



The BIOCARD Study

Biomarkers of Cognitive Decline
Among Normal Individuals

CSF Data
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

CSF Data Limited Dataset Characteristics

Number of variables:20

Order of variables:

1)	JHUANONID	<i>Participant ID Anonymized by JHU</i>
2)	VISITNO	<i>CSF visit number</i>
3)	CSFMOBL	<i>Months since baseline visit</i>
4)	AB142	<i>Amyloid Beta 1-42 pg/mL</i>
5)	TAU	<i>Tau pg/mL</i>
6)	PTAU	<i>Phosphorylated Tau 181 pg/mL</i>
7)	S4101	<i>If lumbar puncture was not completed, indicate the primary reason</i>
8)	S4102	<i>Lumbar puncture completed</i>
9)	S4103	<i>If lumbar puncture was not completed, indicate the primary reason</i>
10)	S4104	<i>If lumbar puncture was completed, indicate the space at which the LP needle was inserted</i>
11)	S4105	<i>Indicate the position for the LP procedure</i>
12)	S4105s	<i>Indicate the position for the LP procedure Other</i>
13)	S4106a	<i>After the participant had rested for ½ hour, the participant reported Headache</i>
14)	S4106b	<i>After the participant had rested for ½ hour, the participant reported Dizziness</i>
15)	S4106c	<i>After the participant had rested for ½ hour, the participant reported Back pain</i>
16)	S4106d	<i>After the participant had rested for ½ hour, the participant reported Other</i>
17)	S4106ds	<i>After the participant had rested for ½ hour, the participant reported Other-specify</i>
18)	S4107a	<i>Record the number of aliquots that were prepared for storage</i>
19)	S4107b	<i>Record the number of aliquots that were prepared for storage</i>
20)	S4108	<i>Record the number of minutes after the lumbar puncture ended that the specimen tubes were frozen</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	VISITNO
	Short Description	CSF visit number
	Source	CSF
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	Integers and decimals from 1 to 10
	Missing OK If	NA
	Audit Findings	NA
	Comments	Visit at which CSF specimen was collected.

3)	Variable Name	CSFMOBL
	Short Description	Months since baseline visit
	Source	DERIVED
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	Min = 0 Max = 999
	Missing OK If	NA
	Audit Findings	NA
	Comments	Calculated as months between the baseline start date and the recorded CSF date.

4)	Variable Name	AB142
	Short Description	Amyloid Beta 1-42 pg/mL
	Source	NA
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	Min = 68 Max = 4400
	Missing OK If	NA
	Audit Findings	NA
	Comments	Measurement information available at: Moghekar A, Li S, Lu Y, Li M, Wang M-C, Albert M, O'Brien R, for the JHU Research Team. Cerebrospinal fluid biomarker changes precede symptom onset of mild cognitive impairment. Neurology, 2013 Nov 12; 81(20):1753-1758 PMID: PMC3821715

5)	Variable Name	TAU
	Short Description	Tau pg/mL
	Source	NA
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	Min = 14 Max = 245
	Missing OK If	NA
	Audit Findings	NA
	Comments	Measurement information available at: Moghekar A, Li S, Lu Y, Li M, Wang M-C, Albert M, O'Brien R, for the JHU Research Team. Cerebrospinal fluid biomarker changes precede symptom onset of mild cognitive impairment. Neurology, 2013 Nov 12; 81(20):1753-1758 PMID: PMC3821715

6)	Variable Name	PTAU
	Short Description	Phosphorylated Tau 181 pg/mL
	Source	NA
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	Min = 10 Max = 162
	Missing OK If	NA
	Audit Findings	NA
	Comments	Measurement information available at: Moghekar A, Li S, Lu Y, Li M, Wang M-C, Albert M, O'Brien R, for the JHU Research Team. Cerebrospinal fluid biomarker changes precede symptom onset of mild cognitive impairment. Neurology, 2013 Nov 12; 81(20):1753-1758 PMID: PMC3821715

7)	Variable Name	S4101
	Short Description	Lumbar puncture attempted
	Source	S4 #1
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1 = Yes
	Missing OK If	NA
	Audit Findings	[JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	If “No” clinician stops here

8)	Variable Name	S4102
	Short Description	Lumbar puncture completed
	Source	S4 #2
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1= Yes
	Missing OK If	NA
	Audit Findings	[JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	If “Yes” clinician skips to #4

9)	Variable Name	S4103
	Short Description	If lumbar puncture was not completed, indicate the primary reason
	Source	S4 #3
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	1 = Subject withdrew 2 = Subject complications 3 = Environmental- complications
	Missing OK If	NA
	Audit Findings	[JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	Clinician stops here

10)	Variable Name	S4104
	Short Description	If lumbar puncture was completed, indicate the space at which the LP needle was inserted
	Source	S4 #4
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	1=L2-L3 2= L3-L4 3= L4-L5 4=L5-S1
	Missing OK If	NA
	Audit Findings	[JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

11)	Variable Name	S4105
	Short Description	Indicate the position for the LP procedure
	Source	S4 #5
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	1=Sitting up 2=Lying down 3=Other, specify
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

12)	Variable Name	S4105s
	Short Description	Indicate the position for the LP procedure Other
	Source	S4 #5s
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Character
	Allowable Codes	Text
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

13)	Variable Name	S4106a
	Short Description	After the participant had rested for ½ hour, the participant reported Headache
	Source	S4 #6a
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1 = Yes
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

14)	Variable Name	S4106b
	Short Description	After the participant had rested for ½ hour, the participant reported Dizziness
	Source	S4 #6b
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1 = Yes
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

15)	Variable Name	S4106c
	Short Description	After the participant had rested for ½ hour, the participant reported Back pain
	Source	S4 #6c
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1 = Yes
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

16)	Variable Name	S4106d
	Short Description	After the participant had rested for ½ hour, the participant reported Other
	Source	S4 #6d
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0 = No 1 = Yes
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

17)	Variable Name	S4106ds
	Short Description	After the participant had rested for ½ hour, the participant reported Other-specify
	Source	S4 #6ds
	Question Text	NA
	Time of Collection	Baseline and Follow-up
	Data Type	Character
	Allowable Codes	Text
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

18)	Variable Name	S4107a
	Short Description	Record the number of aliquots that were prepared for storage
	Source	S4 #7a
	Question Text	Number of 250 µl tubes
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0-Min 50-Max 99-Unknown
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

19)	Variable Name	S4107b
	Short Description	Record the number of aliquots that were prepared for storage
	Source	S4 #7b
	Question Text	Number of 500 µl tubes
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	0-Min 35-Max 99-Unknown
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None

20)	Variable Name	S4108
	Short Description	Record the number of minutes after the lumbar puncture ended that the specimen tubes were frozen
	Source	S4 #8
	Question Text	Number of minutes after the lumbar puncture ended that specimen tubes were frozen
	Time of Collection	Baseline and Follow-up
	Data Type	Numeric
	Allowable Codes	30-Min 150-Max
	Missing OK If	NA
	Audit Findings	JHU Audits]: S4 form error rate = 0.0% (based on 29 forms as of FEB2020)
	Comments	None