

Revised Syllabus Pages Second Quarter 2006

Compiled and Distributed by the
**Traumatic Brain Injury
Model Systems National Data Center**

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LIVING STATUS OF PERSON WITH BRAIN INJURY

Variable 20Aa

Date of last revision: 04/01/06

DEFINITION:

Code the living status of the person with brain injury. If patient has died, code the cause of death.

Instructions for coding ICD-9-CM primary and secondary causes of death are in [16a.Guidelines coding cause of death](http://syllabus/pdf/16a_Guidelines_coding_cause_of_death.pdf) (http://syllabus/pdf/16a_Guidelines_coding_cause_of_death.pdf) in Appendix C. Instructions for coding the E-code cause of death are in [24b.Guidelines for Coding Cause of Injury and Etiology of Injury \(E-codes\)](http://syllabus/pdf/v133b_guide_2.pdf) (http://syllabus/pdf/v133b_guide_2.pdf) in Appendix K.

CODE:

Code the two boxes for the ICD-9-CM codes and the box for the External Cause of Injury Codes (E-codes) as follows.

ICD-9-CM code boxes:

For a list of ICD-9 codes, refer to an ICD-9 code manual at your facility.

777.77 Person expired but cause of death unknown

888.88 Not Applicable--person alive, or no other internal cause of death indicated, or death due to external causes

999.99 Unknown if person expired

E-code box:

For an abbreviated list of E-codes, see: [24a.ICD-9-CM E-code categories](http://syllabus/pdf/v133b_categories_3.pdf)

(http://syllabus/pdf/v133b_categories_3.pdf) in Appendix K. A complete list of E-codes is available at [E-Code list-complete](http://syllabus/pdf/ECodes_52.pdf) (http://syllabus/pdf/ECodes_52.pdf).

*77777 Person expired but cause of death unknown

*88888 Not Applicable--person alive or death not due to external causes

*99999 Unknown if person expired

CHARACTERS:

3 numeric

4 numeric

5 numeric

NOTE:

If autopsy was performed obtain report, document cause(s) of death by use of ICD-9-CM diagnosis codes or E-code if applicable. Record date of death in *Variable 201*.

If patient expired, complete only variables 20Aa through 201 then stop.

The look-up boxes on the database screen provide the E-Codes and their definitions. When taking E-Codes from the Medical Record, they should be checked to ensure that they reflect the best / most current information available about the cause of the injury. Data collectors may submit E-Codes that differ from those recorded in the Medical Record in cases where they feel the Medical Record E-Codes may not reflect the best / most current information available. There should be clear documentation on the data collection form when an E-Code entered into the database does not reflect the E-Code recorded in the Medical Record. In unusual cases where no E-Code relative to the injury that resulted in traumatic brain injury is recorded in the Medical Record, the data collector should use best judgement and the consultation of other personnel, as necessary, to determine the appropriate E-Code from the TBIMS database list.

SOURCE:

UAB

ICD-9-CM 2001: International Classification of Diseases 9th Revision Clinical Modification, AMA Press. Volume 1, 2000, 251-279. ISBN: 1579471501.

EXAMPLE:

Patient died of Septicemia (primary cause) and Pneumonia (secondary)

ICD-9-CM CODES: 038.90 primary; 486.00 (secondary)

E CODE: 88888

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	Changed "Unk if expired" code for E-code from 999.9 to 99999.
2006-04-01	Changed "NA" code for E-code from 888.8 to 88888.
2006-04-01	Changed "Expired cause unk" code for E-code from 777.7 to 77777.
2004-07-01	In CODES, corrected the labels for 888.88 (ICD-9) and 888.8 (E-code). For 888.88, "NA-Person alive, or no other cause of death indicated" has been changed to "NA-Person alive, or no other internal cause of death indicated, or death due to external causes". For 888.8, "NA-Person alive, or no other cause of death indicated" has been changed to "NA-Person alive, or death not due to external causes".
2004-04-01	Added link to comprehensive list of E-Codes.
2004-04-01	Revised the format of the CODES box.
2002-10-14	Changed data entry mask so parts A and B can accept 3-digit codes without decimals.
2002-04-01	Added note about instructions for E-codes.
2002-04-01	Added reference to Appendix K.
1995-01-01	Dropped 3rd ICD-9 code and 2nd and 3rd E-codes.
1995-01-01	Revised code description for 999.99 and 999.9.
1995-01-01	Added codes 777.77 and 777.7.
1994-08-19	Corrected references to E-codes, corrected description of Not applicable code to be consistent with V146.

METHOD OF INTERVIEW DATA COLLECTION -PERSON WITH BRAIN INJURY

Variable 20Ab

Date of last revision: 04/01/06

DEFINITION:

The manner in which interview data were collected from the person with brain injury.

CODE:

- 1 In-person interview
- 2 Telephone interview
- 3 Questionnaire mailing
- 4 NA-data obtained out of window from secondary source
- 6 Variable did not exist at time data were collected
- 7 No data to be collected at this time (e.g., no funding)
- 8 No interview data provided by person with brain injury

CHARACTERS:

- 1 numeric

NOTE:

Interview data includes all Form II data collected from the person with brain injury.

If multiple methods are used to collect data, record the method used the most with this participant.

Code 7 is not shown on Form II because it is a special purpose code and should not be used in normal data collection/submission.

Use code "4" for both V20Ab and V20Ac if most of the data were obtained out of window from a secondary source. These data must have originally been collected within window and must be high quality.

*Every effort should be made to collect data from the participant or an appropriately informed significant other. Data from other sources (indicated by code "4") should be entered only if: (1)it has not been possible to obtain that information from the person or SO during the follow-up window, (2) those data were originally collected during the follow-up window, and (3) the data meet TBIMS standards for data collection procedures and data quality standards.

EXAMPLE:

Data were collected via telephone interview.

2

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	In NOTE, added "All possible effort is to be made to collect data from the participant or an SO. Data from other sources (as indicated by code "4") should be entered only if: (1)it has not been possible to obtain the data from the person or SO during the follow-up window, (2) those data were originally collected during the follow-up window, and (3) the data meet TBIMS standards for data collection procedures and data quality standards".
2006-01-01	Added CODE "4 NA-data obtained out of window from secondary source".
2006-01-01	Added CODE "6=Variable did not exist at time data were collected"
2006-01-01	Added instruction in NOTE about using code 4.
2004-04-01	Added NOTE about code 7 not being in Form II.
2004-01-01	Added code 7.
2003-10-01	Corrected example (added code).

Date of last Revision	Description
2003-10-01	In note, removed reference to (deleted) neuropsych battery and physical exam.
2001-08-20	Note added about how to code if multiple methods are used to collect data.
1996-01-01	Clarified that this variable refers to interview data collection only.
1994-08-19	Added code 8 to be consistent with data collection form.

QUESTIONS AND ANSWERS:

QUESTION:	On the syllabus I have and on the list of Form II Syllabus changes, it is noted "Added code 7" but that code isn't on the new Form II. Should it be? 01-13-2004
ANSWER:	This code is used only for very specific purposes that data collectors will not run into. So, the code should not be on the Form II. 01-15-2004
QUESTION:	On the Form II, variable 20Ab & 20Ac now have a code "4". Do I understand this to actually be a form of chart review? How will this code be treated in calculation of follow-up rates in the Quarterly Report? 12-31-1969
ANSWER:	The "4" code was added in response to a center's need to be able to enter a code for V20Ab and V20Ac for a few respondents who had withdrawn authorization during the follow-up window but re-authorized TBIMS data collection after the window had closed, and for whom, it turned out, data usable in their Form IIs were obtainable later from sources that had happened to have collected that information for clinical purposes, during the follow-up window. The key elements in this situation are: (a) data could not be obtained by TBIMS data collectors (or their proxies) from any source during the follow-up window, and (b) data that were appropriate for entering into the Form II were collected elsewhere during the follow-up window and became available to TBIMS data collectors after the follow-up window had closed. This is a rare situation. The availability of this new code should not affect your data collection practices or your use of the 1, 2, and 3 codes under any circumstances other than when the above two key elements are present. Form II data that are obtained by chart review during the follow-up window should be coded 1, 2, or 3, depending on how the original data collector obtained it for entering into the chart. In the Quarterly Report follow-up rates, the "4" code will be counted the same as the 1, 2, and 3 codes. That is, Form IIs with a "4" in V20Ab and V20Ac will be counted as having been submitted with data. 12-31-1969

METHOD OF INTERVIEW DATA COLLECTION -SIGNIFICANT OTHER

Variable 20Ac

Date of last revision: 04/01/06

DEFINITION:

The manner in which interview data is collected from the main significant other.

CODE:

- 1 In-person interview
- 2 Telephone interview
- 3 Questionnaire mailing
- 4 NA-data obtained out of window from secondary source
- 6 Variable did not exist at time data were collected
- 7 No data to be collected at this time (e.g., no funding)
- 8 No interview data provided by significant other. *(Use this code if participant is incarcerated.)

CHARACTERS:

- 1 numeric

NOTE:

Interview data includes all Form II data collected from a family member/significant other of the person with brain injury, which includes any patient-related medical/functional/historical information which cannot be reliably obtained from the person with brain injury, or if the person with brain injury cannot be interviewed.

If multiple methods are used to collect data, record the method used the most with this participant.

Code 7 is not shown on Form II because it is a special purpose code and should not be used in normal data collection/submission.

Use code "4" for both V20Ab and V20Ac if most of the data were obtained out of window from a secondary source. These data must have originally been collected within-window and must be high quality. *Every effort should be made to collect data from the participant or an appropriately informed significant other. Data from other sources (indicated by code "4") should be entered only if: (1)it has not been possible to obtain that information from the person or SO during the follow-up window, (2) those data were originally collected during the follow-up window, and (3) the data meet TBIMS standards for data collection procedures and data quality standards.

EXAMPLE:

Data were collected by in-person interview:via telephone interview.

2

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	In NOTE, added "All possible effort is to be made to collect data from the participant or an SO. Data from other sources (as indicated by code "4") should be entered only if: (1)it has not been possible to obtain the data from the person or SO during the follow-up window, (2) those data were originally collected during the follow-up window, and (3) the data meet TBIMS standards for data collection procedures and data quality standards".
2006-04-01	Added instruction to code 8 that it is to be used if participant is incarcerated.
2006-01-01	Added CODE "6=Variable did not exist at time data were collected"
2006-01-01	Added instruction in NOTE about using code 4.
2006-01-01	Added CODE "4 = NA-data obtained out of window from secondary source".
2004-04-01	Added NOTE about code 7 not being in Form II.

Date of last Revision	Description
2004-01-01	Added code "7=No data to be collected at this time (e.g., no funding)", to be used by Center that was not funded for a period of time.
2003-10-01	Reinstated variable in database (otherwise, if SO is only source of information, there is no information about method of interview data collection).
2003-10-01	In NOTE, removed reference to CIQ and to significant other-only community integration questions.
2003-01-01	Deleted this variable from database.
2001-08-20	Note added about multiple methods of collecting data.
1996-01-01	Clarified that this variable refers to interview data collection only.
1994-08-19	Added code 8 to be consistent with data collection form.

QUESTIONS AND ANSWERS:

QUESTION:	On the syllabus I have and on the list of Form II Syllabus changes, it is noted "Added code 7" but that code isn't on the new Form II. Should it be? 01-13-2004
ANSWER:	This code is used only for very specific purposes that data collectors will not run into. So, the code should not be on the Form II. 01-15-2004

PREMORBID LIMITATIONS

Variable 123

Date of last revision: 04/01/06

DEFINITION:

The purpose of this variable is to help determine the preinjury functional level of the Model System participant. This variable was taken from the wording of the Long Form of the 2000 Census, which asks about current function. To meet our needs, this question was revised to ask specifically about the patient's difficulty in doing the following activities due to a physical, mental, or emotional condition that has been present for at least 6 months:

- a. Learning, remembering, or concentrating
- b. Dressing, bathing, or getting around inside the home
- c. Going outside the home alone to shop or visit a doctor's office
- d. Working at a job or business

CODE:

- 1 No
- 2 Yes
- 6 Variable did not exist at time of data collection
- 9 Unknown

CHARACTERS:

- 1 numeric

NOTE:

Variable was successfully pilot tested in first quarter 2005.

Include effects due to alcoholism.

If respondent asks for clarification of what is meant by "mental and emotional conditions", the following explanation is acceptable: "Mental conditions affect a person's ability to think or their intelligence. Examples include learning disabilities, dementia, or mental retardation. Emotional conditions refer to psychological or psychiatric problems."

*If the participant was not working at the time of injury, code 123d on the basis of estimated difficulty had he/she been working.

SOURCE:

Questions were taken from the long form of the 2000 census and modified to ask about premorbid function instead of current level of function. (Developed by a group headed by Flora Hammond.)

EXAMPLE:

Participant had attention deficit disorder (diagnosed by psychologist) prior to the injury.

- a. 2
- b. 1
- c. 1
- d. 1

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	Added NOTE about coding part d for persons not working at injury.
2006-01-01	Added wording for data collectors to use in clarifying the meaning of "mental or emotional conditions".
2005-07-01	Variable added to database.

QUESTIONS AND ANSWERS:

QUESTION:	How should 123d be coded for participants who at the time of injury were retired due to age ? 03-02-2006
ANSWER:	Probe to determine if at the time of injury they had physical, mental, or emotional problems that--if they had been working--would have caused them difficulty and which they had had for the past 6 months. 03-14-2006
QUESTION:	How should 123d be coded if the person was not working at the time of injury? 03-14-2006
ANSWER:	If the participant was not working at the time of injury, the data collector should probe to determine if the participant would have had difficulty if he/she were working. If the participant would have had difficulty, then determine if the difficulty would have been due to physical, mental, or emotional problems that had been present for at least 6 months. If the participant would have had difficulty and if the difficulty would have been due to physical, mental, or emotional problems that had been present for at least 6 months, then code 2=yes. Otherwise code 1=no. 03-14-2006

CAUSE(S) OF DEATH

Variable 146

Date of last revision: 04/01/06

DEFINITION:

The first coded cause of death is the primary cause. Thereafter list secondary cause and/or external cause of death, if applicable. For more information, see: [16a.Guidelines coding cause of death \(http://syllabus/pdf/16a_Guidelines_coding_cause_of_death.pdf\)](http://syllabus/pdf/16a_Guidelines_coding_cause_of_death.pdf), in Appendix C.

CODE:

Code the two boxes for the ICD-9-CM codes and the box for the External Cause of Injury Codes (E-codes) as follows.

ICD-9-CM code boxes:

For a list of ICD-9 codes, refer to an ICD-9 code manual at your facility.

777.77 Person expired but cause of death unknown.

888.88 Not Applicable--person alive, or no other internal cause of death indicated, or death due to external causes.

999.99 Unknown if person expired

E-code box:

For an abbreviated list of E-codes, see: [24a.ICD-9-CM E-code categories](http://syllabus/pdf/v133b_categories_3.pdf)

(http://syllabus/pdf/v133b_categories_3.pdf) in Appendix K. A complete list of E-codes is available at [E-Code list-complete](http://syllabus/pdf/ECodes_52.pdf) (http://syllabus/pdf/ECodes_52.pdf).

*77777 Person expired but cause of death unknown.

*88888 Not Applicable--person alive, or death not due to external causes.

*99999 Unknown if person expired

CHARACTERS:

3 numeric

4 numeric

5 numeric

NOTE:

Submit Form I data to the data base on patients which expire anytime after inpatient rehabilitation has begun and prior to definitive discharge from inpatient rehabilitation; even if the patient was transferred back to acute care from rehabilitation prior to expiring.

If autopsy was performed obtain report, document cause(s) of death by use of ICD-9-CM diagnosis codes or E-codes if applicable.

If using death certificate information, usually code the 3rd number. First number is immediate cause, second number is the cause of the immediate cause, and the third number is the more underlying cause.

Numbers should be coded just as they appear on the record and not padded with zeros.

The look-up boxes on the database screen provide the E-Codes and their definitions. When taking E-Codes from the Medical Record, they should be checked to ensure that they reflect the best / most current information available about the cause of the injury. Data collectors may submit E-Codes that differ from those recorded in the Medical Record in cases where they feel the Medical Record E-Codes may not reflect the best / most current information available. There should be clear documentation on the data collection form when an E-Code entered into the database does not reflect the E-Code recorded in the Medical Record. In unusual cases where no E-Code relative to the injury that resulted in traumatic brain injury is recorded in the Medical Record, the data collector should use best judgement and the consultation of other personnel, as necessary, to determine the appropriate E-Code from the TBIMS database list.

Do not use the codes on the death certificate because they may not be accurate and because they may be ICD-10 codes.

*ICD-9 codes that are preceded by "E" or "V" are entered into 146c, never into 146a or b.

SOURCE:
UAB

EXAMPLE:

Patient died of unspecified septicemia (primary cause) and unspecified pneumonia (secondary).

ICD-9-CM codes: 038.9 (primary); 486. (secondary)

E CODE: 88888

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	In NOTE, added "ICD-9 codes that are preceded by "E" or "V" are entered into 146c, never into 146a or b".
2006-04-01	Changed "NA" code for E-codes from 888.8 to 88888.
2006-04-01	Changed "Expired cause unk" code for E-code from 777.7 to 77777.
2006-04-01	Changed "Unk" code for E-code from 999.9 to 99999.
2006-01-01	Added note to not use codes on death certifiante.
2004-07-01	In CODES, added "777.7(7)=Person expired but cause of death unknown". Corrected the labels for 888.88 (ICD-9) and 888.8 (E-code). For 888.88, "NA-Person alive, or no other cause of death indicated" has been changed to "NA-Person alive, or no other internal cause of death indicated, or death due to external causes". For 888.8, "NA-Person alive, or no other cause of death indicated" has been changed to "NA-Person alive, or death not due to external causes".
2004-04-01	Added reference to Coding Guidelines in Appendix C.
2002-04-01	Added reference to instructions for E-codes in Appendix K.
1995-01-01	Dropped 3rd ICD-9 code and 2nd and 3rd E-codes.
1994-02-01	Added NOTE clarifying the submission of patients which expire during inpatient rehabilitation.
1994-02-01	Removed reference to Appendix D (coding cause of death) which was never written.

FUNCTIONAL INDEPENDENCE MEASURE (FIM)

Variable 152

Date of last revision: 04/01/06

DEFINITION:

The FIM is a measure of disability. It is intended to measure what the person with the disability actually does, not what he or she ought to be able to do, or might be able to do if certain circumstances were different. It is to be completed within 72 hours after Rehab Admission and again within 72 hours before Rehab Discharge.

FIM data are to be collected according to the current (4/1/04) IRF-PAI coding instructions * IRF-PAI Coding Instructions: 4/1/2004 version ([http://www.udsmr.org/pdfs/irfpaimanual040104%20\(1\).pdf](http://www.udsmr.org/pdfs/irfpaimanual040104%20(1).pdf)), supplemented by any further instructions in your syllabus. Information about the FIM can be found in the IRF-PAI manual in section III, pages 40-57, Appendix H, and pages 29-34. A copy of the FIM-related sections of this manual should be in your syllabus *binder (if your center maintains a binder), in Appendix A. If it is not possible for your Center to follow the correct manual, notify the TBINDC.

Information about the FIM is available from COMBI at these two links: Introduction (COMBI) (<http://www.tbims.org/combi/FIM/index.html>); Background (COMBI) (<http://www.tbims.org/combi/FIM/fimbg.html>).

*IRF-PAI instructions used between 1/2002 and 4/2004

(<http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manualint.pdf>).

*Summary of the differences between the 4/2004 instructions and the 1/2002 instructions

(<http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manual040104.pdf>).

CODE:

- 7 Complete Independence (Timely, Safely)
- 6 Modified Independence (Extra time, device)
- 5 Supervision (pt does 100%)
- 4 Minimal Assist (subject does 75% or more of task)
- 3 Moderate Assist (50 - 74% of task)
- 2 Maximal Assist (25 - 49% of task)
- 1 Total Assist (subject 72 hours)
- *0 Activity does not occur. (Use only at admission and only for #1-6,10-15; else use code "9".)
- 66 Variable did not exist

Items 8b and 9b

- 7 No accidents
- 6 No accidents, uses device (e.g., catheter, ostomy)
- 5 One accident in the past 7 days
- 4 Two accidents in the past 7 days
- 3 Three accidents in the past 7 days
- 2 Four accidents in the past 7 days
- 1 Five or more accidents in the past 7 days
- 9 Unknown / assessed at more than 72 hours
- 66 Variable did not exist

Item 14: Primary mode of locomotion on discharge

- w Walking
- c Wheelchair
- 9 Unknown

Item 17: Primary mode of comprehension

- a Auditory comprehension more than 50% of the time
- v Visual comprehension more than 50% of the time
- b Both used equally
- 9 Unknown

Item 18: Primary mode of expression

- v Verbal expression more than 50% of the time
- n Nonverbal expression more than 50% of the time
- b Both used equally
- 9 Unknown

CHARACTERS:

- 1 numeric
- 2 numeric
- 1 alpha-numeric

NOTE:

All FIM items must be scored. Record what patient actually does. If FIM assessment cannot be completed within the 72 hour window, it should still reflect the patients' status within that time period. If this is not possible and the assessments are done out of the 72 hour window, code with 9's. Every effort should be made to obtain the FIM assessments; however, if any items are not assessed, use code 9 -- do not leave blanks.

For admission item #14, if patient is walking and not using wheelchair, code item 14b (wheelchair) "8=not applicable". If patient is unable to walk on admission, code item 14a (walking) "1=total assist". If, at discharge, patient is walking AND using a wheelchair, code 14 (mode) as the more frequently used mode of locomotion. Do not use the code "b=Both" (as is indicated by UDS instructions). If FIM scores provided by your hospital include "b" codes, use all sources of information to determine the more frequent mode of locomotion at the time of evaluation and code either "w" or "c" as appropriate. If the more frequent mode of locomotion cannot be determined, code "9".

According to the UDS Procedures for Scoring the FIM, "if the subject would be put at risk for injury if tested or does not perform the activity, enter 1". Use this same rule for the TBI Model Systems FIM data collection.

According to the UDS procedures for scoring the FIM, "the mode of locomotion for FIM item #14 (Walk/Wheelchair) must be the same on admission and discharge; if the subject changes the mode of locomotion from admission to discharge (usually wheelchair to walking), record the admission mode and score based on the most frequent mode of locomotion at discharge". Therefore, for the TBI Model Systems FIM data collection for FIM item #14, score both modes of locomotion (Walking and Wheelchair) on admission. The total admission score will be calculated by the computer and based on the UDS procedure described above (i.e., if the discharge mode is walking, the admission score for walking is used; if the discharge mode is wheelchair, the admission score for wheelchair is used).

If patient has an intermittent acute care stay during inpatient rehabilitation, use the FIM scores from the first rehabilitation admission and the last definitive discharge. In addition, if a patient has an intermittent stay which is longer than 30 days, it is then considered a system discharge and the discharge date from rehabilitation is the system discharge date and the FIM scores should correspond to that date.

"Level of assistance" (part a) and "Frequency of accidents" (part b) are recorded for #8 (Bladder Management) and #9 (Bowel Management).

For items 1-6 and 10-15 *at the admission evaluation only*, if patient does not perform the activity and a helper does not perform the activity for the patient, assign code "0=Activity does not occur". If the patient is simply not *observed* performing an activity, do not code "0" until all available sources of information have been consulted (e.g., other clinicians, medical record, family members). If at discharge evaluation an activity is not performed, assign code "1=Total assistance" (do not use the "0" code at the discharge evaluation).

For #8 (Bladder Management), if patient does not void (e.g., renal failure and on hemodialysis), assign code "7=Complete independence".

According to new FIM instructions (effective 1/1/02), all FIM items now have an "assessment time period". The person's score on a given FIM item is determined by his/her functional level during this "assessment time period"--a specified number of days prior to the evaluation. (FIM instructions prior to 1/1/02 did not indicate an assessment time period.) The assessment time period for all FIM items (except 8b and 9b-see below) is 3 days. Scoring reflects the patient's *poorest (most dependent) functioning* during the assessment time period¹. The evaluation is therefore not a snap-shot of the patient's performance at the time of evaluation, but a summary of performance over the entire assessment time period.

For items 8b and 9b (number of bladder accidents, number of bowel accidents), the assessment time period is 7 days-that is, the number of accidents is counted across the 7 days prior to the patient's FIM evaluation. Because the admission FIM evaluation must be done at the end of the first 3 days after rehab admission, the assessment time period therefore includes the 4 days prior to rehab admission. If information is not available from this 4-day period, then treat only the 3 days after rehab admission as the assessment time period. No adjustment in scoring of items 8b and 9b is made when the assessment time period is shorter than 7 days.

Wearing of eyeglasses causes Comprehension to be scored "6" only if the person's primary form of comprehension is visual (rather than auditory, which is usually primary).

See: Properties of the FIM instrument (COMBI) (<http://www.tbims.org/combi/FIM/fimprop.html>)

¹ However, the current training manual qualifies this, as follows: "The patient's score on measures of function should not reflect arbitrary limitations or circumstances imposed by the facility. For example, a patient who can routinely ambulate more than 150 feet throughout the day with supervision (score of 5 for FIM Locomotion: Walk/Wheelchair

item), but who is observed to ambulate only 20 feet at night to use the toilet because that is the distance from his/her bed, should receive a Walk score of 5 rather than a lower score" (IRF-PAI Training Manual 1/16/02, page III-4).

TRAINING:

FIM training will follow guidelines from the Uniform Data System (UDS). It is the responsibility of each center to assure that all staff who perform FIM assessments (Form I and Form II) are certified by a recognized credentialing organization (e.g., UDS, e-Rehab) and remain certified for the duration of the time that they collect data/assess patients for the TBIMS National Database.

CHARACTERISTICS OF DATA:

On 4/1/02 new fields were created to accept data collected with the new (1/1/02)IRF-PAI instructions. The old fields are still in the database. At present there are no calculated variables that merge old data and with new data. Calculated variables based on either old or new scoring are available.

SOURCE:

Uniform Data System for Medical Rehabilitation
232 Parker Hall
SUNY South Campus
3435 Main Street
Buffalo, New York 14214 3007
(716) 829 2076; FAX (716) 829 2080

The IRF-PAI instructions for the FIM are disseminated through the website of The Centers for Medicare and Medicaid Services. For information about the CMMS, go to: <http://www.cms.hhs.gov/researchers/projects/APR/2003/facts.pdf>.

EXAMPLE:

[It is not possible to display information in columns in the live syllabus, which is important for displaying the example for V152. A more neatly formatted example is available at:[FIM example \(http://syllabus/pdf/F1_FIM_Example.pdf\)](http://syllabus/pdf/F1_FIM_Example.pdf).]

Admission Discharge

SELF CARE ITEMS:

- 2 4 1. Feeding
- 1 4 2. Grooming
- 2 3 3. Bathing
- 3 5 4. Dressing Upper Body
- 3 5 5. Dressing Lower Body
- 2 4 6. Toileting

SPHINCTER CONTROL:

- 3 5 8. Bladder Management
 - 4 5 a. Level of assistance
 - 3 6 b. Frequency of accidents
- 4 5 9. Bowel Management
 - 4 6 a. Level of assistance
 - 5 5 b. Frequency of accidents

MOBILITY ITEMS:

- Transfers technique
- 3 4 10. Bed, Chair, Wheelchair
- 4 6 11. Toilet
- 3 3 12. Tub or Shower
 - Locomotion
 - 3 14a. Walking on admission
 - 3 14b. Wheelchair on admission
 - w 3 14. Walking/Wheelchair on discharge (w/c/9)
 - 3 3 15. Stairs

COMMUNICATIONS:

- b 7 b 7 17. Comprehension (a/v/b/9)
- v 6 v 6 18. Expression (v/n/b/9)

PSYCHOSOCIAL ADJUSTMENT ITEMS:

- 6 5 22. Social Interaction

COGNITIVE FUNCTION:

- 5 6 26. Problem Solving
- 4 5 27. Memory

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	Updated the URL at which the IRF-PAI manual is located.
2006-04-01	Added CODE "0" to syllabus. (Has been collected correctly all along (since 2002)because it has been in the data collection form).
2006-04-01	Changed symbols for "more than" to text so would be read correctly by Live Syllabus.
2004-07-01	Added information about training and certification to TRAINING (from 22f.Data Quality Guidelines).
2004-07-01	In DEFINITION fixed the link to the current (4/1/2004) IRF-PAI manual and added a description of where in the manual to look for FIM-related information.
2004-04-01	Updated link to IRF-PAI manual (4/1/04 version).
2004-04-01	Added links to COMBI.
2004-01-01	Added note about scoring Comprehension when person wears eyeglasses.

Date of last Revision	Description
2003-01-01	In SOURCE, updated the URL at which the IRF-PAI Training Manual can be viewed & printed.
2002-07-01	Revised 1st sentence in code "66" to read "Data not available with new (1/1/02) scoring."
2002-07-01	Updated SOURCE.
2002-07-01	Improved DEFINITION: added first two sentences; added reference to SOURCE; made explicit the requirement to follow current instructions.
2002-07-01	Added NOTE that score is to reflect poorest functioning during the assessment time period.
2002-07-01	Added note about admission score for 8b and 9b regarding use of 3-day rather than 7-day assessment period.
2002-04-01	Modified DEFINITION to refer to Center's instruction manual rather than Appendix.
2002-04-01	Corrected code 4 "Minimal Assist" -- ">75%" rather than ">75%".
2002-04-01	Added code "0=Activity does not occur" and NOTE about code "0".
2002-04-01	Added "66=Variable not available [data did not exist].
2002-04-01	Added to CODE 5 that "(pt does 100%)".
2002-04-01	Replaced in CODE 9 "doesn't perform task" with "or, for all items at discharge and for items 8, 8a, 8b,9,9a, 9b, and 17-27 at admission, if the activity does not occur."
2002-04-01	Added function modifier items "a=Level of assistance" and "b=Frequency of accidents" for #8 and 9, CODES for #8b and #9b, NOTE explaining scoring of #8 and 9, and EXAMPLES.
2002-04-01	Added NOTE about "assessment time period".
2002-04-01	Added note about how to score #8b if patient does not urinate.
2002-04-01	Added note about coding 14 (mode of locomotion) if patient both walks and uses wheelchair.
2002-04-01	Updated SOURCE.
2002-04-01	Added NOTE for #8 and 9 to obtain patient's function during last few days prior to discharge from acute hospital (4, 5, 6, or 7 days, depending on number of days after discharge the evaluation is done).
1999-10-01	Revised note and unknown code used if patient does not perform activity.
1999-07-01	FAM items deleted.
1998-04-15	Added note how to code optional FAM items not collected.
1998-04-01	Added note that 12 FAM items are now optional for collection. FIM items must be collected.
1995-07-01	Added code 8=not applicable, walking and not using wheelchair for item #14b (wheelchair admission) only.
1995-07-01	Clarified how to code person not walking at admission.
1995-07-01	Dropped mode of locomotion code "b" at discharge.
1995-03-24	Added unknown code for mode items 14, 17, and 18.
1994-09-13	Added unknown code.
1994-09-13	Added notes for coding clarification.
1994-09-13	Added admission score for walking and wheelchair.
1994-09-13	Deleted dates of assessment.
1994-09-13	Updated source to include FIM Version 4.0 and descriptors for #16, 23, and 25.
1994-02-01	Added codes for unknown.
1994-02-01	Deleted not applicable date code since Level I data collection has been discontinued.

Date of last Revision	Description
1994-02-01	Added notes for coding data collected out of 72 hour window.
1994-02-01	Updated source to include FIM Version 4.0.

QUESTIONS AND ANSWERS:

QUESTION:	Does the database calculate total admission FIM using walking score or wheelchair score? Is that score directly related to mode of locomotion at discharge? E.g., if walking at d/c then is the walking at adm score used in calculating total score? 11-26-2003
ANSWER:	Walking score at admission is used if person is walking at dc, and wheelchair at admission score is used if person is in wheelchair at dc. (This answer can be found in the Data Dictionary in the database.) 11-26-2003

FUNCTIONAL INDEPENDENCE MEASURE (FIM)

Variable 252

Date of last revision: 04/01/06

DEFINITION:

The FIM is a measure of disability. It is intended to measure what the person with the disability actually does, not what he or she ought to be able to do, or might be able to do if certain circumstances were different.

FIM data are to be collected according to the current (4/1/04) IRF-PAI coding instructions IRF-PAI Coding Instructions: 4/1/2004 version ([http://www.udsmr.org/pdfs/irfpaimanual040104%20\(1\).pdf](http://www.udsmr.org/pdfs/irfpaimanual040104%20(1).pdf)), supplemented by any further instructions in your syllabus. Information about the FIM can be found in the IRF-PAI manual in section III, pages 40-57, Appendix H, and pages 29-34. A copy of the FIM-related sections of this manual should be in your syllabus, in Appendix A. If it is not possible for your Center to follow the correct manual, notify the TBINDC.

Information about the FIM is available from COMBI at these two links: Introduction (COMBI) (<http://www.tbims.org/combi/FIM/index.html>); Background (COMBI) (<http://www.tbims.org/combi/FIM/fimbg.html>).

*IRF-PAI instructions used between 1/2002 and 4/2004

(<http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manualint.pdf>).

*Summary of the differences between the 4/2004 instructions and the 1/2002 instructions

(<http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manual040104.pdf>).

CODE:

7 Complete Independence (Timely, Safely)
6 Modified Independence (Extra time, device)
5 Supervision
4 Minimal Assist (subject does 75% *or more of task)
3 Moderate Assist (50 - 74% of task)
2 Maximal Assist (25 - 49% of task)
1 Total Assist (subject does less than 25% of task)
8 Not due this year [Code no longer used; data now collected in all follow-up years.]
9 Unknown

Items 8b and 9b

7 No accidents
6 No accidents, uses devise (catheter, ostomy)
5 One accident in the past 7 days
4 Two accidents in the past 7 days
3 Three accidents in the past 7 days
2 Four accidents in the past 7 days
1 Five or more accidents in the past 7 days
8 Not due this year [Code no longer used; data now collected in all follow-up years.]
9 Unknown - assessment not done
66 Variable did not exist

Item 14: Primary mode of locomotion

w Walking
c Wheelchair
8 Not due this year [Code no longer used; data now collected in all follow-up years.]
9 Unknown

Item 17: Primary mode of comprehension

a Auditory comprehension *more than 50% of the time
v Visual comprehension *more than 50% of the time
b Both used equally
8 Not due this year [Code no longer used; data now collected in all follow-up years.]
9 Unknown

Item 18: Primary mode of expression

v Verbal expression *more than 50% of the time
n Nonverbal expression *more than 50% of the time
b Both used equally
8 Not due this year [Code no longer used; data now collected in all follow-up years.]
9 Unknown

CHARACTERS:

1 numeric
2 numeric
1 alpha-numeric

NOTE:

All FIM items must be scored. Record what patient actually does. Every effort should be made to obtain the FIM assessments, however, if any items are not assessed, use code 9. Do not leave blanks.

According to the UDS Procedures for Scoring the FIM, "if the subject would be put at risk for injury if tested or does not perform the activity, enter 1". Use this same rule for the TBI Model Systems FIM data collection.

If at follow-up evaluation, patient is walking AND using a wheelchair, code 14 (mode) as the more frequently used mode of locomotion. Do not use the code "b=Both" (as is indicated by UDS instructions). Use all sources of information to determine the more frequent mode of locomotion at the time of evaluation and code either "w" or "c" as appropriate. If more frequent mode of locomotion cannot be determined, code "9".

For #8 (Bladder Management), if patient does not void (e.g., renal failure and on hemodialysis), assign code "7=Complete independence".

According to new FIM instructions (effective 1/1/02), all FIM items now have an "assessment time period". The person's score on a given FIM item is determined by his/her functional level during this "assessment time period"--a specified number of days prior to the evaluation. (FIM instructions prior to 1/1/02 did not indicate an assessment time period.) The assessment time period for all FIM items (except 8b and 9b-see below) is 3 days. Scoring reflects the patient's *poorest (most dependent) functioning* during the assessment time period¹. The evaluation is therefore not a snap-shot of the patient's performance at the time of evaluation, but a summary of performance over the entire assessment time period.

Wearing of eyeglasses causes Comprehension to be scored "6" only if the person's primary form of comprehension is visual (rather than auditory, which is usually primary).

"Level of assistance" (part a) and "Frequency of accidents" (part b) are recorded for #8 (Bladder Management) and #9 (Bowel Management). For items 8b and 9b, the assessment time period is 7 days--that is, the number of accidents is counted across the 7 days prior to the patient's FIM evaluation. If information is not available from the entire 7-day period, then record over the number of days (at least the 3 days prior to evaluation) for which information is available. No adjustment in scoring is made when the when the assessment time period is shorter than 7 days.

See: Properties of the FIM instrument (COMBI) (<http://www.tbims.org/combi/FIM/fimprop.html>)

¹ However, the current training manual qualifies this, as follows: "The patient's score on measures of function should not reflect arbitrary limitations or circumstances imposed by the facility. For example, a patient who can routinely ambulate more than 150 feet throughout the day with supervision (score of 5 for FIM Locomotion: Walk/Wheelchair item), but who is observed to ambulate only 20 feet at night to use the toilet because that is the distance from his/her bed, should receive a Walk score of 5 rather than a lower score" (IRF-PAI Training Manual 1/16/02, page III-4).

TRAINING:

FIM training will follow guidelines from the Uniform Data System (UDS). It is the responsibility of each center to assure that all staff who perform FIM assessments (Form I and Form II) are certified by a recognized credentialing organization (e.g., UDS, e-Rehab) and remain certified for the duration of the time that they collect data/assess patients for the TBIMS National Database.

CHARACTERISTICS OF DATA:

On 4/1/02 new fields were created to accept data collected with the new (1/1/02)IRF-PAI instructions. The old fields are still in the database. At present there are no calculated variables that merge old data and with new data. Calculated variables based on either old or new scoring are available.

SOURCE:

Uniform Data System for Medical Rehabilitation
232 Parker Hall
SUNY South Campus
3435 Main Street
Buffalo, New York 14214 3007
(716) 829 2076; FAX (716) 829 2080

The IRF-PAI instructions for the FIM are disseminated through the website of The Centers for Medicare and Medicaid Services. For information about the CMMS, go to: <http://www.cms.hhs.gov/researchers/projects/APR/2003/facts.pdf>.

EXAMPLE:**SELF CARE ITEMS:**

- 2 1. Feeding
- 1 2. Grooming
- 2 3. Bathing
- 3 4. Dressing Upper Body
- 3 5. Dressing Lower Body
- 2 6. Toileting

SPHINCTER CONTROL:

- 4 8. Bladder Management
 - 4 a. Level of assistance
 - 5 b. Frequency of accidents
- 5 9. Bowel Management
 - 6 a. Level of assistance
 - 5 b. Frequency of accidents

MOBILITY ITEMS

Transfers technique:

- 3 10. Bed, Chair, Wheelchair
- 4 11. Toilet
- 3 12. Tub or Shower

Locomotion:

- 3 14. Walking/Wheelchair (1/2/9)
- 3 15. Stairs

COMMUNICATIONS:

- 7 17. Comprehension (1/2/3/9)
- 6 18. Expression (1/2/3/9)

PSYCHOSOCIAL ADJUSTMENT ITEMS:

- 6 22. Social Interaction

COGNITIVE FUNCTION:

- 5 26. Problem Solving
- 4 27. Memory

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	Updated the link to the IRF-PAI instruction manual.
2006-04-01	Changed symbols for "more than" to text so would be read correctly by Live Syllabus.
2004-07-01	In TRAINING, added instructions regarding certification that are found in "22f.Data Quality Guidelines".
2004-07-01	In CODES, added back in the code for "Not due this year", plus a statement that the code is no longer used.
2004-07-01	In DEFINITION fixed the link to the current (4/1/2004) IRF-PAI manual and added a description of where to look in the manual for FIM-related information.
2004-04-01	Updated link to IRF-PAI manual (4/1/04 version).
2004-04-01	Added links to COMBI.
2004-01-01	Added note about scoring Comprehension when person wears eyeglasses.
2003-01-01	Deleted "less dynamic schedue" instruction (because FIM is now collected in all years due to reduced schedule).
2003-01-01	Deleted codes for "Not due", because data are now being collected in all follow-up years (due to less dynamic follow-up schedule).
2002-07-01	Updated SOURCE.
2002-07-01	Improved DEFINITION: added first two sentences; added reference to SOURCE; made explicit the requirement to follow current instructions.
2002-07-01	Added note to record what participant actually does.
2002-07-01	Added note about coding of #8 if participant does not void.
2002-07-01	Added note about assessment time period, including that score is to reflect poorest functioning.
2002-07-01	Added note about coding 8a, 8b, 9a, 9b, including coding of 8b and 9b if information is not available for the full 7-day assessment time period.
2002-07-01	Added code "66=Variable did not exist".
2002-04-01	Corrected the "mode" codes for #14, 17, 18 (alphabetic rather than numeric).
2002-04-01	In DEFINITION, added reference Center's instruction manual.
2002-04-01	For #8 and #9, added function modifier items "a=Level of assistance" and "b=Frequency of accidents", the codes for 8b and 9b, and examples for 8a,b & 9a,b.
2002-04-01	Added note about coding 14 (mode of locomotion) if patient both walks and uses wheelchair.
2002-04-01	Corrected code 4 "Minimal Assist" that ptn does greater than or equal to 75% rather than greater than 75%.
2002-04-01	Updated SOURCE.
2002-01-01	Added code "8=Not due" to #14 & 18 in these pages.
2001-07-01	Added definition of FIM.
2001-01-01	Changed collection schedule to years 1,2,5,10 and every 5 years thereafter.
1999-10-01	Revised note and unknown code used if patient does not perform activity.
1999-07-01	Deleted FAM items.
1998-04-15	Added note how to code optional FAM items not collected.
1998-04-01	Added note that the 12 FAM items are now optional for collection.
1995-07-01	Dropped mode of locomotion code "b" for item #14.
1995-03-24	Added unknown code for mode items 14,17 and 18.
1994-09-13	Added unknown code.
1994-09-13	Added notes for coding clarification.
1994-09-13	Deleted date of assessment.

Date of last Revision	Description
1994-09-13	Updated source to include FIM Version 4.0.
1994-09-13	Updated descriptors for #16, 23, and 25.

INCOME AND SOURCE

Variable 292c

Date of last revision: 04/01/06

DEFINITION:

Family income of person with brain injury and sources of non-employment income for person with brain injury at follow-up evaluation as reported by the best source of information, which is the person with brain injury unless he or she is considered unreliable or is not available.

(1) What is your total family income (approximate combined income of all members of the household)?

(2a) Do you receive income from the following sources? (This applies only to the person with the brain injury.)

(a) Supplemental Security Income (SSI)

(b) Supplemental Security Disability (SSD)

(c) Temporary Assistance to Needy Families (TA or TANF) (Formerly, Aid to Families with Dependent Children - AFDC)

(d) State/Local Welfare (incl. General Relief, Home Relief)

(e) Unemployment Insurance

(f) Workers' Compensation

(g) Private Insurance

(h) Income from Settlement

(i) Other non-employment sources

(2b (a-i)) DELETED - How much income a month do you receive from each source?

CODE:

Item (1):

01 \$9,999 or less

02 \$10,000-\$19,999

03 \$20,000-\$29,999

04 \$30,000-\$39,999

05 \$40,000-\$49,999

06 \$50,000-\$59,999

07 \$60,000-\$69,999

08 \$70,000-\$79,999

09 \$80,000-\$89,999

10 \$90,000-\$99,999

11 \$100,000 or more

55 Data collected before codes 06-11 existed; data exist in calculated variable "income".

66 Not due this year. [Code no longer used; data now collected at all follow-ups.]

77 Refused

88 N/A-no *income

99 Unknown

Items (2a: a-i):

1 No

2 Yes

7 Not due this year. [Code no longer used; data now collected in all follow-up years.]

9 Unknown

CHARACTERS:

2 numeric

1 numeric

NOTE:

*To collect this variable, see the instructions and advice in Appendix D, document "17c.Scripts and Strategies for Collecting Income Variable".

For source: "Settlement", exclude legal fees to be paid out of the settlement.

This variable can be collected along with V2111.

CHARACTERISTICS OF DATA:

All data on income level are available in the calculated variable "income". In this variable, new data (starting 7/1/01) are merged with old data by transforming the new codes (06-11) into the old code "06".

In 2003, the TBIMS had difficulty obtaining this information (24% missing data). Eleven Model Systems had 10% or more missing data.

EXAMPLE:

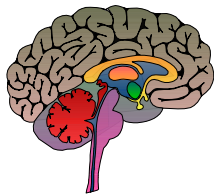
Person with brain injury has an annual family income of \$16,500, and receives \$1,274.35 a month from an account established with money obtained through a lawsuit associated with the injury.

- (1) 02
- (2a) (1) 1
- (2) 1
- (3) 1
- (4) 1
- (5) 1
- (6) 1
- (7) 1
- (8) 2
- (9) 1

VARIABLE HISTORY:

Date of last Revision	Description
2006-04-01	Added NOTE to refer to appendix doc 17c for wording and advice in collecting this variable.
2005-01-01	Changed label of code "88" from "N/A-no salary" to "N/A-no income" On data collection form, changed "N/A-not employed" to "N/A-no income".
2004-07-01	In DEFINITION, removed reference to amount of income from supplemental sources.
2004-07-01	In CODES, added back the codes for "Not due this year" plus a statement that the codes are no longer used.
2004-04-01	Added CODES for (2a).
2004-04-01	Corrected number of characters (was 10 iems, 1 character each).
2004-04-01	Corrected example so item (1) has two characters (rather than one).
2004-04-01	Replaced reference to "annual evaluation" with "follow-up evaluation".
2004-01-12	Added to code label for code 55: "data exist in calculated variable "inc"".
2003-01-01	Deleted v292c2b variables (amount of income from non-employment sources) and made appropriate changes in syllabus.
2003-01-01	Deleted code "66=Not due" (because this variable is always collected in the new,less frequent follow-up schedule).
2003-01-01	Deleted the question that identifies respondent as the person with TBI or significant other.

Date of last Revision	Description
2002-04-01	Corrected example so code is "99998" rather than "8".
2002-04-01	Added code "55= Data collected before codes 06-11 existed". (Data on such cases are available only in a calculated variable that merges current data with data based on the original 01-06 codes.)
2002-04-01	Updated CODE 3 label to replace "AFDC" with "TA".
2002-01-01	Added note that this variable can be collected along with V211i.
2002-01-01	In example, changed "0" to "8" in 2b when 2a = 1(No).
2002-01-01	Added note about calculated variable that includes new and old cases.
2002-01-01	Added code "99995 Variable did not exist".
2002-01-01	Corrected syllabus: code 99998 changed from "NA not due this year" to "NA no income from this source", which matches Form II.
2001-10-01	Added income codes to match V211i.
2001-08-20	Added note about excluding legal fees from settlement amount.
2001-07-01	Added amount of income obtained monthly from each non-employment source.
2001-07-01	Integrated with V293c to create a "best source of information" variable. (Initially, was named V300c, but reverted to V292c plus V292c1 before variable was renamed in the database.)
1998-04-15	Changed code N/A, not due this year or no SO.
1996-04-01	Added code 7 for additional CIQ questions not due this year.
1994-08-19	Clarified #1 by adding "total" family income.
1994-08-19	Removed statement from #2 "in addition to employment income".



TRAUMATIC BRAIN INJURY MODEL SYSTEMS NATIONAL DATABASE SYLLABUS

**Funded by the National Institute on
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National Data Center
Kessler Medical Rehabilitation Research and
Education Corporation**

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**National Institute on Disability and
Rehabilitation Research**

**Program Manager:
*Ruth Brannon, MSPH***

Version 10.3
April 2006

TRAUMATIC BRAIN INJURY MODEL SYSTEMS NATIONAL DATA BASE SYLLABUS

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TRAUMATIC BRAIN INJURY MODEL SYSTEMS
DATA COLLECTION FORM FOR INITIAL HOSPITALIZATION AND REHABILITATION - FORM I
Use for cases first admitted to System acute hospital 4/1/2006 or later, until replaced by a newer Form I.

100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.3

121. HISTORY OF TBI:

1=No 2=Yes 9=Unknown

122. PREMORBID CONDITIONS

At the time of injury did the patient have any of these following long-lasting conditions?

a. Blindness, deafness, or a severe vision or hearing impairment.

1=No 2=Yes 9=Unknown

b. A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying.

1=No 2=Yes 9=Unknown

123. PREMORBID LIMITATIONS

At the time of injury was the patient having difficulty doing any of the following activities due to a physical, mental, or emotional condition that had been present for at least 6 months?

a. Learning, remembering, or concentrating

1=No 2=Yes 9=Unknown

b. Dressing, bathing, or getting around inside the home

1=No 2=Yes 9=Unknown

c. Going outside the home alone to shop or visit a doctor's office

1=No 2=Yes 9=Unknown

d. Working at a job or business

1=No 2=Yes 9=Unknown

TRAUMATIC BRAIN INJURY MODEL SYSTEMS
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100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.3

151. DISABILITY RATING SCALE:

	<u>Rehab</u>		<u>Rehab</u>		
	<u>Admit</u>		<u>Disch</u>		
1. Eye Opening	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0=Spontaneous 2=To Pain 9=Unknown 1=To Speech 3=None
2. Communication Ability	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0=Oriented 2=Inappropriate 4=None 1=Confused 3=Incomprehensible 9=Unknown
3. Motor Response	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0=Obeying 2=Withdrawing 4=Extending 1=Localizing 3=Flexing 5=None 9=Unknown
4. Feeding	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0.0=Complete 1.5=Btw partial/minimal 3.0=None 0.5=Btw complete/partial 2.0=Minimal 1.0=Partial 2.5=Btw minimal/none 9.9=Unknown
5. Toileting	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
6. Grooming	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
7. Level of Functioning	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0.0=Completely Independent 3.0=Moderately Dependent 0.5=Btw Comp, Indep/Spec Environ 3.5=Btw Mod Dep/Mark Dependent 1.0=Independent-Special Environ 4.0=Markedly Dependent 1.5=Btw Spec Envir/Mild Dependent 4.5=Btw Mark Dep/Tot Dependent 2.0=Mildly Dependent 5.0=Totally Dependent 2.5=Btw Mild Dep/Mod Dependent 9.9=Unknown
8. "Employability"	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	0.0= Not Restricted 2.0=Sheltered Wrkshop/Non-comp 0.5= Btw not restrict/select jobs 2.5=Btw Sheltered/Not Employable 1.0= Selected Jobs/Competitive 3.0=Not Employable 1.5= Btw select jobs/sheltered wkshp 9.9=Unknown

*Items 4,5,6 indicate the effects of cognitive disability—extent to which person knows how and when to feed, toilet, groom self.
 Items 7,8 indicate the effects of physical and cognitive disability.*

TRAUMATIC BRAIN INJURY MODEL SYSTEMS
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100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.3

152. FUNCTIONAL INDEPENDENCE MEASURE:

SELF CARE ITEMS:

ADMISSION DISCHARGE

1. Feeding	<input type="text"/>	<input type="text"/>
2. Grooming	<input type="text"/>	<input type="text"/>
3. Bathing	<input type="text"/>	<input type="text"/>
4. Dressing Upper Body	<input type="text"/>	<input type="text"/>
5. Dressing Lower Body	<input type="text"/>	<input type="text"/>
6. Toileting	<input type="text"/>	<input type="text"/>

SPHINCTER CONTROL:

8. Bladder Management	<input type="text"/>	<input type="text"/>
a. Level of assistance.....	<input type="text"/>	<input type="text"/>
b. Frequency of accidents.....	<input type="text"/>	<input type="text"/>
9. Bowel Management	<input type="text"/>	<input type="text"/>
a. Level of assistance.....	<input type="text"/>	<input type="text"/>
b. Frequency of accidents	<input type="text"/>	<input type="text"/>

7=Complete Independence (Timely, safely)
 6=Modified Independence (Extra time, device)
 5=Supervision (pt does 100%)
 4=Minimal Assistance (pt ≥75% of task)
 3=Moderate Assistance (pt 50-74% of task)
 2=Maximum Assistance (pt 25-49% of task)
 1=Total Assistance (pt <25% of task)
 0=Activity does not occur. (Use only at admission and only for #1-6,10-15; else use code "9".)
 8=N/A, pt walking/not using wheelchair. (only for item #14b)
 9=Unknown / assessed at >72 hours / activity does not occur (see instructions in code "0", above).
 66=Data not available with new (1/1/02) scoring. (Use only at admission and only for #1-8a, 9, 9a, 10-15)

MOBILITY ITEMS:

Transfer Technique

10. Bed, Chair, Wheelchair	<input type="text"/>	<input type="text"/>
11. Toilet	<input type="text"/>	<input type="text"/>
12. Tub or Shower	<input type="text"/>	<input type="text"/>

Locomotion

14a. Walking on admission	<input type="text"/>	
14b. Wheelchair on admission	<input type="text"/>	
14. Walking/Wheelchair-discharge (w/c/9)	<input type="text"/>	<input type="text"/>
15. Stairs	<input type="text"/>	<input type="text"/>

Use with 8b and 9b
 7=No accidents
 6=No accidents; uses device (catheter, ostomy)
 5=One accident in the past 7 days
 4=Two accidents in the past 7 days
 3=Three accidents in the past 7 days
 2=Four accidents in the past 7 days
 1=Five or more accidents in the past 7 days
 9= Unknown / assessed at >72 hours
 66=Variable did not exist

COMMUNICATIONS:

17. Comprehension ...(a/v/b/9)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
18. Expression (v/n/b/9)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

PSYCHOSOCIAL ADJUSTMENT ITEMS:

22. Social Interaction	<input type="text"/>	<input type="text"/>
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COGNITIVE FUNCTION:

26. Problem Solving	<input type="text"/>	<input type="text"/>
27. Memory	<input type="text"/>	<input type="text"/>

TRAUMATIC BRAIN INJURY MODEL SYSTEMS
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100. SYSTEM/SUBJECT ID: ENTER INTO DATABASE **10.3**

192h. PREMORBID HISTORY OF PENAL INCARCERATIONS WITH CONVICTION FOR FELONY:

1=No 2=Yes 9=Unknown

192i(3). PREMORBID HISTORY OF LEARNING AND/OR BEHAVIOR PROBLEMS IN SCHOOL:

Officially classified as Special Education student

1=No 2=Yes 9=Unknown

*** END ***

9a. Guidelines and Strategies for Maximizing Follow-up

4/1/2006

This form should be used as a checklist when a subject cannot be reached for data collection. If the data collector cannot reach a subject after 2 weeks of attempted contact, methods 1 – 9 are to be employed until the subject is reached or until the window closes. Pages 1 & 2 are minimum expectations for methods that are to be employed to find a lost subject (with the exception of items that are unavailable to a center or subject situation). These methods can be applied in any sequence to best fit the circumstances of each center. The “Additional Strategies” on pages 4 & 5 are recommended for each site to consider as it applies to them, but are not required.

PROCEDURE for FOLLOW UP CONTACT

Window Opens: ___/___/___ Window Closes: ___/___/___ Subject ID #: _____

1. PHONE CONTACT

Success?

Staff initials Date completed

4 attempts during normal business hours (at different times of the day)

4 attempts during weekday evenings (on different days of the week)

4 attempts during weekends

2. DIRECTORY ASSISTANCE

Success?

Call directory assistance (411) in last known city of residence, and surrounding areas, to obtain updated information about subject and contacts.

3. INTERNET SITES

Success?

Superpages.com, Anywho.com, theultimates.com
Search engines (ex., Google and Yahoo)

4. SEND LETTER TO SUBJECT and CONTACTS

Success?

Letter to subject at last known address

Letter to contacts at last known address

Send all letters via first class mail, marked ‘Forwarding & Address Correction Requested’, so that you can make note of any address changes.

5. HOSPITAL INFORMATION/MEDICAL RECORDS	Success? <input type="checkbox"/>
	Staff initials Date completed

Check for post-discharge contact and updated information in the outpatient section of medical record. _____

Check appointment schedules, outpatient clinic lists, and/or other hospital database for new information. _____

6. CONSULT HOSPITAL STAFF INVOLVED WITH PATIENT	Success? <input type="checkbox"/>
--	-----------------------------------

Ask social workers, clinic staff, and other hospital employees involved with the subject's care for additional or updated information. _____

7. DEATH SEARCH	Success? <input type="checkbox"/>
------------------------	-----------------------------------

Contact Social Security Administration at (800) 772-1213 or <http://www.ancestry.com/ssdi/advanced.htm>

- need SS #
- Determine subject's living status

Local online newspaper obituary search _____

8. INMATE SEARCH	Success? <input type="checkbox"/>
-------------------------	-----------------------------------

County Jail _____

State Prison – Department of Corrections

- Info required: full name and either SS# or DOB

Federal Prison System

- (202) 307-3126
- Call 10:30am to 4:30PM EST
- Info required: full name, DOB, and SS#

9. LOCATION SERVICES	Success? <input type="checkbox"/>
-----------------------------	-----------------------------------

Accurint and/or Comserv are recommended by many sites (there is a fee involved for these services). _____

UPDATED CONTACT INFORMATION

PATIENT INFORMATION

Street Address: _____

City, State, Zip: _____

Home #: _____ **Cell #:** _____ **Work #:** _____

Email address: _____

Additional Comments/Information: _____

CONTACT INFORMATION

Name/Relation to subject: _____

Street Address: _____

City, State, Zip: _____

Home #: _____ **Cell #:** _____ **Work #:** _____

Email address: _____

Additional Comments/Information: _____

CONTACT INFORMATION

Name/Relation to subject: _____

Street Address: _____

City, State, Zip: _____

Home #: _____ **Cell #:** _____ **Work #:** _____

Email address: _____

AdditionalComments/Info: _____

ADDITIONAL STRATEGIES FOR MAXIMIZING FOLLOW UP CONTACT

Before Discharge from Rehabilitation Facility

- **Ask participant to tell his/her contacts that the study site has been given their name, the reasons why, and that they may be contacted in the future.**
- **Give business cards, magnet, or pens with logo/name of site to participant and/or contacts.**
- **Note the participant's professional organizations (bar associations, licensures, etc.)**
- **Ask for a current list of healthcare providers for participant, especially primary care physician. Obtain permission/signed release forms from the subject if assistance in information gathering is needed in the future.**

Hospital Contacts

- **Contact billing office and/or hospital pharmacy for recent contact information and address changes.**
- **Work with doctors to schedule rehab appointments that will coincide with follow up windows.**
- **Regularly check clinic appointment schedules for opportunities to make contact with subject. Even if window is not open at the time of the clinic visit, this is a good time to confirm current contact information and just say hello.**

Possible Contact Updates

- **Contact Voter Registration/Electoral Registries**
- **Contact Public Health Nurses in last known county of residence.**
- **Contact VNA (Visiting Nurse Association) or CCS (California Children's Services – participant must be 18 or under at time of injury) if available in your area.**
- **Check nursing homes in last known area of residence.**
- **Contact the Vital Statistics Department/Registry of Births, Deaths, and Marriages (there is a fee to obtain this information) <http://www.vitalrec.com/>**

Phone/Mail Contact

- **Mail reminder cards a few weeks before window opens, to let them know they will be hearing from you soon.**
- **Begin attempts to contact immediately when window opens.**
- **Send 'attempt to contact' letters via Certified mail.**
- **Ask rehab doctor for updated contact information, and/or have doctor contact via mail/phone.**

- **During follow up calls, ask participant if they have plans to move, or any new contact information, such as a new work, cell phone number, or email address.**
- **When attempting to reach participant by phone for follow up data collection, use a land line with a TBI Model System Identifier, rather than using a cell phone or a blocked identifier (as is the case with many hospital lines).**
- **Have the same staff member complete all follow up calls, in the interest of building rapport and trust between the data collector and the subject. If possible, have the person who consented the subject also complete that subject's follow up.**

Other methods

- **Develop monthly or quarterly newsletters for distribution to all the subjects enrolled in your site. Send these via first class mail, so that they will be returned to your site with changed address information.**
- **Send birthday and/or holiday cards (also sent first class).**
- **Give gift certificates or monetary rewards for completing follow up data collection, or for notifying site of an address/phone number change.**
- **Discuss status of subject tracking at weekly/monthly meetings. Review call attempts, lost subjects, open and closed windows, and additional strategies for data collection.**
- **Call on a rainy day (especially Saturday)!**

GUIDELINES FOR COLLECTION OF FOLLOW-UP DATA

4/1/2006

1. For the first year of follow-up, data collection should occur within 2 months before to 2 months after the anniversary date of the injury. For follow-up year 2, data collection should occur within 3 months before to 3 months after the anniversary date of the injury. For follow-up years 5 and thereafter, data collection should occur within 6 months before to 6 months after the anniversary date of the injury.
2. If a participant expires during initial inpatient rehabilitation, no Form II is to be completed.
3. Follow-up should be attempted according to the TBIMS schedule for every participant (person with TBI) for whom a Form I was submitted, unless the participant was reported as expired or refused (withdrew authorization to collect data) in a prior Form II.
4. The primary source of information for the annual follow-up should be the participant. If the participant does not or cannot respond to certain questions or to all questions, then the significant other who knows the participant best becomes the participant's proxy and may answer for the participant.

A "significant other" is someone who knows the participant well and is available, able, and willing to answer questions reliably about that individual's daily life. This person is typically a family member, but is not required to be related to the participant or to live with that person. A significant other may be a non-traditional person such as a nurse at the facility where the person resides, a legal/public guardian, a roommate, etc. The significant other must know the participant sufficiently well to answer questions accurately. The significant other may qualify to answer some questions but not others.

Questions that the proxy cannot answer reliably are coded as "unknown". The proxy must not answer V292g:SATISFACTION WITH LIFE (see #8, below).

5. When a person has expired or has withdrawn authorization (i.e., definitive refusal to continue participation) since the last follow-up (or since Form I data collection) or is incarcerated, a limited amount of information--shown in the table below--is to be entered onto the Form II and submitted. Instructions specific to expired participants, refusals, and incarcerated participants follow the table.



**Form II Information to be Submitted
if Expired, Refused, or Incarcerated**

VARIABLE	EXPIRED	WITHDREW	INCARCERATED
200	Center ID Subject ID Follow-up year	Center ID Subject ID Follow-up year	Center ID Subject ID Follow-up year
20Aa(a,b)	[ICD-9 code]	888.88	888.88
20Aa(c)	[E code]	88888	88888
20Ab	8	8	8
20Ac	8	8	8
20Ad	09	05	04
20Ae	88	88	88
201a	06/06/6666	05/05/5555	07/07/7777
201b	[expiration date]	08/08/8888	08/08/8888
209	blank	blank	04
all other variables	blank	blank	blank

- **EXPIRED or WITHDREW AUTHORIZATION.** For participants who have expired or who refused to continue with the study, submit the information shown in the table above. If the data collector learns prior to window opening that the person expired or refused, the above information may be submitted any quarter up to and including the quarter in which the submission would have been due if the participant were still in the study. Regardless of the quarter in which this information is submitted, the “follow-up year” (last 2 digits of V200) is coded as the year of the follow-up that would have been due (e.g., year 01, year 02, year 05, etc). For expired participants, no additional Form II’s are ever submitted. For refusals, data collection may start again if the participant again agrees to participate. In this case, complete Form II data should be submitted for the follow-up year in which the participant again agreed to participate, and the data shown in the table above is submitted for the interim follow-up years in which no Form II’s had been submitted due to refusal.
- **INCARCERATED.** Data should not be collected from the participant or from a proxy while the participant is incarcerated. *Find out if the incarcerated person will be released prior to the closing of the data collection window (only if obtaining such information is acceptable to your IRB and Investigator). If



the person will be released before the window closes, then complete Form II data should be collected between the time of release and window closing. Do not collect follow-up information about participants who are incarcerated throughout the follow-up window. For these participants--and for participants who were released prior to window closing but about whom data was not able to be collected--submit the data shown in the table above, according to the submission schedule in the syllabus.

6. Follow-up evaluations that have not been completed by the time the data collection window closes are to be completed as soon as possible. Data from such evaluations must not be submitted if collected more than two weeks after the window closes.
7. Missing data may not be filled in using data obtained outside the follow-up window. Data collected outside the follow-up window may not be added to Form II's that were originally submitted without data. Data may be obtained outside the follow-up window from sources that had collected the data within the follow-up window--for example, data collected by clinicians during a clinical follow-up which occurred during the follow-up window.
8. If phone contact with the participant is not possible, all information except V292g:SATISFACTION WITH LIFE should be collected from a significant other by phone. The participant should be sent the V292g:SATISFACTION WITH LIFE items by mail, along with a self-addressed return envelope.
9. If telephone contact with the participant and significant others is not successful, the participant should be sent the mailout version of the Form II after personalized information (name, enrollment date, name and contact information of Form II data collector) has been added to the form, along with a self-addressed return envelope.
10. If adequate data are not obtained from the participant by telephone or by mailout, the mailout Form II should be sent to the significant other after personalized information (name, enrollment date, name and contact information of Form II data collector) has been added to the form, along with a self-addressed return envelope.

09c.Guidelines for Follow-up Data Collection_060321a



TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

Follow-up evaluations are done in years 1, 2, 5, 10 and every fifth year thereafter. All items are collected at every follow-up. Items not collected due to skip instructions must be filled in with the appropriate "N/A" code.

20Aa. LIVING STATUS: a. ICD-9-CM Primary . 777.77=Expired cause unknown
 888.88=N/A-alive/no other internal cause/external cause
 999.99=Unknown if expired
 b. ICD-9-CM Secondary .
 c. E-code E . 77777 =Expired cause unknown
 88888 =NA-alive/not an external cause of death
 99999 =Unknown if expired
 (Use small boxes only w/ missing data codes)

20Ab. METHOD OF INTERVIEW DATA COLLECTION – PERSON WITH TBI :
 1=In-person 2=Telephone 3=Mailing 8=No data from person w/ TBI 4=NA-out of window, secondary source

20Ac. METHOD OF INTERVIEW DATA COLLECTION – SIGNIFICANT OTHER:
 1=In-person 2=Telephone 3=Mailing 8=No data from SO (use if incarcerated) 4=NA-out of window, secondary source

20Ad. REASON PERSON WITH TBI NOT PROVIDING DATA:
 03=Physically or cognitively unable 07=Lost to follow-up
 04=Not available 08=Language barrier 88=N/A-data provided by person with TBI
 05=Stated refusal 09=Expired 99=Unknown reason why no data provided by person w/ TBI
 06=No response to contact

20Ae. IDENTITY OF SIGNIFICANT OTHER:
 01=Spouse 04=Adult child 08=Friend
 02=Parent(s) 05=Boy/girlfriend 09=Professional caregiver
 03=Sibling 07=Other relative 77=Other 88=N/A-no SO interviewed

201. DATES: (MM/DD/YYYY)
 Follow-up evaluation Date: / /
 Date of Death: / /
 05/05/5555=N/A-withdrew authorization
 06/06/6666=N/A-deceased
 07/07/7777=N/A-other (including incarcerated)
 09/09/9999=Unknown date of evaluation
 07/07/7777=Person expired, unk date
 08/08/8888=N/A-alive
 09/09/9999=Unknown if person expired

QUESTIONS FOR BEST SOURCE (person with TB unless unreliable/unavailable)

207. MARITAL STATUS: 1=Single (never married) 3=Divorced 5=Widowed 9=Unknown
 2=Married/Cohabit >= 7yrs 4=Separated 7=Other

208. PRIMARY PERSON LIVING WITH:
 01=Alone 05=Child aged <21 09=Other patients
 02=Spouse 06=Child >= 21/other rel 10=Other residents
 03=Parent(s) 07=Roommate/friend 11=Personal care attendant
 04=Sibling 08=Significant other 77=Other 99=Unknown

209. RESIDENCE:
 01=Private 05=Hotel 09=Other hospital
 02=Nursing home 06=Homeless 10=Subacute care
 03=Adult Home 07=Acute hospital 77=Other
 If "04", code V201a as 07/07/7777 04=Correct. Inst. 08=Rehab hospital 99=Unknown

209a. ZIP CODE:
 8=N/A-lives outside US 9=Unknown

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

210a. YEARS OF EDUCATION:

- | | | | |
|-------------------|-------------|--|---------------------------------------|
| 01= \leq 1 year | 06=6 years | 11=11 years/ 12 years, no diploma | 16=Bachelors degree |
| 02=2 years | 07=7 years | 12=High school diploma | 17=Work toward Master’s dgr, no dpl |
| 03=3 years | 08=8 years | 13=Work toward Associate’s dgr, no dpl | 18=Master’s degree |
| 04=4 years | 09=9 years | 14=Associate’s degree | 19=Work toward doctoral level, no dpl |
| 05=5 years | 10=10 years | 15=Work toward Bachelor’s degree, no dpl | 20=Doctoral level degree |
| | | | 77=Other 99=Unknown |

210b. GED:

- 1=No 2=Yes 3=N/A-HS diploma or attended college 9=Unknown

211a. EMPLOYMENT STATUS:

CODING PRIORITY: competitively empl, degree-oriented ed, taking care of house/fam, job-directed/on-the-job training,

supported empl, sheltered empl, non-directed coursewrk, volunteer wrk, retiremt (age), retiremt (disab), no productive activity.

- | | | | |
|---------------------------|---------------------------------|--------------------------|-------------------------------|
| 02=Full-time student | 07=Taking care of house or fam. | 11=Volunteer | 15=Retired (other) |
| 03=Part-time student | 08=Special employment | 12=Retired (disability) | 16=On leave from work, no pay |
| 04=Special education | 09=Retired (age) | 13=Unempl. (not looking) | 55=Other |
| 05=Competitively employed | 10=Unemployed (looking) | 14=Hospitalized, no pay | 77=Refused 99=Unknown |

777=Refused

211b. HOURS (PER WEEK) PAID COMPETITIVE EMPLOYMENT:

(Enter data if 211a=05, otherwise enter the correct missing data code.)

- 888=N/A-nt currently comp. employed
999=Unknown

If 211a NOT=05, ask: Have you ever been competitively employed since your injury?

If YES, go to 211c

If NO and 211a NOT=08, go to 221

If NO and 211a=08, go to 212

211c. DATE OF FIRST COMPETITIVE EMPLOYMENT:

(Obtain this answer only once. Estimate day, if unknown.)

M M D D Y Y Y Y

1) When did you begin competitive employment following your injury? / /

08/08/8888 = N/A-no post-injury competitive employment

07/07/7777 = Refused

08/08/8899 = N/A-employment started prior to last annual evaluation

09/09/9999 = Unknown date of 1st employment

If competitive employment started prior to this year, ask: Have you been competitively employed in the past year?

If YES, go to 211d

If NO and 211a NOT=05 or 08, go to 221

If NO and 211a=08, go to 212

211d. WEEKS OF PAID COMPETITIVE EMPLOYMENT:

1) Ask at one year: During the year after your injury and since you began competitive employment, how many weeks have you worked?

77=Refused

88=NA-no compet. employmt

99=Unknown

Ask other years: In the past year since your return to work, during how many weeks were you competitively employed?

211i. ANNUAL EARNINGS OF PERSON:

(Enter data if V211a=05, otherwise enter the correct missing data code.)

1) What is your total annual salary, based on all jobs held at the time of annual evaluation?

(Cue respondent that salary=total earnings from all competitive employment, but not from nonemployment sources.)

- | | | | |
|-------------------------------|----------------------|----------------------|---------------------------------------|
| 01=\$9,999 or less (employed) | 05=\$40,000-\$49,999 | 09=\$80,000-\$89,999 | 77=Refused |
| 02=\$10,000-\$19,999 | 06=\$50,000-\$59,999 | 10=\$90,000-\$99,999 | 88=N/A-not currently compet. employed |
| 03=\$20,000-\$29,999 | 07=\$60,000-\$69,999 | 11=\$100,000 or more | 99=Unknown |
| 04=\$30,000-\$39,999 | 08=\$70,000-\$79,999 | | |

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

212. CENSUS OCCUPATIONAL CATEGORY:

(Enter data if V211a=05 or 08, otherwise code 88)

- | | | |
|---------------------------|--------------------------------------|--|
| 01=Exec/Admin/Manager | 06=Private household | 11=Machine Operators/Assemblers/Inspectors |
| 02=Professional specialty | 07=Protective services | 12=Transportation/Material Moving |
| 03=Technicians/support | 08=Service, other | 13=Handlers/Equip Cleaner/Helpers/Laborers |
| 04=Sales | 09=Farm/Forest/Fish | 14=Military |
| 05=Adm support/Clerical | 10=Precision Production/Craft/Repair | 77=Refused |
| | | 88=N/A |
| | | 99= Unknown |

CLINICAL ASSESSMENTS

221. DATE OF SUBSEQUENT TRAUMATIC BRAIN INJURY:

M M Y Y Y Y

 /

77/7777=had subsequent TBI date unknown
88/8888=no subsequent TBI

99/9999=unknown if subsequent TBI

QUESTIONS FOR BEST SOURCE

251. DISABILITY RATING SCALE:

1. Eye Opening.....	<input type="text"/>	0=Spontaneous 1=To Speech	2=To Pain 3=None	9=Unknown
2. Communication Ability.....	<input type="text"/>	0=Oriented 1=Confused	2=Inappropriate 3=Incomprehensible	4=None 9=Unknown
3. Motor Response	<input type="text"/>	0=Obeying 1=Localizing	2=Withdrawing 3=Flexing	4=Extending 5=None 9=Unknown
4. Feeding	<input type="text"/> <input type="text"/>	0.0=Complete 0.5=Btw Complete/Partial 1.0=Partial	1.5=Btw Partial/Minimal 2.0=Minimal 2.5=Btw Minimal/None	3.0=None 9.9=Unknown
5. Toileting	<input type="text"/> <input type="text"/>			
6. Grooming	<input type="text"/> <input type="text"/>			
7. Level of Functioning	<input type="text"/> <input type="text"/>			
8. "Employability"	<input type="text"/> <input type="text"/>	0.0=Not Restricted 0.5=Btw not restricted/Selected jobs 1.0=Selected Jobs/Competitive 1.5=Btw selected jobs/sheltered wkshp	3.0=Moderately Dependent 3.5=Btw Mod Dep/Mark Dependent 4.0=Markedly Dependent 4.5=Btw Mark Dep/Tot Dependent 5.0=Totally Dependent 9.9=Unknown	2.0=Sheltered Workshop/Non-competitive 2.5=Btw Sheltered/Not Employable 3.0=Not Employable 9.9=Unknown

Items 4,5,6 indicate the effects of cognitive disability—extent to which person knows how and when to feed, toilet, groom self. Items 7,8 indicate the effects of physical and cognitive disability.

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – **FORM II**

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

297. SUPERVISION RATING SCALE (Refer to syllabus for definitions and clarification.)

Independent

01=Alone, Independent

02=Unsupervised at night, sometimes during day

<input type="text"/>	<input type="text"/>
----------------------	----------------------

Overnight supervision

03=Supervised only at night

Part Time supervision

04=Supervised at night and selected day times.

05=Supervised at night and part-time during day; not supervised during working hours (full time)

06=Supervised at night and most of day except for few unsupervised hours.

07=Only unsupervised for periods less than one hour at a time.

Full-time indirect supervision

08=Full time indirect supervision; does not check more than once every 30 minutes

09=Same as 08, and requires overnight safety precautions (lock, etc.)

Full time direct supervision

10=Full time direct supervision; checked more than once every thirty minutes

11=Full time direct supervision in confined, controlled setting.

12=Same as 11, but with constant visual watch

13=Person is in physical restraints.

99=Unknown

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

252. FUNCTIONAL INDEPENDENCE MEASURE:

SELF CARE ITEMS:

- 1. Feeding
- 2. Grooming
- 3. Bathing
- 4. Dressing Upper Body
- 5. Dressing Lower Body
- 6. Toileting

7=Complete Independence (Timely, safely)
 6=Modified Independence (Extra time, device)
 5=Supervision
 4=Minimal Assistance (pt ≥75% of task)
 3=Moderate Assistance (pt 50-74% of task)
 2=Maximum Assistance (pt 25-49% of task)
 1=Total Assistance (pt <25% of task; doesn't do)
 9=Unknown/assessment not done
 66=Variable did not exist (8a,9a only)

SPHINCTER CONTROL:

- 8. Bladder Management.....
- a. Level of assistance
- b. Frequency of accidents
- 9. Bowel Management.....
- a. Level of assistance
- b. Frequency of accidents

Use with 8b and 9b

7=No accidents
 6=No accidents; uses device (catheter, ostomy)
 5=One accident in the past 7 days
 4=Two accidents in the past 7 days
 3=Three accidents in the past 7 days
 2=Four accidents in the past 7 days
 1=Five or more accidents in the past 7 days
 9=Unknown/assessment not done
 66=Variable did not exist (8b,9b only)

MOBILITY ITEMS:

Transfer Technique

- 10. Bed, Chair, Wheelchair
- 11. Toilet
- 12. Tub or Shower

Locomotion

- 14a. Walking/Wheelchair (w/c/9).....
- 15. Stairs

COMMUNICATIONS:

- 17. Comprehension...(a/v/b/9).....
- 18. Expression.....(v/n/b/9).....

PSYCHOSOCIAL ADJUSTMENT ITEMS:

- 22. Social Interaction

COGNITIVE FUNCTION:

- 26. Problem Solving.....
- 27. Memory

273. REHOSPITALIZATION(S): (Code one reason for each hospitalization in the past year) 1.

- 00=Rehabilitation (inpatient) 05=Orthopedic
- 01=Seizures 06=General Health Maintenance or OB/GYN
- 02=Neurologic disorder (non-seizure) 07=Other not specified above
- 03=Psychiatric 08=NA-no rehospitalizations or no further rehospitalizations
- 04=Infectious 09=Unknown--rehospitalized but reason is unknown
- 99=Unknown if rehospitalized

- 2.
- 3.
- 4.
- 5.

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

296. GLASGOW OUTCOME SCALE – EXTENDED: (See Appendix O for administration and coding guidelines)

Take into account all available information.

Enter data into boxes that are not skipped per instructions.

1. Is the head-injured person able to obey simple commands, or say any words ? 2=Yes 1=No
If NO, skip rest of questions, code GOS-E = 2 “VS”. 9=Unknown
- 2a. Is the assistance of another person at home essential every day for some activities of daily living? 2=Yes 1=No
If NO, skip to 3a. 9=Unknown
- 2b. Do they need frequent help or someone around at home most of the time ? 9=Unknown
 1=No 2=Yes
- 2c. Was assistance at home essential before the injury ? 2=Yes 1=No
If NO, skip rest of questions, code GOS-E=3 “LSD” if 2b=2, or code GOS-E=4 “USD” if 2b=1. 9=Unknown
- 3a. Are they able to shop without assistance ? 2=Yes 1=No
If YES, skip to 4a. 9=Unknown
- 3b. Were they able to shop without assistance before the injury ? 2=Yes 1=No
If YES, skip rest of questions, code GOS-E=4 “USD”. 9=Unknown
- 4a. Are they able to travel locally without assistance ? 2=Yes 1=No
If YES, skip to 5a. 9=Unknown
- 4b. Were they able to travel without assistance before the injury ? 2=Yes 1=No
If YES, skip rest of questions, code GOS-E=4 “USD”. 9=Unknown
- 5a. Are they currently able to work to their previous capacity ? 2=Yes 1=No
If YES, skip to 6a. 9=Unknown
- 5b. How restricted are they ? *Choose one.* 9=Unknown
 1=Reduced work capacity
 2=Able to work only in a sheltered workshop or non-competitive job, or currently unable to work.
- 5c. Were they either working or seeking employment before the injury (answer ‘yes’) or were they doing neither (answer ‘no’) ? 2=Yes 1=No
If YES, skip rest of questions, code GOS-E=5 “LMD” if 5b=2 or code GOS-E=6 “UMD” if 5b=1. 9=Unknown
- 6a. Are they able to resume regular social and leisure activities outside home ? 2=Yes 1=No
If YES, skip to 7a. 9=Unknown
- 6b. What is the extent of restriction on their social and leisure activities ? *Choose one.* 9=Unknown
 1=Participate a bit less: at least half as often as before injury
 2=Participate much less: less than half as often
 3=Unable to participate: rarely, if ever, take part.

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

296. GLASGOW OUTCOME SCALE – EXTENDED (cont.)

Enter data into boxes that are not skipped per instructions.

6c. Did they engage in regular social and leisure activities outside the home before the injury ? 2=Yes 1=No
*If YES, skip rest of questions, code GOS-E=5 “LMD” if 6b=3,
 or code GOS-E=6 “UMD” if 6b=2,
 or code GOS-E=7 “LGR” if 6b=1.* 9=Unknown

7a. Have there been psychological problems which have resulted in ongoing family disruption or disruption of friendships ? 2=Yes 1=No
If NO, skip to 8a 9=Unknown

7b. What has been the extent of disruptions or strain ? *Choose one.* 9=Unknown
 1=Occasional – less than weekly.
 2=Frequent or constant – once a week or more but tolerable.
 3=Constant – daily and intolerable.

7c. Were there problems with family or friends before the injury ? 2=Yes 1=No
*If NO, skip rest of questions, code GOS-E=5 “LMD” if 7b=3,
 or code GOS-E=6 “UMD” if 7b=2,
 or code GOS-E=7 “LGR” if 7b=1.* 9=Unknown

8a. Are there any other current problems relating to the injury which affect daily life ? 2=Yes 1=No
If NO, skip 8b, code GOS-E=8 “UGR”. 9=Unknown

8b. Were similar problems present before the injury ? 2=Yes 1=No
If NO, code GOS-E=7 “LGR”. 9=Unknown
*If YES: If pre and post injury status essentially equal, code GOS-E=8 “UGR”,
 or if pre and post injury status not essentially equal, use judgement to code GOS-E*

The patient’s overall rating is based on the lowest outcome category indicated on the scale. Refer to guidelines in Appendix O for further information concerning administration and scoring.

- 0=Variable didn’t exist
- 1=Dead
- 2=Vegetative State (VS)
- 3=Lower Severe Disability (LSD)
- 4=Upper Severe Disability (USD)
- 5=Lower Moderate Disability (LMD)
- 6=Upper Moderate Disability (UMD)
- 7=Lower Good Recovery (LGR)
- 8=Upper Good Recovery (UGR)
- 9=Unknown

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

292a1(1). DRUG USE:

During the last 12 months did you use any illicit or non-prescription drugs? 1=No 2=Yes 9=Unknown

292a2. ALCOHOL USE:

(Use the higher score if a range is given. Probe for size of drink, and adjust scoring accordingly.)

1) During the past month, have you had at least one drink of any alcoholic beverage such as beer, wine, wine coolers, or liquor?

1=No 2=Yes 7= Refused 9= Unknown/Don't know/not sure

2) During the past month, how many days per week or per month did you drink any alcoholic beverages, on the average? *(Enter data into one of the following; code the other "66")*

Enter number of days per week : **OR** Enter number of days per month:

66=N/A 77= Refused 99= Unknown/Don't know/Not sure

3) A drink is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. On the days when you drank, about how many drinks did you drink on the average? Enter number of drinks:

66=N/A 77= Refused 99= Unknown/Don't know/Not sure

4) Considering all types of alcoholic beverages, how many times during the past month did you have five or more drinks on an occasion? Enter number of times:

00=None 66=N/A 77= Refused 99=Unknown/Don't know/Not sure

292b. TRANSPORTATION: Primary motorized transport mode

1=Drives vehicle 3=Public transit 5=N/A-no motorized transp. 8=N/A
2=Rides w/someone else 4=Special bus 9=Unknown

292c. INCOME AND SOURCE: (1) Family income

01=\$9,999 or less	05=\$40,000-\$49,999	09=\$80,000-\$89,999	77=Refused
02=\$10,000-\$19,999	06=\$50,000-\$59,999	10=\$90,000-\$99,999	88=N/A-no income
03=\$20,000-\$29,999	07=\$60,000-\$69,999	11=\$100,000 or more	99=Unknown
04=\$30,000-\$39,999	08=\$70,000-\$79,999		

(2) Person with brain injury's non-employment income:

1=No 2=Yes 9=Unknown

a) SSI SSD TA/TANF (formerly AFDC) Welfare Unemp Ins Work Comp Pvt Ins Settlement Other

292e(1). ARRESTS:

In the past year, have you been arrested ? 1=No 2=Yes 9=Unknown

TRAUMATIC BRAIN INJURY MODEL SYSTEMS

DATA COLLECTION FORM FOR ANNUAL FOLLOW-UP EVALUATION – FORM II

Use for cases with follow-up completion date or window closing date (if no contact) 4/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: - - **ENTER INTO DATABASE 10.3**

292f. PSYCHIATRIC PROBLEMS:

- 1) Attempted suicide in the past year ?
- 2) Any psychiatric hospitalizations in the past year ?

<input type="text"/>
<input type="text"/>

1=No 2=Yes 9=Unk

QUESTION FOR PERSON WITH BRAIN INJURY ONLY

292g. SATISFACTION WITH LIFE *(Do not embellish or interpret for the respondent.)*

- 1) In most ways my life is close to my ideal.....
- 2) The conditions of my life are excellent
- 3) I am satisfied with my life.....
- 4) So far I have gotten the important things I want in life.....
- 5) If I could live my life over, I would change almost nothing

1=Strongly disagree
2=Disagree
3=Slightly disagree
4=Neither agree nor disagree
5=Slightly agree
6=Agree
7=Strongly agree
9=Unknown
10=N/A-no data from person w/ TBI

*** END ***

TBI MODEL SYSTEMS FOLLOW-UP SURVEY

[Firstname Lastname] has been a participant in our TBI Model Systems Study since [enrollment date]. We need information about [Firstname] that is asked on the next few pages in order to better understand the course of recovery and outcomes after brain injury. All the information will be kept confidential. All terms of the initial TBI Model System consent apply.

These questions are to be answered by [Firstname] (the person with brain injury). If that is not possible, someone who knows [Firstname] well may answer the questions.

If you would like more information or if answering these questions over the telephone would be better than writing out the answers, please contact me.

[Name], [TBIMS title], [phone number]

THANK YOU FOR PARTICIPATING IN THIS STUDY!

What is the name of the person answering these questions?

Mr/Mrs/Ms _____

If the person with brain injury is in jail, check here _____ and skip to the last page.

1. How are you (the person answering these questions) related to the person with the brain injury (TBI)?

20Ae

I AM the person with the brain injury.

I am the person with brain injury's. . .

- | | |
|--|---|
| <input type="checkbox"/> Spouse | <input type="checkbox"/> Boyfriend or girlfriend |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Brother or sister | <input type="checkbox"/> Professional caregiver |
| <input type="checkbox"/> Son or daughter over 21 years old | <input type="checkbox"/> Other (please describe)_____ |
| <input type="checkbox"/> Other relative | |

2. Which is true at present for the person with TBI? (Check one)

207

- Never married
 Married (or living with someone as a couple for 7 or more years)
 Divorced
 Separated
 Widowed
 Other (please describe) _____

3. Who is the main person that the person with TBI is living with? (Check one)

208

- | | |
|--|--|
| <input type="checkbox"/> No one (lives alone) | <input type="checkbox"/> Son or daughter or step-child who is less than 21 years old |
| <input type="checkbox"/> Spouse | <input type="checkbox"/> Son or daughter or step-child who is 21 years or older |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Other relative |
| <input type="checkbox"/> Brother or sister | <input type="checkbox"/> Significant other (like a spouse, but not married) |
| <input type="checkbox"/> Roommate | <input type="checkbox"/> Other patients in a hospital or place like a hospital |
| <input type="checkbox"/> Friend | <input type="checkbox"/> Other residents in a group home |
| <input type="checkbox"/> Personal care attendant | <input type="checkbox"/> Other (describe)_____ |

4. Where is the person with TBI currently living? (Check one)

209

- | | |
|---|---|
| <input type="checkbox"/> Private home or apartment | <input type="checkbox"/> Rehabilitation Hospital |
| <input type="checkbox"/> Nursing home | <input type="checkbox"/> Mental hospital |
| <input type="checkbox"/> Adult Home (group home, foster care) | <input type="checkbox"/> Prison/Jail |
| <input type="checkbox"/> Hotel | <input type="checkbox"/> Other (describe)_____ |
| <input type="checkbox"/> Regular hospital | <input type="checkbox"/> Not living anywhere (homeless) |
| <input type="checkbox"/> Subacute care (1-3 hrs of therapy a day, medical care available) | |

What is the ZIP code there? _____ (zip code)

209a

5. What is the highest level of school that the person with TBI has successfully completed? (Check one)

- | | | |
|--|---|------|
| <input type="checkbox"/> 1 st grade or less | <input type="checkbox"/> 12 th grade but did not graduate | 210a |
| <input type="checkbox"/> 2 nd grade | <input type="checkbox"/> High school (12 th grade, graduated with diploma) | |
| <input type="checkbox"/> 3 rd grade | <input type="checkbox"/> Work toward Associates degree (but no degree received) | |
| <input type="checkbox"/> 4 th grade | <input type="checkbox"/> Associates degree | |
| <input type="checkbox"/> 5 th grade | <input type="checkbox"/> Work toward Bachelors degree (but no degree received) | |
| <input type="checkbox"/> 6 th grade | <input type="checkbox"/> Bachelors degree | |
| <input type="checkbox"/> 7 th grade | <input type="checkbox"/> Work toward Masters degree (but no degree received) | |
| <input type="checkbox"/> 8 th grade | <input type="checkbox"/> Masters degree | |
| <input type="checkbox"/> 9 th grade | <input type="checkbox"/> Work toward Doctorate degree (PhD,MD,etc) (but no degree received) | |
| <input type="checkbox"/> 10 th grade | <input type="checkbox"/> Doctorate degree | |
| <input type="checkbox"/> 11 th grade | <input type="checkbox"/> Other (describe) _____ | |

6. Did the person with TBI earn a General Equivalency Diploma (GED) instead of graduating from high school? No Yes

210b

7. What is the person with TBI's current employment or educational status? (Check all that apply) 211a

- | | |
|---|--|
| <input type="checkbox"/> Has a regular job | <input type="checkbox"/> Volunteer work |
| <input type="checkbox"/> Special employment because of disability | <input type="checkbox"/> Retired because of disability |
| <input type="checkbox"/> Takes care of house or family | <input type="checkbox"/> Retired due to age |
| <input type="checkbox"/> Unemployed and looking for work | <input type="checkbox"/> Retired due to other reasons |
| <input type="checkbox"/> Unemployed, not looking for work | <input type="checkbox"/> Hospitalized |
| <input type="checkbox"/> Full-time student | <input type="checkbox"/> Other (describe) _____ |
| <input type="checkbox"/> Part-time student | |
| <input type="checkbox"/> Special education classes (describe) _____ | |

8. After the injury, when did the person with TBI start working in a regular job? _____ / _____ / _____ 211c
(month) (day) (year)

No regular job since the TBI

9. Currently, what kind of work does the person with TBI do? _____ 212

No regular job currently

10. About how many hours a week does the person with TBI work in a regular job?

_____ hours a week No regular job currently 211b

11. In the past year, how many weeks did the person with TBI work in a regular job?

_____ weeks No regular job in the past year 211d

12. Currently, about how much money does the person with TBI make at work each week ?

_____ dollars per week No regular job currently 211i

Thank you for answering our questions

Thanks to people like you, the Traumatic Brain Injury Model Systems Study remains one of the most successful projects that learns about long-term outcomes of people who have had a brain injury. In order to continue this high rate of success, we need to update our contact information.

What is your (person with TBI) current address and phone number?

Street _____

City _____ State _____ Zip _____

Home phone (include area code) _____

Cell phone (include area code) _____

Email address _____ @ _____

What is the name, address, and phone number of someone close to you (person with TBI) whom we may contact if necessary?

Name _____ Relationship _____

Street _____

City _____ State _____ Zip _____

Home phone (include area code) _____

Cell phone (include area code) _____

Email address _____ @ _____

THAT'S ALL.

THANK YOU!

TBINDC Guidelines for Module Data Collection Forms and Syllabus

Subject identification number

- All module databases use the same format for their subject identification number as in the TBIMS syllabus.
 - the 2-digit Model System code
 - 5-digit subject identification number
 - For follow-up data collection (if any), 2-digit code is follow-up year (e.g., yr1, yr2, yr5, etc)
- The same Subject Identification Number is assigned to the person in all projects whose data will be entered into and/or linked to the TBIMS database. It is the responsibility of the Lead Center to ensure that a system is in place so that the same number is not assigned to more than one subject.
- Module subjects are numbered consecutively, without regard for whether they are enrolled in the TBIMS database, one or more module projects, or both.

Non-TBIMS/TBIMS subject All databases must include this variable. This variable identifies the subject as a TBIMS subject or a non-TBIMS (module-only) subject. (1=module-only; 2=TBIMS and module)

Item number All variables must have a number

TBI Model System Research Committee
Module Project Peer Review Procedures

Revised and Adopted by TBIMS 7-05

Module projects do not receive external peer review, and therefore the proposers do not have the benefit of a critique by an outsider who has no vested interest in the project. The Peer Review procedures the TBIMS has adopted aim to fill that gap by providing for a peer review by experts from within the TBIMS, supplemented as needed/ as possible by outside experts. The purpose of the review is to improve the quality of module research, and to optimize use of TBIMS resources.

The following steps constitute the process for initiating new modular research projects and approving them through the Peer Review process.

1. A proposal for a multi-center module project emerges from collaborators in at least 3 centers, preferably but not necessarily from a Special Interest Group (SIG).
2. The idea for the project is sent in draft form via the Notification process used for database projects, with the expectation that all centers signing on in this fashion will be incorporated as collaborators.
3. The proposal is written in the Module Project Template for Peer Review (attached) and submitted to the Chair of the Research Committee (RC).
4. The Chair or Co-Chair of the RC assigns an RC member to organize a Peer Review Panel. The Panel consists of three reviewers with expertise in the proposal's topic area and/ or research methodology/ statistics. These reviewers should not have contributed to the proposal. If insufficient expertise is available within the TBIMS, outside experts may be invited. The assigned RC member will serve as Panel Chair, but need not be one of the reviewers.
5. Coordinated by the Panel Chair, panel members independently review the proposal and complete the Review Form (attached). They rate each section on a 4-point scale (see below), and give the overall proposal a global rating (see scale below), weighting the components as they see fit.
6. Panel Reviews must be returned to the Panel Chair within 15 business days (3 weeks) of receipt. A 30 minute teleconference is pre-scheduled for the Review Panel for the week following this deadline.
7. The Panel Chair distributes the reviews to all panel members prior to the teleconference. The teleconference is used to (a) resolve any major discrepancies between reviewers, (b) highlight the most important needs for revision, if any, and (c) assign a final global score representing the consensus of the panel.
8. The Panel Chair forwards the reviews, with scores and suggested revisions, to the RC Chair, the SIG members who collaborated on the proposal, and the NIDRR officer who oversees the SIG.



9. At the SIG's request, the Panel Chair meets by telephone with the PI to answer questions on the review, and supply additional detail. Other Review Panel and SIG members may join this discussion.
10. The entire process from submission of a proposal to the Research Committee Chair to receipt of a written review by proposer(s) will under normal circumstances take no longer than 2 months.
11. If a global score of 3 or 4 is assigned, the proposal, the reviews with any recommendations for change, and the scores will be forwarded to the PD list server with a recommendation that the project should proceed.
12. If a global score of 1 or 2 is assigned, the proposal, the reviews and the score will still be forwarded to the PD list but the proDocument5ject will not be recommended to proceed. The originators of the proposal may revise and resubmit the proposal to the same review panel once. If the score does not exceed 2 on the second try, the review process ends for that project. However, an appeal may be made to the Research Committee if the decision is perceived as inaccurate or unfair. The Research Committee will convene via phone as needed and consider appeals on a case by case basis.
13. When a project is recommended to proceed, it may still be vetoed if a majority of Project Directors voice disapproval within 3 weeks (15 working days) of the recommendation. Negative votes may be cast anonymously by faxing them to the RC chair. However, it is expected that (a) in most cases the recommendation of the peer review panel and RC will be confirmed by tacit approval of the Project Directors, and that (2) serious concerns would be voiced and addressed prior to this point to the project originators and/ or the RC. Once a project has been recommended (unless vetoed by a majority of PDs), official approval by NIDRR and the assignment of a Project Officer, if necessary, will follow within 1-2 weeks.

Syllabus

Family Members' and Caregivers' Emotional Well Being

A NIDRR-Funded Module Project for the Emotional/Psychological Special Interest Group

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Family Members' and Caregivers' Emotional Well Being

This study uses the core dataset of the National DataBase and is cross-sectional in nature, collecting information at any of the follow-up years (1, 2, 5 year follow-up). Data will be collected from each caregiver only once. Estimated time for administration of measures is 15-20 minutes. Data will be collected via telephone interview, in person, or mail-out questionnaire.

Inclusion Criteria:

- TBI Model System subjects at 1, 2, and 5 years post-injury.
- Participants must be at least 18 years of age.
- Participants must be identified as a relative, friend, or other caregiver.

Exclusion Criteria:

- TBIMS subjects who do not have a family member or friend who is available.

In cases where there is more than one family member/ significant other (S.O.) available, first priority is given to the family member/ S.O. who is living with the TBIMS subject. If more than one family member/ S.O. is living with the subject, then the survivor should choose the person that he/she feels most close to.

The following **script** can be used to help data collectors introduce the study to prospective family members:

"As you know, we've been collecting information for many years from persons with TBI such as *your family member* (name). We realize these injuries have an affect on families as well, so we are now asking questions of the family members, such as yourself, in order to more completely understand the impact of these injuries on families. Your participation is strictly voluntary. Would you be interested in participating in such a project?"

Data Preparation and Submission:

If the mail-out questionnaire is completed by the family member/S.O., data should be transferred to the data collection form prior to data entry.

Data is to be submitted electronically to Slava Gavurin, at the National Data Center, two weeks after centers submit data for the National DataBase. Data collection forms collected for family members of participants not yet submitted to the National Data Center may be submitted as well.

Variable: System/Subject ID

Definition: The 9-digit number assigned to each patient with brain injury for the National DataBase. First 2 digits are system I.D.; next 5 digits are subject I.D.; last 2 digits identify which annual follow-up evaluation year (01, 02, or 05).

Database variable name: System/SubjectID (DEMO table)

Date of last revision: 10/08/04

Variable 1: Relationship of informant to person with TBI

Definition: The relationship of the family member/S.O. to the person with TBI.

Code:

- 01 spouse
- 02 parent
- 03 sibling
- 04 adult child
- 05 boyfriend, girlfriend, fiancée
- 07 other relative
- 08 friend
- 77 other

Database variable name: Relationship (DEMO table)

Date of last revision: 10/08/04

Variable 2: Living with person with TBI

Definition: Does the family member/S.O. live with the person with TBI?

Code:

- 1 no
- 2 yes
- 9 refused

Database variable name: Living (DEMO table)

Date of last revision: 10/08/04

Variable 3: Days per week spent with the person with TBI

Definition: How many days each week does the family member/S.O. typically spend some amount of time with the person with TBI.

Code:

- Record actual number of days
- 9 refused

Database variable name: NumberofDays (DEMO table)

Date of last revision: 10/08/04

Variable 4: Average number of hours caring for/supervising/helping the person with TBI

Definition: Family member/S.O. is asked to estimate the average number of hours they spend caring for, supervising, or helping the person with TBI on days that they are with him or her

Code:

- 1 0 hours
- 2 1-4 hours
- 3 5-8 hours
- 4 9-12 hours
- 5 13-16 hours
- 6 more than 16 hours
- 9 refused

Database variable name: NumberofHours (DEMO table)

Date of last revision: 10/08/04

Variable 5: Age of family member/S.O.

Definition: Age of family member/S.O.

Code:

- Record actual age in years
- 09 refused

Database variable name: Age (DEMO table)

Date of last revision: 10/08/04

Variable 6: Gender of family member/S.O.

Definition: Gender of family member/S.O.

Code:

- 1 female
- 2 male
- 9 refused

Database variable name: Gender (DEMO table)

Date of last revision: 10/08/04

Variable 7: Race of family member/S.O.

Definition: Family member/S.O. self-reported race

Code:

- 1 White
- 2 Black
- 3 Asian/Pacific Islander
- 4 Native American
- 5 Hispanic origin
- 7 other, unclassified
- 9 refused

Database variable name: Race (DEMO table)

Date of last revision: 10/08/04

Variable 8: Marital status of family member/S.O.

Definition: Family member/S.O. marital status

Code:

- 1 single (has never been married)
- 2 married (whether legally or by commonlaw definition of seven years cohabitation)
- 3 divorced (legally divorced)
- 4 separated (includes both legal separation and living apart from a married partner)
- 5 widowed
- 7 other
- 9 refused

Database variable name: Marital Status (DEMO table)

Date of last revision: 10/08/04

Variable 9: Years of education of family member/S.O.

Definition: Number of years of education successfully completed by family member/S.O.

Code:

- 01 1 year
- 02 2 years
- 03 3 years
- 04 4 years
- 05 5 years
- 06 6 years
- 07 7 years
- 08 8 years
- 09 9 years
- 10 10 years
- 11 11 years/ 12 years, no diploma
- 12 high school diploma
- 13 work toward Associate's degree, no diploma
- 14 Associate's degree
- 15 work toward Bachelor's degree, no diploma
- 16 Bachelor's degree
- 17 work toward Master's degree, no diploma
- 18 Master's degree
- 19 work toward Doctoral level degree, no diploma
- 20 Doctoral level degree
- 77 other
- 99 refused

Database variable name: YearsofEducation (DEMO table)

Date of last revision: 10/08/04

Variable 10: Employment status of family member/S.O.

Definition: Employment status of family member/S.O. at (a) time of survivor's injury and (b) currently. If more than one code applies, determine the status using the following prioritization, regardless of the number of hours worked: competitive employment, degree-oriented education, taking care of house or family, job-directed/on-the-job training, non-directed coursework, volunteer work, retirement (age-related), retirement (disability-related), and unemployed.

Code:

- 02 full-time student
- 03 part-time student
- 05 competitively employed (minimum wage or greater, *legal or illegal employment)
- 07 taking care of house or family
- 09 retired (age)
- 10 unemployed (looking)
- 11 volunteer
- 12 retired (disability)
- 13 unemployed (not looking)
- 77 other
- 99 unknown/refused

Notes:

- Status is based on (a) the month prior to survivor's injury, or (b) the month prior to date of data collection.
- Competitive subminimum wage employment such as baby-sitting, newspaper delivery, and piecework should be coded as 77.
- If family member/S.O. works in a foreign country, assume wage is not subminimum unless there is information to the contrary.
- If family member/S.O. is employed for only part of the month prior to the survivor's injury or prior to the date of data collection, code employment status as during the majority of the work days during that month.
- If family member/S.O. had been hired but had not begun work, code as employed.
- Code education as full-time or part-time based on self-report.

Database variable names: EmploymentInjury, EmploymentCurrent (DEMO table)

Date of last revision: 10/08/04

Variable 11: Psychological/psychiatric treatment received in past year

Definition: Code three items regarding family member/S.O. receiving psychological/psychiatric treatment in past year: (a) whether or not family member/S.O. received treatment from a psychologist, psychiatrist, or counselor in past year; (b) likert scale rating of helpfulness of treatment; and (c) whether or not family member/S.O. has received treatment from a psychologist, psychiatrist, or counselor in past 30 days.

Code for 11a. (treatment in past year):

- 1 no
- 2 yes
- 9 refused

Code for 11b. (helpfulness of treatment: 1-5 with 1=not at all and 5=very):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Code for 11c. (treatment in past 30 days):

- 1 no
- 2 yes
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is “no”, then code both subsequent items as “not applicable.”

Database variable names: TreatmentYear, HelpfulTreatmentYear, TreatmentMonth (SUPPORT table)

Date of last revision: 10/08/04

Variable 12: Psychological/psychiatric treatment received before survivor's injury

Definition: Code two items regarding family member/S.O. receiving psychological/psychiatric treatment before the survivor's injury: (a) whether or not family member/S.O. received treatment from a psychologist, psychiatrist, or counselor before the survivor's injury; and (b) likert scale rating of helpfulness of treatment.

Code for 12a. (treatment before survivor's injury):

- 1 no
- 2 yes
- 9 refused

Code for 12b. (helpfulness of treatment: 1-5 with 1=not at all and 5=very):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is "no", then code the subsequent item as "not applicable."

Database variable names: TreatmentInjury, HelpfulTreatmentInjury (SUPPORT table)

Date of last revision: 10/08/04

Variable 13: Medications taken for depression in past year

Definition: Code three items regarding family member/S.O. taking medications for depression in past year: (a) whether or not family member/S.O. took or is taking medication for depression in the past year; (b) likert scale rating of helpfulness of medication; and (c) whether or not family member/S.O. has taken medication for depression in the past 30 days.

Code for 13a. (medications for depression in past year):

- 1 no
- 2 yes
- 9 refused

Code for 13b. (helpfulness of medication: 1-5 with 1=not at all and 5=very):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Code for 13c. (medication in past 30 days):

- 1 no
- 2 yes
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is “no”, then code both subsequent items as “not applicable.”

Database variable names: MedicationYear, HelpfulMedicationYear, MedicationMonth (SUPPORT table)

Date of last revision: 10/08/04

Variable 14: Medications taken for depression before survivor's injury

Definition: Code two items regarding the family member/S.O. taking medication for depression before the survivor's injury: (a) whether or not family member/S.O. took medication for depression before the survivor's injury; and (b) likert scale rating of helpfulness of medication.

Code for 14a. (medications for depression before survivor's injury):

- 1 no
- 2 yes
- 9 refused

Code for 14b. (helpfulness of medication: 1-5 with 1=not at all and 5=very):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is "no", then code the subsequent item as "not applicable."

Database variable names: MedicationInjury, HelpfulMedicationInjury (SUPPORT table)

Date of last revision: 10/08/04

Variable 15: Support from a house of worship in past year

Definition: Code three items regarding family member/S.O. receiving support from a house of worship (church, temple, mosque) in past year: (a) whether or not family member/S.O. received support in the past year; (b) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very); and (c) whether or not family member/S.O. has received support in the past 30 days. Support can be either emotional or financial, whatever the family member/S.O. views as support.

Code for 15a. (receiving support from house of worship in past year):

- 1 no
- 2 yes
- 9 refused

Code for 15b. (helpfulness of support):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Code for 15c. (support received in past 30 days):

- 1 no
- 2 yes
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is “no”, then code both subsequent items as “not applicable.”

Database variable names: HWorshipSupportYear, HelpfuHWorshipYear, HWorshipSupportMonth (SUPPORT table)

Date of last revision: 10/08/04

Variable 16: Support from a house of worship before survivor's injury

Definition: Code two items regarding the family member/S.O. receiving support from a house of worship (church, temple, mosque) before the survivor's injury: (a) whether or not family member/S.O. received support before the survivor's injury; and (b) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very). Support can be either emotional or financial, whatever the family member/S.O. views as support.

Code for 16a. (receiving support from house of worship before survivor's injury):

- 1 no
- 2 yes
- 9 refused

Code for 16b. (helpfulness of support):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is "no", then code the subsequent item as "not applicable."

Database variable names: HWorshipSupportInjury, HelpfulHWorshipSupportInjury (SUPPORT table)

Date of last revision: 10/08/04

Variable 17: Support from a brain injury support group in past year

Definition: Code three items regarding family member/S.O. receiving support from a brain injury support group in past year: (a) whether or not family member/S.O. received support in the past year; (b) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very); and (c) whether or not family member/S.O. has received support in the past 30 days.

Code for 17a. (receiving support from a brain injury support group in past year):

- 1 no
- 2 yes
- 9 refused

Code for 17b. (helpfulness of support):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Code for 17c. (support received in past 30 days):

- 1 no
- 2 yes
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is “no”, then code both subsequent items as “not applicable.”

Database variable names: BISSupportYear, HelpfulBISSupportYear, BISSupportMonth (SUPPORT table)

Date of last revision: 10/08/04

Variable 18: Support from a support group before survivor's injury

Definition: Code two items regarding the family member/S.O. receiving support from a support group (any kind of support group) before the survivor's injury: (a) whether or not family member/S.O. received support before the survivor's injury; and (b) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very).

Code for 18a. (receiving support from a support group before survivor's injury):

- 1 no
- 2 yes
- 9 refused

Code for 18b. (helpfulness of support):

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is "no", then code the subsequent item as "not applicable."

Database variable names: SupportGroupYear, HelpfulSupportGroupYear (SUPPORT table)

Date of last revision: 10/08/04

Variable 19: Support other sources in past year

Definition: Four items are included regarding family member/S.O. receiving support from other sources group in past year: (a) whether or not family member/S.O. received support in the past year; (b) text field to write in the type of support such as Department of Social Services, family, friends; (c) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very); and (d) whether or not family member/S.O. has received support in the past 30 days.

Code for 19a. (receiving support from other sources in past year):

- 1 no
- 2 yes
- 9 refused

Write in text for 19b. (type of support received)**Code for 19c. (helpfulness of support):**

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Code for 19d. (support received in past 30 days):

- 1 no
- 2 yes
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is “no”, then leave text field for type of support blank and code subsequent items as “not applicable.”

Database variable names: OtherSourcesYear, OtherSourcesListYear, HelpfulOtherSourcesYear, OtherSourcesMonth (SUPPORT table)

Date of last revision: 10/08/04

Variable 20: Support from other sources before survivor's injury

Definition: Three items are included regarding family member/S.O. receiving support from other sources before the survivor's injury: (a) whether or not family member/S.O. received support before the survivor's injury; (b) text field to write in the type of support such as Department of Social Services, family, friends; and (c) likert scale rating of helpfulness of support (1-5 with 1=not at all and 5=very).

Code for 20a. (receiving support from other sources before survivor's injury):

- 1 no
- 2 yes
- 9 refused

Write in text for 20b. (type of support received)**Code for 20c. (helpfulness of support):**

- 1 not at all
- 2
- 3
- 4
- 5 very
- 8 not applicable
- 9 refused

Notes:

- If the answer to the initial question is "no", then leave text field for type of support blank and code item c as "not applicable."

Database variable names: OtherSourcesInjury, OtherSourcesListInjuryMonth, HelpfulOtherSourcesInjury (SUPPORT table)

Date of last revision: 10/08/04

Variable: The Neurobehavioral Functioning Inventory Depression subscale

Definition: Questions for the 13 items of the Neurobehavioral Functioning Inventory (NFI-R) Depression subscale, as asked of the family member/S.O. The family member/S.O. is asked, "How often do you currently have any of the following problems?"

Codes for each item:

- 1 never
- 2 rarely
- 3 sometimes
- 4 often
- 5 always
- 9 refused

Notes:

- If the NFI is mailed back and the family member/S.O.: 1) leaves an item blank, code that item as refused; 2) checks more than one response for an item, code the response with the highest number; 3) feels a question is not applicable to them, code as refused.

Database variable names: NFI 1, NFI 2, NFI 3, etc (NFI table)

Date of last revision: 10/08/04

Variable: The Satisfaction with Life Scale

Definition: The family member/S.O. should rate their own satisfaction with life by indicating level of agreement with the five questions below that comprise the Satisfaction with Life Scale (SWLS).

- (1) In most ways my life is close to my ideal.
- (2) The conditions of my life are excellent.
- (3) I am satisfied with my life.
- (4) So far I have gotten the important things I want in life.
- (5) If I could live my life over, I would change almost nothing.

Codes for each item:

- 1 Strongly disagree
- 2 Disagree
- 3 Slightly disagree
- 4 Neither agree nor disagree
- 5 Slightly agree
- 6 Agree
- 7 Strongly agree
- 9 Unknown/Refused

Database variable names: SWLS 1, SWLS 2, SWLS 3, etc (NFI table)

Date of last revision: 10/08/04

Variable: The Brief Symptom Inventory 18 (BSI 18)

Definition: The family member/S.O. should rate how much each of the 18 problems listed has distressed or bothered them during the past 7 days, including the day of questionnaire completion. Each item is answered as 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely). Raw scores for Somatization (SOM), Depression (DEP), Anxiety (ANX), and a Global Severity Index (GSI) are computed according to directions in the manual and on the "Profile for Community Norms" scoring form. T scores for each raw score are determined using the "Profile for Community Norms" scoring form. There are different norms for males and females.

Items and ranges:

- Raw score for SOM (range: 0-24 or 99 for refused/unknown)
- Raw score for DEP (range: 0-24 or 99 for refused/unknown)
- Raw score for ANX (range: 0-24 or 99 for refused/unknown)
- Raw score for GSI (range: 0-76 or 99 for refused/unknown)
- T score for SOM (range: 41-81 or 99 for refused/unknown)
- T score for DEP (range: 40-81 or 99 for refused/unknown)
- T score for ANX (range: 38-81 or 99 for refused/unknown)
- T score for GSI (range: 33-81 or 99 for refused/unknown)

Source:

Derogatis, L.R. (2001). BSI 18 Administration, Scoring, and Procedures Manual. Minneapolis: NCS Pearson, Inc.

Database variable names: Raw_SOM, T_SOM, Raw_DEP, T_DEP, etc (NFI table)

Date of last revision: 10/08/04

Family Members' and Caregivers' Emotional Well Being

A NIDRR-Funded Module Project for the
Emotional/Psychological Special Interest Group

Subject ID: _____ Follow-up Year: _____ Date: _____

NOTE: All questions are asked of the family member/friend. None are asked about the survivor.

1. Relationship to the person with TBI:

- | | | |
|--------------|-------------------|-----------|
| 01=Spouse | 04=Adult child | 08=Friend |
| 02=Parent(s) | 05=Boy/girlfriend | 77=Other |
| 03=Sibling | 07=Other relative | |

2. Living with the survivor: 1=No 2=Yes 9=Refused

3. How many days each week do you typically spend some amount of time with the survivor?

(range of 1-7) 9=Refused

4. Please make a guess about the average number of hours you spend caring for, supervising, or helping the survivor on days that you are with him or her.

1= 0 hours 3= 5-8 hours 5= 13-16 hours
2= 1-4 hours 4= 9-12 hours 6 = more than 16 hours 9=Refused

5. Your Age: years 09=Refused

6. Your Gender: 1=Female 2=Male 9=Refused

7. Your Race: 1=White 3=Asian/Pacific Islander 5=Hispanic origin 7 =Other, unclassified
2=Black 4=Native American 9=Refused

8. Your Marital status: 1=Single (never married) 3=Divorced 5=Widowed
2=Married/Cohab>=7 yrs 4=Separated 7=Other 9=Refused

9. Your Years of Education:

01=1 yr	04=4 yrs	07=7 yrs	11=11 yrs/12 yrs, no diploma	14=Assoc. degree	17=Work twd Master's, no dpl
02=2 yrs	05=5 yrs	08=8 yrs	12=HS diploma	15=Work twd Bach., no dpl	18=Master's degree
03=3 yrs	06=6 yrs	09=9 yrs	13=Work twd Assoc, no dpl	16=Bachelor's degree	19=Work twd Doctoral, no dpl
	10=10 yrs	77=Other		99=Unknown/Refused	20=Doctoral level

10. Your Employment Status:

At time of survivor's injury:

Current:

02=Full time student	11=Volunteer
03=Part time student	12=Retired (disability)
05=Competitively employed	13=Unempl (not looking)
07=Taking care of house or fam.	77=Other
09=Retired (age)	99=Unknown/Refused
10=Unemployed (looking)	

11. **In the past year** have you received treatment from a psychologist, psychiatrist, or counselor?

1=no 2=yes 9=Refused

If yes, how helpful was treatment? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Treatment received in past 30 days? 1=no 2=yes 8=N/A

12. **Before** the survivor's injury did you receive treatment from a psychologist, psychiatrist, or counselor?

1=no 2=yes 9=Refused

If yes, how helpful was treatment? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

13. **In the past year** have you taken medications for depression?

1=no 2=yes 9=Refused

If yes, how helpful was medication? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Have you taken in the last 30 days? 1=no 2=yes 8=N/A

14. **Before** the survivor's injury did you take medications for depression?

1=no 2=yes 9=Refused

If yes, how helpful was medication? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

15. **In the past year** have you received support from a house of worship (church, temple, mosque)?

1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Support received in the last 30 days? 1=no 2=yes 8=N/A

16. **Before** the survivor's injury did you receive support from a house of worship (church, temple, mosque)?

1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

17. **In the past year** have you received support from a brain injury support group?

1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Support received in the last 30 days? 1=no 2=yes 8=N/A

18. **Before** the survivor's injury did you receive support from a support group?

1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

19. **In the past year** have you received support from other sources?

If yes, please list: 1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Support received in the last 30 days? 1=no 2=yes 8=N/A

20. **Before** the survivor's injury did you receive support from other sources?

If yes, please list: 1=no 2=yes 9=Refused

If yes, how helpful was the support? Likert scale: 1 (not at all) to 5 (very)
1-----2-----3-----4-----5 N/A=8

Neurobehavioral Functioning Inventory Depression subscale

How often do you **CURRENTLY** have any of the following problems? Please place an 'X' in the box under the label "never," "rarely," "sometimes," "often," or "always." **Note: enter "9" in the database if refused**

	Never	Rarely	Sometimes	Often	Always		Never	Rarely	Sometimes	Often	Always
1. Feel worthless	[1]	[2]	[3]	[4]	[5]	7. Feel helpless	[1]	[2]	[3]	[4]	[5]
2. Sad, blue	[1]	[2]	[3]	[4]	[5]	8. Scared or frightened	[1]	[2]	[3]	[4]	[5]
3. Lonely	[1]	[2]	[3]	[4]	[5]	9. Bored	[1]	[2]	[3]	[4]	[5]
4. No confidence	[1]	[2]	[3]	[4]	[5]	10. Difficulty enjoying activities	[1]	[2]	[3]	[4]	[5]
5. Frustrated	[1]	[2]	[3]	[4]	[5]	11. Uncomfortable around others	[1]	[2]	[3]	[4]	[5]
6. Sit with nothing to do	[1]	[2]	[3]	[4]	[5]	12. Can't get mind off certain thoughts	[1]	[2]	[3]	[4]	[5]
						13. Restless	[1]	[2]	[3]	[4]	[5]

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Satisfaction with Life Scale

Please answer the following questions with the scale provided

- 1) In most ways my life is close to my ideal
- 2) The conditions of my life are excellent
- 3) I am satisfied with my life.
- 4) So far I have gotten the important things I want in life
- 5) If I could live my life over, I would change almost nothing

- 1=Strongly disagree
- 2=Disagree
- 3=Slightly disagree
- 4=Neither agree nor disagree
- 5=Slightly agree
- 6=Agree
- 7=Strongly agree
- 9=Unknown/Refused

Family Members' and Caregivers' Emotional Well Being

*A NIDRR-Funded Module Project for the
Emotional/Psychological Special Interest Group*

Your Name: _____ **Date** ____ - ____ - ____

Address: _____

Phone Number: (____) _____

Person with brain injury's Name: _____

1. Your relationship to the survivor? Are you the survivor's: (*CIRCLE ONE*)

SPOUSE

ADULT CHILD

FRIEND

PARENT

GIRL/BOYFRIEND

OTHER _____

SIBLING

OTHER RELATIVE

(PLEASE WRITE IN)

2. Do you live with the survivor? (*CIRCLE ONE*) NO YES

3. How many days each week do you typically spend some amount of time with the survivor? _____

4. Please make a guess about the average number of hours you spend caring for, supervising, or helping the survivor on days that you are with him or her. (*CIRCLE ONE*)

0 HOURS

1-4 HOURS

5-8 HOURS

9-12 HOURS

13-16 HOURS

MORE THAN 16 HOURS

5. How old are you? _____ years

6. Your gender? (*CIRCLE ONE*) FEMALE MALE

7. Your race? (*CIRCLE ONE*)

WHITE

ASIAN/PACIFIC ISLANDER

HISPANIC ORIGIN

BLACK

NATIVE AMERICAN

OTHER _____

(PLEASE WRITE IN)

8. Your marital status? (*CIRCLE ONE*)

SINGLE (NEVER MARRIED)

DIVORCED

WIDOWED

MARRIED OR LIVE TOGETHER FOR AT LEAST 7 YEARS

SEPARATED

OTHER _____

(PLEASE WRITE IN)

9. How far have you gone in school? If you have not graduated from high school, circle the number of years spent in school. If you have at least a high school diploma, circle the highest degree earned (or worked toward).

1 YR OR LESS	7 YRS	HIGH SCHOOL DIPLOMA	WORK TOWARD BACH., NO DIPLOMA
2 YRS	8 YRS	WORK TOWARD ASSOC., NO DIPLOMA	BACHELOR'S DEGREE
3 YRS	9 YRS	ASSOCIATE DEGREE	WORK TOWARD MASTER'S, NO DIPLOMA
4 YRS	10 YRS		MASTER'S DEGREE
5 YRS	11 YRS/12 YRS, NO DIPLOMA		WORK TOWARD DOCTORAL, NO DIPLOMA
6 YRS			DOCTORAL LEVEL

10a. Before the survivor's injury, what was your primary employment status? (*CIRCLE ONE*)

FULL TIME STUDENT	RETIRED (AGE)	UNEMPLOYED (NOT LOOKING)
PART TIME STUDENT	UNEMPLOYED (LOOKING)	OTHER _____
COMPETITIVELY EMPLOYED	VOLUNTEER	(PLEASE WRITE IN)
TAKING CARE OF HOUSE/FAMILY	RETIRED (DISABILITY)	

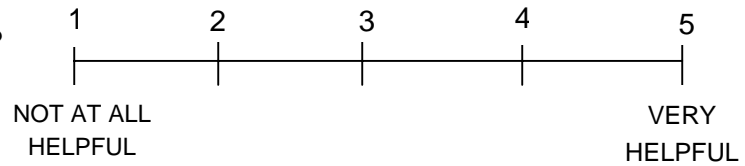
10b. Currently, what is your primary employment status? (*CIRCLE ONE*)

FULL TIME STUDENT	RETIRED (AGE)	UNEMPLOYED (NOT LOOKING)
PART TIME STUDENT	UNEMPLOYED (LOOKING)	OTHER _____
COMPETITIVELY EMPLOYED	VOLUNTEER	(PLEASE WRITE IN)
TAKING CARE OF HOUSE/FAMILY	RETIRED (DISABILITY)	

11. **In the past year** have you received treatment from a psychologist, psychiatrist, or counselor?

NO YES

If yes, how helpful was treatment?

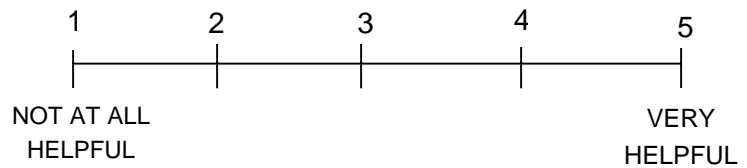


Did you receive treatment in the past 30 days? NO YES

12. **Before** the survivor's injury did you receive treatment from a psychologist, psychiatrist, or counselor?

NO YES

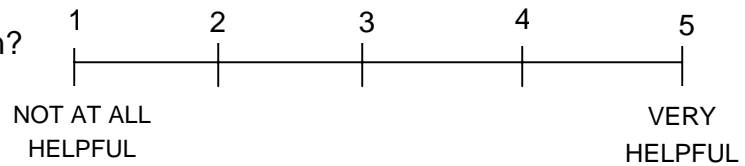
If yes, how helpful was treatment?



13. **In the past year** have you taken medications for depression?

NO YES

If yes, how helpful was medication?

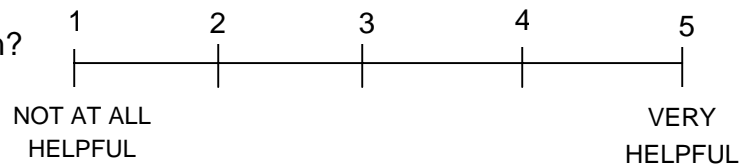


Have you taken medications in the last 30 days? NO YES

14. **Before** the survivor's injury did you take medications for depression?

NO YES

If yes, how helpful was medication?



15. **In the past year** have you received support from a house of worship (church, temple, mosque)?

NO YES

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

Did you receive support in the last 30 days? NO YES

16. **Before** the survivor's injury did you receive support from a house of worship (church, temple, mosque)?

NO YES

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

17. **In the past year** have you received support from a brain injury support group?

NO YES

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

Did you receive support in the last 30 days? NO YES

18. **Before** the survivor's injury did you receive support from any kind of support group?

NO YES

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

19. **In the past year** have you received support from other sources?

NO YES

If yes, please list: _____

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

Did you receive support in the last 30 days? NO YES

20. **Before** the survivor's injury did you receive support from other sources?

NO YES

If yes, what sources of support? (please list): _____

If yes, how helpful was the support?

1 2 3 4 5

NOT AT ALL HELPFUL VERY HELPFUL

Neurobehavioral Functioning Inventory Depression subscale

How often do you **CURRENTLY** have any of the following problems? Please place an 'X' in the box under the label "never," "rarely," "sometimes," "often," or "always."

	Never	Rarely	Sometimes	Often	Always		Never	Rarely	Sometimes	Often	Always
1. Feel worthless	[1]	[2]	[3]	[4]	[5]	7. Feel helpless	[1]	[2]	[3]	[4]	[5]
2. Sad, blue	[1]	[2]	[3]	[4]	[5]	8. Scared or frightened	[1]	[2]	[3]	[4]	[5]
3. Lonely	[1]	[2]	[3]	[4]	[5]	9. Bored	[1]	[2]	[3]	[4]	[5]
4. No confidence	[1]	[2]	[3]	[4]	[5]	10. Difficulty enjoying activities	[1]	[2]	[3]	[4]	[5]
5. Frustrated	[1]	[2]	[3]	[4]	[5]	11. Uncomfortable around others	[1]	[2]	[3]	[4]	[5]
6. Sit with nothing to do	[1]	[2]	[3]	[4]	[5]	12. Can't get mind off certain thoughts	[1]	[2]	[3]	[4]	[5]
						13. Restless	[1]	[2]	[3]	[4]	[5]

Neurobehavioral Functioning Inventory. Copyright © 1999 by The Psychological Corporation. Reproduced by permission. All rights reserved.

Satisfaction with Life Scale

How satisfied with your life are you? Please circle the number which best describes how much you agree or disagree with each of these statements, using the scale below:

a. In most ways, my life is close to ideal.
1 2 3 4 5 6 7

b. The conditions of my life are excellent.
1 2 3 4 5 6 7

c. I am satisfied with my life.
1 2 3 4 5 6 7

d. I have gotten the important things I want in life.
1 2 3 4 5 6 7

e. If I could live my life over, I would change almost nothing.
1 2 3 4 5 6 7

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SLIGHTLY DISAGREE
4 = NEITHER AGREE NOR DISAGREE
5 = SLIGHTLY AGREE
6 = AGREE
7 = STRONGLY AGREE



Brief Symptom Inventory 18

Leonard R. Derogatis, PhD

MALE Profile for Community Norms

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Name _____

ID Number _____ Age _____

Date Tested _____

Scored By _____

T	SOM	DEP	ANX	GSI	T
≥ 80	18+	23+	20+	31+	≥ 80
75	15	19-21	15	28-31	75
70	10	15	10	24-28	70
65	5	10	5	20-24	65
60	0	5	0	18-19	60
55				16-17	55
50				14-15	50
45					45
40	0	0	0		40
35					35
≤ 30					≤ 30

Scoring Directions

1. If the respondent's age is less than 18, STOP. Do not score the test. The BSI 18 norms cannot be used with individuals younger than 18.
2. On the answer sheet, record the value (0-4) of each darkened circle on the line to the right of each item. These lines are arranged in three columns to correspond to the three BSI scales: (1) Somatization, (2) Depression, and (3) Anxiety. (For example, if the respondent filled in the last circle for Item 1, you would write 4 [the value of the response] on the line to the right of Item 1.)
3. Count the number of values in Column 1, in Column 2, and in Column 3. If any column has fewer than four values, STOP. The test is invalid and should not be scored.
4. If the respondent did not answer an item, you must calculate an estimated value for that item. First, add up the values (0-4) for all of the items the respondent answered. Divide the result by the number of items the respondent answered. Round this result to the nearest whole number (if the decimal portion is < .5, round down; if it is ≥ .5, round up). Record this estimated value on the line to the right of each omitted item. For example, if a respondent answered 16 items and the total value of his or her responses was 38, the estimated value for each omitted item would be 2 (38 ÷ 16 = 2.375 = 2).
5. Add up the values in Column 1 and record the result on the line at the bottom of the column. Do the same for Columns 2 and 3.
6. Transfer the totals from Columns 1, 2, and 3 to the Raw Score lines for SOM, DEP, and ANX, respectively, under the profile.
7. Add up the raw scores for SOM, DEP, and ANX. Record the result on the GSI Raw Score line.
8. Plot the raw scores on the profile. For each raw score, find the corresponding T score along the side of the profile. Record the T score on the appropriate line under the profile.
9. Refer to the BSI 18 manual for information about how to interpret these scores.

Raw Score _____

SOM _____

DEP _____

ANX _____

GSI _____

T Score _____

ABCD _____



Product Number 51904

**17c. SCRIPT and STRATEGIES
TO FACILITATE SUCCESSFUL DATA COLLECTION
OF THE TBIMS FAMILY INCOME VARIABLE (V292c)**

Prepared by Jerry Wright and Therese O’Neil-Pirozzi for the 7.05 TBIMS D.C. Meeting

(Our thanks to AL, CA, CO, MI, and OH for their help with this project!)

Recommended Script:

“I understand that you may feel that this is a rather personal question. I want you to know that this information is confidential and not attached to your name. This information will not be reported to any billing department or government agency. Income information is important because it can help describe what happened to you and your family after your brain injury. If it makes you feel more comfortable, you can pick your income out from these income ranges.”

Strategies that have facilitated collecting family income info have five overlapping themes:

1. Data collectors and subjects/families having trusting, mutually beneficial relationships
2. Data collectors informing subjects/families of the need for family income info ahead of when actually requesting it;
3. Data collectors being comfortable and having confidence requesting this info;
4. Data collectors providing the subjects/families with visual aides to help them answer the family income question; and
5. Data collectors contacting involved families for family income info when subjects aren’t able to provide it.

The specific strategies reported to us are as follows:

1. Establishing and maintaining a trusting relationship with each subject and family/significant other is an invaluable way to help obtain this data. Help subjects/families feel that their study participation is of mutual benefit by referring



them to support groups and other community resources/services that would be appropriate/useful to them at the time of each data point;

2. Explain to the subject that the family income info helps the TBIMS to better characterize our patient population and to better understand how brain injury impacts all aspects of a person's life;
3. Remind the subject/family that the requested family income info is confidential, that the subject's name is not in the TBIMS database, and that your Model System is not connected to the hospital's Billing Department;
4. Assure the subject that the info regarding family income is strictly confidential and is not reported to any governmental agency. Don't use the term "W-2";
5. When a person is being consented, be sure to say to that person and to their family/significant other that each subject is asked their total annual income as well as that of their family's where they will be residing each time that they are interviewed;
6. At the beginning of each quarter, mail each subject scheduled for follow-up during that quarter a pre-interview packet that includes a questionnaire that the subject completes and then mails back to you prior to the follow-up phone call; this provides an opportunity for subjects to obtain the family income info that they may not know spontaneously;
7. Subjects and families can smell data collector fear and discomfort! If you are scared or uncomfortable asking a question, they will be scared/reluctant to answer it. Ask the family income question as casually as possible and emphasize that this includes salary and other sources of income. Emphasize that the answer doesn't have to be exact: offer one annual earning category and proceed from there;
8. Write out the annual earning categories on a laminated card in large font and hand it to the subject, explaining that you are asking for a range of income, not their specific income;
9. When a subject simply does not know what their family's income is (especially younger subjects who live with their parents and don't handle the finances), ask if there is someone who is at home at the moment (parent, spouse, etc.), whom the two of you might call to help the subject answer this question. If you reach the person on the phone, establish who they are in relation to the subject and whether or not they are willing to answer for the subject. If no one is at home, code the info as temporarily missing and call again later to obtain it.

17c.Script+Strategies to collect V292c_060321



TRAUMATIC BRAIN INJURY MODEL SYSTEMS NATIONAL CENTER DATA PROCESSING SCHEDULE

When you are in...	Enter and Submit all** Form I's with model system acute care admission dates between...	Enter and Submit all Form II's with follow-up eval. completion date or follow-up window closing date (for those with no contact) between...	Deadline for data submission to National Data Center	Error reports sent to Model Systems	Corrections from error reports submitted to National Data Center	Quarterly Data Summary Reports sent to Model Systems
1 st Quarter, 2004	10/1/2003-3/31/2004	10/1/2003-3/31/2004	3/31/2004	4/30/2004	6/30/2004	5/31/2004*
2 nd Quarter, 2004	1/1/2004-6/30/2004	1/1/2004-6/30/2004	6/30/2004	7/31/2004	9/30/2004	8/31/2004
3 rd Quarter, 2004	4/1/2004-9/30/2004	4/1/2004-9/30/2004	9/30/2004	10/31/2004	12/31/2004	11/30/2004
4 th Quarter, 2004	7/1/2004-12/31/2004	7/1/2004-12/31/2004	12/31/2004	1/31/2005	3/31/2005	2/28/2005
1st Quarter, 2005	10/1/2004-3/31/2005	10/1/2004-3/31/2005	3/31/2005	4/30/2005	6/30/2005	5/31/2005*
2nd Quarter, 2005	1/1/2005-6/30/2005	1/1/2005-6/30/2005	6/30/2005	7/31/2005	9/30/2005	8/31/2005
3rd Quarter, 2005	4/1/2005-9/30/2005	4/1/2005-9/30/2005	9/30/2005	10/31/2005	12/31/2005	11/30/2005
4th Quarter, 2005	7/1/2005-12/31/2005	7/1/2005-12/31/2005	12/31/2005	1/31/2006	3/31/2006	2/28/2006
1 st Quarter, 2006	10/1/2005-3/31/2006	10/1/2005-3/31/2006	3/31/2006	4/30/2006	6/30/2006	5/31/2006*
2 nd Quarter, 2006	1/1/2006-6/30/2006	1/1/2006-6/30/2006	6/30/2006	7/31/2006	9/30/2006	8/31/2006
3 rd Quarter, 2006	4/1/2006-9/30/2006	4/1/2006-9/30/2006	9/30/2006	10/31/2006	12/31/2006	11/30/2006
4 th Quarter, 2006	7/1/2006-12/31/2006	7/1/2006-12/31/2006	12/31/2006	1/31/2007	3/31/2007	2/28/2007

* Annual Data Summary Report

** Data for participants whose discharge information is not available at the time of scheduled submission may be submitted as scheduled and completed at the next submission, or may be held until data are complete and then submitted.



MODEL SYSTEMS OF CARE FOR TRAUMATIC BRAIN INJURY

Please answer these questions about the person's situation before the injury. Your answers will help us understand problems related to the injury. All information will be kept confidential. Please answer all questions and be as accurate as possible. If you have any questions please contact us at _____.

Your Name: _____ Date ____ - ____ - ____

Address: _____

Phone Number: (____) _____ Other phone number: (____) _____

Cell phone number: (____) _____ email address: _____

Patient's Name: _____

Your relationship to the patient: (*CIRCLE ONE*)

MOTHER FATHER WIFE HUSBAND BROTHER SISTER SON
DAUGHTER FRIEND GIRL/BOYFRIEND OTHER _____
(PLEASE WRITE IN)

1. What is the patient's date of birth? ____/____/____
month day year

2. What is the patient's race? (CIRCLE ONE)

WHITE **ASIAN/PACIFIC ISLANDER** **HISPANIC ORIGIN**
BLACK **NATIVE AMERICAN** **OTHER**_____

(PLEASE WRITE IN)

3. What is the patient's marital status? (CIRCLE ONE)

NEVER MARRIED **DIVORCED** **WIDOWED**

(PLEASE WRITE IN)

4. Before the injury, who was the primary person living with the patient? (CIRCLE ONE)

NO ONE (LIVED ALONE) **OWN CHILD LESS THAN 21 YEARS OLD** **OTHER RESIDENTS**
WIFE **OWN CHILD 21 YEARS OR OLDER** **PERSONAL CARE ATTENDANT(S)**
_____(PLEASE WRITE IN) **BROTHER/SISTER** **OTHER PATIENTS**

5. Before the injury, where was the patient living? (CIRCLE ONE)

PRIVATE RESIDENCE (HOME, APARTMENT, ETC) **REHABILITATION CENTER**
NURSING HOME **HOTEL** **OTHER HOSPITAL**
ADULT HOME **HOMELESS** **SUB-ACUTE**

(PLEASE WRITE IN)

5a. What is the zip code at the place where the patient was living before the injury? _____

If the patient is now living in a different place, or will be living in a different place after leaving inpatient rehabilitation, what is the zip code there? _____

6. How far has the patient gone in school? If the patient has not graduated from high school, circle the number of years spent in school. If the patient has at least a high school diploma, circle the highest degree earned (or worked toward). (CIRCLE ONE)

1 YR OR LESS	7 YRS	HIGH SCHOOL DIPLOMA	WORK TOWARD BACH., NO DIPLOMA
2 YRS	8 YRS	WORK TOWARD ASSOC., NO DIPLOMA	BACHELOR'S DEGREE
3 YRS	9 YRS	ASSOCIATE DEGREE	WORK TOWARD MASTER'S, NO DIPLOMA
4 YRS	10 YRS		MASTER'S DEGREE
5 YRS	11 YRS/12 YRS, NO DIPLOMA		WORK TOWARD DOCTORAL, NO DIPLOMA
6 YRS			DOCTORAL LEVEL

6b. Did the patient earn a GED (Graduate Equivalent Degree) instead of graduating from high school?

NO YES

7. At the time of injury did the patient have any of the following long-lasting conditions?

- a. Blindness, deafness, or a severe vision or hearing impairment. NO YES
- b. A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying. NO YES

8. At the time of injury was the patient having difficulty doing any of the following activities due to a physical, mental, or emotional condition that had been present for at least 6 months?

- a. Learning, remembering, or concentrating. NO YES
- b. Dressing, bathing, or getting around inside the home. NO YES
- c. Going outside the home alone to shop or visit a doctor's office. NO YES
- d. Working at a job or business. NO YES

9a. Before the injury, what was the patient's employment status? (CIRCLE ALL THAT APPLY)

FULL TIME STUDENT	SPECIAL EMPLOYMENT/SHELTERED WORKSHOP/JOB COACH	
PART TIME STUDENT	TAKING CARE OF HOUSE/FAMILY	RETIRED (AGE)
SPECIAL EDUCATION	UNEMPLOYED (LOOKING FOR WORK)	RETIRED (DISABILITY)
COMPETITVELY EMPLOYED	UNEMPLOYED (NOT LOOKING FOR WORK)	RETIRED (OTHER)
ON LEAVE FROM WORK, WITH PAY	VOLUNTEER	OTHER _____
ON LEAVE FROM WORK, NO PAY	HOSPITALIZED (NO PAY)	_____

(PLEASE WRITE IN)

9b. If the patient was employed before the injury, please list the following:

Type of job (not name of company) prior to injury: _____

Average number of hours worked per week in the month before injury: _____ hrs/week

Number of weeks employed in the year before injury: _____ weeks

Annual earnings of patient (total salary) for the year before injury. (CIRCLE ONE)

(Earnings from work only. Do not include income from non-work sources such as investments, law suits, lottery, etc.)

Not employed	\$30,000-\$39,999	\$70,000-\$79,999
\$9,999 or less (employed)	\$40,000-\$49,999	\$80,000-\$89,999
\$10,000-\$19,999	\$50,000-\$59,999	\$90,000-\$99,999
\$20,000-\$29,999	\$60,000-\$69,999	\$100,000 or more

10. Was the patient ever hospitalized for a brain injury prior to the current hospitalization? **NO** **YES**

If yes, please explain: _____

11. During the year before the injury did the patient use any illicit or non-prescription drugs? **NO** **YES**

12. During the month before the injury, did the patient have at least one drink of any alcoholic beverage such as beer, wine, wine coolers, or liquor?

NO **YES**

13. During the month before the injury, how many days per week or days per month did he/she drink any alcoholic beverages, on the average?

OR

14. A drink is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. On the days when the patient drank, about how many drinks did he/she drink on the average?

NUMBER OF DRINKS ON DAYS WHEN DRANK: _____

15. Considering all types of alcoholic beverages, how many times during the month before the injury did he/she have five or more drinks on an occasion?

16. Was the patient ever incarcerated for conviction of a felony? **NO** **YES**

17. While in school, was the patient ever classified as a special education student? **NO** **YES**

THAT'S ALL. THANK YOU.

26a-10.3-060221

26a_Premorbid_history_questionnaire_family 10.3.060221

MODEL SYSTEMS OF CARE FOR TRAUMATIC BRAIN INJURY

Please answer these questions about your situation before the injury. Your answers will help us understand problems related to the injury. All information will be kept confidential. Please answer all questions and be as accurate as possible. If you have any questions please contact us at _____.

Your name: _____ Date ____ - ____ - ____

Best person to contact if we cannot reach you:

Name: _____

Address: _____

Phone Number: (____) _____ Other phone: (____) _____

Cell phone: (____) _____ Other cell phone: (____) _____

Email address: _____

This person is my: (CIRCLE ONE)

MOTHER FATHER WIFE HUSBAND BROTHER SISTER SON
DAUGHTER FRIEND GIRL/BOYFRIEND OTHER _____
(PLEASE WRITE IN)

MODEL SYSTEMS OF CARE FOR TRAUMATIC BRAIN INJURY

1. What is your date of birth? _____ / _____ / _____
month day year

2. What is your race? (CIRCLE ONE)

- | | | |
|--------------|-------------------------------|---|
| WHITE | ASIAN/PACIFIC ISLANDER | HISPANIC ORIGIN |
| BLACK | NATIVE AMERICAN | OTHER _____
(PLEASE WRITE IN) |

3. What is your marital status? (CIRCLE ONE)

- | | | |
|--|------------------|---|
| NEVER MARRIED | DIVORCED | WIDOWED |
| MARRIED OR LIVING TOGETHER AT LEAST 7 YEARS | SEPARATED | OTHER _____
(PLEASE WRITE IN) |

4. Before the injury, who was the primary person living with you? (CIRCLE ONE)

- | | | |
|-----------------------------|--|---|
| NO ONE (LIVED ALONE) | MY CHILD LESS THAN 21 YEARS OLD | OTHER RESIDENTS |
| WIFE | MY CHILD 21 YEARS OR OLDER | PERSONAL CARE ATTENDANT(S) |
| HUSBAND | ROOMMATE | OTHER _____
(PLEASE WRITE IN) |
| PARENT | SIGNIFICANT OTHER | |
| BROTHER/SISTER | OTHER PATIENTS | |

5. Before the injury, where were you living? (CIRCLE ONE)

- | | | |
|---|------------------------------|---|
| PRIVATE RESIDENCE (HOME, APARTMENT, ETC) | REHABILITATION CENTER | |
| NURSING HOME | HOTEL | OTHER HOSPITAL |
| ADULT HOME | HOMELESS | SUB-ACUTE |
| CORRECTIONAL | ACUTE CARE HOSPITAL | OTHER _____
(PLEASE WRITE IN) |

5a. What is the zip code at the place where you were living before the injury? _____

If you are now living in a different place or will be living in a different place after leaving inpatient rehabilitation, what is the zip code there? _____

6. How far have you gone in school? If you have not graduated from high school, circle the number of years spent in school. If you have at least a high school diploma, circle the highest degree earned (or worked toward). (CIRCLE ONE)

1 YR OR LESS	7 YRS	HIGH SCHOOL DIPLOMA	WORK TOWARD BACH., NO DIPLOMA
2 YRS	8 YRS	WORK TOWARD ASSOC., NO DIPLOMA	BACHELOR'S DEGREE
3 YRS	9 YRS	ASSOCIATE DEGREE	WORK TOWARD MASTER'S, NO DIPLOMA
4 YRS	10 YRS		MASTER'S DEGREE
5 YRS	11 YRS/12 YRS, NO DIPLOMA		WORK TOWARD DOCTORAL, NO DIPLOMA
6 YRS			DOCTORAL LEVEL

Did you earn a GED (Graduate Equivalent Degree) instead of graduating from high school?

NO YES

7. At the time of injury did you have any of the following long-lasting conditions?

- a. Blindness, deafness, or a severe vision or hearing impairment. NO YES
- b. A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying. NO YES

8. At the time of injury were you having difficulty doing any of the following activities due to a physical, mental, or emotional condition that had been present for at least 6 months?

- a. Learning, remembering, or concentrating. NO YES
- b. Dressing, bathing, or getting around inside the home. NO YES
- c. Going outside the home alone to shop or visit a doctor's office. NO YES
- d. Working at a job or business. NO YES

9a. Before the injury, what was your employment status? (CIRCLE ALL THAT APPLY)

FULL TIME STUDENT	SPECIAL EMPLOYMENT/SHELTERED WORKSHOP/JOB COACH	
PART TIME STUDENT	TAKING CARE OF HOUSE/FAMILY	RETIRED (AGE)
SPECIAL EDUCATION	UNEMPLOYED (LOOKING FOR WORK)	RETIRED (DISABILITY)
COMPETITVELY EMPLOYED	UNEMPLOYED (NOT LOOKING)	RETIRED (OTHER)
ON LEAVE FROM WORK, WITHPAY	VOLUNTEER	OTHER _____
ON LEAVE FROM WORK, NO PAY	HOSPITALIZED (NO PAY)	_____

(PLEASE WRITE IN)

9b. If you were employed before the injury, please list the following:

Type of job (not name of company) prior to injury: _____

Average number of hours worked per week in the month before injury: _____ hrs/week

Number of weeks employed in the year before injury: _____ weeks

Annual earnings (total salary) for the year before injury. (CIRCLE ONE)

(Earnings from work only. Do not include income from non-work sources such as investments, law suits, lottery, etc.)

Not employed	\$30,000-\$39,999	\$70,000-\$79,999
\$9,999 or less (employed)	\$40,000-\$49,999	\$80,000-\$89,999
\$10,000-\$19,999	\$50,000-\$59,999	\$90,000-\$99,999
\$20,000-\$29,999	\$60,000-\$69,999	\$100,000 or more

10. Were you ever hospitalized for a brain injury prior to the current hospitalization? **NO** **YES**

If **yes**, please explain: _____

11. During the year before the injury did you use any illicit or non-prescription drugs? **NO** **YES**

12. During the month before the injury, did you have at least one drink of any alcoholic beverage such as beer, wine, wine coolers, or liquor?

NO **YES**

13. During the month before the injury, how many days per week or days per month did you drink any alcoholic beverages, on the average?

NUMBER OF DAYS PER WEEK: _____ **OR** **NUMBER OF DAYS PER MONTH:** _____

14. A drink is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. On the days when you drank, about how many drinks did you drink on the average?

NUMBER OF DRINKS ON DAYS WHEN DRANK: _____

15. Considering all types of alcoholic beverages, how many times during the month before the injury did you have five or more drinks on an occasion?

NUMBER OF TIMES PER MONTH: _____

16. Were you ever incarcerated for conviction of a felony? **NO** **YES**

17. While in school, were you ever classified as a special education student? **NO** **YES**

THAT'S ALL. THANK YOU.

DETAILED LIST OF SYLLABUS CHANGES COMPLETED IN 1st QUARTER 2006 for 2th QUARTER 2006 (V10.3)

Var/Topic	Description
GENERAL	
FORM I	
123d	Add note that for participants who aren't working, coding should be on the basis of difficulty that they would have if they WERE working.
146a,b	Add NOTE: "ICD-9 codes that are preceded by "E" or "V" are entered into 146c, never into 146a or b." [Be sure that the data entry screen is consistent with this.]
146c	Change missing data codes to "77777=Expired cause unknown", "88888=N/A-alive/no other internal cause/external cause", and "99999=Unknown if expired".
151	Update the list of persons certified.
152	Add the URL for the 2004 IRF-PAI manual, which should be used with patients admitted after April 1, 2004: http://www.udsmr.org/pdfs/irfpaimanual040104%20(1).pdf Update the URL for the 2002 manual: < http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manualint.pdf > Add the URL for the description of the 2004 updates: < http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manual040104.pdf >
152	Add code "0" to syllabus page, plus an explanation that the 0 code is to be used only for admission and only for certain items (see Form I for details).
FORM II	
20Aa(c)	Change missing data codes to "77777=Expired cause unknown", "88888=N/A-alive/not an external cause of death", and "99999=Unknown if expired". On the data collection form, reduce to three the number of data entry boxes to the left of the decimal point.
20Ab,20Ac	Add note: "All possible effort is to be made to collect data from the participant or an SO. Data from other sources (as indicated by code "4") should be entered only if: (1)it has not been possible to obtain the data from the person or SO during the follow-up window, (2) those data were originally collected during the follow-up window, and (3) the data meet TBIMS standards for data collection procedures and data quality standards.
20Ac	Add NOTE to code "8" if participant is incarcerated.
252	Add the URL for the 2004 IRF-PAI manual, which should be used with patients admitted after April 1, 2004: http://www.udsmr.org/pdfs/irfpaimanual040104%20(1).pdf Update the URL for the 2002 manual: < http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manualint.pdf > Retain the URL for the description of the 2004 updates: < http://www.cms.hhs.gov/InpatientRehabFacPPS/downloads/irfpai-manual040104.pdf >
292c1.Fam income	At the end of DEFINITION, add a note: "To collect this variable, see Appendix E document "17c.Script+Strategies to collect income variable".
292c1.Fam	Remove the "*" in the first sentence in the DEFINITION.

DETAILED LIST OF SYLLABUS CHANGES COMPLETED IN 1st QUARTER 2006 for 2th QUARTER 2006 (V10.3)

Var/Topic	Description
income	
CONTACT INFO	
	Delete Renee Morrison (NY)
	Add Angelica Ortiz (NY)
LISTSERVER LISTS	
Data	Delete Renee Morrison (NY)
Data	Add Angelica Ortiz (NY)
OTHER DOCS	
00e	Change NC's name to "Carolinas..."
9a	Delete old 9a ("Procedure for tracking lost patients form") Add new 9a ("Guidelines and Strategies for Maximizing Followup")
9b	Delete 9b ("Collecting fup data from hospitalized participants")
9c. Guidelines for collection of fup data	Incorporate changes by Allison & Flora. Delete item 8 (hospitalized participants) Add table showing the codes to use for expired, withdrawn, and incarcerated participants. Consolidate the instructions for coding expired, withdrawn, and incarcerated participants. Add to incarcerated section that it is okay (contingent on IRB/PI) to find out when participant will released and to collect data after release and prior to closing of window.
12b. Mailout Form II	Change the location of the instruction regarding filling out form if participant is incarcerated, so only the appropriate (as of 1/1/06) data will be provided.
15e. TBINDC Guidelines for Module DCF + syllabus.	First bullet, 3 rd point. Correct the explanation that the 2-digit code for follow-up year is the "calendar year"-- it is in fact the "follow-up year (e.g., yr1, yr2, yr5, etc)".
15e. TBINDC Guidelines for Module DCF + syllabus.	Second bullet. Add the words "to more than one subject.", which are missing from the end of the sentence.
15g. Module Peer Review Procedure	In the version label at the end of the document, change "15f" to "15g".
17: APPENDIX D.	Change the title of Appendix D from "Census Occupational Codes" to "Employment and Income"
17c. Scripts & strats for collecting income data	Add to Appendix D.
22c. Data Proc Schedule	Schedule shows only through 12/31/2005, so needs to be extended at least through 12/3/2006.
22e. Syllabus order form	Delete this document. (The syllabus is now available to the public via the website.)
26a. Premorb hist Q-fam	Revise so only personal (nonTBIMS) variables are on the first page.
26b. Premorb hist	Revise so only personal (nonTBIMS) variables are on the first page

DETAILED LIST OF SYLLABUS CHANGES COMPLETED IN 1st QUARTER 2006 for 2th QUARTER 2006 (V10.3)

Var/Topic	Description
Q-pers	
REPORTS	
Quarterly	Add the formula used to calculate follow-up rate; add text as needed to explain how the formula is applied (adapt from appendix 22o).
STANDARD UPDATES	
00d.Title page	Update the version number.
03a.Contact Information	Update the date.
03c.Committee list	Update the date.
03e.Listserver subscribers-by center	Update the date.
03f.Listserver subscribers-by Listserver	Update the date.
07a.Form I dcf	Update version and date.
12a.Form II data collection form	Update version and date.
12b.Mailout Form II	Update version and date.
26a. Premorbid Hist-Family	Update version number
26b. Premorbid Hist-Patient	Update version number