



The BIOCARD Study

Biomarkers of Cognitive Decline
Among Normal Individuals

**Demographics and Status
Limited Dataset
November 2015**

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 <i>[Note: some data may have been collected prior to this date]</i> |
| 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 <i>[Note: Dates are numeric data]</i> 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 <i>[Note: Variables will follow the NACC naming scheme as closely as possible]</i> |

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 Limited Dataset Characteristics

Number of variables: 25

Order of variables:

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

Demographics and Status Limited Dataset

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|-----------|--------------------|----------------------------------|
| 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 |

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| 2) | 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. |

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| 3) | 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 |

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| 4) | 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). |

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| 5) | 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. |

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| 6) | 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 |

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| 7) | 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. |

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| 8) | 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. |

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| 9) | 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. |

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| 10) | 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 |

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| 11) | 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 |

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| 12) | 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 |

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| 13) | 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 |

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| 14) | 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 |

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| 15) | 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. |

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| 16) | 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 |
| 17) | 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 |

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| 18) | 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 |

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| 19) | 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 | |

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| 20) | 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. |
| 21) | 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 |

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| 22) | 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. |
| 23) | 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 |

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| 24) | 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 | |

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| 25) | 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 | |