The BIOCARD Study

Biomarkers of Cognitive Decline
Among Normal Individuals

Demographics and Status
September 2016

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

Demographics and Status Dataset Characteristics

Number of variables: 28

Order of variables:

1)	JHUANONID	*Participant ID Anonymized by JHU*
2)	CODENAME	*Participant Codename*
3)	NIHID	*Participant NIH ID*
4)	STUDY_ID	*Participant Study ID*
5)	SEX	*Participant's sex*
6)	STARTYEAR	*Year of study start*
7)	FOLLJHU	*Participant has visits in JHU phase*
8)	BIRTHYR	*Year of participant's birth*
9)	DEATHYR	*Year of participant death*
10)	EDUC	*Education*
11)	HANDED	*Left- or right-handed*
12)	RACE	*Race*
13)	RACEX	*Race, other specify*
14)	RACESEC	*Additional race*
15)	RACESECX	*Additional race, other specify*
16)	RACETER	*Additional race*
17)	RACETERX	*Additional race, other specify*
18)	HISPANIC	*Hispanic/Latino ethnicity*
19)	HISPOR	*Hispanic origins*
20)	HISPORX	*Hispanic origins, other specify*
21)	MARISTAT	*Marital status*
22)	MARISTAX	*Marital status, other specify*
23)	MARSTAT2	*2nd marital status*
24)	MARSTA2X	*Year of change to 2nd marital status*
25)	MARSTAT3	*3rd marital status*
26)	MARSTA3X	*Year of change to 3rd marital status*
27)	PRIMLANG	*Primary language*
28)	PRIMLANX	*Other primary language - specify*

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 **CODENAME**

Short Description Participant Codename

Source NA

Question Text NA

Time of Collection Baseline

Data Type Character

Allowable Codes

Missing OK If NA

Audit Findings NA

Comments None

3)   Variable Name   **NIHID**

Short Description   Participant NIH ID

Source   NA

Question Text   NA

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes

Missing OK If   NA

Audit Findings   NA

Comments   None

4)   Variable Name   **STUDY_ID**

Short Description   Participant Study ID

Source   NA

Question Text   NA

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes

Missing OK If   NA

Audit Findings   NA

Comments   None

5) Variable Name **SEX**

Short Description Participant's sex

Source A1 #8

Question Text Participant's sex

Time of Collection Baseline

Data Type Numeric

Allowable Codes 1 = Male
2 = Female

Missing OK If NA

Audit Findings [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

6 participants had inconsistent sex across NIH and JHU datasets = 3.8% - these inconsistencies were corrected

Comments If value was missing or no A1 form was completed, the NIH phase value SEX from the DEMO dataset was used, if available.

6) Variable Name **STARTYEAR**

Short Description Year of study start

Source DERIVED

Question Text NA

Time of Collection Baseline

Data Type Numeric

Allowable Codes Min = 1995
Max = 2005

Missing OK If NA

Audit Findings NA

Comments Derived variable: Year from the DEMO dataset variable STARTDATE

7)   Variable Name   **FOLLJHU**

Short Description   Participant has visits in JHU phase

Source   V1

Question Text   Derived

Time of Collection   Baseline and Follow-up

Data Type   Numeric

Allowable Codes   0 = No
1 = Yes

Missing OK If   NA

Audit Findings   [JHU Audits]: V1 form error rate = 0.7% (based on 36 forms as of NOV2015)

No NIH phase audits.

Comments   Derived variable.

If the participant had at least one visit with JHU, this variable value is 1 (Yes).

8)   Variable Name   **BIRTHYR**

Short Description   Year of participant's birth

Source   A1 #7B

Question Text   participant's year of birth

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   Min = 1875
Max = current year minus 15

Missing OK If   NA

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

Comments   If value was missing or no A1 form was completed, the NIH phase value BIRTHYR from the DEMO dataset was used, if available.

9)   Variable Name   **DEATHYR**

Short Description   Year of participant death

Source   M1 #1d

Question Text   Date of death

Time of Collection   Follow-up

Data Type   Numeric

Allowable Codes   Min = 1995
Max = Current year

Missing OK If   Not deceased (no M1 form where M1 #1 = "Yes")

Audit Findings   [JHU Audits]: M1 form error rate = 0.2% (based on 31 forms as of NOV2015)

Comments   None

10)   Variable Name   **EDUC**

Short Description   Education

Source   A1 #14

Question Text   Participant's years of education (report achieved level using the codes below; if an attempted level is not completed, enter the number of years completed):
High school/GED = 12;
Bachelors degree = 16;
Master's degree = 18;
Doctorate = 20

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   0 - 36

Unknown Code   99

Missing OK If   NA

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

All participants analyzed for NIH phase and JHU phase inconsistencies with 1 participant's education changing by more than 2 years = 0.01%

Comments   If value was missing or no A1 form was completed, the NIH phase value EDUCATION from the the DEMO dataset was used, if available.

11)   Variable Name   **HANDED**

Short Description   Left- or right-handed

Source   A1 #20

Question Text   Is the participant left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)?

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   1 = Left-handed
2 = Right-handed
3 = Ambidextrous

Unknown Code   9

Missing OK If   NA

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   If value was missing or no A1 form was completed, the NIH phase value HAND from the the BLRNEW dataset was used, if available.

12)	Variable Name	**RACE**
	Short Description	Race
	Source	A1 #10
	Question Text	What does participant report as his/her race?
	Time of Collection	Baseline
	Data Type	Numeric
	Allowable Codes	1 = White 2 = Black or African American 3 = American Indian or Alaska Native 4 = Native Hawaiian or Other Pacific Islander 5 = Asian 50 = Other
	Unknown Code	99
	Missing OK If	NA
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015) No NIH phase audits.
	Comments	If value was missing or no A1 form was completed, the NIH phase value RACE from the DEMO dataset was used, if available.
13)	Variable Name	**RACEX**
	Short Description	Race, other specify
	Source	A1 #10A
	Question Text	Race, other specify
	Time of Collection	Baseline
	Data Type	Character
	Allowable Codes	Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).
	Missing OK If	A1 #10, RACE ≠ 50 (Other).
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015) No NIH phase audits.
	Comments	None

14)   Variable Name   **RACESEC**

Short Description   Additional race

Source   A1 #11

Question Text   What additional race does participant report?

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   1 = White
2 = Black or African American
3 = American Indian or Alaska Native
4 = Native Hawaiian or Other Pacific Islander
5 = Asian
50 = Other
88 = None reported

Unknown Code   99

Missing OK If   Not a part of the JHU phase of the study.

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

15)   Variable Name   **RACESECX**

Short Description   Additional race, other specify

Source   A1 #11A

Question Text   Additional race, other specify

Time of Collection   Baseline

Data Type   Character

Allowable Codes   Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).

Missing OK If   A1 #11, RACESEC ≠ 50 (Other).

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

16)   Variable Name   **RACETER**

Short Description   Additional race

Source   A1 #12

Question Text   What additional race, beyond what was indicated above in questions 10 and 11, does participant report?

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   1 = White
2 = Black or African American
3 = American Indian or Alaska Native
4 = Native Hawaiian or Other Pacific Islander
5 = Asian
50 = Other
88 = None reported

Unknown Code   99

Missing OK If   Not a part of the JHU phase of the study.

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

17)   Variable Name   **RACETERX**

Short Description   Additional race, other specify

Source   A1 #12A

Question Text   Additional race, other specify

Time of Collection   Baseline

Data Type   Character

Allowable Codes   Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).

Missing OK If   A1 #12, RACETER ≠ 50 (Other).

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

18) Variable Name **HISPANIC**

Short Description Hispanic/Latino ethnicity

Source A1 #9

Question Text Does the participant report being of Hispanic/Latino ethnicity. (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?

Time of Collection Baseline

Data Type Numeric

Allowable Codes 0 = No
1 = Yes

Unknown Code 9

Missing OK If Not a part of the JHU phase of the study AND/OR neither NIH RACE nor NIH HISPANIC indicated Hispanic ethnicity. See Additional Comments.

Audit Findings [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments If value was missing or no A1 form was completed, the NIH phase value RACE from the DEMO dataset or HISPANIC from GPBDEMO dataset was used, if available. Hispanic=1 if NIH phase RACE="H" or NIH phase HISPANIC = 1.

19)   Variable Name   **HISPOR**

Short Description   Hispanic origins

Source   A1 #9A

Question Text   If the participant reports being of Hispanic/Latino ethnicity, what are the participant's reported origins?

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   1 = Mexican/Chicano/Mexican-American
2 = Puerto Rican
3 = Cuban
4 = Dominican
5 = Central American
6 = South American
50 = Other

Unknown Code   99

Missing OK If   A1 #9, HISPANIC ≠ 1 (YES).

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

20)   **Variable Name**   HISPORX

Short Description   Hispanic origins, other specify

Source   A1 #9A1

Question Text   Hispanic origins, other specify

Time of Collection   Baseline

Data Type   Character

Allowable Codes   Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).

Missing OK If   A1 #9, HISPANIC ≠ 1 (YES) or if A1 #9A, HISPOR ≠ 50 (Other).

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

21) Variable Name **MARISTAT**

Short Description   Marital status

Source   A1 #19

Question Text   Participant's baseline marital status

Time of Collection   Baseline

Data Type   Numeric

Allowable Codes   1 = Married
2 = Widowed
3 = Divorced
4 = Separated
5 = Never married
6 = Living as married
8 = Other

Unknown Code   9

Missing OK If   NA

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

22) Variable Name **MARISTAX**

Short Description   Marital status, other specify

Source   A1 #19A

Question Text   Baseline marital status, other specify

Time of Collection   Baseline

Data Type   Character

Allowable Codes   Any text or numbers but cannot use single quotes ('), double quotes ("),
ampersands (&), or percentage signs (%).

Missing OK If   A1 #19, MARISTAT ≠ 8 (Other).

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments

23)   Variable Name   **MARSTAT2**

Short Description   2nd marital status

Source   A1 #19

Question Text   Subject's current marital status

Time of Collection   Follow-up

Data Type   Numeric

Allowable Codes   1 = Married
2 = Widowed
3 = Divorced
4 = Separated
5 = Never married
6 = Living as married

Unknown Code   9

Missing OK If   Always okay

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   If, during follow-up, a participant or his or her informant indicates a change in marital status, this variable will contain a value; otherwise, the participant has maintained the same marital status since baseline.

24)   Variable Name   **MARSTA2X**

Short Description   Year of change to 2nd marital status

Source   A1

Question Text   Derived

Time of Collection   Follow-up

Data Type   Numeric

Allowable Codes   Min = 2009
Max = present year

Missing OK If   A1 #19 MARSTAT2 is blank

Audit Findings   [JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)

No NIH phase audits.

Comments   None

25)	Variable Name	**MARSTAT3**
	Short Description	3rd marital status
	Source	A1 #19
	Question Text	Subject's current marital status
	Time of Collection	Follow-up
	Data Type	Numeric
	Allowable Codes	1 = Married
		2 = Widowed
		3 = Divorced
		4 = Separated
		5 = Never married
		6 = Living as married
	Unknown Code	9
	Missing OK If	Always okay
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)
		No NIH phase audits.
	Comments	If, during follow-up, a participant or his or her informant indicates a change in marital status, this variable will contain a value; otherwise, the participant has maintained the same marital status since either marital status 2 or baseline.

26)	Variable Name	**MARSTA3X**
	Short Description	Year of change to 3rd marital status
	Source	A1
	Question Text	Derived
	Time of Collection	Follow-up
	Data Type	Numeric
	Allowable Codes	Min = 2009
		Max = present year
	Missing OK If	A1 #19 MARSTAT3 is blank
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015)
		No NIH phase audits.
	Comments	None

27)	Variable Name	**PRIMLANG**
	Short Description	Primary language
	Source	A1 #13
	Question Text	Participant's primary language
	Time of Collection	Baseline
	Data Type	Numeric
	Allowable Codes	1 = English 2 = Spanish 3 = Mandarin 4 = Cantonese 5 = Russian 6 = Japanese 8 = Other primary language
	Unknown Code	9
	Missing OK If	NA
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015) No NIH phase audits.
	Comments	
28)	Variable Name	**PRIMLANX**
	Short Description	Other primary language - specify
	Source	A1 #13A
	Question Text	Other primary language - specify
	Time of Collection	Baseline
	Data Type	Character
	Allowable Codes	Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).
	Missing OK If	A1 #13, PRIMLANG ≠ 8 (Other primary language).
	Audit Findings	[JHU Audits]: A1 form error rate = 0.2% (based on 38 forms as of NOV2015) No NIH phase audits.
	Comments	