

# The BIOCARD Study

Biomarkers of Cognitive Decline Among Normal Individuals

Neuropsychiatric Symptoms Limited Dataset July 2019

## **Glossary of Terms**

Allowable Codes	codes (and their meaning) allowed to be values for that variable
Audit findings	error rates based on BIOCRAD 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 [Noted: Dates are numeric data]
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 in the variable
Variable Name	the name of the variable in the provided dataset {Noted: Variables will follow the NACC naming scheme as closely as possible]

# Acronyms and Definitions

AD	Alzheimer's Disease
CDR	Clinical Dementia Rating
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CNS	Central Nervous System
CSF	Cerebrospinal Fluid
CVD	Cardiovascular disease
CVLT	California Verbal Learning Test
FAQ	Functional Assessment Questionnaire
FTD	Frontotemporal Degenerations
GDS	Geriatric Depression Scale

JHU	The Johns Hopkins University
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
NACC	National Alzheimer's Coordinating Center
NART	National Adult Reading Test
NIA	National Institute on Aging
NINDS	National Institute of Neurological Disorders and Stroke
NPI-Q	Neuropsychiatric Inventory Questionnaire
PDRS	Unified Parkinson's Disease Rating Scale
WAIS	Wechsler Adult Intelligence Scale
WMS	Wechsler Memory Scale

# Neuropsychiatric Symptoms-Limited Dataset Characteristics

## Number of variables: 48

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1)	JHUANONID	Participant ID Anonymized byJHU
2)	VISITNO	Chronological visit number
3)	MOFROMBL	Months since baseline visit
4)	H_TOTAL	Hamilton Depression Score-Total
5)	H_ATOTAL	Hamilton Anxiety Score-Total
6)	B5201	NPI-Q-Informant type
7)	B5202a	NPI-DELUSIONS present/absent
8)	B5202b	NPI-DELUSIONS-SEVERITY
9)	B5203a	NPI-HALLUCINATIONS present/absent
10)	B5203b	NPI-HALLUCINATIONS-SEVERITY
11)	B5204a	NPI-AGITATION OR AGGRESSION present/absent
12)	B5204b	NPI-AGITATION OR AGGRESSION-SEVERITY
13)	B5205a	NPI-DEPRESSION OR DYSPHORIA present/absent
14)	B5205b	NPI-DEPRESSION OR DYSPHORIA-SEVERITY
15)	B5206a	NPI-ANXIETY present/absent
16)	B5206b	NPI-ANXIETY-SEVERITY
17)	B5207a	NPI-ELATION OR EUPHORIA present/absent
18)	B5207b	NPI-ELATION OR EUPHORIA-SEVERITY
19)	B5208a	NPI-APATHY OR INDIFFERENCE present/absent
20)	B5208b	NPI-APATHY OR INDIFFERENCE-SEVERITY
21)	B5209a	NPI-DISINHIBITION present/absent
22)	B5209b	NPI-DISINHIBITION-SEVERITY
23)	B5210a	NPI-IRRITABILITY OR LABILITY present/absent
24)	B5210b	NPI-IRRITABILITY OR LABILITY-SEVERITY
25)	B5211a	NPI-MOTOR DISTURBANCE present/absent
26)	B5211b	NPI-MOTOR DISTURBANCE-SEVERITY
27)	B5212a	NPI-NIGHTTIME BEHAVIORS present/absent
28)	B5212b	NPI-NIGHTTIME BEHAVIORS-SEVERITY
29)	B5213a	NPI-APPETITE AND EATING present/absent
30)	B5213b	NPI-APPETITE AND EATING-SEVERITY
31)	NPI-Q present/	
	absent total	NPI-Q Total Score-present/absent
32)	NPI-Q severity total	NPI-Q Total Score-severity

33)	B6201	GDS-item 1
34)	B6202	GDS-item 2
<i>35)</i>	B6203	GDS-item 3
36)	B6204	GDS-item 4
<i>37)</i>	B6205	GDS-item 5
38)	B6206	GDS-item 6
39)	B6207	GDS-item 7
40)	B6208	GDS-item 8
41)	B6209	GDS-item 9
42)	B6210	GDS-item 10
43)	B6211	GDS-item 11
44)	B6212	GDS-item 12
45)	B6213	GDS-item 13
46)	B6214	GDS-item 14
47)	B6215	GDS-item 15
48)	B6216	GDS-Total Score

#### 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

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

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

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 (HAMDATE - fsvis).

4) Variable Name **H\_TOTAL** 

Short Description Hamilton Depression Score, Total

Source NIH Hamilton file

Question Text Hamilton Depression Score Total

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes Min = 0

Max = 27

Unknown Code Reasons:

Missing OK If NA

Comment NIH phase only.

5) Variable Name **H\_ATOTAL** 

Short Description Hamilton Anxiety Score, Total

Source NIH Hamilton file

Question Text Hamilton Anxiety Score Total

Time of Collection Baseline and Follow-up

Data Type Numeric

Allowable Codes Min = 0

Max = 26

Unknown Code Reasons:

Missing OK If NA

Comment NIH phase only.

6) Variable Name **B5201** 

Short Description NPI-Q Informant

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Behavioral Assessment – Neuropsychiatric Inventory Informant

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Spouse

2=Child 3=Other

Missing OK If NA

Comments JHU phase only.

7) Variable Name B5202a

Short Description NPI DELUSIONS present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient believe that others are stealing from him or her, or planning to

him or her in some way?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

8) Variable Name B5202b

Short Description NPI DELUSIONS SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

9) Variable Name B5203a

Short Description NPI HALLUCINATIONS present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient act as if he or she hears voices? Does he or she talk to people

who are not there?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

10) Variable Name B5202b

Short Description NPI HALLUCINATIONS SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

11) Variable Name B5204a

Short Description NPI AGITATION OR AGGRESSION present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Is the patient stubborn and resistive to help from others?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

12) Variable Name B5204b

Short Description NPI AGITATION OR AGGRESSION SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

13) Variable Name B5205a

Short Description NPI DEPRESSION OR DYSPHORIA present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient act as if he or she is sad or in low spirits? Does he or she cry?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

14) Variable Name B5205b

Short Description NPI DEPRESSION OR DYSPHORIA SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

15) Variable Name B5206a

Short Description NPI ANXIETY present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient become upset when separated from you? Does he or she have

any other signs of nervousness, such as shortness of breath, sighing, being

unable to relax, or feeling excessively tense?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

16) Variable Name B5206b

Short Description NPI ANXIETY SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

17) Variable Name B5207a

Short Description NPI ELATION OR EUPHORIA present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient appear to feel too good or act excessively happy?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

18) Variable Name B5207b

Short Description NPI ELATION OR EUPHORIA SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

19) Variable Name B5208a

Short Description NPI APATHY OR INDIFFERENCE present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient seem less interested in his or her usual activities and in the

activities and plans of others?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

20) Variable Name B5208b

Short Description NPI APATHY OR INDIFFERENCE SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

21) Variable Name B5209a

Short Description NPI DISINHIBITION present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient seem to act impulsively? For example, does the patient talk to

strangers as if he or she knows them, or does the patient say things that may

hurt people's feelings?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

22) Variable Name B5209b

Short Description NPI DISINHIBITION SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

23) Variable Name B5210a

Short Description NPI IRRITABILITY OR LABILITY present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Is the patient impatient or cranky? Does he or she have difficulty coping with

delays or waiting for planned activities?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

24) Variable Name B5210b

Short Description NPI IRRITABILITY OR LABILITY SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

25) Variable Name B5211a

Short Description NPI MOTOR DISTURBANCE present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient engage in repetitive activities, such as pacing around the

house, handling buttons, wrapping string, or doing other things repeatedly?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

26) Variable Name B5211b

Short Description NPI MOTOR DISTURBANCE SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

27) Variable Name B5212a

Short Description NPI NIGHTTIME BEHAVIORS present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Does the patient awaken you during the night, rise too early in the morning, or

take excessive naps during the day?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

28) Variable Name B5212b

Short Description NPI NIGHTTIME BEHAVIORS SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

29) Variable Name B5213a

Short Description NPI APPETITE AND EATING present/absent

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Has the patient lost or gained weight, or had a change in the food he or she

likes?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

30) Variable Name B5213b

Short Description NPI APPETITE AND EATING SEVERITY

Source Behavioral Assessment – Neuropsychiatric Inventory Questionnaire

Question Text Rate the severity of the symptom

Time of Collection Baseline and Follow-up

Data Type Character
Allowable Codes 1=Mild

2=Moderate 3=Severe

Missing OK If NA

Comments JHU phase only.

31) Variable Name NPI-Q present absent

Short Description NPI-Q Total Score-present/absent

Source Generated

Time of Collection Baseline and Follow-up

Data Type Number

Allowable Codes 0=Min

9=Max

Missing OK If NA

32) Variable Name NPI-Q severity

Short Description NPI-Q Total Score-severity

Source Generated

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Min

17=Max

Missing OK If NA

Comments JHU phase only.

33) Variable Name B6201

Short Description GDS-item 1, SATISFIED WITH YOUR LIFE

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Are you basically satisfied with your life?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 0=Yes

1=No

Missing OK If NA

Short Description GDS-item 2, DROPPED ACTIVITIES AND INTERESTS

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Have you dropped many of your activities and interests?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

35) Variable Name B6203

Short Description GDS-item 3, FEEL THAT YOUR LIFE IS EMPTY

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel that your life is empty?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Short Description GDS-item 4, GET BORED

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you often get bored?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

37) Variable Name B6205

Short Description GDS-item 5, GOOD SPIRIT MOST OF THE TIME

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Are you in good spirits most of the time?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 0=Yes

1=No

Missing OK If NA

Short Description GDS-item 6, AFRAID THAT SOMETHING BAD IS GOING TO HAPPEN

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Are you afraid that something bad is going to happen to you?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

39) Variable Name B6207

Short Description GDS-item 7, HAPPY MOST OF THE TIME

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel happy most of the time?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 0=Yes

1=No

Missing OK If NA

Short Description GDS-item 8, FEEL HELPLESS

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you often feel helpless?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

41) Variable Name B6209

Short Description GDS-item 9, PREFER STAY AT HOME

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you prefer to stay at home, rather than going out and doing new things?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

42) Variable Name B6210

Short Description GDS-item 10, MORE PROBLEMS WITH MEMORY

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel you have more problems with memory than most?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

43) Variable Name **B6211** 

Short Description GDS-item 11, WONDERFUL TO BE ALIVE

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you think it is wonderful to be alive now?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 0=Yes

1=No

Missing OK If NA

Short Description GDS-item 12, WORTHLESS THE WAY YOU ARE NOW

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel pretty worthless the way you are now?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

45) Variable Name B6213

Short Description GDS-item 13, FULL OF ENERGY

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel full of energy?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 0=Yes

1=No

Missing OK If NA

46) Variable Name B6214

Short Description GDS-item 14, SITUATION IS HOPELESS

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you feel that your situation is hopeless?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Comments JHU phase only.

47) Variable Name **B6215** 

Short Description GDS-item 15, MOST PEOPLE ARE BETTER OFF

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Do you think that most people are better off than you are?

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 1=Yes

0=No

Missing OK If NA

Short Description GDS-item 16, GDS SCORE, TOTAL

Source Behavioral Assessment – Geriatric Depression Scale

Question Text Sum all circled answers for a Total GDS Score

Time of Collection Baseline and Follow-up

Data Type Character

Allowable Codes 15=Max

88=Did not complete

Missing OK If NA

Comments JHU phase only.

The item scores for Hamilton Depression and Hamilton Anxiety scales are available on request