

The BIOCARD Study

Biomarkers of Cognitive Decline Among Normal Individuals

Neuropsychiatric Symptoms Limited Dataset

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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|-----|----|----------|-----|-----|------|
| Ord | n- | \sim t | VAR | inh | loc. |
| CHU | | ()I | vai | เสเ | 115. |

| 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