The BIOCARD Study

Biomarkers of Cognitive Decline
Among Normal Individuals

Functional Evaluation
Limited Dataset
February 2019

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	JHU	The Johns Hopkins University
CDR	Clinical Dementia Rating	MCI	Mild Cognitive Impairment
CERAD	Consortium to Establish a Registry for Alzheimer's Disease	MMSE	Mini-Mental State Examination
CNS	Central Nervous System	NACC	National Alzheimer's Coordinating Center
CSF	Cerebrospinal Fluid	NIA	National Institute on Aging
CVD	Cardiovascular Disease	NINDS	National Institute of Neurological Disorders and Stroke
CVLT	California Verbal Learning Test	NPI-Q	Neuropsychiatric Inventory Questionnaire
FAQ	Functional Assessment Questionnaire	UPDRS	Unified Parkinson's Disease Rating Scale
FTD	Frontotemporal Degenerations	WAIS	Wechsler Adult Intelligence Scale
GDS	Geriatric Depression Scale	WMS	Wechsler Memory Scale

Functional Evaluation Limited Dataset Characteristics

Number of variables: 25

Order of variables:

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)	HOMEHOBB	*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

Comments   None

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 impairment
2.0 = Moderate impairment
3.0 = Severe impairment

Missing OK If NA

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

Comments None

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 impairment
2.0 = Moderate impairment
3.0 = 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 impairment
2.0 = Moderate impairment
3.0 = Severe impairment

Missing OK If NA

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

Comments None

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 impairment
2.0 = Moderate impairment
3.0 = 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 impairment
2.0 = Moderate impairment
3.0 = Severe impairment

Missing OK If NA

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

Comments None

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 impairment
2.0 = Moderate impairment
3.0 = 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 impairment
2.0 = Moderate impairment
3.0 = 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 impairment
2.0 = Moderate impairment
3.0 = Severe impairment

Missing OK If   NA

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

Comments   None

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 impairment
2.0 = Moderate impairment
3.0 = 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)

Comments   None

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)

Comments   None

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)

      Comments   None

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)

Comments   None

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)

Comments   None

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)

Comments   None