



The BIOCARD Study

Biomarkers of Cognitive Decline Among Normal
Individuals

Visits

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 <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

Visits Limited Dataset Characteristics

Number of variables: 6

Order of variables:

1)	JHUANONID	<i>Participant ID Anonymized by JHU</i>
2)	STARTYEAR	<i>Year of study start</i>
3)	VISITNO	<i>Chronological visit number</i>
4)	MOFROMBL	<i>Months since baseline visit</i>
5)	STATUS	<i>Participant's current status</i>
6)	DEATHYR	<i>Year of participant death</i>

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	STARTYEAR
	Short Description	Year of study start
	Source	DERIVED
	Question Text	NA Time
	Time of Collection	Baseline
	Data Type	Numeric
	Allowable Codes	Min = 1995 Max = Current year
	Missing OK If	NA
	Audit Findings	NA
	Comments	Derived variable: Year from the DEMO dataset variable STARTDATE

3)	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	<p>NIH visit: Integers and decimals from 0 to 10, where a visit 0 represents a visit that occurred prior to the established baseline date</p> <p>JHU visit: 101, 102, 103, 104, 1XX where XX is from 01 to 99</p> <p>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.</p>
	Missing OK If	NA
	Audit Findings	NA
	Comments	None

4)	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.

5)	Variable Name	STATUS
	Short Description	Participant's current status
	Source	DERIVED
	Question Text	NA
	Time of Collection	Follow-up
	Data Type	Character
	Allowable Codes	"Died - participated in NIH phase only." "Died - participated in both NIH phase and JHU phase." "Participating in JHU phase." "Considering participation." "Refused further participation." "Participating in JHU phase - new cohort"
	Missing OK If	NA
	Audit Findings	NA
	Comments	Completed V1 forms indicate whether the participant is participating in the JHU phase of the study. Death before the JHU phase began in late September 2009 indicates participation in only the NIH phase. Participants who died after September 2009 may or may not have participated in the JHU phase. Alive participants without a completed V1 form either refused participation or are still considering participation as of August 2014.

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