information about the variable not covered in the above fields
Data Type	numeric or character [Note: Dates are numeric data] numeric or character classifications are strictly related to how the data are stored and not how the data should be analyzed
JHU phase	the study phase at JHU from 2009 - present
Missing OK If	instances (such as skips) or reasons why a blank or missing value is acceptable
NA	not applicable for this variable
NIH / NIH phase	the study phase that was performed at the NIH from 1995-2005
Question Text	the question as it appears on the NACC or BIOCARD data collection forms
Short Description	a short explanation of what the variable means
Source	the name of the NACC form, BIOCARD form, or NIH dataset containing the variable information (or "DERIVED" if the variable was derived) and the variable question number located on the form or in the dataset, if applicable
Unknown Code	the codes for the "unknown", "don't know", or missing values for the variable
Variable Name	the name of the variable in the provided dataset [Note: Variables will follow the NACC naming scheme as closely as possible]

## Acronyms and Definitions

AD	Alzheimer's Disease
CDR	Clinical Dementia Rating
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CNS	Central Nervous System
CSF	Cerebrospinal Fluid
CVD	Cardiovascular Disease
CVLT	California Verbal Learning Test
FAQ	Functional Assessment Questionnaire
FTD	Frontotemporal Degenerations
GDS	Geriatric Depression Scale

JHU	The Johns Hopkins University
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
NACC	National Alzheimer's Coordinating Center
NIA	National Institute on Aging
NINDS	National Institute of Neurological Disorders and Stroke
NPI-Q	Neuropsychiatric Inventory Questionnaire
UPDRS	Unified Parkinson's Disease Rating Scale
WAIS	Wechsler Adult Intelligence Scale
WMS	Wechsler Memory Scale

## Functional Evaluation Limited Dataset Characteristics

Number	of variables:	25
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#### Order of variables:

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	1)	JHUANONID	Participant ID Anonymized by JHU			
	2)	VISITNO	Chronological visit number			
	3)	MOFROMBL	Months since baseline visit			
	4)	MEMORY	CDR: Memory			
	5)	ORIENT	CDR: Orientation			
	6)	JUDGMENT	CDR: Judgment & problem solving			
	7)	COMMUN	CDR: Community affairs			
	8)	НОМЕНОВВ	CDR: Home & hobbies			
	9)	PERSCARE	CDR: Personal care			
	10)	CDRSUM	CDR: Standard CDR sum of boxes			
	11)	CDRGLOB	CDR: Standard global CDR			
	12)	COMPORT	CDR: Behavior, comportment and personality			
	13)	CDRLANG	CDR: Language			
	14)	SCDRSUM	CDR: Supplemental CDR sum of boxes			
	15)	SSCDRSUM	CDR: Standard and supplemental CDR sum of boxes			
	16)	BILLS	FAQ: Paying bills			
	17)	TAXES	FAQ: Taxes and business affairs			
	18)	SHOPPING	FAQ: Shopping alone			
	19)	GAMES	FAQ: Games and hobbies			
	20)	STOVE	FAQ: Using stove			
	21)	MEALPREP	FAQ: Preparing a balanced meal			
	22)	EVENTS	FAQ: Current events			
	23)	PAYATTN	FAQ: Paying attention			
	24)	REMDATES	FAQ: Remembering dates			
	25)	TRAVEL	FAQ: Traveling and driving			

1) Variable Name JHUANONID

Short Description Participant ID Anonymized by JHU

Source NA

Question Text NA

Time of Collection Baseline

Data Type Character

Allowable Codes JHU + 6 numbers

Missing OK If NA

Audit Findings NA

Comments None

2) Variable Name VISITNO

Short Description Chronological visit number

Source NA

Question Text NA

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes NIH visit: Integers and decimals from 0 to 10, where a visit 0 represents a visit that

occurred prior to the established baseline date

JHU visit: 101, 102, 103, 104, ..... 1XX where XX is from 01 to 99

Visit number 999 used for all participants that have died before a 101 visit for forms: A4, A5, A5a, B1, B2, B3, B3a, B8, B9, and D1. For participants that are alive, an A5 may have a 999 visit number to capture medical data acquired during the

NIH phase of the study.

Missing OK If NA

Audit Findings NA

3) Variable Name MOFROMBL

Short Description Months since baseline visit

Source DERIVED

Question Text NA

Time of Collection Follow-up

Data Type Numeric

Allowable Codes Min = 0

Max = 999

Missing OK If NA

Audit Findings NA

Comments Derived variable.

[JHU phase] Calculated as months between the baseline start date and the V1

VISITDATE (formerly V11\_Date) for follow-up visits.

[NIH phase] Calculated as months between the baseline start date and the

recorded visit date.

4) Variable Name MEMORY

Short Description CDR: Memory

Source B4 #1

Question Text Memory

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

5) Variable Name ORIENT

Short Description CDR: Orientation

Source B4 #2

Question Text Orientation

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments None

6) Variable Name JUDGMENT

Short Description CDR: Judgment & problem solving

Source B4 #3

Question Text Judgment & problem solving

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

7) Variable Name COMMUN

Short Description CDR: Community affairs

Source B4 #4

Question Text Community Affairs

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments None

8) Variable Name HOMEHOBB

Short Description CDR: Home & hobbies

Source B4 #5

Question Text Home & hobbies

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

9) Variable Name PERSCARE

Short Description CDR: Personal care

Source B4 #6

Question Text Personal Care

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments None

10) Variable Name CDRSUM

Short Description CDR: Standard CDR sum of boxes

Source B4 #7

Question Text Standard CDR sum of boxes

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes Min = 00.0

Max = 18.0

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

No NIH phase audits.

Comments CDR sum is calculated by adding the scores for memory, orientation, judgment &

problem solving, community affairs, home & hobbies, and personal care (B4 #1-6).

11) Variable Name CDRGLOB

Short Description CDR: Standard global CDR

Source B4 #8

Question Text Global CDR

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

No NIH phase audits.

Comments Values from NIH phase come from Hughes Clinical Dementia Rating Scale

administered at each NIH phase visit.

The global CDR scoring algorithm can be accessed online at http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html

12) Variable Name COMPORT

Short Description CDR: Behavior, comportment and personality

Source B4 #9

Question Text Behavior, Comportment and Personality

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

13) Variable Name CDRLANG

Short Description CDR: Language

Source B4 #10

Question Text Language

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0.0 = No impairment

0.5 = Questionable impairment

1.0 = Mild impairment2.0 = Moderate impairment3.0 = Severe impairment

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments None

14) Variable Name SCDRSUM

Short Description CDR: Supplemental CDR sum of boxes

Source B4 #11

Question Text Supplemental CDR sum of boxes

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes Min = 0.0

Max = 6.0

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments Supplemental CDR sum is calculated by adding the scores for behavior,

comportment, and personality and language (B4 #9-10).

15) Variable Name SSCDRSUM

Short Description CDR: Standard and supplemental CDR sum of boxes

Source B4 #12

Question Text Standard & supplemental CDR sum of boxes

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes Min = 0.0

Max = 24.0

Missing OK If NA

Audit Findings [JHU Audits]: B4 form error rate = 2% (based on 36 forms as of NOV2015)

Comments Supplemental and standard CDR sum is calculated by adding B#7 (standard CDR

sum of boxes) and B#11 (supplemental CDR sum of boxes).

16) Variable Name BILLS

Short Description FAQ: Paying bills

Source B7 #1

Question Text In the past four weeks, did the subject have any difficulty or need help with writing

checks, paying bills, or balancing a checkbook.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

17) Variable Name TAXES

Short Description FAQ: Taxes and business affairs

Source B7 #2

Question Text In the past four weeks, did the subject have any difficulty or need help with

assembling tax records, business affairs, or other papers.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

Comments None

18) Variable Name SHOPPING

Short Description FAQ: Shopping alone

Source B7 #3

Question Text In the past four weeks, did the subject have any difficulty or need help with

shopping alone for clothes, household necessities, or groceries.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

19) Variable Name GAMES

Short Description FAQ: Games and hobbies

Source B7 #4

Question Text In the past four weeks, did the subject have any difficulty or need help with

playing a game of skill such as bridge or chess, working on a hobby.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

Comments None

20) Variable Name STOVE

Short Description FAQ: Using stove

Source B7 #5

Question Text In the past four weeks, did the subject have any difficulty or need help with

heating water, making a cup of coffee, turning off the stove.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

21) Variable Name MEALPREP

Short Description FAQ: Preparing a balanced meal

Source B7 #6

Question Text In the past four weeks, did the subject have any difficulty or need help with

preparing a balanced meal.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

Comments None

22) Variable Name **EVENTS** 

Short Description FAQ: Current events

Source B7 #7

Question Text In the past four weeks, did the subject have any difficulty or need help with

keeping track of current events.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

23) Variable Name PAYATTN

Short Description FAQ: Paying attention

Source B7 #8

Question Text In the past four weeks, did the subject have any difficulty or need help with paying

attention to and understanding a TV program, book or magazine.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

Comments None

24) Variable Name REMDATES

Short Description FAQ: Remembering dates

Source B7 #9

Question Text In the past four weeks, did the subject have any difficulty or need help with

remembering appointments, family occasions, holidays, medications.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)

25) Variable Name TRAVEL

Short Description FAQ: Traveling and driving

Source B7 #10

Question Text In the past four weeks, did the subject have any difficulty or need help with

traveling out of the neighborhood, driving, or arranging to take public

transportation.

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes 0 = Normal

1 = Has difficulty, but does by self

2 = Requires assistance

3 = Dependent

8 = Not applicable (e.g., never did)

Missing OK If NA

Audit Findings [JHU Audits]: B7 form error rate = 0.2% (based on 35 forms as of NOV2015)