

## **Revised Syllabus Pages First Quarter 2006**

Compiled and Distributed by the  
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Model Systems National Data Center**

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# METHOD OF INTERVIEW DATA COLLECTION -PERSON WITH BRAIN INJURY

## Variable 20Ab

Date of last revision: 01/01/06

### 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.

### EXAMPLE:

Data were collected via telephone interview.

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### VARIABLE HISTORY:

Date of last Revision	Description
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).
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:

<b>QUESTION:</b>	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
<b>ANSWER:</b>	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

# METHOD OF INTERVIEW DATA COLLECTION -SIGNIFICANT OTHER

## Variable 20Ac

Date of last revision: 01/01/06

### 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 a significant other

### 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.

### EXAMPLE:

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

2

### VARIABLE HISTORY:

Date of last Revision	Description
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.
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.

Date of last Revision	Description
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:**

<b>QUESTION:</b>	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
<b>ANSWER:</b>	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

# REASON PERSON WITH BRAIN INJURY NOT PROVIDING DATA

## Variable 20Ad

*Date of last revision: 01/01/06*

**DEFINITION:**

If no interview data were provided by the person with brain injury, what was the reason?

**CODE:**

Person with brain injury....

03 is physically or cognitively unable to respond

04 is not available for interview (e.g., not at home, in the hospital or jail, is working or in school and not available for interview)

05 has stated refusal to take part in interview

06 has not responded to contact (i.e., center staff know the whereabouts of the person with brain injury but he/she has not responded to contact)

07 is lost to follow-up (unknown whereabouts of person with brain injury)

08 has a language barrier (person with brain injury does not speak English and no interpreter was available)

09 expired during follow-up year.

\*66 Variable did not exist at time data were collected

77 No data collected at this time (e.g., no funding)

88 Not applicable--interview data was provided by person with brain injury

99 Unknown reason why no interview data was provided by person with brain injury, or unknown reason why no follow-up was attempted.

**CHARACTERS:**

2 numeric

**NOTE:**

If in jail, code: 04=not available.

Code 77 is not shown on Form II because it is a special purpose code and should not be used in normal data collection/submission.

**EXAMPLE:**

Patient unable to respond because of dysarthria.

03

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added CODE "66=Variable did not exist at time data were collected"
2004-04-01	Variable added back into database.
2004-04-01	Added NOTE that Code 77 is not shown on Form II because it is a special purpose code and should not be used in normal data collection/submission.
2004-01-01	Added code 77 (So VA can add fup cases retroactively.)
2003-01-01	Variable deleted.
2002-01-01	Added NOTE about if in jail
2000-07-01	Combined "01=physically unable" and "02=cognitively unable" into "03=physically or cognitively unable".
1996-01-01	Revised codes to combine information from v20Ad and V20Ag.

## DATES (AND TIMES)

### Variable 101a

Date of last revision: 01/01/06

#### **DEFINITION:**

The "Dates" set of variables includes the following:

1. Date of injury
2. Date admitted to Model System emergency department
3. Date discharged from acute care
4. Date admitted to inpatient rehabilitation facility
5. Date discharged from inpatient rehabilitation facility
6. Date of death

#### **CODE:**

MM/DD/YYYY

08/08/8888 = Not Applicable

09/09/9999 = Unknown

#### **CHARACTERS:**

8 date

#### **NOTE:**

If a patient completes acute care and inpatient rehabilitation and is then transferred to an alternate level of care (regardless of whether it is a designated Model System facility or not), this is considered the rehabilitation discharge date and the residence at discharge (V109) should reflect this alternate level of care discharge.

An alternate level of care is defined as a transfer of a patient from inpatient rehabilitation to a lower level of care (usually with maintenance therapy) after he/she is medically stable and reaches functional plateau (as determined by a medical doctor and utilization review committee).

If a patient is transferred to an alternate level of care within the designated Model System prior to inpatient rehabilitation, the ALC length of stay should be added to the Model System acute care stay or inpatient rehabilitation stay, which ever is most applicable.

Day hospital treatment should not to be included as part of inpatient rehabilitation stay.

Do not assume that the date of discharge from the acute care hospital is the same as the date of admission to inpatient rehab.

Do not include rehab in a day hospital as part of the inpatient stay.

#### **CHARACTERISTICS OF DATA:**

\*Length of stay may be expected to increase slightly as of 1/1/05 simply due to a change in TBIMS Inclusion Criteria which allows patients to not be considered discharged from System if they go to a long term care facility that is able to provide patients with a specified minimum level of services (see definition in Inclusion Criteria), even though this patient does not receive those services.

#### **EXAMPLE:**

Date of injury was April 13, 1988.

04/13/1988

#### **VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added to CHARACTERISTICS OF DATA that LOS is likely to increase slightly simply due to a change in TBIMS Inclusion Criteria.
2004-10-01	In DEFINITION, numbered the six parts of this item. (In order to make them easier to identify.)
2003-01-01	Deleted 101B: Times of Injury and ER Admission
2002-04-01	Removed typo from first 1/1/02 note.
2002-04-01	Removed second 1/1/02 note (regarding family consent).
2002-01-01	Added NOTE to not assume that date of acute discharge is the same as admission to inpatient rehab.
2002-01-01	Added NOTE about consent from family if patient dies before consent.
1999-04-01	Revised unknown date codes to be compatible with the new software.
1998-08-15	Year expanded to four digits.
1995-07-01	Added codes for unknown time less than 8 hours or less than 24 hours to correspond to new inclusion criteria.
1995-07-01	Clarified code 99:99. Now refers only to unknown time of ED admit.
1994-09-13	Deleted these date variables: "admitted to acute care", "first acute rehab services", "admitted to/discharged from an alternate level of care".
1994-09-13	Added notes for clarification of ALC (alternative level of care).
1994-02-01	Added note to clarify what the Date of First Acute Care Rehab Services refers to.

#### QUESTIONS AND ANSWERS:

<b>QUESTION:</b>	Person entered hospital NOT for TBI. Received a TBI in hospital. How to handle various issues in coding? 05-19-2004
<b>ANSWER:</b>	If in-house TBI meets inclusion criteria, then enroll this person and code accordingly. Please contact if any specific coding questions. 05-20-2004

# PATIENT BIRTHDATE

## Variable 103

Date of last revision: 01/01/06

**DEFINITION:**

Date of birth. Only patients 16 or older at the time of injury are to be entered into the database.

**CODE:**

MM/DD/YYYY

09/09/9999      Unknown

**CHARACTERS:**

8 date

**NOTE:**

If exact date of birth is unknown, then estimate. If month is known but day cannot be estimated, enter the mid-point of the month.

**EXAMPLE:**

Patient was born on October 31, 1952.

10/31/1952

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE to estimate day of birth, if unknown.
2003-04-01	Removed code "08/08/8888=N/A" from data collection form starting 4/1/2003.
1999-04-02	Revised unknown codes to be compatible with new software.

**QUESTIONS AND ANSWERS:**

<b>QUESTION:</b>	We have a patient who just turned 16 but was not 16 at the time of injury. Can we enroll him? 02-18-2005
<b>ANSWER:</b>	No. Patients must be 16 at the time of injury. 02-18-2005

RACE  
Variable 105

Date of last revision: 01/01/06

**DEFINITION:**

Self-reported race.

**CODE:**

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

For a list of the specific racial/ethnic groups that fall within in each of the five categories (above), see the "2000 Census of Population and Housing" (US Department of Commerce, 2003), "Summary 1": [19a.Race Codes](http://www.census.gov/prod/cen2000/doc/sf1.pdf) (<http://www.census.gov/prod/cen2000/doc/sf1.pdf>). The race codes are in the "Technical Documentation" section, starting on page 587. This list should be printed and inserted in Appendix F. (For TBIMS purposes, this list of race codes used in the 2000 census is sufficiently similar to the list used in the 1990 census, which was previously in Appendix F of the syllabus.)

**CHARACTERS:**

1 numeric

**NOTE:**

Patient's or SO's statement is preferred to hospital record information.

Record participant's statement regarding his/her race, or record race of father.

\*In obtaining a statement from the participant regarding his/her race/ethnicity, ambiguity may be resolved by asking which race/ethnicity is more important in his/her daily life.

The following Bureau of the Census guidelines are to be used to code mixed race: in the event of a mixed white and other race, the other race is used; in the event of mixed races other than white, the race of the father is used.

**SOURCE:**

2000 Census, Department of Commerce: [19a.Race Codes](http://www.census.gov/prod/cen2000/doc/sf1.pdf) (<http://www.census.gov/prod/cen2000/doc/sf1.pdf>)

**EXAMPLE:**

Patient is a Native American

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**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE to ask which plays the biggest role in their daily life.
2004-04-01	Added link to 2000 census report.
2003-10-01	Added NOTE that person's or SO's information is preferred to hospital records.
2001-08-20	Added note about determining race.
1995-01-01	Corrected reference to Appendix F (not E) did not change page date.
1994-09-13	Added code for Hispanic; added reference to Appendix E for coding.

PRIMARY PERSON LIVING WITH  
Variable 108

Date of last revision: 01/01/06

**DEFINITION:**

The primary person living with the subject:  
-- at time just prior to injury, and  
-- at discharge from Rehabilitation

**CODE:**

01 Alone  
02 Spouse (including commonlaw partners of 7 or more years)  
03 Parent(s)  
04 Sibling(s)  
05 Child/children (under 21 years of age)  
06 Other relative(s) or adult child(ren) 21+ years of age  
07 Roommate(s)/friend(s)  
08 Significant other (partners, not married)  
09 Other patients (in hospital or nursing home)  
10 Other residents (group living situation, \*boarding house)  
11 Personal Care Attendant  
77 Other (includes correctional facility inmates)  
88 Not Applicable patient expired in rehab  
99 Unknown

**CHARACTERS:**

2 numeric

**NOTE:**

If the patient is living with more than one person, list the person most involved in the patient's life and care.

**SOURCE:**

SCVMC

**EXAMPLE:**

Patient was living with a sibling and a roommate at time of injury, and alone after discharge from Rehabilitation.

At time of injury 04  
After rehab discharge 01

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	If lives in a boarding house, use code 10.
1995-07-01	Dropped 2nd and 3rd persons living with, revised code 88 to correspond.
1994-09-13	Dropped "living with at time of acute discharge".
1994-02-01	Deleted reference to Level I data collection.

# YEARS OF EDUCATION

## Variable 110a

Date of last revision: 01/01/06

### DEFINITION:

Number of years of education successfully completed at the time just prior to injury.

### CODE:

01 1 year or less  
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 HS diploma  
13 Work toward Associate's degrees, no diploma  
14 Associate's degrees  
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  
66 Var didn't exist at the time of interview  
77 Other  
99 Unknown

### CHARACTERS:

2 numeric

### NOTE:

The number of years of education coded may not equal the actual number of years spent in school. For example, a person who is held back two years in elementary school and then drops out of school in the 10th grade (for a total of 11 full years) would be coded as having completed 9 years; or, a person may take 6 years to complete a BA (for a total of 18 years), but, as indicated, only 16 years are coded.

GED, trade school, and other types of schooling not listed, are not counted toward years of education

If person is not sure of number of years, code the greater number.

\*If person takes a few courses in a college setting with no intention of earning a degree, code "associate".

\*Code years of foreign education completed the same as years of US education. The TBIMS has not yet found a satisfactory method for determining equivalence.

### CHARACTERISTICS OF DATA:

All data on educational level are available in the calculated variable "EDUCATION". This calculated variable merges data for V110a with data for V110 "Highest grade of school completed", which V110a replaced on 1/1/01.

### SOURCE:

Heaton RK, Miller SW, Taylor MJ, Grant I. Revised Comprehensive Norms for an Expanded Halstead-Reitan Battery: Demographically Adjusted Neuropsychological Norms for African American and Caucasian Adults. Lutz, FL: Psychological Assessment Resources, Inc., 2004, pages 17-18.

**EXAMPLE:**

Patient finished high school.

12

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE to code "associate" if person took a few college courses without intending to earn a BA.
2006-01-01	Added note about coding foreign education the same as US education.
2004-04-01	Added "successfully" prior to "completed" in DEFINITION.
2004-04-01	Added EXAMPLE of being held back in elementary school.
2004-04-01	Updated SOURCE.
2004-04-01	Added information about the calculated education variable, in CHARACTERISTICS OF DATA.
2003-01-01	Changed label of code 01 from "1 year" to "1 year or less".
2003-01-01	Corrected code for "Variable did not exist at time of interview" from "00" to "66".
2001-08-20	NOTE added about recording the higher number, if person is uncertain.
2001-07-01	Added note that actual years of education may not equal the actual number of years in school.
2001-07-01	Added instruction to not count GED, trade school, or other types of education not listed in the syllabus toward years of education.
2001-01-01	Variable added to database (replaced V110:HIGHEST GRADE OF SCHOOL COMPLETED).

# EMPLOYMENT STATUS

## Variable 111a

Date of last revision: 01/01/06

### DEFINITION:

Code employment status in the month prior to injury. Code up to two statuses, if applicable.

Determine primary status and then secondary 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, supported employment, sheltered employment, non-directed coursework, volunteer work, retirement (age-related), retirement (disability-related), and no productive activity.

\*The purpose of the premorbid employment variables (111a-112) is to record the extent to which participants were engaging in productive work and, also, their personal earning power (111i) at the time of injury. Whether employment was legal or illegal is not relevant to coding any of the employment variables. (But see NOTE below about collecting information about illegal employment.)

### CODE:

- 02 Full-time student (regular class)
- 03 Part-time student (regular class)
- 04 Special Education/other non-regular education
- 05 Competitively employed (minimum wage or greater, legal or illegal employment, \*includes on leave with pay)
- 07 Taking care of house or family
- 08 Special employed (sheltered workshop, supportive employment, has job coach)
- 09 Retired (age)
- 10 Unemployed (looking for work in the 4 weeks prior to injury)
- 11 Volunteer work
- 12 Retired (disability)
- 13 Unemployed (not looking for work in 4 weeks prior to injury for any reason)
- 14 Hospitalized without pay during most of 4 weeks prior to injury
- 15 Retired (other)
- \*16 On leave from work, not receiving pay
- \*55 Other
- 77 \*Refused
- 88 No secondary employment status
- 99 Unknown

### CHARACTERS:

2 numeric

**NOTE:**

If less than two employment categories are coded, then code 88 in the remaining field. Do not leave field blank.

Competitive subminimum wage employment such as baby-sitting, newspaper delivery, and piecework should be coded 77.

Code "09=Retired (age)" if respondent indicates that retirement was due to age (use respondent's definition).

Ignore non-employment sources of income such as pension, settlement, or disability income support.

If participant works in a foreign country, assume wage is not subminimum unless there is information to the contrary.

If participant is employed for only part of the month prior to the follow-up evaluation, code employment status as during the majority of the work days during that month.

If person had been hired but had not begun work, code as employed.

Code education as full-time or part-time based on self-report.

\*Illegal employment includes work that is illegal (e.g., selling drugs) as well as illegally engaging in legal work (e.g., non-citizens doing construction work without a green card).

\*DATA COLLECTORS: Do not ask the respondent if employment at the time of injury was legal or illegal. That distinction is not needed for any of the employment questions. If in the course of the interview you learn that some or all employment was illegal, continue asking the employment questions as long as providing that information does not become uncomfortable for the respondent and would therefore risk jeopardizing the rest of the interview.

**CHARACTERISTICS OF DATA:**

Starting 7/1/01, data are entered into a new field that uses the additional coding categories implemented on 7/1/01. The old field has been retained in the database. Data for all cases is available in the calculated variable "EMPLOYMENT", which merges these two fields.

\*As of 1/1/06, all cases with "77" were recoded as "55", in order to allow "77" to be used for "refused".

**EXAMPLE:**

Patient was taking care of family at the time of injury, with no other employment status.

07

88

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added definition of illegal employment.
2006-01-01	Added to DEFINITION that no distinction is to be made between legal and illegal employment.
2006-01-01	Added NOTE about appropriate strategy to use in collecting information if employment was illegal.
2006-01-01	Added code: 16=on leave from work not receiving pay.
2006-01-01	Added to code 05 that person may be on leave with pay.
2006-01-01	Changed the "Other" code from 77 to 55.
2006-01-01	Add code "77=Refused". (Changed "Other" to 55.)
2004-04-01	Moved prioritization list from NOTES to DEFINITION.
2004-04-01	Added information to CHARACTERISTICS OF DATA about the employment calculated variable, which merges current data with data collected before the response categories were expanded.

Date of last Revision	Description
2004-01-01	Added NOTE to code education as full-time or part-time based on self-report.
2003-10-01	Added to DEFINITION an instruction to use the priority list to determine primary and secondary, if more than two employment statuses.
2003-10-01	Added NOTE to use the priority list to determine primary and secondary, irrespective of relative number of hours worked in the various statuses.
2003-10-01	Added NOTE to code as employed if had been hired but had not started work.
2002-07-01	Added NOTE about minimum wage in foreign country.
2002-07-01	Added NOTE about coding if did not work all days in prior month.
2001-07-01	Replaced "at the time of injury" with "in the month prior to injury".
2001-07-01	For code 7, replaced "Homemaker" with "Taking care of house or family".
2001-07-01	For code 10, added "(looking for work in the last 4 weeks)".
2001-07-01	Added code 12=Retired (disability).
2001-07-01	Added code 13=Unemployed (not looking for work in the last 4 weeks).
2001-07-01	Added code 15=Retired (other).
2001-07-01	Removed [i]source of income support for disability[/i] as a criterion for classification.
2001-07-01	Revised the prioritization list as follows: "taking care of house or family" replaces "home management (homemaker)", "job-directed/on-the-job training" reverses position with "supported employment", "volunteer work" replaces "volunteer activity", "retirement (age-related), retirement (disability-related)" replaces "active leisure/retirement, disability-related retirement".
2001-07-01	Added NOTE that for the code "09=Retired (age)", accept the respondent's statement as to whether age was the cause of retirement.
1999-10-01	Added use of job coach to code 8.
1999-10-01	Added list to prioritize employment status if more than one.
1999-04-02	Added clarification for some codes.
1995-07-01	Dropped reference to variable 112 to make coding consistent between all employment-related variables.
1994-09-13	Dropped "3rd employment status".

#### QUESTIONS AND ANSWERS:

<b>QUESTION:</b>	I have a 61 year-old man who worked most of his life in an engineering position. A few months ago he was laid off and went to work as a salesman in a large home supply store where he subsequently was injured. In the year after his injury, he returned to this job. However, after 24 weeks, he decided to retire because of fatigue, and because it really wasn't the kind of work he was trained to do. He has no plans to work again. 12-03-2004
<b>ANSWER:</b>	Recall that "employment status" is coded according to the coding priority as shown on the data collection form and in the syllabus. The coding priority is applied in cases when more than one employment status is indicated by the respondent. In your example the person says that he retired due to fatigue (presumably "disability" due to the brain injury) and to the job not being the kind of work he was trained to do (ie., an "other" reason). The coding priority lists "retired (disability)" but does not list "retired (other)", so "retired (disability)" is the higher priority and is the correct choice. The other two categories you wonder about--"retired (age)" and "unemployed (not looking)"--can be ruled out because they aren't indicated by the respondent. 12-03-2004

# HOURS OF PAID COMPETITIVE EMPLOYMENT

## Variable 111b

Date of last revision: 01/01/06

### DEFINITION:

Average number of hours per week usually worked at all paid competitive jobs (minimum wage or greater) in the month prior to injury. \*Includes illegal employment (see V111a for more information and for data collection instructions).

### CODE:

?? Hours per week

\*777 Refused

888 NA-not currently competitively employed

999 Unknown

### CHARACTERS:

3 numeric

### NOTE:

Fractions are to be rounded to the nearest whole number. 0.5 should be rounded upward.

Code actual number of hours per week **only** for those cases coded 05 (competitively employed) in either the primary or secondary status of variable 111a (employment status), otherwise this variable must be coded 88.

If patient was employed more than 98 hours per week, code as 98 hours.

If patient works two jobs, add all hours together to code.

*\*If data collector does not ask this question because the participant was illegally employed, code "999=Unknown".*

### CHARACTERISTICS OF DATA:

When missing data codes were changed from 88 and 99 to 888 and 999 (4/1/05), the TBINDC changed all 88 and 99 codes in the database to 888 and 999. (There were almost no other codes in the 80-100hr/wk range.)

### EXAMPLE:

Patient was employed 37.5 hours per week.

38

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added code "777=Refused".
2006-01-01	Added NOTE to code "999=Unknown" if data collector does not ask question because employment was illegal.
2006-01-01	Removed NOTE that this include only legal employment.
2005-07-01	Added to CHARACTERISTICS OF DATA that the TBINDC changed all 88 and 99 codes in the database to 888 and 999 when the missing data codes were changed (4/1/05)from 88 and 99 to 888 and 999.
2005-04-01	Changed missing data codes 88 and 99 to 888 and 999.
2005-04-01	Deleted missing data code 66=variable did not exist. (Variable has always existed.)

Date of last Revision	Description
2005-04-01	Changed field width from 2 characters to 3.
2002-07-01	Changed code 88 to "not currently competitively employed".
2002-04-01	Added "not competitively employed" to code "88=NA".
2002-01-01	Clarified instruction to code this variable if "05=competitive employment" is coded for either the primary or secondary status of V111a.
2001-08-20	Added CODE "66=Variable did not exist".
2001-07-01	In DEFINITION, added "usually worked at all" prior to "paid competitive".
2001-07-01	In DEFINITION, replaced "employment" with "jobs".
2001-07-01	In DEFINITION, replaced "at time of injury" with "in the month prior to injury".
1999-04-02	Added NOTE regarding hours for more than one job.
1998-09-01	Added NOTE regarding coding hours greater than 98.
1995-07-01	Added note clarifying when to code variable in relationship to variable V111a.

# JOB STABILITY: WEEKS EMPLOYED

## Variable 111d

Date of last revision: 01/01/06

### DEFINITION:

Number of weeks patient was competitively employed during the year prior to injury. \*Includes illegal employment (see V111a for more information and for data collection instructions).

### CODE:

?? Number of weeks

66 Variable did not exist

\*77 Refused

88 N/A-no competitive employment in the last year

99 Unknown

### CHARACTERS:

2 numeric

### NOTE:

Include all weeks employed at minimum wage or higher. \* Include vacation time and other types of leave if the person was paid during that time. Round partial weeks up to the nearest whole week.

If employment is infrequent but on a regularly scheduled basis, or if it is related to a specific function, then code the number of weeks during which the person has been employed. But, if days of employment are just random and the person might or might not do it again, then code the total number of weeks in which the person worked. (E.g., if the person worked 2 times a month for 9 months, then in the first situation 39 weeks should be coded. In the second situation 18 weeks should be coded.)

\*If data collector does not ask this question because the participant was illegally employed, code "99=Unknown".

### EXAMPLE:

Patient worked October 11 through December 21.

11

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added code "77=Refused".
2006-01-01	Added NOTE to code "99=Unknown" if data collector does not ask because employment was illegal.
2006-01-01	Removed NOTE that this include only legal employment.
2003-01-01	Added NOTE about coding infrequent employment.
2002-07-01	Changed label of code 88 from "not competitively employed" to "no competitive employment in the last year", to indicate that 88 should be used only if person has not been competitively employed at all during year prior to evaluation.
2002-04-01	Added "not competitively employed" to code "88".
2001-08-20	Added "66=Variable did not exist".
2001-07-01	Variable added to database.

# ANNUAL EARNINGS

## Variable 111i

Date of last revision: 01/01/06

### DEFINITION:

Dollar earnings from all jobs held by patient during the year prior to injury. \*Includes illegal employment (see V111a for more information and for data collection instructions).

### CODE:

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  
66 Variable did not exist  
77 Refused  
88 N/A, no competitive \* employment in the last year  
99 Unknown

### CHARACTERS:

2 numeric

### NOTE:

Include income only from competitive \* employment. Exclude income support, investment income, and settlements. Include tips.

This is pre-tax income.

\*If data collector does not ask this question because participant was illegally employed, code "99=Unknown".

### CHARACTERISTICS OF DATA:

In 2003, four Model Systems had difficulty obtaining this information (10% or more missing data).

### EXAMPLE:

Patient earned \$75,956 in the year prior to injury.

08

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Removed that this includes only legal employment.
2006-01-01	Added NOTE to code "99=Unknown" if data collector did not ask question because employment was illegal.
2004-07-01	Corrected VARIABLE HISTORY for 7/1/02: changed "year prior to evaluation" to "year prior to injury".

Date of last Revision	Description
2004-01-01	Added NOTE to include tips.
2002-07-01	Changed code 88 from "not competitively employed" to "no competitive employment", to indicate that 88 should be used only if person has not been competitively employed for the entire year prior to injury.
2002-04-01	Added "not competitively employed" to code 88.
2002-01-01	Added NOTE that this is pretax earnings.
2001-08-20	Added CODE "66=Variable did not exist".
2001-07-01	Variable added to database.

# CENSUS OCCUPATIONAL CATEGORY

## Variable 112

Date of last revision: 01/01/06

### DEFINITION:

The major census occupational category in which the patient's occupation is included for his/her primary occupation in the month prior to injury.

\*Instructions from Bureau of Census for collecting this information appear to not distinguish legal from illegal employment. The TBIMS Data Committee clarified that illegal employment is to be included (to take effect 1/1/06). See V111a for more information and for data collection instructions.

### CODE:

Code the patient's primary occupation using the categories below. For a list of the specific occupations in each category, see the "1990 Census of Population Occupational Classification System", pages 9-22 of this document: [1990 Census Industrial & Occupational Classification Codes](http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf) (http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf). A copy of this list should be in Appendix D of your syllabus binder. For instructions using this document see: [17a.Instructions for 1990 Census Occupational Codes](http://syllabus/pdf/Occ_codes_w_govt_URL.pdf) (http://syllabus/pdf/Occ\_codes\_w\_govt\_URL.pdf) in Appendix D.

- 01 Executive, Administrative, and Managerial
- 02 Professional Speciality
- 03 Technicians and Related Support
- 04 Sales
- 05 Administrative Support Including Clerical
- 06 Private Household
- 07 Protective Service
- 08 Service, except Protective and Household
- 09 Farming, Forestry, and Fishing
- 10 Precision Production, Craft, and Repair
- 11 Machine Operators, Assemblers, and Inspectors
- 12 Transportation and Material Moving
- 13 Handlers, Equipment Cleaners, Helpers, and Laborers
- 14 Military Occupations
- \*77 Refused
- 88 Not Applicable, not coded 05 or 08 for variable 111a
- 99 Unknown occupation

### CHARACTERS:

2 numeric

### NOTE:

Code only if variable 111a (employment status) is coded 05 or 08 (competitively employed or special employed) for either either the primary or secondary occupation; otherwise this variable must be coded 88.

\*If data collector does not ask this question because participant was illegally employed, code "99=Unknown".

### CHARACTERISTICS OF DATA:

\*

### SOURCE:

1990 Occupational Classification System, Alphabetical Index of Industries and Occupations, 1990 Census of Population and Housing, Bureau of the Census, U.S. Department of Commerce, pp 9-22. [1990 Census Industrial & Occupational Classification Codes](http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf) (http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf)

**EXAMPLE:**

Patient was primarily a secretary at the time of injury.

05

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE to code "99=Unknown" if data collector does not ask question because employment was illegal.
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Removed from CHARACTERISTICS OF DATA the statement that 4 centers have trouble collecting this information. As of 12/05, all centers meet benchmark for missing data (10%).
2006-01-01	Added CODE "77=Refused".
2004-04-01	Added link to website with occupation codes information.
2004-04-01	Added instructions for using the occupations codes document and a link to the instructions.
2002-01-01	Added NOTE to code this variable if V111a is 05 or 08 in either primary or secondary occupation.
2001-07-01	In DEFINITION, substituted "in the month prior to injury" for "at the time of injury".
1995-07-01	Added NOTE clarifying when to code variable in relationship to variable V111a.
1994-09-13	Converted to using the 1990 Census codes and only coding major category of occupation instead of specific classification.
1994-02-01	Added "1990" to clarify which codes are being used.
1994-02-01	Added NOTE to refer to Appendix D for codes.
1994-01-01	Removed NOTE referring to a new census code for homemaker.

# PREMORBID CONDITIONS

## Variable 122

Date of last revision: 01/01/06

### 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 specific function prior to the TBI regarding:

- a. Blindness, deafness, or a severe vision or hearing impairment, and
- b. A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying.

### 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.

\*Alcoholism can be considered a premorbid condition if it interferes with the person's functioning.

### 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 is an amputee with no other physical impairments.

- a. 1
- b. 2

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added NOTE about alcoholism being a premorbid condition.
2005-07-01	Variable added to database.

# PREMORBID LIMITATIONS

## Variable 123

Date of last revision: 01/01/06

### 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."

### 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
2006-01-01	Added wording for data collectors to use in clarifying the meaning of "mental or emotional conditions".
2005-07-01	Variable added to database.

# DATE ABLE TO FOLLOW COMMANDS

## Variable 130a

Date of last revision: 01/01/06

### DEFINITION:

Date that the individual with brain injury is able to follow simple motor commands. The individual has the ability to follow simple motor commands if: 1) follows simple motor commands accurately at least two out of two times within a 24-hour period, or 2) GCS motor component = 6 (follows simple motor commands), two out of two times within a 24-hour period.

### CODE:

MM/DD/YYYY= Date patient able to follow simple motor commands

07/07/7777 = Patient never able to follow simple motor commands

09/09/9999 = Unknown

### CHARACTERS:

8 date

### NOTE:

A patient with severe motor or sensory impairment (i.e. spinal cord injury, locked in syndrome) must demonstrate some ability to follow eye commands such as close your eyes, look to the right or left, blink eyes. If patient is able to follow commands, then following surgery he/she can not follow commands for a period of time, use the first date the patient was able to follow commands.

If the two assessments of ability to follow simple motor commands within a 24-hour period fall across two dates, use the second date.

If patient was always able to follow simple motor commands, code date of admission to emergency room.

\*The purpose of this variable is to establish the date of emergence from coma.

### EXAMPLE:

Patient first followed simple motor commands accurately at 9 a.m. on November 15, 1990 and again at 3 p.m. on the same day.

11/15/1990

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added not about included effects of alcoholism.
2003-10-01	Added NOTE that the purpose of this variable is to establish the date of emergence from coma.
2003-01-01	Deleted code 08/08/8888=NA.
2003-01-01	Added instruction to code as date of admission to ER if ptn was never unable to follow commands.
1999-10-01	Added NOTE regarding if patient is able to follow commands, declines, then can again follow commands at a later date.
1999-10-01	Added NOTE regarding if two assessments of following commands falls across two dates.
1999-04-02	Revised "unknown" codes to be compatible with new software.
1998-08-15	Year expanded to four digits.

Date of last Revision	Description
1994-09-13	Dropped reference as this variable being a precondition to collect the physical exam data.

# CAUSE OF INJURY

## Variable 133a

Date of last revision: 01/01/06

### CODE:

#### VEHICULAR:

- 01 = Motor vehicle (does not include auto racing. Auto racing is coded 18).
- 02 = Motorcycle: 2-wheeled, motorized vehicle including mopeds and motorized dirt bikes
- 03 = Bicycle (includes tricycles and unicycles)
- 04 = All-terrain vehicle (ATV) and all-terrain cycle (ATC): includes both 3-wheeled and 4-wheeled recreational vehicles, dune buggy and go-cart.
- 05 = Other vehicular, unclassified: includes tractor, bulldozer, steam roller, train, road grader, forklift, aircraft

NOTE: If two vehicles are involved, the cause of injury should be coded according to the vehicle on/in which the patient was riding.

#### VIOLENCE:

- 10 = Gunshot Wound
- 11 = Assaults with blunt instrument (non-penetrating)
- 12 = Other Violence: includes all other penetrating wounds: stabbing, impalement. Also includes explosions (e.g. those caused by bomb, grenade, dynamite, gasoline)

#### SPORTS:

- 13 = Water Sports: includes diving, water skiing, surfing (includes body surfing), swimming, boating, etc.
- 14 = Field/Track Sports: includes football, baseball, softball, basketball, volleyball, field hockey, lacrosse, soccer, rugby, high jump and pole vault
- 15 = Gymnastic activities: includes trampoline, breakdancing and other gym activities
- 16 = Winter Sports: includes snow skiing, sled, snow tube, toboggan, snowmobile, etc.
- 17 = Air Sports: includes hang gliding, parachuting, para-sailing, glider kite, etc. (Does not include airplane. Airplane is coded 05.)
- 18 = Other unclassified sports: includes wrestling, horseback riding, rodeo (e.g. bronco/bull riding), skateboard, auto racing, etc.

#### FALLS/FLYING OBJECTS:

- 19 = Fall: includes jumping and being pushed
- 20 = Hit by falling/flying object: includes ditch cave-in, avalanche, rock slide

NOTE: If person jumps from a moving vehicle, use code 19 in this variable, however, use appropriate vehicular ecode (E818.?) for variable 133b.

#### PEDESTRIAN:

- 21 = Pedestrian

#### OTHER:

- 77 = Other unclassified: includes lightning, kicked by an animal, machinery accidents

#### UNKNOWN:

- 99 = Unknown

### CHARACTERS:

2 numeric

### NOTE:

\*If person is found "down", try to determine what happened.

\*This is an important variable. If the cause is not known, investigate as thoroughly as feasible and make a determination if possible. Also, be alert to information becoming available at a later time and be ready to record and submit it.

**EXAMPLE:**

Patient was injured in a diving accident.

13

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added instruction about person found "down".
2006-01-01	Added note about importance of this variable.
1999-04-01	Added NOTE on how to code person jumping from moving vehicle.
1996-04-01	Variable added back into database. Retrospective data collection done.
1995-01-01	Variable dropped.

# ICD-9-CM EXTERNAL CAUSE OF INJURY CODE

## Variable 133b

Date of last revision: 01/01/06

### DEFINITION:

Guidelines for Coding: 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))

### CODE:

Abbreviated list of E-codes: 24a. ICD-9-CM E-code categories ([http://syllabus/pdf/v133b\\_categories\\_3.pdf](http://syllabus/pdf/v133b_categories_3.pdf))

Complete list of E-codes: E-Code list-complete ([http://syllabus/pdf/ECodes\\_52.pdf](http://syllabus/pdf/ECodes_52.pdf))

\*88888 Not Applicable (no other E-codes)

\*99999 Unknown

### CHARACTERS:

3 numeric

4 numeric

### NOTE:

Obtain ICD-9-CM guide from your Medical Records department for a listing of E-codes.

Numbers should be coded just as they appear on the record and not padded with zeros. (Some codes have more digits to the right of the decimal place than others).

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.

If person jumps from a moving vehicle, use appropriate vehicular ecode (E818.?), however, use code "19 = fall/jump" for variable 133a.

### SOURCE:

SCVMC

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

### EXAMPLE:

Patient injured in diving accident.

E CODES: 883.0      88888

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Changed NA code from 888.8 to 88888, because 888.8 is now a valid code. (Need to determine when 888.8 became a valid code and determine which if any cases with codes of 888.8 need to be changed 88888.)
2006-01-01	Change "unknown" code from 999.9 to 99999 to match new format of "88888=NA".
2002-04-01	Added coding instructions in NOTES.
1999-04-01	Added NOTE on how to code person jumping from moving vehicle.

# ICD-9-CM Diagnosis codes for brain injury

## Variable 137

Date of last revision: 01/01/06

### CODE:

Examples:

310.2 Post-traumatic encephalopathy post concussion syndrome  
800 Skull fracture (vault)  
801 Skull fracture (base)  
803 Other and unqualified skull fractures  
804 Multiple fractures involving skull or face with other bones  
850 Concussion  
851 Cerebral laceration and contusion  
852 Subarachnoid, subdural, and extradural hemorrhage following injury  
853 Other and unspecified intracranial hemorrhage following injury  
854 Intracranial injury of other non-specified nature  
905 Late effect of fracture of skull and face bones  
907 Late effect of intracranial injury without mention of skull fracture  
666.66 Variable didn't exist  
888.88 No further code necessary  
999.99 Unknown

### CHARACTERS:

3 numeric  
4 numeric  
5 numeric

### NOTE:

\*Enter only codes that refer to brain injury.

These codes should be assigned by medical records and recorded on the chart at acute discharge. Numbers should be coded just as they appear on the record and not padded with zeros. The "unknown" code (999.99) used in this syllabus should not be confused with the ICD-9-CM code for "other unspecified complication" (999.9).

If more than six ICD-9-CM codes listed on the medical record, use all codes listed above first. If more than six brain injury related codes, use those which indicate the most significant diagnoses. Codes do not need to be prioritized.

If you suspect errors in ICD-9 coding and can verify correct codes, please use corrected codes.

If there are no brain injury-related codes, ask your medical director for assistance in determining codes.

### EXAMPLE:

Patient had a vault skull fracture with no further information specified.

800.  
888.88  
888.88  
888.88  
888.88  
888.88

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added instruction to include only codes that refer to brain injury.
1999-10-01	Added NOTE regarding if no brain injury-related codes.
1999-01-01	Added coding clarification and three additional coding fields.

# DATE EMERGED FROM PTA

## Variable 144a

Date of last revision: 01/01/06

### **DEFINITION:**

Date of emergence from Post-Traumatic Amnesia (PTA).

PTA emergence may be determined by any one of the following:

- 1) Two consecutive GOAT scores of 76 or greater within a period of 24-72 hours.
- 2) Two consecutive scores of 11 or greater on the Revised GOAT within a period of 24-72 hours.
- 3) Two consecutive scores of 25 or greater on the Orientation-Log within a period of 24-72 hours.
- 4) In the judgement of a qualified clinician (i.e., speech-language pathologist, physician, neuropsychologist), the person has cleared PTA but administration of the GOAT is not possible due to language functioning.

A modified GOAT may be used. The examiner presents three alternatives, in written form and orally, including the correct choice for each question. The patient is to indicate a choice in some manner, such as nodding or pointing. This procedure may be used for all questions except numbers 4 and 5. The three response alternatives for each question should be arranged vertically in large print on an index card. Errors points are assigned and subtracted from 80 (the maximum score with items 4 and 5 removed). A score of 61 or higher is reflective of orientation. PTA is considered resolved when a score of 61 or greater is achieved on two consecutive occasions within a period of 24-72 hours. \*

In the case of a responsive patient, it is the choice of the neuropsychologist whether to use the GOAT, Revised GOAT (Bode, Heinemann, & Semik, 2000--see SOURCES) or the Orientation-Log (Jackson, Novack, & Dowler, 1998; Novack, Dowler, Bush, Glen, & Schneider, 2000--see SOURCES) to establish the duration of PTA. Alternating use of the scales in an individual patient is not acceptable, however.

Date of emergence from PTA can also be determined via chart review. For those patients who are oriented at rehabilitation admission (as defined by first two GOAT scores after rehab. Admission  $\geq$ 75), the following procedure can be used to determine the length of PTA based on hospital records.

1. Obtain all available physician, nursing and therapy notes from the acute hospitalization. In most hospital medical records, physician, nursing and therapy notes are filed in different sections. You may have to specifically request therapy and nursing notes, if you routinely only receive the physician progress notes.
2. Review all notes to determine the first date on which all notes referencing orientation indicate that the patient is fully oriented, oriented X3 (or 4, or OX#, etc.). This is orientation day 1.
3. Review notes from the next calendar day to determine that all relevant notes indicate that the patient is fully oriented.
4. If Orientation Day 2 falls within three calendar days of Orientation Day 1, and if no notes from intervening days indicate less than full orientation, record Orientation Day 1 as the resolution date of PTA.
5. If any note from calendar days intervening between Orientation Days 1 and 2 indicate less than full orientation, use Day 2 as the new starting point (i.e. new Day 1) and repeat procedure from Step 3 above.
6. If there is no Orientation Day 2 (i.e., if the patient is never fully oriented on more than one day; or if more than 3 days elapse after Orientation Day 1 with no further notation about orientation), code date of PTA resolution as unknown. An exception would be if on the day before or the day of transfer to rehabilitation, the patient is specifically noted not to be oriented. If the patient then produces GOATs  $\geq$  75 on the first two examinations after rehabilitation admission, code the date of PTA resolution in the usual manner

### **CODE:**

MM/DD/YYYY

07/07/7777 Never had amnesia. [Code replaced with date of admission to ER.]

08/08/8888 Not Applicable - ptn still has amnesia or is unconscious as of discharge from TBI system.

09/09/9999 Unknown

Code date of admission to ER if person was never in PTA.

### **CHARACTERS:**

8 date

**NOTE:**

Computer calculates duration of post traumatic amnesia by subtracting the date of injury from this date. Duration of PTA is calculated only for those cases which emerge from PTA prior to discharge from inpatient rehabilitation.

Neuropsych Committee databusters has confirmed that duration of PTA is not to be calculated from date of emergence from coma (V130a).

The date emerged from PTA is the date of the first of the two consecutive GOAT scores greater than 75.

Administer the test every 1 to 3 days until patient emerges from PTA.

**\*O-LOG**

Dr. Novack clarifies assessing with the OLog : "I have no problem with someone looking at the calendar or clock in the room, which requires awareness that there is a calendar and some movement on the part of the person to see the calendar. That is a functional response that I employ as well. In my experience, when a person is confused they do not look for a calendar. I do not tell the person there is a calendar in the room or a clock. I do not ask the person to refer to either as a means of cueing."

\*If at your Model System emergence from PTA is not assessed for clinical purposes by a method appropriate for the TBIMS, be prepared to assess and document emergence from PTA retrospectively by chart review if the participant was not consented during the time of emergence from PTA.

**CHARACTERISTICS OF DATA:**

A few participants have a very long time in PTA. These have been checked and found to be correct.

**SOURCE:****GOAT:**

Levin, HS, O'Donnell, VM, & Grossman, RG. (1979). The Galveston Orientation and Amnesia Test: A practical scale to assess cognition after head injury. *Journal of Nervous and Mental Diseases*, 167, 675-684. Link to PubMed: Levin, HS, O'Donnell, VM, & Grossman, RG for v144a  
([http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list\\_uids=501342](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=501342))

**Revised GOAT:**

Bode RK, Heinemann AW, Semik P. Measurement properties of the Galveston Orientation and Amnesia Test (GOAT) and improvement patterns during inpatient rehabilitation. *J Head Trauma Rehabil*. 2000 Feb;15(1):637-55. Link to PubMed: Bode RK, Heinemann AW, Semik P. for v144a  
([http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list\\_uids=10745181](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=10745181))

**Orientation-Log:**

Jackson WT, Novack TA, Dowler RN. Effective serial measurement of cognitive orientation in rehabilitation: the Orientation Log.

*Arch Phys Med Rehabil*. 1998 Jun;79(6):718-20. Link to PubMed: Jackson WT, Novack TA, Dowler RN for v144a  
([http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list\\_uids=9630156](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=9630156))

Novack, TA, Dowler, RN, Bush, BA, Glen, T, Schneider, JJ. Validity of the Orientation Log, Relative to the Galveston Orientation and Amnesia Test. *J Head Trauma Rehabil*, 2000, 15(3), 957-961. Link to PubMed: Novack TA, Dowler RN, Bush BA, Glen T, Schneider JJ. for v144a

([http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list\\_uids=10785625](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=10785625))

[Introduction to O-Log \(COMBI\) \(http://www.tbims.org/combi/olog/index.html\)](http://www.tbims.org/combi/olog/index.html).

[O-Log frequently asked questions \(COMBI\) \(http://www.tbims.org/combi/olog/ologfaq.html\)](http://www.tbims.org/combi/olog/ologfaq.html).

[O-Log Syllabus \(COMBI\) \(http://www.tbims.org/combi/olog/ologsyl.html\)](http://www.tbims.org/combi/olog/ologsyl.html).

[O-Log Rating Form \(COMBI\) \(http://www.tbims.org/combi/olog/olograt.html\)](http://www.tbims.org/combi/olog/olograt.html).

[O-Log Properties \(COMBI\) \(http://www.tbims.org/combi/olog/ologprop.html\)](http://www.tbims.org/combi/olog/ologprop.html).

[O-Log References \(COMBI\) \(http://www.tbims.org/combi/olog/ologref.html\)](http://www.tbims.org/combi/olog/ologref.html).

**EXAMPLE:**

Patient entered inpatient rehab on 8/2/05. GOAT tests occurred on these dates in August:

date/score

04 57  
 06 56  
 07 61  
 10 72  
 12 64  
 14 70  
 17 79  
 19 74  
 20 75  
 22 78  
 23 76  
 26 72  
 29 77  
 30 79

Patient emerged from PTA on August 22, 2005.

MM/DD/YYYY  
 08/22/2005

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Improved the example.
2006-01-01	Added to NOTES: Dr Novack's comment that clocks, calendars are okay for testee to use.
2006-01-01	Added instruction about determining date by chart review if person not consented (and if not assessed clinically).
2006-01-01	Removed the instruction that the Modified GOAT is to be used only for determining PTA, because this instruction is no longer needed. (Because the neuropsych battery was dropped, there is no reason for using the GOAT [i]except[/i] to determine emergence from PTA.)
2004-07-01	Added links to COMBI.
2004-07-01	Added to CHARACTERISTICS OF DATA that cases with long time in PTA have been checked and found to be correct.
2004-04-01	Added full references to SOURCES.
2004-04-01	In DEFINITION removed reference to the neuropsychological battery.
2004-04-01	Added links to COMBI.
2004-04-01	Added links to PubMed.
2004-01-01	Added NOTE that NP databusters confirmed current procedure for calculation (approx 9/02).
2003-01-01	Deleted code "07/07/7777=Never had amnesia".
2003-01-01	Added to NOTES that if person never had PTA, code date of admission to ER.
2002-01-01	Added to DEFINITION the Revised GOAT, Orientation-Log, and modified GOAT.
2002-01-01	SOURCES section added, with references for Revised GOAT and Orientation-Log.
2001-10-01	Clarified DEFINITION and instruction in NOTES that date of emergence from PTA is the date of the first of 2 [u]consecutive[/u] scores greater than 75.
2000-07-01	Added PTA determination based on Chart Review (see 144b on following page).
1999-10-01	Added NOTE to clarify which date to use.
1999-04-02	Revised unknown codes to be compatible with new software.
1998-09-01	Revised definition of PTA.
1998-08-15	Year expanded to four digits.

Date of last Revision	Description
1995-07-01	Added NOTE regarding calculation of duration of PTA.
1994-09-13	Added reference regarding use of modified GOAT.

# CAUSE(S) OF DEATH

## Variable 146

Date of last revision: 01/01/06

### 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).

(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).

777.7 Person expired but cause of death unknown.

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

999.9 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.

**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: 888.8

**VARIABLE HISTORY:**

Date of last Revision	Description
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.

# PREMORBID DRUG USE

## Variable 192a1

Date of last revision: 01/01/06

### DEFINITION:

Indices of drug use and abuse prior to injury: During the year before your injury, did you use any illicit or non-prescription drugs? \*"Non-prescription drugs" refers to non-prescribed prescription drugs and street drugs.

### CODE:

1 No  
2 Yes  
0 Variable not in existence when data collected for this case  
9 Unknown

(DELETED Items 1a-f about specific drugs)

### CHARACTERS:

1 numeric

### NOTE:

Use patient's response, even if response contradicts other information. This is a self-report variable.

If cannot get patient's response, get family, if not family then medical chart.

\*A report on substance use that is based on TBIMS data can be found on COMBI: Problematic Substance Use Identified in the TBIMS National Dataset (<http://www.tbims.org/combi/subst/index.html>)

### CHARACTERISTICS OF DATA:

Some cases older than 1/1/97 have data for this variable because Centers were encouraged to collect these data retrospectively for older cases.

In 2003, three Model Systems had difficulty obtaining this information (10% or more missing data).

### EXAMPLE:

EXAMPLE #1: Person with brain injury used crack and marijuana.

(1) 2

EXAMPLE #2: Person with brain injury did not use any illicit/non-prescription drugs.

(1) 1

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added definition of "non-prescription" drugs.
2004-07-01	Added to CHARACTERISTICS OF DATA, an explanation for data in cases existing prior to implementation date (1/1/97).
2004-04-01	Added link to report on COMBI using TBIMS data.
2003-01-01	Items 1a-f deleted (specific drugs used).
2001-10-01	Added note about getting data from medical chart, if not available from ptn or SO.
1998-09-01	Added note regarding contradictory information from patient.

Date of last Revision	Description
1997-01-01	Variable added to database.

# DATE OF FOLLOW-UP

## Variable 201

*Date of last revision: 01/01/06*

**DEFINITION:**

- 1) Date of Follow-up Evaluation
- 2) Date of Death

**CODE:**

- 1) Date of Follow-up Evaluation  
MM/DD/YYYY
  
- 05/05/5555 N/A-withdrew authorization
- 06/06/6666 N/A-deceased
- 07/07/7777 N/A-other (including incarceration)
- 08/08/8888 Not applicable, no follow-up evaluation. [DROPPED]
- 09/09/9999 Unknown date of follow-up evaluation \*, or data have been collected out of window from an in-window secondary source
  
- 2) Date of Death  
MM/DD/YYYY
  
- 07/07/7777 Person expired but unknown date
- 08/08/8888 Not applicable, person alive
- 09/09/9999 Unknown if person expired

**CHARACTERS:**

8 date

**NOTE:**

For date of follow-up evaluation, enter date when first data are collected (if data collection is done with more than one contact) with patient or significant other. If no follow-up data are collected from patient or significant other, code the reason (05/05/5555, 06/06/6666, etc).

**EXAMPLE:**

Follow-up evaluation was conducted on May 13, 1989.

Date of Follow-up Evaluation 05/13/1989  
Date of Death 08/08/8888

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added to CODE 09/09/9999 that it should be used if data are obtained out of window from an in-window secondary source.
2005-04-01	Changed the label for 07/07/7777 from "N/A-other" to "N/A-other (including incarceration)"
2004-04-01	Corrected label for code 05/05/5555. Changed "permission" to "authorization".
2004-04-01	In CODES, removed statement that TBINDC will recode the old code 08/08/8888 as the new code 07/07/7777.
2003-04-01	For Date of Follow-up, added codes: "05/05/5555=N/A-withdrew authorization", "06/06/6666=N/A-deceased", and "07/07/7777=N/A-other". No longer use "08/08/8888=N/A-no eval" (is still in database).

Date of last Revision	Description
2003-04-01	Added note to use new N/A codes.
1999-04-02	Revised unknown date codes to be compatible with new software.
1998-08-15	Year expanded to 4 digits.
1995-07-01	Added note to clarify coding of date of follow-up evaluation.
1995-01-01	Dropped date of injury.
1995-01-01	Clarified code descriptions for date of follow-up evaluation and date of death.
1995-01-01	Added date of death code 77/77/77= person expired but unknown date.

## YEARS OF EDUCATION

### Variable 210a

Date of last revision: 01/01/06

**DEFINITION:**

Number of years of education successfully completed at the time of follow-up interview.

**CODE:**

01 1 year or less  
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 HS diploma  
13 Work toward Associate's degrees, no diploma  
14 Associate's degrees  
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  
66 Var didn't exist at the time this form was filled out  
77 Other

**CHARACTERS:**

2 numeric

**NOTE:**

The number of years of education coded may not equal the actual number of years spent in school. For example, a person who is held back two years in elementary school and then drops out of school in the 10th grade (for a total of 11 full years) would be coded as having completed 9 years; a person may take 6 years to complete a BA (for a total of 18 years), but, as indicated, only 16 years are coded.

GED, trade school, and other types of schooling not listed, are not counted toward years of education.

\*If person takes a few courses in a college setting with no intention of earning a degree, code "associate".

\*Code years of foreign education completed the same as years of US education. The TBIMS has not yet found a satisfactory method for determining equivalence.

**CHARACTERISTICS OF DATA:**

All data on educational level are available in the calculated variable "EDUCATION2". This calculated variable merges data for V210a with data for V210 "Highest grade of school completed", which V210a replaced on 1/1/01.

**SOURCE:**

Heaton RK, Miller SW, Taylor MJ, Grant I. Revised Comprehensive Norms for an Expanded Halstead-Reitan Battery: Demographically Adjusted Neuropsychological Norms for African American and Caucasian Adults. Lutz, FL: Psychological Assessment Resources, Inc., 2004, 17-18.

**EXAMPLE:**

At the time of interview, person with disability had completed high school but no work toward an advanced degree.

12

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added instruction to code foreign education the same as US education.
2006-01-01	Added NOTE to code "associate" if person took a few college courses without intending to earn a BA
2004-04-01	Added "successfully" prior to "completed" in DEFINITION.
2004-04-01	Added EXAMPLE of being held back in elementary school.
2004-04-01	Updated SOURCE.
2003-01-01	Changed code 01 from "1 year" to "1 year or less".
2003-01-01	Changed code "01 = Var didn't exist at the time this form was filled out" to "66= Var didn't exist at the time this form was filled out".
2002-01-01	Added SOURCE box; added info about NAFFSA website.
2001-07-01	Note added that actual years of education may not equal the actual number of years in school.
2001-07-01	Note added to not count GED, trade school, or other types of education not listed toward years of education.
2001-01-01	Variable added.

# EMPLOYMENT STATUS

## Variable 211a

Date of last revision: 01/01/06

### DEFINITION:

Code primary employment status in the month prior to the evaluation.

Determine primary status by 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, supported employment, sheltered employment, non-directed coursework, volunteer work, retirement (age-related), retirement (disability-related), and no productive activity.

\*The purpose of the employment variables (211a-212) is to record the extent to which participants are engaging in productive work and, also, their personal earning power (211i). Whether employment is legal or illegal is not relevant to coding any of the employment variables. (But see NOTE below about collecting information about illegal employment.)

### CODE:

- 02 Full-time student (regular class)
- 03 Part-time student (regular class)
- 04 Special education/other non-regular education
- 05 Competitively employed (minimum wage or greater, legal or illegal employment, \*includes on leave with pay)
- 07 Taking care of house or family
- 08 Special employed (sheltered workshop, supportive employment, has job coach)
- 09 Retired (age)
- 10 Unemployed (looking for work in the last 4 weeks)
- 11 Volunteer work
- 12 Retired (disability)
- 13 Unemployed (not looking for work in the last 4 weeks, for any reason)
- 14 Hospitalized without pay during most of the last 4 weeks
- 15 Retired (other)
- \*16 On leave from work, not receiving pay
- \*55 Other
- 66 Variable did not exist at time of data collection
- 77 \*Refused
- 99 Unknown

### CHARACTERS:

2 numeric

**NOTE:**

If patient is in the hospital at the time of follow-up, employment status is that status existing at the time of admission to the hospital.

Competitive subminimum wage employment such as babysitting, newspaper delivery, and piecework should be coded 77.

Code "09=Retired (age)" if respondent indicates that retirement was due to age (use respondent's definition).

Ignore non-employment sources of income such as pension, settlement, or disability income support.

If participant is in jail, code "\*\*55=other".

If participant works in a foreign country, assume wage is not subminimum unless there is information to the contrary.

If participant is employed for only part of the month prior to the follow-up evaluation, code employment status as during the majority of the work days during that month.

If person has been hired but has not begun work, code as employed.

Code education as full-time or part-time based on self-report.

\*Illegal employment includes work that is illegal (e.g., selling drugs) as well as illegally engaging in legal work (e.g., non-citizens doing construction work without a green card).

\*DATA COLLECTORS: Do not ask the respondent if employment is legal or illegal. That distinction is not needed for any of the employment questions. If in the course of the interview you learn that some or all employment is illegal, continue asking the employment questions as long as providing that information does not become uncomfortable for the respondent and would therefore risk jeopardizing the rest of the interview.

**CHARACTERISTICS OF DATA:**

Starting 7/1/01, data are entered into a new field that uses the additional coding categories implemented on 7/1/01. The old field has been retained in the database. Data from both these fields is merged in the calculated variable "EMPLOYMENT2".

\*As of 1/1/06, all cases with "77" were been recoded as "55", in order to allow "77" to be used for "refused".

**EXAMPLE:**

Patient was a homemaker at the time of evaluation, with no other employment status.

07

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE about appropriate strategy to use in collecting information if employment is illegal.
2006-01-01	Added to NOTES the definition of illegal employment.
2006-01-01	Added code "16=On leave from work, not receiving pay"
2006-01-01	Added CODE "77=Refused". (Changed "Other" to 55.)
2006-01-01	Added to code 05 that person may be on leave with pay.
2006-01-01	Added to CHARACTERISTICS OF DATA that as of 1/1/06 the codes for "Other" have been changed from "77" to "55".
2006-01-01	Added to DEFINITION that no distinction is to be made between legal and illegal employment.

Date of last Revision	Description
2004-07-01	In CODES, corrected the labels for codes 10, 13, 14: Replaced "4 weeks prior to injury" with "last 4 weeks".
2004-07-01	Added CODE 66=Variable did not exist at time of data collection. (This code has been used in the database for some time.)
2004-07-01	Removed "annual" from references to follow-up evaluation.
2004-07-01	In Variable History for 1/1/04 regarding "DATABASE" box, corrected a typo so prior text "...added that variable added..." has been changed to "...added that new variable added..."
2004-04-01	Added information to CHARACTERISTICS OF DATA about the employment calculated variable, which merges current data with data collected before the response categories were expanded.
2004-04-01	Moved prioritization list from NOTES to DEFINITION.
2004-04-01	Renamed "DATABASE" box as "CHARACTERISTICS OF DATA".
2004-01-01	Added DATABASE box. Added that the new variable was added and the old variable was kept in the database.
2004-01-01	Added note to code education as full-time or part-time based on self-report.
2003-10-01	Added note to code as employed if hired prior to evaluation but has not yet started work.
2003-01-01	Deleted Secondary Employment variable; instructions adjusted as needed.
2003-01-01	Deleted code "88=No secondary employment status".
2003-01-01	Added note to use priority list to determine primary status, regardless of hours worked.
2002-07-01	Added note about minimum wage in foreign country.
2002-07-01	Added note about coding if did not work all days in prior month.
2001-07-01	Replaced "at annual evaluation" with "in the month prior to the annual evaluation".
2001-07-01	For code 7, replaced "Homemaker" with "Taking care of house or family".
2001-07-01	For code 10, added "(looking for work in the last 4 weeks)".
2001-07-01	Added code "12=Retired (disability)".
2001-07-01	Added code "13=Unemployed (not looking for work in the last 4 weeks)".
2001-07-01	Added code "14 =Hospitalized without pay during most of the last 4 weeks".
2001-07-01	Added code "15=Retired (other)".
2001-07-01	Removed [i]source of income support for disability[/i] as a criterion for classification.
2001-07-01	Revised the prioritization list as follows: "taking care of house or family" replaces "home management (homemaker)", "job-directed/on-the-job training" reverses position with "supported employment", "volunteer work" replaces "volunteer activity", "retirement (age-related), retirement (disability-related)" replaces "active leisure/retirement, disability-related retirement".
2001-07-01	Added note that for the code"09=Retired (age)", accept the respondent's statement as to whether age was the cause of retirement.
1999-10-01	Added use of job coach to code 8.
1999-10-01	Added list to prioritize employment status if more than 1.
1999-04-02	Added clarification for some codes.
1995-07-01	Dropped reference to variable 112 so coding is consistent among employment-related vars.
1994-09-13	Dropped third employment status.
1994-08-19	Removed note regarding collecting data from subject and SO.
1994-08-19	Added code 88 and added 88's to example.
1994-08-19	Added notes to be consistent with V111a.

## QUESTIONS AND ANSWERS:

<b>QUESTION:</b>	I have a 61 year-old man who worked most of his life in an engineering position. A few months ago he was laid off and went to work as a salesman in a large home supply store where he subsequently was injured. In the year after his injury, he returned to this job. However, after 24 weeks, he decided to retire because of fatigue, and because it really wasn't the kind of work he was trained to do. He has no plans to work again. 12-03-2004
<b>ANSWER:</b>	Recall that "employment status" is coded according to the coding priority as shown on the data collection form and in the syllabus. The coding priority is applied in cases when more than one employment status is indicated by the respondent. In your example the person says that he retired due to fatigue (presumably "disability" due to the brain injury) and to the job not being the kind of work he was trained to do (ie., an "other" reason). The coding priority lists "retired (disability)" but does not list "retired (other)", so "retired (disability)" is the higher priority and is the correct choice. The other two categories you wonder about--"retired (age)" and "unemployed (not looking)"--can be ruled out because they aren't indicated by the respondent. 12-03-2004

# HOURS OF PAID COMPETITIVE EMPLOYMENT

## Variable 211b

Date of last revision: 01/01/06

### DEFINITION:

Average number of hours per week usually worked in all paid competitive jobs (minimum wage or greater) in the month prior to evaluation. \*Includes illegal employment (see V211a for more information and for data collection instructions).

### CODE:

?? Hours per week

\*777 Refused

888 NA-not currently competitively employed

999 Unknown

### CHARACTERS:

3 numeric

### NOTE:

Fractions are to be rounded to the nearest whole number. 0.5 should be rounded upward.

Code actual number of hours per week **only** for those cases coded 05 (competitively employed) in V211a (employment status), otherwise this variable must be coded 88.

If patient is employed more than 98 hours per week, code as 98 hours.

If patient works two jobs, add all hours together to code.

Skip this question if the person is not currently competitively employed.

\*If data collector does not ask this question because the participant is illegally employed, code "999=Unknown".

### CHARACTERISTICS OF DATA:

When missing data codes were changed from 88 and 99 to 888 and 999 (4/1/05), the TBINDC changed all 88 and 99 codes in the database to 888 and 999. (There were almost no other codes in the 80-100hr/wk range.)

### EXAMPLE:

Patient was employed 37.5 hours per week.

38

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added instruction to include illegal employment.
2006-01-01	Added CODE "777 Refused".
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added NOTE to code "999=Unknown" if data collector does not ask question because employment is illegal.
2005-07-01	Added to CHARACTERISTICS OF DATA that the TBINDC changed all 88 and 99 codes in the database to 888 and 999 when the missing data codes were changed (4/1/05) from 88 and 99 to 888 and 999.
2005-04-01	Changed missing data codes 88 and 99 to 888 and 999.

Date of last Revision	Description
2005-04-01	Deleted missing data code 66=variable did not exist. (Variable has always existed.)
2005-04-01	Changed number of characters from 2 to 3.
2004-07-01	Deleted references to primary and secondary employment status.
2004-07-01	Deleted references to "annual" evaluation.
2002-07-01	Added "currently" to code "8=NA".
2002-07-01	Added instruction to skip this question if the person is not currently competitively employed.
2002-04-01	Added "not competitively employed" to code "8=NA".
2002-01-01	Clarified instruction to code this variable if "05=competitive employment" is coded for either the primary or secondary status of V211a.
2001-08-20	Added code "66=Variable did not exist".
2001-07-01	In the definition, added "usually worked in all" prior to "paid competitive"; replaced "employment" with "jobs"; added "in the month prior to the" before "annual evaluation".
1999-04-02	Added note regarding coding hours greater than 98 and hours for more than one job.
1996-11-01	Corrected note.
1995-07-01	Added note clarifying when to code variable in relationship to variable V211a.
1994-08-19	Removed note regarding collecting data from subject and SO.

# DATE OF FIRST COMPETITIVE EMPLOYMENT

## Variable 211c

Date of last revision: 01/01/06

### DEFINITION:

Date the person with brain injury began competitive employment after discharge from inpatient rehabilitation.  
\*Includes illegal employment (see V211a for more information and for data collection instructions).

### CODE:

??/??/???? Month, day, year

06/06/6666 Variable did not exist

\*07/07/7777 Refused

08/08/8888 NA - no post-injury competitive employment

08/08/8899 NA - competitive employment started prior to last evaluation

09/09/9999 Unknown

### CHARACTERS:

8 date

### NOTE:

The first day of work in which reimbursement was at or above the minimum wage.

If the exact date is unknown, estimate to the nearest half-month and code the day in the middle of that half month.

\*

Length of employment does not matter (e.g., employed for 1 day counts).

If on disability payments and return to work, count this as the first day (if competitive).

Ask this question if the person has been competitively employed since the last evaluation even if not currently competitively employed.

\*If data collector does not ask this question because the participant's first employment was (or may have been) illegal, code "09/09/9999 = Unknown".

### EXAMPLE:

Began paid, competitive work sometime in the first half of March 2000.

03/08/2000

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added code "07/07/7777 = Refused"
2006-01-01	Added NOTE to code "09/09/9999=Unknown" if data collector does not ask question because first employment was illegal (or may have been).
2006-01-01	Deleted instruction to exclude illegal employment.
2004-04-01	Removed reference to "annual" evaluation.

Date of last Revision	Description
2002-07-01	Changed 08/08/8888 from "not competitively employed" to "no post-injury competitive employment".
2002-07-01	Added note to ask this question even if participant is not currently competitively employed.
2002-01-01	Added code to syllabus "06/06/6666 Variable did not exist" [already added to database?].
2001-08-20	Added notes.
2001-07-01	Variable added to database.

# JOB STABILITY: WEEKS EMPLOYED

## Variable 211d

Date of last revision: 01/01/06

### DEFINITION:

**AT 1 YEAR FOLLOW-UP:** Number of weeks of competitive employment during the year after injury.

**AT OTHER FOLLOW-UPS:** Number of weeks of competitive employment in the last year.

\*Include illegal as well as legal employment (see V211a for more information and for data collection instructions).

### CODE:

?? Number of weeks

66 Variable did not exist

\*77 Refused

88 N/A-no competitive employment in the last year.

99 Unknown

### CHARACTERS:

2 numeric

### NOTE:

Include all weeks employed at minimum wage or higher.

\*

Include vacation time and other types of leave if the person was paid during that time.

Partial weeks are rounded up to the nearest whole week.

Ask this question if the person has been competitively employed since the last evaluation, even if not currently competitively employed.

If employment is infrequent but on a regularly scheduled basis, or if it is related to a specific function, then code the number of weeks during which the person was employed. But, if days of employment were just random and the person might or might not do it again, then code the total number of weeks in which the person worked. (E.g., if the person worked 2 times a month for 9 months, then in the first situation 39 weeks should be coded. In the second situation 18 weeks should be coded.)

\*If data collector does not ask this question because the participant was illegally employed, code "99=Unknown".

### EXAMPLE:

Patient worked October 11 through December 21.

11

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added code "77=Refused".
2006-01-01	Added NOTE to code "99=Unknown" if data collector does not ask because employment was illegal.
2006-01-01	Removed NOTE that this includes only legal employment.

Date of last Revision	Description
2004-07-01	In DEFINITION and CODES, changed time period from "since the last evaluation" to "in the last year"
2004-07-01	Removed reference to "annual" evaluation.
2003-01-01	Added note about coding infrequent employment.
2002-07-01	Added note to ask this question even if person is not currently competitively employed.
2002-07-01	Changed code 88 to "no competitive employment since last evaluation", from "not competitively employed".
2002-04-01	Added "not competitively employed during prior year" to code "8=NA".
2002-01-01	Added code "66=Variable did not exist".
2001-07-01	Variable added to database.

# ANNUAL EARNINGS

## Variable 211i

Date of last revision: 01/01/06

### DEFINITION:

Annualized income from \* competitive employment, based on all competitive employment at the time of the evaluation. Calculate the person's income for the next year as if he/she were to continue to earn at the rate at the time of the follow-up evaluation. Do not take into account anticipated future changes in income--no matter how large or how temporary the present rate of earning.

\*Includes illegal as well as legal employment (see V211a for more information and for data collection instructions).

### CODE:

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 NA-illegal employment; respondent did not want to provide data. (Use only if respondent resists providing such information.)

66 Variable did not exist

77 Refused

88 N/A- not currently \* competitively employed

99 Unknown

### CHARACTERS:

2 numeric

### NOTE:

Include only competitive, above-minimum wage employment.

Include salary, commissions, tips, and bonuses.

Exclude income support, investment income, and settlements.

This question may be asked along with V292c.

Ask this question only if person is currently competitively employed, because this is a measure of projected income based on current competitive employment.

\*If patient is illegally employed and--in the data collector's judgement--it would be inappropriate to ask about this participant's income, then use code 55.

### CHARACTERISTICS OF DATA:

In 2003, one Model System had difficulty obtaining this information.

**EXAMPLE:**

Until this month, employment income was \$675 a week from a full-time job. Employment income is now \$255 a week from part-time work and about \$425 a month from a home business.

02

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added NOTE to code "99=Unknown" if data collector does not ask question because employment is illegal.
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Removed that this is only legal employment.
2004-04-01	Removed reference to "annual" evaluation.
2004-01-01	Added note to include tips.
2004-01-01	Added note explaining why to include only participants who are competitively employed.
2002-07-01	Changed code 8 to "not currently competitively employed".
2002-07-01	Added note to ask this question only if person is currently competitively employed.
2002-04-01	Added "not competitively employed" to code 8=NA.
2002-01-01	Definition modified to instruct not to take into account known future changes in earning.
2002-01-01	Removed note added in 10/1/01 regarding taking into account future changes in income.
2002-01-01	Added note that this variable can be collected along with V292c.
2002-01-01	Replaced code "66=Not due" with "66=Variable did not exist" (error in syllabus, not forms).
2001-10-01	Definition modified to emphasize this is an annualized estimate based on current jobs.
2001-10-01	Note added to take into account definite future changes in income.
2001-07-01	Variable added to database.

# CENSUS OCCUPATIONAL CATEGORY

## Variable 212

Date of last revision: 01/01/06

### DEFINITION:

The major census occupational category in which the patient's occupation is included for his/her primary occupation in the month prior to the follow-up evaluation.

\*Instructions from Bureau of Census for collecting this information appear to not distinguish legal from illegal employment. The TBIMS Data Committee clarified that illegal employment is to be included (to take effect 1/1/06). See V111a for more information and for data collection instructions.

### CODE:

Code the patient's primary occupation using the categories below. For a list of the specific occupations in each category, see the "1990 Census of Population Occupational Classification System", pages 9-22 of this document: [1990 Census Industrial & Occupational Classification Codes](http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf) (http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf). A copy of this list should be in Appendix D of your syllabus binder. \*For instructions using this document see: [17a.Instructions for 1990 Census Occupational Codes](http://syllabus/pdf/Occ_codes_w_govt_URL.pdf) (http://syllabus/pdf/Occ\_codes\_w\_govt\_URL.pdf) in Appendix D.

- 01 Executive, Administrative, and Managerial
- 02 Professional Speciality
- 03 Technicians and Related Support
- 04 Sales
- 05 Administrative Support Including Clerical
- 06 Private Household
- 07 Protective Service
- 08 Service, except Protective and Household
- 09 Farming, Forestry, and Fishing
- 10 Precision Production, Craft, and Repair
- 11 Machine Operators, Assemblers, and Inspectors
- 12 Transportation and Material Moving
- 13 Handlers, Equipment Cleaners, Helpers, and Laborers
- 14 Military Occupations
- \*77 Refused
- 88 Not Applicable, not coded 05 or 08 for variable 111a
- 99 Unknown occupation

### CHARACTERS:

2 numeric

### NOTE:

Code only if V211a (employment status) is coded 05 or 08 (competitively employed or special employed)\*; otherwise this variable must be coded 88.

\*If data collector does not ask this question because participant is illegally employed, code "99=Unknown".

### SOURCE:

1990 Occupational Classification System, Alphabetical Index of Industries and Occupations, 1990 Census of Population and Housing, Bureau of the Census, U.S. Department of Commerce. [1990 Census Industrial & Occupational Classification Codes](http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf) (http://www.bls.gov/nls/quex/r1/y97r1cbka1.pdf)

**EXAMPLE:**

Patient was primarily a sales clerk at the time of the follow-up evaluation.

04

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added to DEFINITION that this includes illegal employment.
2006-01-01	Added CODE "77=Refused".
2006-01-01	Added NOTE to code "99=Unknown" if data collector does not ask question because employment is illegal.
2004-04-01	Added link to website with occupation codes information.
2004-04-01	Added instructions for using the occupations classification document and an link to the instructions.
2004-04-01	In DEFINITION and EXAMPLE, removed "annual".
2004-01-01	Deleted note referring to primary and secondary employment status (secondary employment was no longer as of 1/1/03).
2002-01-01	Added note to code this variable if V211a is 05 or 08 in either primary or secondary occupation.
1995-07-01	Added note clarifying when to code variable in relationship to variable V211a.
1994-09-13	Converted to using the 1990 Census codes and only coding major category of occupation instead of specific classification.
1994-08-19	Removed note regarding collecting data from subject and SO.
1994-08-19	Added "1970" to clarify which codes are being used.
1994-08-19	Added note to refer to Appendix D for codes.

# REHOSPITALIZATION

## Variable 273

Date of last revision: 01/01/06

### DEFINITION:

The reason for each patient rehospitalization since inpatient rehabilitation discharge or in the past year (whichever is shorter).

### CODE:

Code one reason for each rehospitalization

0 Rehabilitation (inpatient)

1 Seizures

2 Neurologic disorder (non-seizure)

3 Psychiatric

4 Infectious

5 Orthopedic

6 General Health Maintenance or OB/GYN

7 Other not specified above

8 Not applicable--no rehospitalizations or no further rehospitalizations

9 Unknown--rehospitalized but reason is unknown

\* 66 Variable did not exist at time of data collection. [Used only with variables 273(3-5)]

99 Unknown if rehospitalized

### CHARACTERS:

2 numeric

### NOTE:

This variable includes all types of hospitalizations (i.e., an inpatient stay in any hospital, whether part of a TBI Model System or not).

If more than five hospitalizations, have your Medical Director prioritize which two to code.

Data for follow-ups prior to 10/1/99 will be recoded from text field to the categories above.

Prior to 1/1/02 the code "9=unknown" did not distinguish between "unknown if rehospitalized" and "unknown reason for rehospitalization". On 1/1/02 "9=unknown" was clarified to mean "unknown reason for rehospitalization". On 1/1/04 the code "99=unknown if rehospitalized" was added. Thus, between 1/1/02 and 1/1/04 there was no way to record rehospitalization for unknown reason.

### EXAMPLE:

Patient has been hospitalized twice since the last evaluation. Once for seizures related to TBI, and once for complications of diabetes.

01            06

08

08

08

### VARIABLE HISTORY:

Date of last Revision	Description
2006-01-01	Updated references to number of rehospitalizations to be coded from two to five.
2005-04-01	Added code "66=variable did not exist at time of data collection" for variables 273(3-5).
2004-04-01	Added to DEFINITION to ask for the last year (not since last evaluation).
2004-04-01	Added three more variables for recording types of rehospitalizations (for a total of 5).
2004-04-01	Improved wording of NOTE about "unknown" codes.
2004-01-01	Added code 99.
2004-01-01	Added note that prior to 1/1/02 the code "9=unknown" did not distinguish between "unknown if rehospitalized" and "unknown reason for rehospitalization" (etc)..
2004-01-01	Changed field width from 1 to 2.
2002-01-01	Added clarification to code 9.
1999-10-01	Dropped date fields and changed reason for rehospitalization from text field to a categorical variable.
1999-04-02	Revised unknown date codes to be compatible with new software.
1998-09-01	Added clarification of how to code if more than two rehospitalizations.
1998-08-15	Year expanded to 4 digits.
1995-01-01	Dropped rehospitalizations #3-#6.

**DRUG USE**  
**Variable 292a1**

*Date of last revision: 01/01/06*

**DEFINITION:**

Index of drug use; asked of best source at every follow-up evaluation. "During the last 12 months (or during the time since your injury -- if year 1 follow-up) did you use any illicit or non-prescription drugs?" \*"Non-prescription drugs" refers to prescription drugs obtained without a prescription and street drugs.

**CODE:**

1 No  
2 Yes  
7 Not due this year. [Code no longer used; data now collected in all follow-up years.]  
8 No other drug use. [Code no longer used; data not collected on use of specific drugs.]  
9 Unknown

**CHARACTERS:**

1 numeric

**NOTE:**

A report on substance use that is based on TBIMS data can be found on COMBI: [Problematic Substance Use Identified in the TBIMS National Dataset](http://www.tbims.org/combi/subst/index.html) (<http://www.tbims.org/combi/subst/index.html>)

**EXAMPLE:**

Person with brain injury used marijuana in past year.

2

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added definition of "non-prescription drugs".
2004-07-01	In CODES, added back in code for "Not due this year", plus a statement that the code is no longer used.
2004-07-01	Removed references to "annual" follow-up.
2004-04-01	Added NOTE regarding the report in COMBI that uses TBIMS data on substance use.
2003-01-01	Deleted v292a1 1a-f (questions about specific drugs used).
2003-01-01	Removed references to this variable as being asked of the person with TBI and added instruction to ask of best source at every annual evaluation.
2003-01-01	Deleted code "7=This variable not due this year"
2003-01-01	Deleted the question that identified respondent as the person with TBI or significant other.
1999-10-01	Revised time period from 6-12 months to 12 months.
1997-01-01	Expanded variable, moved alcohol questions to separate variable.

# SATISFACTION WITH LIFE SCALE (SWLS) -FOR PERSON WITH BRAIN INJURY

Variable 292g

Date of last revision: 01/01/06

## DEFINITION:

The person with brain injury should rate his/her satisfaction with life at the time of the follow-up evaluation by indicating his/her level of agreement with the five questions below.

- (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.

For more information, see: Introduction to the SWLS (COMBI) (<http://www.tbims.org/combi/swls/index.html>).

## CODE:

- 1 Strongly disagree
- 2 Disagree
- 3 Slightly disagree
- 4 Neither agree nor disagree
- 5 Slightly agree
- 6 Agree
- 7 Strongly agree
- \*8 Not due this year. [Code no longer used; data now collected in all follow-up years.]
- 0 Variable not in existence when data collected
- 9 Unknown
- 10 N/A - no data from person w/ TBI

## CHARACTERS:

2 numeric

## NOTE:

See: [SWLS Frequently Asked Questions/Tips \(COMBI\)](http://www.tbims.org/combi/swls/swlsfaq.html) (<http://www.tbims.org/combi/swls/swlsfaq.html>)

See: (<http://syllabus/pdf/>)

\*Do not embellish when obtaining this information. If appropriate, use the cue "If that's what it means to you."

## CHARACTERISTICS OF DATA:

In 2003, the TBIMS had difficulty obtaining this information (11% missing data). Five Model Systems had missing data rates of 10% or more. Data managers report that missing data are due to some persons with TBI being unable to provide information for the Form II, combined with the requirement that the SWLS must not be answered by anyone other than the person with TBI. A new code was been added to this item to identify these cases.

## SOURCE:

Diener E, Emmons R, Larsen J, Griffin S. (1985). The Satisfaction With Life Scale. *J Personality Assessment*, 49(1), 71-75.

Pavot W, Deiner E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment*. 5(3), 164-172.

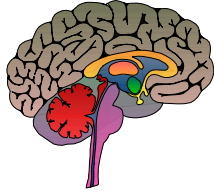
(<http://syllabus/pdf/>)

**EXAMPLE:**

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

**VARIABLE HISTORY:**

Date of last Revision	Description
2006-01-01	Added instruction not to embellish.
2004-07-01	In CODES, added back in the code for "Not due this year" plus a statement that this code is no longer used.
2004-07-01	Removed reference to "annual" evaluation.
2004-04-01	Added links to COMBI.
2003-10-01	Added CODE "10=N/A-no data from person w/ TBI"
2003-01-01	Deleted code "8=This variable not collected this year".
1998-04-01	Dropped quality of life and health questions, added Satisfaction With Life Scale (self-assessment by person with brain injury).
1997-01-01	Quality of Life and Health - new variable added to database.



# **TRAUMATIC BRAIN INJURY MODEL SYSTEMS NATIONAL DATABASE SYLLABUS**

**Funded by the National Institute on  
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Version 10.2  
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1/1/06

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Partic  
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Treat

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Health

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## Databusters

*At the July 2005 meeting, at the request of the Data Committee the Project Directors voted to create a group of volunteer databusters-at-large who would answer questions about variables in the database that are beyond the expertise of the Data Committee and the TBINDC. As of July 2005 these Databusters are:*

Allen W. Brown, MD

Ramon Diaz-Arrastia, MD

Sureyya Dikmen, PhD

Jeff Englander, MD

Gale Whiteneck, PhD

03g.Databusters.060101



# TRAUMATIC BRAIN INJURY MODEL SYSTEMS NATIONAL DATA BASE INCLUSION CRITERIA

1/01/2006

## CASE DEFINITION:

Traumatic brain injury is defined as damage to brain tissue caused by an external mechanical force as evidenced by loss of consciousness or post traumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination.

Penetrating wounds fitting definition listed above are included. Lacerations and/or bruises of the scalp or forehead without other criteria listed above are excluded. Primary anoxic encephalopathy is excluded.

## INCLUSION CRITERIA:

All persons:

1. fitting the above definition;
2. meeting at least one of the following criteria for moderate to severe TBI:
  - PTA > 24 hours
  - Trauma related intracranial neuroimaging abnormalities
  - Loss of consciousness exceeding 30 minutes (unless due to sedation or intoxication)
  - GCS in the emergency department of less than 13 (unless due to intubation, sedation, or intoxication);
3. who are age 16 or older at the time of injury;
4. presenting to the Model System's acute care hospital within 72 hours of injury;
5. must receive both acute hospital care and comprehensive rehabilitation in a designated brain injury inpatient rehabilitation program within the Model System. Comprehensive rehabilitation must occur in a hospital, rehabilitation unit, rehabilitation hospital, hospital-based skilled nursing facility, skilled nursing facility, or long-term acute care hospital that meets the following criteria:
  - Medical and rehabilitation care are supervised on a regular basis by a physician affiliated with the Model System
  - 24-hour nursing care is provided to the patient
  - \*PT, OT, Speech, Rehabilitation Psychology/Neuropsychology, and/or family support/education are provided in an integrated, team approach with the expectation of further gain.
  - \*Regardless the setting in which it is constituted, a comprehensive rehabilitation program operates in a manner consistent with (a) CARF standards for brain injury inpatient rehabilitation and/or (b) Medicare requirements for inpatient rehabilitation.
  - \*If a Model Systems comprehensive rehabilitation program co-exists with programming that does not meet the above criteria, the Model Systems center must explicitly define its



methodology for establishing the dates of admission and discharge from comprehensive rehabilitation that will be reported to the TBIMS Data Center. These dates will represent the period of time during which CARF and/or Medicare criteria are met. This period may include interruptions during which the criteria are not met for medical reasons but after which a rehabilitation programming meeting CARF and/or Medicare criteria is resumed.

- All data required by the National TBI Model System Database are accessible and transferable to the National Data Center with appropriate informed consent;
6. who understand and provide informed consent to participate or, if unable, family or legal guardian understands and provides informed consent for the patient.

#### **ADDITIONAL GUIDELINES FOR INCLUSION/EXCLUSION OF CASES:**

1. Submit cases which expire anytime after inpatient rehabilitation has begun; even if the patient was transferred back to acute care from rehabilitation prior to expiring.
2. Subjects who have a preexisting central nervous system problem (anoxia, stroke, aneurysm, etc.) will be included in the database as long as all other inclusion criteria are met.
3. Subjects who have concurrent events (e.g., aneurysm rupture with TBI, syncope/stroke/fall with TBI) will be included if the admitting physiatrist determines that the predominant mode of central nervous system injury is traumatic, as long as all other inclusion criteria are met.
4. Subjects are included if the time of injury can be approximated within a 12 hour window. If time of injury cannot be approximately determined within 12 hours, the subject should be excluded.
5. If date of injury is in question, it will be decided by the midpoint of the theoretical 12 hour (or less) window.
6. If, prior to admission to comprehensive rehabilitation, a patient leaves a designated Model System facility for more than 72 hours, the patient should be excluded from the study. Once the patient enters comprehensive rehabilitation and meets the inclusion criteria, the subject should be retained even if she/he is subsequently transferred to a non-model system facility.
7. If a patient completes acute care and comprehensive rehabilitation and is then transferred outside of the Model System or to an alternate level of care that does not meet the criteria for comprehensive rehabilitation specified above (regardless of whether it is a designated Model System facility or not), this is considered the rehabilitation discharge date, and the residence at discharge (V109) should reflect this alternate level of care discharge (see variable 101).
8. If a patient is transferred to an alternate level of care (ALC) within the designated Model System prior to inpatient rehabilitation, the ALC length of stay should be added to the Model System acute care stay or comprehensive rehabilitation stay, whichever is most applicable (see variable 101).
9. Do not exclude a person from the database because of early discharge from inpatient rehabilitation.
10. If patient expires prior to consenting, attempts should be made to obtain consent from family members in order to include data in the dataset (to avoid biasing the dataset).

04a.Inclusion criteria\_060101a







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

100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.2

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

100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.2

**139. GLASGOW COMA SCALE:**

ED Admission

a. Eye Opening .....	<input type="text"/>	4=Spontaneous 3=To Voice	2=To Pain 1= None	7=Chemical Coma/Paralysis/Sedated* 9=Unknown
b. Verbal .....	<input type="text"/>	5=Oriented 4=Confused 3=Inapp. Words	2=Incomp Words 1=None	8=Intubated 9=Unknown 7=Chemical Coma/Paralysis/ Sedated*
c. Motor.....	<input type="text"/>	6=Obeys Commands 5=Localizes pain 4=Withdraw from pain	3=Flexion to pain 2=Extension to pain 1=None	7=Chemical Coma/Paralysis/ Sedated* 9=Unknown
d. Total (a+b+c)	<input type="text"/> <input type="text"/>	77=Chemical Coma/Paralysis/Sedated; Chem Coma/Paralysis/Sedated* & Intubated 88=Intubated                      99=Unknown		

*\*code "7" & "77" if administered any of the following: midazolam (VERSED), lorzaepam (ATIVAN), vecuronium (NORCURON), pentobarbital (NEMBUTAL).*

**140. REVISED TRAUMA SCORE AT ADMISSION TO ED:**

a. Respiratory Rate  (#/minute)                      888=Unmeasurable    999=Unknown

c. Systolic Blood Pressure.  (mm Hg)                      888=Unmeasurable    999=Unknown

**144 a. DATE EMERGED FROM PTA (MM/DD/YYYY):**

/  /

*(if person was never in PTA, code date of admission to ER)*

08/08/8888=Still had PTA or unconsciousness at TBI system discharge  
09/09/9999=Unknown

**b. METHOD OF PTA DETERMINATION**

2=GOAT	3=GOAT-R	4=O-LOG	8=NA
1=Chart Review (while in acute hospital, or if no consent at the time)			

**146. ICD-9-CM CAUSE(S) OF DEATH CODES:**

a. Primary cause                      ICD-9  .                       777.77 Expired cause unknown  
888.88 N/A-alive/no other internal cause/external cause

b. Secondary cause                      ICD-9  .                       999.99 Unknown if expired

c. E-code                                      E                        777.7 Expired cause unknown  
888.8 NA-alive/not an external cause of death  
999.9 Unknown if expired

**148h. CRANIAL COMPLICATIONS-INTRACRANIAL HYPERTENSION:**

                     1=No    2= $\leq$  24hr    3=peaks > 24hr    4=Sustained>24hrs  
8=not monitored                      9=Unknown

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

100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.2

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

100. SYSTEM/SUBJECT ID:

ENTER INTO DATABASE 10.2

**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"/>

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)

**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"/>

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

100. SYSTEM/SUBJECT ID:         ENTER INTO DATABASE **10.2**

**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 \*\*\*

## GUIDELINES FOR COLLECTION OF FOLLOW-UP DATA

1/1/2006

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. Follow-up should be attempted according to TBIMS schedule for every participant (person with TBI) for whom a Form I (initial hospitalization and rehabilitation) was submitted, unless the participant expires or refuses to continue participation.
3. The primary source of information for the annual follow-up should be the participant. In all cases, the participant is interviewed to complete the questions to be asked specifically of the participant or specifically of the "best source".
4. If the participant does not or cannot respond to certain "best source" questions, then the person who knows the participant best--either a professional caregiver or significant other--becomes the participant proxy and can answer for the participant. The proxy cannot provide information for item V292g: SATISFACTION WITH LIFE. 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 live with that person. A significant other can be a non-traditional person such as a nurse at the SNF where the person resides, a legal/public guardian, a roommate, etc. The significant other knows the participant sufficiently well to answer the questions accurately. The significant other may qualify to answer some questions but not others. Those questions the significant other cannot answer reliably are coded as "unknown".
5. If a participant expires during initial inpatient rehabilitation, no Form II is to be completed.
6. If a participant expires during any follow-up year, a Form II should be submitted. However, only items V200, V20Aa, V20Ab, V20Ac, V20Ad, V20Ae and V201 are to be completed. All other items are left blank. Thereafter, no additional Form II forms are submitted.
7. If a participant withdraws authorization to use his/her data (i.e., definitive refusal to continue participation) during any follow-up year, a Form II should be submitted indicating that he/she withdrew authorization (enter code 05/05/5555 into the first part of V201). Only items V200, V20Aa, V20Ab, V20Ac, V20Ad, V20Ae, and V201 are to be completed. All other items are left blank. Thereafter, no additional Form II forms are to be submitted unless the participant agrees to again participate. In this situation, submit a Form II form for the follow-up year in which the participant again agreed to participate, and submit Form IIs without data (except V200, V20's, and V201) for the interim years in which no Form IIs had been submitted due to refusal.



8. \*If a participant will be incarcerated through the end of a follow-up window, submit a Form II but do not collect follow-up data. Enter data into only the following variables, as indicated:
- V200 = Center ID, subject ID, follow-up year
  - V20Aa(a,b,c) = 888.88
  - V20Ab = 8
  - V20Ac = 8
  - V20Ad = 88
  - V20Ae = 88
  - V201a = 07/07/7777
  - V201b = 08/08/8888
  - V209 = 04
9. No data in the TBIMS dataset must be collected only from a significant other. Therefore, a significant other needs to be interviewed only if needed information cannot be obtained from the participant.
10. For expired participants, Living Status (V20Aa) and Dates (V201a:FOLLOW-UP EVALUATION DATE; V201b:DATE OF DEATH) may be collected at any time. These variables may be submitted in any quarter. If the quarter in which this information is submitted is not within a data collection window for the participant, then “follow-up year” (last 2 digits of V200) is coded as the year of the next follow-up that would have been due for the person.
11. 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.
12. 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. \*If data could not be collected within window by the TBIMS data collector, data collected within the window for non-TBIMS purposes may be submitted if it meets TBIMS standards. In this case, enter code “4” into V20Ab and V20Ac and code “09/09/9999” into V201a.

### **Follow-up Years:**

1. Every living participant for whom a Form I was submitted, other than those who are incarcerated or have previously withdrawn authorization to use their data, should complete the annual follow-up evaluation (Form II) for all follow-up years (1, 2, 5, and every 5<sup>th</sup> year thereafter). This evaluation consists of all data items in the Form II.
2. If in-person contact with the participant is not feasible, he/she should be contacted by phone to complete all data items in the Form II .



3. An appropriate significant other should be contacted by phone to complete any “best source” questions for which the participant failed to provide an adequate answer.
4. If phone contact with the participant is not possible, all “best source” information should be collected from a significant other by phone. The participant should be sent the “person with TBI only” item (V292g:SATISFACTION WITH LIFE) by mail with a self-addressed return envelope.
5. If phone contact with the participant and significant others is not successful, the participant should be mailed the Form II with appropriate instructions for self-administration, with a self-addressed return envelope.
6. If adequate data are not obtained from the participant by mailout, the Form II with appropriate instructions for self-administration should be mailed to the significant other, with a self-addressed return envelope
7. If no form of contact is successful with either the participant or a significant other, a Form II is to be submitted with only items V200, V20Aa, V20Ab, V20Ac, V20Ad, V20Ae and V201 completed. All other items are left blank.

09c.Guidelines for Follow-up Data Collection.060101b



**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) 1/1/06 or later, until replaced by a newer Form II

**200. SYSTEM/SUBJECT ID:**   -     -   **ENTER INTO DATABASE 10.2**

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**    .  777.7 =Expired cause unknown  
 888.8 =NA-alive/not an external cause of death  
 999.9 =Unknown if expired

**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 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) 05/05/5555=N/A-withdrew authorization  
 06/06/6666=N/A-deceased  
 Follow-up evaluation Date:   /   /     07/07/7777=N/A-other (including incarcerated)  
 09/09/9999=Unknown date of evaluation  
 Date of Death: .....   /   /     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) 1/1/06 or later, until replaced by a newer Form II

**200. SYSTEM/SUBJECT ID:**   -     -   **ENTER INTO DATABASE 10.2**

**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         |

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

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

- 777=Refused  
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.)

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

M M D D Y Y Y Y  
  /   /

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 1<sup>st</sup> 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) 1/1/06 or later, until replaced by a newer Form II

**200. SYSTEM/SUBJECT ID:**   -      -   **ENTER INTO DATABASE 10.2**

**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) 1/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID:   -      -   **ENTER INTO DATABASE 10.2**

**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) 1/1/06 or later, until replaced by a newer Form II

**200. SYSTEM/SUBJECT ID:**   -      -   **ENTER INTO DATABASE 10.2**

**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) 1/1/06 or later, until replaced by a newer Form II

**200. SYSTEM/SUBJECT ID:**   -       -   **ENTER INTO DATABASE 10.2**

**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) 1/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID:   -      -   **ENTER INTO DATABASE 10.2**

**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) 1/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID: [ ] [ ] - [ ] [ ] [ ] [ ] [ ] [ ] - [ ] [ ] ENTER INTO DATABASE 10.2

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

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

[ ] [ ]

Table with 4 columns of income ranges: 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, 77=Refused, 88=N/A-no income, 99=Unknown

(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) 1/1/06 or later, until replaced by a newer Form II

200. SYSTEM/SUBJECT ID:   -      -   **ENTER INTO DATABASE 10.2**

**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\_\_\_\_\_**

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



22. If the person with TBI has non-employment income, where does it come from? (Check all that apply)

- |   |   |      |
|---|---|------|
| <input type="checkbox"/> SSI (Supplemental Security Income)                 | <input type="checkbox"/> Private Insurance                      | 292c |
| <input type="checkbox"/> SSD (Social Security Disability)                   | <input type="checkbox"/> Legal settlement (lawsuit)             |      |
| <input type="checkbox"/> TA/TANF (Temporary Assistance/ for Needy Families) | <input type="checkbox"/> Other (please list) _____              |      |
| <input type="checkbox"/> General Assistance (state interim welfare)         |   |      |
| <input type="checkbox"/> Unemployment Insurance                             |   |      |
| <input type="checkbox"/> Workers' Compensation                              | <input type="checkbox"/> Does not receive non-employment income |      |

23. Has the person with TBI been arrested in the past year? 292e

No  Yes

24. Has the person with TBI attempted suicide in the past year? 292f

No  Yes

25. Has the person with TBI been hospitalized for a psychiatric problem in the past year? 292f

No  Yes

26. For each of the following statements, circle the number that best describes how much you (the person with TBI) agree or disagree with the statement. For instance, if you slightly agree with the statement "I am satisfied with my life", you would circle the number 5 to the right of "I am satisfied with my life." 292g

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
In most ways my life is close to my ideal.	1	2	3	4	5	6	7
The conditions of my life are excellent.	1	2	3	4	5	6	7
I am satisfied with my life.	1	2	3	4	5	6	7
So far I have gotten the important things I want in life.	1	2	3	4	5	6	7
If I could live my life over, I would change almost nothing.	1	2	3	4	5	6	7

27. Date this survey was completed: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
(month) (day) (year)

201a

GO TO THE NEXT PAGE

## 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!**

## DVT Study Syllabus – Version 6.2

### DVT Module Inclusion Criteria

The recruitment of subjects will include those patients who have suffered Traumatic Brain Injuries (TBI) and have required admission for inpatient rehabilitation services. The TBI patients must be at least 16 years of age and must have received rehabilitation care at a designated TBI MS inpatient rehabilitation unit. Eligible patients include those concurrently enrolled in the TBIMS, as well as additional subjects who do not meet TBIMS inclusion criteria (e.g., patients who were not admitted to the TBIMS-affiliated acute care hospital within 72 hours of TBI occurrence, mild TBI patients, TBI patients who received hospital treatment in acute centers outside the model system). The enrollment of non- TBIMS patients will be at the discretion of the participating center. Patients will be excluded from the study if they or their family are unable to provide consent.

*Original Date: 03/04/04*

*Version 6.2*

### TBI MS Health Module ID

*VARIABLE 500*

*Revised: 07/21/2005*

*Version 6.2*

**DEFINITION:** A unique 7-digit number assigned to each patient with brain injury by Project Staff at each center. The first two digits are the system ID; last five digits are the unique subject's ID.

#### CODE:

A: Code according to site specific subject ID's:

0400000 Rehabilitation Institute of Michigan  
0500000 Santa Clara Valley Medical Center  
0600000 Ohio State University  
0800000 University of Alabama  
1100000 Spaulding Rehabilitation Hospital  
1200000 Mayo Clinic  
1400000 Mississippi Methodist Rehabilitation Center  
1600000 Charlotte Institute  
1900000 JFK Johnson Rehabilitation Institute  
2000000 University of Pittsburgh  
2100000 UT Southwestern Med Ctr/Baylor Institute for Rehabilitation  
2200000 Mt. Sinai School of Medicine

**CHARACTERS:** 1 item; 7 characters

#### EXAMPLE:

Patient is at UT Southwestern Medical Center / Baylor Institute for Rehabilitation with the patient number 12345.

/ A = 2112345 /

**VARIABLE HISTORY:** Deleted non-participating Centers

## DVT Study Syllabus – Version 6.2

<b>TBI Model System Subject</b> <i>VARIABLE 500a</i>	
<i>Original Date 03/04/04</i>	<i>Version 6.2</i>
DEFINITION: Each patient will be classified as a TBI MS subject or non TBI MS subject in the TBI MS Health Module DVT study.	
CODE: A – TBI MS subject status  1 – No    2 – Yes	
CHARACTERS: 1 item; 1 character	
EXAMPLE: Patient does not meet strict TBI MS inclusion criteria due to receiving acute care in a trauma hospital that is not affiliated with the TBIMS, but does meet criteria for inclusion in the TBI MS Health Module DVT Study.  / A = <u>1</u> /	
VARIABLE HISTORY:	

## DVT Study Syllabus – Version 6.2

<b>Acute Care (Pre-Rehab) DVT</b> <i>VARIABLE 501</i>	
<i>Last Revised 01/14/05</i>	<i>Version 6.2</i>
DEFINITION: History of DVT/PE during this acute care hospitalization. A DVT that occurred after the TBI for which the patient is currently being treated, but prior to admission to acute inpatient rehabilitation. If the “Pre-rehab DVT” is symptomatic (based on the signs/ symptoms listed in variable 507) at the time of initial exam on admission to the acute rehab hospital, it will be recorded here in variable 501- B.	
CODE: A- Pre-rehab DVT/PE 1 – No/ Autofill B-D N/A 2 – Yes 9 – Unknown or Missing data  B- Pre-rehab DVT/PE is symptomatic (signs/symptoms listed invariable 507) 1 – No 2 – Signs or symptoms found on rehab admission evaluation 3 – Signs or symptoms developed subsequent to rehab admission 9 – Unknown or missing data 8 = Not Applicable  C – Pre-rehab DVT – Limb involved 1 – Unilateral right LE DVT 2 – Unilat left LE DVT 3 – Bilat LE DVT 4 – Unilat right UE DVT 5 – Unilat left UE DVT 6 – Bilat UE DVT 9 – Unknown or Missing Data 8 – Not applicable  D – Central/PICC Line-relative to Pre-Rehab DVT 1 – Ipsilateral 2 – Contralateral 3 – Bilateral 9 – Unknown or Missing Data 8 – Not applicable	
CHARACTERS: 1 item; 1 character	
NOTES: Complete data from the acute hospitalization may not be available to the rehabilitation hospital. If the family reports a history of testing for DVT/PE and positive results of this testing, and if the patient is on full DVT treatment doses of anticoagulation, existence of a pre-rehab DVT/PE can be inferred. If the involved extremity with known Pre-rehab DVT shows signs/ symptoms on initial exam at the time of admission to rehab, or signs/symptoms developed subsequent to rehab admission this will be recorded in variable 501-B. Signs or symptoms that are described in variable 507 will be used to determine if the pre-rehab DVT is symptomatic- 501-B. These include any one or more of the following: pain and tenderness of the involved limb, positive Homan’s sign, redness/discoloration of the involved limb, pyrexia (systemic fever $\geq 38$ degrees C), limb swelling of the involved limb ( $> 2$ cm asymmetry with the uninvolved limb), and warmth localized to the involved limb.	
EXAMPLE: Patient Jones was diagnosed with a DVT/PE in the acute care hospital. / A = <u>2</u> /	
VARIABLE HISTORY: 11/4/04: Added PE to definition. Changed unknown/missing data code to 9. 1/14/05: Added 501B-D.	

## DVT Study Syllabus – Version 6.2

<b>DVT Risks</b> <i>VARIABLE 502</i>	
<i>Last Revised 01/14/05</i>	<i>Version 6.2</i>
DEFINITION: This variable describes the risk factors for deep vein thrombosis that will be monitored in this study. Multiple risk factors may be present in the same patient.	
CODE: A- Lower extremity long bone fracture B- Pelvic fracture C- LE Weight bearing restricted D- Lower extremity weakness (weakness of grade 3 or lower) E- History of venous thromboembolism any time before this TBI. F- Other lower extremity fractures such as ankle or foot G- Any known history of neoplasms H- Hypercoagulable state (Protein C or S deficiency, +Anti-cardiolipin antibody, abnormal homocysteine level, + Lupus-like anticoagulant, Factor V Leiden Mutation, Antithrombin III deficiency, Prothrombin Gene Mutation) I – Central line/PICC Line  use codes for items above: 1- No 2- Yes 9 – Unknown or missing data	
CHARACTERS: 8 items; 1 character each.	
NOTES: - Lower extremity long bones are defined as femur, tibia, and fibula - Pelvic fractures include: acetabular, pubic ramus, ilium, and ischium. - Grade 3 = (lacks full active joint range of motion against gravity)	
EXAMPLE: Patient Jones has sustained fractures to his left femur and is non-weight bearing.  / A = <u>2</u> / B = <u>1</u> / C = <u>2</u> / D = <u>1</u> / E = <u>1</u> / F = <u>1</u> / G = <u>1</u> / H = <u>1</u> /	
VARIABLE HISTORY: 11/04/04: Added LE to code C. Changed unknown missing data code to 9. 1/14/05: Added 502 I.	



## DVT Study Syllabus – Version 6.2

### Results of Serial Venous Doppler Studies

#### VARIABLE 504

*Last Revised 01/14/05*

*Version 6.2*

**DEFINITION:** This variable documents the results of up to three subsequent/ serial venous Doppler studies performed whether or not an initial screening ultrasound was done. If subsequent ultrasound studies are done, the date of these studies and the positive or negative results of these studies will be documented. If findings on serial ultrasound represent propagation of a distal DVT or Pre-Rehab DVT, this will be recorded. The initial screening US is labeled “0” in variable 503; subsequent ultrasounds will be labeled “1”, “2”, and “3”

**CODE:**

A – Serial ultrasound

1 = No/Auto fill B-E N/A 2 = Yes 9 = Unknown or Missing Data

B – Propagation DVT

1 = No/autofill B1 and B2 2 = Yes 9 = Unknown or Missing Data 8 = N/A

B1 Propagation of Pre-Rehab DVT

1 = No 2 = Yes 9 = Unknown/Missing Data 8 = N/A

B2 Propagation of Distal (calf) DVT

1 = No 2 = Yes 9 = Unknown/Missing Data 8 = N/A

C – Ultrasound1

Date:

Results1:

D – Ultrasound2

Date:

Results2:

E – Ultrasound3

Date:

Results3:

code D-F Date MM/DD/YYYY 08 / 08 / 8888 if no test 09 / 09 / 9999 if unknown

code D-F Results 1 = Negative results 2 = Positive results 9 = Unknown or Missing Data  
8 = Not done/Not applicable

**CHARACTERS:** 5 items; 1 character 3 items; dates

**NOTES:** The performance of subsequent serial venous Doppler studies and the time frame in which they are done will be at the discretion of the treating physician. Serial Venous Doppler’s are not a requirement of this study. Room is provided to record results of up to three subsequent venous Doppler studies in addition to the screening venous Doppler study in variable 503. If A = 1/no then variables B – E will be auto-filled with not applicable.

## DVT Study Syllabus – Version 6.2

### Results of Serial Venous Doppler Studies

VARIABLE 504(continued)

Last Revised 01/14/05

Version 6.2

#### EXAMPLE:

Patient Jones had a calf DVT in the Right leg on initial screen on 8/01/03. Subsequent venous Doppler was ordered by the treating MD on 8/08/03. It revealed propagation of the clot into the Right common femoral vein.

/ A = 2 / B = 2 / B1 = 1 / B2 = 2 / C date = 08/08/2003 / C results1 = 2 / D date = 08/08/8888 / D results2 = 8 / E date = 08/08/8888 / E results3 = 8

VARIABLE HISTORY: Note on auto-filled added in ver 5.0 -11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no test/not done to 8 or 08/08/8888. Deleted code 4 = Not done. 1/14/05: Changed variable 504 C-E. Added variable 504 B1, B2 and E. Changed Example to include new variable.

## DVT Study Syllabus – Version 6.2

<b>DVT Prophylaxis</b> <i>VARIABLE 505</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: This variable documents the use of DVT prophylactic measures in the rehabilitation setting.	
CODE: A- DVT Prophylaxis 1 – No    2 – Yes    9 – Unknown or missing data	
CHARACTERS: 1 item, 1 character	
NOTES:	
EXAMPLE: When patient Jones arrived in the acute rehabilitation hospital, lower extremity sequential compression devices were ordered by his physician to be used whenever he was in bed.  / A = <u>2</u> /	
VARIABLE HISTORY: 11/04/04 Code: Changed missing data/unknown to 9.	

## DVT Study Syllabus – Version 6.2

<b>Prophylaxis with Mechanical Agents</b> <i>VARIABLE 505a</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Documentation of mechanical agents used for DVT prophylaxis during rehabilitation.	
CODE: A – IVC (Inferior Vena Cava) Filter  B – Sequential compression devices (SCD)  use codes for above 1 = No      2 = Yes      9 = Unknown or missing data  C – Prophylactic agent initiated in ...  1 = Acute care setting      2 = Rehabilitation unit 9 = Unknown or missing data      8 = Not applicable	
CHARACTERS: 3 items; 1 character	
NOTES: Indicate which items are/were in use and when they were started. If both variables A and B = “no”, then variable C will be auto-filled not applicable. An IVC filter may have been placed for prophylaxis purposes during the acute care hospital stay, but is still in place in the rehabilitation setting, providing DVT prophylaxis. If so, this will be recorded as A = 2 (yes). C= 1 (initiated in the acute care setting)	
EXAMPLE: On admission to the acute rehabilitation unit, SCD’s were ordered for patient Jones. No IVC filter is in place for prophylaxis.  / A = 1 / B = 2 / C = <u>2</u> /	
VARIABLE HISTORY: Note on auto-filled added in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 and not applicable/no test to 8.	

## DVT Study Syllabus – Version 6.2

### Pharmacologic Prophylaxis with Anticoagulation

VARIABLE 505b

Last Revised 11/04/04

Version 6.2

DEFINITION: Documentation of anticoagulation agent used for DVT prophylaxis in acute rehabilitation.

CODE:

1– Pharmacologic prophylaxis with anticoagulation  
1 = Not administered 2 = Prophylaxis initiated prior to rehabilitation admission  
3 = Prophylaxis initiated during rehabilitation 9 = Unknown or missing data

A1 – Low Molecular Weight Heparin

A2- Characteristics \_\_\_\_\_ generic name, dose,  
route (IV, SC, Oral), frequency

A3- Date initiated DD

B1 – Unfractionated Heparin

B2- Characteristics \_\_\_\_\_ dose, route (IV, SC, oral), frequency

B3- Date initiated

C1 – Coumadin

C2- Characteristics \_\_\_\_\_ dose, route (IV, SC, oral), frequency

C3- Date initiated

D1 – Ximelagatran

D2- Characteristics \_\_\_\_\_ dose, route (IV, SC, oral), frequency

D3- Date initiated

code A1, B1, C1, D1 1 = No 2 = Yes 9 = Unknown or missing data  
8 = Not Applicable

code A2, B2, C2, D2 with (generic name), dose, route, frequency of drug or  
Not applicable

code A3, B3, C3, D3 MM/DD/YYYY code 08 / 08 / 8888 for no drug  
09 / 09 / 9999 if unknown

CHARACTERS: 5 items; 1 character 4 items; text entry 4 items, dates

NOTES: Route assumed to be subcutaneous for LMWH and unfractionated heparin and oral for coumadin. Dose of the agent will need to be specified since it varies with different agents and per the discretion of the treating physician. If variable 1 is either “not administered” or “unknown”, variables A –D will auto-filled as “no” and “08/08/8888”

EXAMPLE: Patient Smith was placed on LMWH while in the acute trauma hospital on 10/15/2003 prior to his admission to rehabilitation.

/ 1 = 2 / A1 = 2 / A2 = enoxaparin 30 mg SC q 12 / A3 = 10/15/2003 /  
/ B1 = 1 / B2 = \_\_\_\_\_ / B3 = 08/08/8888 /  
/ C1 = 1 / C2 = \_\_\_\_\_ / C3 = 08/08/8888 /  
/ D1 = 1 / D2 = \_\_\_\_\_ / D3 = 08/08/8888 /

VARIABLE HISTORY: Note on auto-filled added in ver. 5.0. 11/04/04 Code:  
Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no drug to 8 or 08/08/8888.

## DVT Study Syllabus – Version 6.2

<b>Pharmacologic Prophylactic Anticoagulation Discontinued</b> <i>VARIABLE 505c</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: If prophylactic anticoagulation is discontinued prior to discharge from the inpatient rehabilitation unit, the date will be recorded here.	
CODE: A- Date discontinued MM/DD/YYYY	
code 08 / 08 / 8888 if no drug 02 / 02 / 2222 if not discontinued 09 / 09 / 9999 if unknown	
CHARACTERS: 1 item; 1 date	
NOTES:	
EXAMPLE: Patient Jones was ambulating community distances and had no signs or symptoms of DVT. His prophylactic anticoagulation was therefore discontinued on 10/31/2003.  / A = <u>10/31/2003</u> /	
VARIABLE HISTORY: 11/04/04 Code: Changed not applicable/no drug to 08/08/8888. Auto fill added to electronic database. If 505b1= 1 then auto fill 505c with no drug.	

## DVT Study Syllabus – Version 6.2

<b>Mobility Status at Time of Anticoagulation Discontinuation</b> <i>VARIABLE 505d</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: The distance the patient was able to ambulate when prophylactic anticoagulation was discontinued is recorded here.	
CODE: A- Mobility distance 1 – Ambulating less than 50 feet 2 – Ambulating equal to or greater than 50 feet 9 – Unknown or Missing Data 8 – Not applicable	
CHARACTERS: 1 item; 1 character	
NOTES: If the patient remains on anticoagulation prophylaxis throughout rehabilitation and it is not discontinued before or at the time of discharge, this will be recorded as 8= not applicable.	
EXAMPLE: Patient Jones was ambulating greater than 50 feet at the time prophylactic anticoagulation with LMWH was discontinued. / A = <u>2</u> /	
VARIABLE HISTORY: Not applicable added in ver. 5.0. 11/04/04 Code: Changed unknown or missing data to 9 and not applicable to 8.	

## DVT Study Syllabus – Version 6.2

<b>DVT Occurrence During Rehabilitation</b> <i>VARIABLE 506</i>	
<i>Last Revised 01/14/05</i>	<i>Version 6.2</i>
DEFINITION: The identification and/or occurrence of signs and/or symptoms of DVT will be recorded at any time from admission to discharge from the rehabilitation unit.	
CODE: A – DVT identified during admission to discharge period of rehabilitation 1 = No 2 = Yes 9 = Unknown or missing data B – DVT symptomatic during the period from admission to discharge from rehabilitation 1 = No 2 = Signs or symptoms found on admission evaluation 3 = Signs or symptoms developed subsequent to admission to rehabilitation 9 = Unknown or missing data 8 = Not applicable C – Results of lower extremity ultrasound on screening (ultrasound “0”) or subsequent ultrasound when signs or symptoms of DVT or elevated D-Dimer prompt an additional ultrasound (“1”, “2”, or “3”) to be done 1 – No DVT 2 – Proximal (popliteal vein or above) DVT 3 – Distal (distal to popliteal fossa) DVT 4 – Both proximal and distal DVT 9 – Unknown or Missing Data 8 – Not applicable/Not Done D – Side of LE DVT 1 – Unilateral right DVT 2- Unilateral left DVT 3 – Bilateral DVT 9 – Unknown or Missing Data 8 – Not applicable E – Date DVT identified: Code date or 08/08/ 888 if not identified 09/09/9999 if unknown F – LE DVT side specified 1 = Left proximal 2 = Right proximal 3 = Left & Right Proximal 4 = Left distal 5 = Right distal 6 = Left & Right distal 7 = Left proximal & left distal 8 = Right proximal & Right distal 9 = Left proximal & Right distal 10 = Right proximal & Left distal 11 = Both Left & Right, Both proximal & distal 99 = Unknown or missing data 88 = Not applicable/Not Done G – UE DVT 1 = No 2 = Yes 9 = Unknown or missing data 8 = Not applicable H – Side of UE DVT 1 = Unilateral right DVT 2 = Unilateral left DVT 3 = Bilateral DVT 4 = Unknown 8 = Not applicable I – Central / PICC Line (relative to identified UE or LE DVT) 1 = Ipsilateral to UE or LE DVT 2 = Contralateral 3 = Bilateral 8 = Not Applicable	
CHARACTERS: 7 items; 1 character 1 Item; 2 characters 1 item; date	
NOTES: Review of systems and physical evaluation for signs and symptoms of DVT will be completed by specially trained and identified staff within the first 72 hours of admission to rehabilitation within each participating center. This will be completed prior to screening for DVT (in those centers that routinely use screening procedures) or will be done by an individual who is blinded to the result of the DVT screening procedure. Added LE to variables D and F, and UE to variables G – I to better characterize UE DVT.	

## DVT Study Syllabus – Version 6.2

### DVT Occurrence During Rehabilitation

VARIABLE 506 (continued)

Last Revised 01/14/05

Version 6.2

NOTES CONTINUED: If a second diagnostic ultrasound (DUS) is done subsequent to rehab admission and is positive for DVT, but the DVT is asymptomatic, it will be recorded in variable 506 as A-2; B-1; and the site, side, and date of identification will be recorded in 506 C, D, and E.

If an asymptomatic DVT is found on initial screening DUS and the patient subsequently develops a DVT that is symptomatic, the DUS results for the symptomatic DVT will be recorded in 506C, the side of the symptomatic DVT will be recorded in 506D, and the date of its identification in 506E. Variable 506F will allow the location to be documented for both the asymptomatic and symptomatic DVT if they have different locations.

Variable 506F is provided to capture location if multiple DVTs are present.

EXAMPLE: Patient Jones was noted on admission to the rehab unit on 10/31/2003 to have swelling in his left thigh with a circumference that was 2.5 cm greater than on the right. A Screening venous Doppler revealed a left LE DVT

/ A = 2 / B = 2 / C = 2 / D = 2 / E = 10/31/2003 / F = 1 / G = 1 / H = 8 / I = 8 /

VARIABLE HISTORY: F was added in Ver. 4. Added “Not applicable” to variable F. Added LE to variables D and F, and variables G – I in ver. 5.0.

11/04/04 Code: Changed missing data/unknown to 9, 99 or 09/09/9999 and not applicable/not identified/not done to 8, 88 or 08/08/8888. Added auto fill to electronic database. If A=1 auto fill B thru I. Deleted 6 = not done for variable C and 13 = Not Done for variable F. 1/14/05: Edited variable 506C and I. Edited Notes for clarification of variable.

**\*\*If no DVT or PE identified (Pre-rehab or During rehab), Skip to 511\*\*  
(If 507 to 510 skipped, variables will automatically code not applicable)**

**DVT/PE Identified 1 = No 2 = Yes**

**\*\*\*If DVT /PE Identified either pre-rehab or during rehab, please complete variables 507-510 to document signs/symptoms of DVT, treatment with IVC Filter, and/or treatment with anticoagulation\*\*\***

## DVT Study Syllabus – Version 6.2

<b>DVT Symptoms of Involved Limb</b>	
<i>VARIABLE 507</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Signs or symptoms that lead the physician or evaluating staff member to suspect the presence of deep vein thrombosis are recorded here.	
CODE: Specific numbers and letters below pair symptoms with involved limb(s). Summary of DVT symptoms for all UE / LE involved limbs	
	1   2   3   4   5   6
Symptomatic LE DVT of	
Left Proximal	7   8            9   10   11
Left Distal	12   13           14   15   16
Right Proximal	17   18           19   20   21
Right Distal	22   23           24   25   26
	A   B   C   D   E   F
A - Pain and tenderness of the involved limb, positive Homan's sign	(1,7,12,17,22)
B - Redness/discoloration of the involved limb	(2,8,13,18,23)
C - Pyrexia (systemic fever $\geq 38^{\circ}\text{C}$ )	(3)
D - Limb swelling of the involved limb	(4,9,14,19,24)
E - Warmth localized to the involved limb	(5,10,15,20,25)
F - Other symptoms	(6,11,16,21,26)
use codes for above 1- No   2-Yes   9-Unknown or Missing Data   8 – Not Applicable	
CHARACTERS: 26 items; 1 character	
NOTES: Summarize symptoms across all limbs into items 1, 2, 3, 4, 5, & 6- this will be the only place where symptomatic UE DVT signs/ symptoms are recorded. For LE DVT signs/ symptoms—variables 1- 6 will provide a summary of symptoms. Variables 7- 26 will allow record of signs/ symptoms for each location in the event that there is multiple LE DVT. Pain or tenderness will include positive Homan's, subjective unprovoked limb pain, or pain to palpation/touch. Asymmetric limb swelling greater than 2 cm will constitute limb swelling of the involved limb. Systemic fever is coded only once on item 3. If no DVT or PE identified (per skip instructions) all variables will be auto-filled with "not applicable."	
EXAMPLE: Patient Jones was noted upon initial examination to have swelling of his left leg above the popliteal vein as well as a low grade fever.	
	/ 1 = <u>1</u> / 2 = <u>1</u> / 3 = <u>2</u> / 4 = <u>2</u> / 5 = <u>1</u> / 6 = <u>1</u> /
	/ 7 = <u>1</u> / 8 = <u>1</u> /            / 9 = <u>2</u> / 10 = <u>1</u> / 11 = <u>1</u> /
	/ 12 = <u>1</u> / 13 = <u>1</u> /            / 14 = <u>1</u> / 15 = <u>1</u> / 16 = <u>1</u> /
	/ 17 = <u>1</u> / 18 = <u>1</u> /            / 19 = <u>1</u> / 20 = <u>1</u> / 21 = <u>1</u> /
	/ 22 = <u>1</u> / 23 = <u>1</u> /            / 24 = <u>1</u> / 25 = <u>1</u> / 26 = <u>1</u> /
VARIABLE HISTORY: Items 6 through 26 added and Items 1 – 6 revised to reflect summary across all limbs in Ver. 4. UE and LE added to descriptions of signs and symptoms of DVT as well as auto-fill of "not applicable" if no DVT or PE identified in skip instruction in ver. 5.0 11/04/04 Code: Changed missing data/unknown to 9 and added not applicable code assigned variable 8.	

## DVT Study Syllabus – Version 6.2

<b>IVC Filter Placed</b> <i>VARIABLE 508</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Documentation of if and when the patient had Inferior Vena Cava filter placement for TREATMENT of known DVT	
CODE: A- IVC Filter Placed for Treatment of DVT 1 – No 2 – Yes 9 – Unknown or Missing Data 8 – Not applicable  B- Date placed MM/DD/YYYY code 08 / 08 / 8888 if no filter/Not applicable 09 / 09 / 9999 if unknown	
CHARACTERS: 1 item; 1 character 1 item; date	
NOTES: This variable will record the date of IVC filter placement for TREATMENT of DVT. Data missing will allow documentation of inability to verify date if records from prior hospital cannot be obtained. It will be auto-filled “not applicable” if no DVT or PE identified (as in skip instruction).	
EXAMPLE: Patient Jones had an IVC filter placed on 11/04/2003 when he was found to have a DVT in the left lower extremity.  / A = <u>2</u> / B = <u>11/04/2003</u> /	
VARIABLE HISTORY: 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no filter to 8.	

## DVT Study Syllabus – Version 6.2

<b>Full Anticoagulation Treatment Initiated after Development of DVT/PE</b> <i>VARIABLE 509</i>	
<i>Last Revised 01/14/05</i>	<i>Version 6.2</i>
DEFINITION: Documentation of the initiation of therapeutic anticoagulation for treatment of DVT/PE, if necessary, and the date it was begun. Anticoagulation for treatment of all DVTs- both pre-rehab DVT or DVT which was identified on screening at the time of rehab admission or subsequently during rehab will be recorded here.	
CODE: A Full anticoagulation treatment initiated after development of DVT / PE 1 – No 2 – Yes 9 – Unknown or missing data 8 – Not applicable  B Date full anticoagulation started MM/DD/YYYY code 08 / 08 / 8888 if no drug 09 / 09 / 9999 if unknown	
CHARACTERS: 1 item; 1 character 1 item; date	
NOTES: If anticoagulation is not related to thromboembolic episode, do not include it here. Variable 509 will be auto-filled with “not applicable” if no DVT or PE identified (as in skip instruction) and date initiated will be auto-filled with 08/08/8888.	
EXAMPLE: A proximal DVT was identified in the patient’s left lower extremity. He was started on full dose anticoagulation with adjusted dose LMWH, Lovenox on 11/04/2003.  / A = <u>2</u> / B = <u>11/04/2003</u> /	
VARIABLE HISTORY: Added PE to variable in ver. 5.0 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no drug to 8 or 08/08/8888. 1/14/05: Expounded definition.	

## DVT Study Syllabus – Version 6.2

<b>Anticoagulation Method</b> <b>VARIABLE 510</b>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
<b>DEFINITION:</b> Documentation of the clinician’s choice of anticoagulation method for the treatment of known DVT.	
<b>CODE:</b> <div style="padding-left: 20px;">           A1 – Adjusted Dose Low Molecular Weight Heparin used            A2 – Date started - MM/DD/YYYY            A3 – Date discontinued – MM/DD/YYYY             B1 – IV Unfractionated Heparin used            B2 – Date started - MM/DD/YYYY            B3 – Date discontinued – MM/DD/YYYY             C1 – Coumadin used            C2 – Date started - MM/DD/YYYY            C3 – Date discontinued – MM/DD/YYYY             D1 – Ximelagatran used            D2 – Date started - MM/DD/YYYY            D3 – Date discontinued – MM/DD/YYYY         </div>	
Code A1; B1; C1; D1 1- No 2- Yes 9- Unknown or missing data 8- Not applicable Code A2; A3; B2; B3; C2; C3; D2; D3 with 08 / 08 / 8888 if no drug <div style="text-align: right;">02 / 02 / 2222 if not discontinued</div>	
<b>CHARACTERS:</b> 4 items; 1 character 8 items; dates	
<b>NOTES:</b> Most occurrences of DVT and/or PE in the rehab setting will be treated with full dose anticoagulation. This variable will record the anticoagulation treatment method used for the patient with known DVT, if full anticoagulation is initiated. Usually, after a period of overlap with LMWH or IV heparin, the patient will be converted to oral coumadin for long term treatment of DVT or PE. This variable also documents the date of initiation of coumadin, if it is started. If no DVT or PE identified (as in skip instruction) A- D will be auto-filled with “8 not applicable” and “08/08/8888 no drug”. Patients who have had DVT identified in the acute hospital setting but were not treated with full dose anticoagulation, may later develop “symptomatic” DVT in the rehabilitation setting. They may then be treated with full dose anticoagulation, and it will be recorded in variable 510.	
<b>EXAMPLE:</b> Left lower extremity DVT was identified in patient on 11/04/2003. He was started on adjusted dose LMWH on that date. He was started on oral Coumadin on 11/07/2003. LMWH was discontinued on 11/14/2003. / A1 = <u>2</u> / A2 = <u>11/04/2003</u> / A3 = <u>11/14/2003</u> / / B1 = <u>1</u> / B2 = <u>08/08/8888</u> / B3 = <u>08/08/8888</u> / / C1 = <u>2</u> / C2 = <u>11/07/2003</u> / C3 = <u>02/02/2222</u> / / D1 = <u>1</u> / D2 = <u>08/08/8888</u> / D3 = <u>08/08/8888</u> /	
<b>VARIABLE HISTORY:</b> 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no drug to 8 or 08/08/8888.	



## DVT Study Syllabus – Version 6.2

<b>Confirmatory Test for P.E.</b> <i>VARIABLE 511a</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Indicate what, if any, methods were used to confirm the diagnosis of pulmonary embolism.	
CODE : A – Ventilation/perfusion (VQ) Scan B - Spiral CT Scan C – Angiogram  Use codes for items A – C 1 = Negative result 2 = Positive result 9 = Unknown or missing data 8 = Not applicable/Not Done	
NOTES: Confirmatory tests for PE may be recorded on the case report form as above; however, such testing is not required for the diagnosis of symptomatic PE. In the event of death from probable PE, it may be impossible to obtain definitive confirmatory testing, and a clinical diagnosis of PE will be sufficient for the purposes of this study. If no DVT or PE identified fill A- C with “Not applicable/not done.” If a patient who developed a DVT during the acute hospital course has a subsequent PE in the rehabilitation setting, it will be recorded in variable 511 and 511a.	
EXAMPLE: Patient Jones developed signs and symptoms of P.E. as above. Spiral CT Scan was used to confirm the diagnosis of P.E.  / A = 8 / B = <u>2</u> / C = 8 /	
VARIABLE HISTORY: Added auto-fill instruction in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 and added variable not applicable assigned 8 to the variable. Deleted code 4 = Not Done.	

## DVT Study Syllabus – Version 6.2

<b>Morbidity Associated with DVT</b> <i>VARIABLE 512</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Documentation of problems associated with deep venous thrombosis in the affected limb.	
CODE: Morbidity Associated with DVT? 1 – No 2 – Yes 8 – Not Applicable.  A- Limb pain requiring narcotic analgesics B – Positive blood culture from thrombophlebitis C- Local limb cellulites requiring antibiotics D – Limitation of function in affected limb that affects participation in physical therapy  Use following codes for items A – D 1- No 2- Yes 9 – Unknown 8 – Not applicable E – The patient is unable to participate in rehabilitation therapy for what duration?  1 = 1 day 2 = 2 days 3 = 3 days 4 = greater than 3 days 9 = Unknown or Missing Date 8 = Not applicable  F - Transferred to acute care hospital or off of the rehabilitation service  1 = Due to DVT 2 = Due to PE 3 = Due to other causes 9 = Unknown 8 = Not applicable/Not transferred	
CHARACTERS: 6 items; 1 character	
NOTES: This variable is no longer skipped. If no DVT or PE identified, code Morbidity Associated with DVT “8 not applicable” and A-F will auto fill with “not applicable”. Variable 512 will also allow documentation of “symptoms” of DVT that occur in a “Pre-rehab DVT” as well as symptoms of a DVT that occurred DURING rehab.	
EXAMPLE: Patient Jones had significant pain in his lower limb requiring narcotic analgesics related to a known DVT. His pain was so significant that he did not participate in rehab therapies for 24 hours.  / A = 2 / B = 1 / C = 1 / D = 2 / E = 1 / F = 8 /	
VARIABLE HISTORY: Item F was added in Ver. 4. Added auto-fill instruction in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 and not applicable to 8. Added morbidity question. If morbidity question is “8 not applicable” then auto fill A-F.	

## DVT Study Syllabus – Version 6.2

### Development of New Intracranial Hemorrhage or Expansion of Existing ICH

VARIABLE 513

Last Revised 11/04/04

Version 6.2

**DEFINITION:** Documentation of the development of new intracranial hemorrhage or expansion of existing intracranial hemorrhage associated with the use of anticoagulation for prophylaxis or treatment of DVT.

**CODE:**

A- Development of new hemorrhage or expansion of existing ICH  
1 – No    2 – Yes    9 = Unknown

B- Type of new or expanded hemorrhage

- 1- Subdural Hematoma
- 2- Subarachnoid Hemorrhage
- 3- Intraventricular Hemorrhage
- 4- Epidural Hemorrhage
- 5- Intraparenchymal Hemorrhage
- 9- Unknown or Missing Data
- 8-Not applicable

C-Size of new or expanded Intracranial Hemorrhage/ Compression

- 1- No visible intracranial compression diagnosed by CT or MRI
- 2- Cisterns present but midline shift is noted 1-5 mm
- 3- Cisterns compressed or absent with midline shift of 0-5 mm
- 4- Midline shift of greater than 5 mm
- 5- Extent not specified
- 6- CT or MRI not done
- 9- Unknown if intracranial compression or Missing data
- 8-Not applicable

D-Date of imaging study for identification of new or expanded intracranial hemorrhage- MM/DD/YYYY    code 08 / 08 /8888 if not applicable  
09 / 09 / 9999 if unknown

**CHARACTERS:** 3 items; 1 character    1 item; date

**NOTES:** Use of anticoagulation encompasses both prophylactic and full treatment doses of anticoagulant. If variable A is “no”, auto-fill variables B – D with “not applicable.”

**EXAMPLE:** Patient Jones had a new EDH with ML shift of 8 mm without mention of scan date.

/ A = 2 / B = 4 / C = 4 / D = 09/09/9999 /

**VARIABLE HISTORY:** New and expanded qualifiers added to type and size items in Ver. 4. Auto-fill instructions added in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable to 8 or 08/08/8888.

## DVT Study Syllabus – Version 6.2

<b>Complications of Intracranial Hemorrhage</b> <i>VARIABLE 514</i>	
<i>Last Revised 01/14/05</i>	<i>Version 6.2</i>
DEFINITION: Complications of intracranial hemorrhage while the patient was receiving anticoagulation for prophylaxis or treatment of DVT are documented under this variable.	
CODE:  1) Complications of intracranial hemorrhage 1 – No   2- Yes   9 – Unknown or missing data 8 – Not applicable (No ICH) Auto fill A-C,2, and 3 N/A Types of complications A- Altered Neuro Status Prompting CT Scan B- Neurosurgery required to evacuate ICH C- Patient unable to participate in therapies.* 1 = No   2 = Yes   9 = Unknown or missing data   8 = Not applicable *1 = able to participate in important therapies *2 = not able to participate in important therapies  2) ICH caused by anticoagulant? 1 = Unlikely   2 = Possible   3 = Probable   8 = Not applicable  3) Date of occurrence of the complication: MM/DD/YYYY code 08 / 08 / 8888 if no ICH complication 09 / 09 / 9999 if unknown	
CHARACTERS: 5 items; 1 character   1 item; date	
NOTES: If variable 5141 is “no”, then variables 5141, 2, and A – C are auto-filled with “not applicable” and variable 3 is auto-filled “08/08/8888.”	
EXAMPLE: Patient Jones was receiving subcutaneous LMWH in prophylactic doses. He became increasingly somnolent on 10/31/2003, and a CT Scan was ordered which revealed an expanding SDH with significant mass effect and midline shift of 7mm. The patient was sent for neurosurgical evacuation of this SDH.  / 1) = <u>2</u> / A = <u>2</u> / B = <u>2</u> / C = <u>2</u> / 2) = <u>3</u> / 3 = <u>10/31/2003</u> /	
VARIABLE HISTORY: ICH complications were accepted for any reason with previous qualifier of anticoagulation for prophylaxis or treatment of DVT eliminated from Ver. 4. Variable 2 had “not applicable” added to choices and auto-fill instructions were added in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no ICH complications to 8 or 08/08/8888. 1/14/05: Added 8 – Not applicable (No ICH) Auto fill A-C,2, and 3 NA	

## DVT Study Syllabus – Version 6.2

<b>Development of a Systemic Hemorrhage</b> <i>VARIABLE 515</i>	
<i>Last Revised 11/04/04</i>	<i>Version 6.2</i>
DEFINITION: Documentation of a systemic hemorrhage	
CODE: 1- Occurrence of a systemic hemorrhage 1 – No    2 – Yes    9 - Unknown or missing data  A- Hypotension occurred with SBP Less than 90 B- Transfusion required C- No transfusion or treatment required, but HCT falls greater than 5% D- Bleeding caused the discontinuation of anticoagulation 1 = No    2 = Yes    9 = Unknown or missing data    8 = Not applicable  2- Date of occurrence: MM/DD/YYYY code 08 / 08 / 8888 if no systemic complication 09 / 09 / 9999 if unknown	
CHARACTERS: 5 items; 1 character    1 item; date	
NOTES: e.g., GI bleed, GU bleed    If variable 1 is “no”, then variables A – D will be auto-filled with “not applicable” and variable 2 will be auto-filled with “08/08/8888.”	
EXAMPLE: Patient Jones vomited coffee grounds emesis and had an episode of syncope. His systolic blood pressure was 85 over palpable when the code team arrived on that date of 10/31/2003. A GI consult was obtained, anticoagulation was stopped, and the patient received two units of packed red blood cells for a Hemoglobin of 7.2.  / 1) = <u>2</u> / A = <u>2</u> / B = <u>2</u> / C = <u>1</u> / D = <u>2</u> / 2 = <u>10/31/2003</u> /	
VARIABLE HISTORY: Systemic hemorrhage was accepted for any reason with previous qualifier of anticoagulation for prophylaxis or treatment of DVT eliminated in Ver. 4. Not applicable for variables A – D and auto-fill instructions were added in ver. 5.0. 11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no systemic complication to 8 or 08/08/8888.	

## DVT Study Syllabus – Version 6.2

### Death during Rehabilitation

VARIABLE 516

*Last Revised 11/04/04*

*Version 6.2*

**DEFINITION:** Documentation of date of death during rehabilitation or within two weeks after transfer to Emergency Department or Intensive Care Unit from any cause with specific attention to P.E. and ICH associated with the use of anticoagulant.

**CODE:**

- A- Death occurred during acute inpatient rehabilitation or within two weeks after transfer to ED or ICU. 1 = No/Auto fill B-E NA 2 = Yes 9 = Unknown or missing data
- B- Clinical assessment of likelihood of death due to PE:  
1 = Unlikely 2 = Possible 3 = Probable 4 = Definite 8 = Not applicable
- C – In the opinion of the treating clinician, death was due to ICH associated with the use of prophylactic or therapeutic anticoagulant  
1 = Unlikely 2 = Possible 3 = Probable 4 = Definite 8 = Not applicable
- D- Date of death MM/DD/YYYY  
code 08 / 08 /8888 if no death during rehab  
09 / 09 / 9999 if unknown
- E – Autopsy confirmed PE as cause of death  
1 = No 2 = Yes 9 = Unknown or missing data 8 = Not applicable

**CHARACTERS:** 4 items; 1 character 1 item; date

**NOTES:** The term anticoagulant above includes both prophylactic and full treatment doses of anticoagulant.

- PE** Definite = Requires autopsy proof of saddle embolism  
Probable = In opinion of treating clinician, most likely related to cause of death.  
Most of the symptomatic PE’s will fall under this probable category.  
Possible = In opinion of treating physician, possibly related to cause of death.

**ICH** Definite = requires autopsy or MRI scan documenting herniation  
If variable A is “no”, variables B, C, and E are auto-filled with “not applicable” and variable D is auto-filled with “08/08/8888.”

**EXAMPLE:** Patient Jones died on 10/29/2003 while in the acute inpatient rehabilitation unit, and death was in the opinion of the attending physician most likely related to a P.E.  
/ A = 2 / B = 3 / C = 1 / D = 10/29/2003 / E = 1 /

Patient Jones died suddenly on the rehabilitation unit one night on 10/31/2003. He had been treated with prophylactic doses of lovenox for known left lower extremity P.E. The treating physician felt that based on his known SDH that had been managed conservatively due to his operative risk; ICH was possibly related to his death. The family did not want an autopsy performed.  
/ A = 2 / B = 1 / C = 2 / D = 10/31/2003 / E = 8 /

**VARIABLE HISTORY:** Autopsy added during Ver. 4 with acceptance of any death within two weeks after transfer to ED or ICU.11/04/04 Code: Changed missing data/unknown to 9 or 09/09/9999 and not applicable/no death during rehab to 8 or 08/08/8888....Added auto fill If A=1 No then Auto fill B-E

## TBI MS Health Module DVT Study

### Case Report Form version 6.2

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
System ID      Unique Subject ID

**501**

- |          |  |                          |   |
|----------|--|--------------------------|---|
| <b>A</b> | Acute Care (Pre-Rehab) DVT/PE  | <input type="checkbox"/> | 1 = No / Autofill B-D N/A    2 = Yes    9 = Unknown or missing data   |
| <b>B</b> | Pre-Rehab DVT symptomatic<br>(signs/symptoms listed in variable 507) | <input type="checkbox"/> | 1 = No    2 = signs or symptoms found on rehab admission evaluation<br>3 = signs or symptoms developed subsequent to rehab admission<br>8 = Not applicable    9 = Unknown or missing data |
| <b>C</b> | Pre-Rehab DVT -limb involved   | <input type="checkbox"/> | 1 = Unilateral right LE DVT    2 = Unilat left LE DVT    3 = Bilat LE DVT<br>4 = Unilat right UE DVT    5 = Unilat left UE DVT    6 = Bilat UE DVT<br>8 = Not applicable    9 = Unknown   |
| <b>D</b> | Central/PICC Line-relative to<br>Pre-Rehab DVT                       | <input type="checkbox"/> | 1 = Ipsilateral    2 = Contralateral    3 = Bilateral<br>8 = Not applicable    9 = Unknown  |

**502 DVT Risks**

- |          |                              |                          |  |
|----------|------------------------------|--------------------------|--|
| <b>A</b> | Lower ext long bone fracture | <input type="checkbox"/> | 1 = No    2 = Yes    9 = Unknown or Missing Data |
| <b>B</b> | Pelvic fractures             | <input type="checkbox"/> |  |
| <b>C</b> | LE Weight bearing restricted | <input type="checkbox"/> |  |
| <b>D</b> | LE weakness                  | <input type="checkbox"/> |  |
| <b>E</b> | History of VTE               | <input type="checkbox"/> |  |
| <b>F</b> | Other lower ext Fractures    | <input type="checkbox"/> |  |
| <b>G</b> | Any known H/O neoplasm       | <input type="checkbox"/> |  |
| <b>H</b> | Hypercoagulable state        | <input type="checkbox"/> |  |
| <b>I</b> | Central line/ PICC Line      | <input type="checkbox"/> |  |

**503 Results of DVT Screening within 72 hours of Admission to Rehabilitation  
(If symptoms present, code on variable 507)**

- |          |   |   |   |
|----------|---|---|---|
| <b>A</b> | DVT Screening   | <input type="checkbox"/>  | 1 = No/Auto fill B-G N/A    2 = Yes    9 = Unknown or missing data  |
| <b>B</b> | D-Dimer Test  | <input type="checkbox"/>  | 1 = Low risk for DVT    2 = Indeterminate to rule out DVT<br>8 = Not applicable/Not Done    9 = Unknown or missing data   |
| <b>C</b> | LE ultrasound0<br>(Ultrasound "0" identifies<br>initial "screening" ultrasound) | <input type="checkbox"/>  | 1 = No DVT    2 = Proximal (popliteal vein or above) DVT<br>3 = Distal (distal to popliteal fossa) DVT    4 = Both proximal/distal DVT<br>8 = Not applicable/Not Done    9 = Unknown or missing data  |
| <b>D</b> | Side of DVT   | <input type="checkbox"/>  | 1 = Unilateral right DVT    2 = Unilateral left DVT    3 = Bilateral DVT<br>8 = Not applicable    9 = Unknown or missing data   |
| <b>E</b> | Date of screening<br>ultrasound0  | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | code    08 / 08 / 8888 if no test<br>09 / 09 / 9999 if unknown  |
| <b>F</b> | Date of D-Dimer   | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | code    08 / 08 / 8888 if no test<br>09 / 09 / 9999 if unknown  |
| <b>G</b> | DVT side specified  | <input type="checkbox"/>  | 1 = Left proximal    2 = Right proximal    3 = Left & Right Proximal<br>4 = Left distal    5 = Right distal    6 = Left & Right distal<br>7 = Left proximal & left distal    8 = Right proximal & Right distal<br>9 = Left proximal & Right distal    10 = Right proximal & Left distal<br>11 = Both Left & Right, Both proximal & distal<br>88 = Not applicable/Not Done    99 = Unknown or missing data |

## TBI MS Health Module DVT Study Case Report Form version 6.2

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
System ID      Unique Subject ID

**504 Results of Serial Venous Doppler Studies (May be done for additional screening purposes to assess signs/symptoms of DVT which have developed subsequent to initial screening, or to assess for propagation of distal (calf) DVT or propagation of pre-Rehab DVT)**

**A** Serial ultrasound  **1** = No/Auto fill B-E N/A **2** = Yes  
**9** = Unknown or missing data

**B** Propagation of DVT  **1** = No/Autofill B1 & B2 N/A **2** = Yes  
**8** = Not applicable **9** = Unknown or missing data

**B1** Propagation of Pre-Rehab DVT  **1** = No **2** = Yes  
**8** = Not applicable **9** = Unknown or missing data

**B2** Propagation of Distal (Calf) DVT  **1** = No **2** = Yes  
**8** = Not applicable **9** = Unknown or missing data

**C** Date of ultrasound1    Results1  **1** = Negative results  
Month      Date      Year **2** = Positive results  
**8** = Not applicable/  
missing data  
**9** = Unknown or  
not done

**D** Date of ultrasound2    Results2

Month      Date      Year

**E** Date of ultrasound3    Results3

Month      Date      Year

Code      08 / 08 / 8888 if no test  
09 / 09 / 9999 if unknown

(Ultrasound "0" refers to initial screening US; Ultrasound "1, 2, & 3" above refer to subsequent studies which may be done)

**505 DVT Prophylaxis**  **1** = No **2** = Yes **9** = Unknown or missing data

**505a Prophylaxis with Mechanical Agents**

**A** IVC filter  **1** = No **2** = Yes **9** = Unknown or missing data  
If A and B = 1 then C will auto fill N/A.

**B** Sequential compression device  **1** = No **2** = Yes **9** = Unknown or missing data

**C** Initiated in  **1** = Acute care setting **2** = Rehabilitation unit  
**8** = Not applicable/ not done **9** = Unknown or missing data

**505b Pharmacologic Prophylaxis with Anticoagulation**

**1** Pharmacologic prophylaxis  **1** = Not administered/Auto fill A-D, 505c N/A  
**2** = Init. prior to rehab admission **3** = Init. during rehab  
**9** = Unknown or missing data/Auto fill A-D, 505c N/A

---

**A1 Low mol wt Heparin**  **1** = No **2** = Yes **8** = Not applicable  
**9** = Unknown or missing data

**A2** Characteristics \_\_\_\_\_ (generic name / dose / route / frequency)

**A3** Date initiated    code      08 / 08 / 8888 if no drug  
Month      Date      Year      09 / 09 / 9999 if unknown

**TBI MS Health Module DVT Study  
Case Report Form version 6.2**

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
System ID Unique Subject ID

**B1 Unfractionated Heparin**  1 = No 2 = Yes 8 = Not applicable  
9 = Unknown or missing data

**B2 Characteristics** \_\_\_\_\_ (dose / route / frequency)

**B3 Date initiated**    code 08 / 08 / 8888 if no drug  
Month Date Year 09 / 09 / 9999 if unknown

**C1 Coumadin**  1 = No 2 = Yes 8 = Not applicable  
9 = Unknown or missing data

**C2 Characteristics** \_\_\_\_\_ (dose / route / frequency)

**C3 Date initiated**    code 08 / 08 / 8888 if no drug  
Month Date Year 09 / 09 / 9999 if unknown

**D1 Ximelagatran**  1 = No 2 = Yes 8 = Not applicable  
9 = Unknown or missing data

**D2 Characteristics** \_\_\_\_\_ (dose / route / frequency)

**D3 Date initiated**    code 08 / 08 / 8888 if no drug  
Month Date Year 09 / 09 / 9999 if unknown

**505c Pharmacologic Prophylactic Anticoagulation Discontinued**

**Date discontinued**    code 08 / 08 / 8888 if no drug  
Month Date Year 02 / 02 / 2222 if not discontinued  
09 / 09 / 9999 if unknown

**505d Mobility Status at Time of Anticoagulation Discontinuation**

Ambulation distance  1 = less than 50 feet 2 = equal to or greater than 50 feet  
8 = not applicable 9 = Unknown or missing

**506 DVT Occurrence During Rehabilitation (Includes DVT found on initial screening exam as well as subsequently during rehab) (Do not record data for pre-rehab DVT in variable 506)**

**A DVT identified**  1 = No/Auto fill B-I N/A 2 = Yes  
9 = Unknown or missing data

**B DVT identified during rehab is symptomatic**  1 = No 2 = signs or symptoms found on admission evaluation  
3 = signs or symptoms developed subsequent to admission  
8 = Not applicable 9 = Unknown or missing data  
(Signs/symptoms listed in variable 507)  
(Includes DVT found on initial screening exam as well as subsequently during rehab)

**C LE ultrasound**  1 = No DVT 2 = Proximal (popliteal vein or above) DVT  
3 = Distal (distal to popliteal fossa) DVT  
4 = Both proximal/distal DVT  
8 = Not applicable/Not Done 9 = Unknown or missing data

**D Side of LE DVT**  1 = Unilateral right DVT 2 = Unilateral left DVT  
3 = Bilateral DVT 8 = Not applicable 9 = Unknown

**E Date identified**    code 08 / 08 / 8888 if not identified  
Month Date Year 09 / 09 / 9999 if unknown

## TBI MS Health Module DVT Study Case Report Form version 6.2

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
System ID Unique Subject ID

- F** LE DVT side specified     
 1 = Left proximal 2 = Right proximal  
 3 = Left & Right Proximal 4 = Left distal 5 = Right distal  
 6 = Left & Right distal 7 = Left proximal & left distal  
 8 = Right proximal & Right distal  
 9 = Left proximal & Right distal  
 10 = Right proximal & Left distal  
 11 = Both Left & Right, Both proximal & distal  
 88 = Not applicable/Not Done 99 = Unknown or missing data
- G** UE DVT    
 1 = No 2 = Yes  
 8 = Not applicable 9 = Unknown or missing data
- H** Side of UE DVT    
 1 = Unilateral right DVT 2 = Unilateral left DVT  
 3 = Bilateral DVT 8 = Not Applicable 9 = Unknown
- I** Central / PICC Line    
 1 = Ipsilateral to UE or LE DVT 2 = Contralateral  
 3 = Bilateral 8 = Not Applicable 9 = Unknown

**\*\* If no DVT or PE identified (Pre-rehab or During rehab), Skip to 511 \*\***  
 (If 507 to 510 skipped, variables will be automatically coded)

**DVT/PE Identified**  1 = No 2 = Yes

\*\*\* If DVT/PE Identified either pre-rehab or during rehab, please complete variables 507-510 to document signs/symptoms of DVT, treatment with IVC Filter, and/or treatment with anticoagulation \*\*\*

**507 DVT Signs or Symptoms**

	<b>A</b> Pain Tenderness + Homan's	<b>B</b> Redness discoloration	<b>C</b> Pyrexia (system Fever ≥ 38°C)	<b>D</b> Limb swelling	<b>E</b> Localized warmth	<b>F</b> Other
Summary of DVT Symptoms across all UE / LE Involved Limbs (A, B, D, E,F) or systemic fever (C-3 only)	<b>1</b> <input type="checkbox"/>	<b>2</b> <input type="checkbox"/>	<b>3</b> <input type="checkbox"/>	<b>4</b> <input type="checkbox"/>	<b>5</b> <input type="checkbox"/>	<b>6</b> <input type="checkbox"/>
Symptomatic DVT of Left Proximal LE	<b>7</b> <input type="checkbox"/>	<b>8</b> <input type="checkbox"/>		<b>9</b> <input type="checkbox"/>	<b>10</b> <input type="checkbox"/>	<b>11</b> <input type="checkbox"/>
Symptomatic DVT of Left Distal LE	<b>12</b> <input type="checkbox"/>	<b>13</b> <input type="checkbox"/>		<b>14</b> <input type="checkbox"/>	<b>15</b> <input type="checkbox"/>	<b>16</b> <input type="checkbox"/>
Symptomatic DVT of Right Proximal LE	<b>17</b> <input type="checkbox"/>	<b>18</b> <input type="checkbox"/>		<b>19</b> <input type="checkbox"/>	<b>20</b> <input type="checkbox"/>	<b>21</b> <input type="checkbox"/>
Symptomatic DVT of Right Distal LE	<b>22</b> <input type="checkbox"/>	<b>23</b> <input type="checkbox"/>		<b>24</b> <input type="checkbox"/>	<b>25</b> <input type="checkbox"/>	<b>26</b> <input type="checkbox"/>

1 = No                      2 = Yes                      8 = Not applicable                      9 = Unknown or missing data

**TBI MS Health Module DVT Study**  
**Case Report Form version 6.2**

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
 System ID Unique Subject ID

**508 IVC Filter Placed for Treatment of DVT**  **1 = No 2 = Yes**  
**8 = Not applicable**  
**9 = Unknown or missing data**

Date initiated      code 08 / 08 / 8888 if no filter/not applicable  
 Month Date Year 09 / 09 / 9999 if unknown

**509 Full Anticoagulation Treatment after Development of DVT/PE**  
 (Includes anticoagulation for pre-rehab or during rehab DVT)  **1 = No 2 = Yes**  
**8 = Not Applicable**  
**9 = Unknown or missing data**

Date initiated      code 08 / 08 / 8888 if no filter/not applicable  
 Month Date Year 09 / 09 / 9999 if unknown

**510 Anticoagulation Method Chosen**

**A1 Low mol wt Heparin**  **1 = No 2 = Yes**  
**8 = Not applicable 9 = Unknown or missing data**

**A2** Date initiated      code 08 / 08 / 8888 if no drug  
 Month Date Year 02 / 02 / 2222 if not discontinued

**A3** Date discontinued      09 / 09 / 9999 if unknown  
 Month Date Year

**B1 IV Unfractionated Heparin**  **1 = No 2 = Yes**  
**8 = Not applicable 9 = Unknown or missing data**

**B2** Date initiated      code 08 / 08 / 8888 if no drug  
 Month Date Year 02 / 02 / 2222 if not discontinued

**B3** Date discontinued      09 / 09 / 9999 if unknown  
 Month Date Year

**C1 Coumadin**  **1 = No 2 = Yes**  
**8 = Not applicable 9 = Unknown or missing data**

**C2** Date initiated      code 08 / 08 / 8888 if no drug  
 Month Date Year 02 / 02 / 2222 if not discontinued

**C3** Date discontinued      09 / 09 / 9999 if unknown  
 Month Date Year

**D1 Ximelagatran**  **1 = No 2 = Yes**  
**8 = Not applicable 9 = Unknown or missing data**

**D2** Date initiated      code 08 / 08 / 8888 if no drug  
 Month Date Year 02 / 02 / 2222 if not discontinued

**D3** Date discontinued      09 / 09 / 9999 if unknown  
 Month Date Year

**TBI MS Health Module DVT Study**  
**Case Report Form version 6.2**

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
 System ID Unique Subject ID

**511 1) Symptomatic P.E. Occurrence During Rehabilitation**  1 = No/Auto fill A-H,2 N/A 2 = Yes  
 9 = Unknown or missing data

**Symptoms of P.E.**

- A** Dyspnea/Hypoxia
- B** Anxiety/Behavioral Δ's
- C** Chest pain
- D** Hypotension SBP < 90
- E** Tachycardia HR > 110
- F** Syncope
- G** Pyrexia ≥ 38° C
- H** Other

1 = No/Auto fill A-H,2 N/A  
 2 = Yes  
 8 = Not applicable  
 9 = Unknown or missing data

**2) Date of P.E. occurrence**         code 08 / 08 / 8888 if no P.E.  
 09 / 09 / 9999 if unknown  
 Month Date Year

**511a Confirmatory Test for P.E.**

- A** Ventilation / Perfusion scan
- B** Spiral CT scan
- C** Angiogram data

1 = Negative result 2 = Positive result  
 8 = Not applicable/Not Done  
 9 = Unknown/missing data

**512 Morbidity Associated with DVT?**  1 = No 2 = Yes 8 = Not applicable/Auto fill A-F N/A

- A** Limb pain requiring narcotic analgesics
- B** Positive blood culture from thrombophlebitis
- C** Local limb cellulitis requiring antibiotics
- D** Limitation of function in limb that affects participation in physical therapy

1 = No  
 2 = Yes  
 8 = Not applicable  
 9 = Unknown or missing data

**E** Unable to participate in therapy for

1 = 1 day  
 2 = 2 days  
 3 = 3 days  
 4 = greater than 3 days  
 8 = Not applicable  
 9 = Unknown or missing data

**F** Transferred to Acute Care Hospital or off of the Rehabilitation Service

1 = Due to DVT  
 2 = Due to PE  
 3 = Due to other causes  
 8 = Not applicable/Not transferred  
 9 = Unknown

**TBI MS Health Module DVT Study**  
**Case Report Form version 6.2**

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
 System ID Unique Subject ID

**513**

- A** Development of New Intracranial Hemorrhage or Expansion of Existing ICH  1 = No/Auto fill B-D N/A 2 = Yes 9 = Unknown
- B** Type of new or expanded hemorrhage  1 = subdural 2 = subarachnoid  
 3 = intraventricular 4 = epidural  
 5 = intraparenchymal  
 8 = Not applicable  
 9 = Unknown or missing data
- C** Size of new or expanded hemorrhage or compression  1 = no visible compression by CT or MRI  
 2 = cisterns present, midline shift 1 – 5 mm  
 3 = cisterns compressed or absent with midline shift 0 – 5 mm  
 4 = midline shift > 5 mm  
 5 = extent not specified  
 6 = CT / MRI not done  
 8 = Not applicable  
 9 = Unknown or missing
- D** Date of imaging study for identification of new or expanded ICH         code 08 / 08 / 8888 if not applicable  
 Month Date Year 09 / 09 / 9999 if unknown

**514**

- 1** Complications of ICH  1 = No/ Auto fill A-C,2 and 3 N/A 2 = Yes  
 8 = Not applicable (No ICH) Auto fill A-C, 2, and 3 N/A  
 9 = Unknown or missing data
- 
- A** Altered neuro status prompting CT or MRI scan  1 = No 2 = Yes 8 = Not applicable  
 9 = Unknown or missing data
- B** Neurosurgery required
- C** Patient unable to participate in therapies
- 
- 2** ICH caused by anticoagulant  1 = Unlikely 2 = Possible  
 3 = Probable 8 = Not applicable
- 
- 3** Date of occurrence of ICH complication         code 08 / 08 / 8888 if  
 Month Date Year no ICH complication  
 09 / 09 / 9999 if unknown

**TBI MS Health Module DVT Study**  
**Case Report Form version 6.2**

**500 TBI MS HEALTH MODULE ID:**         **500a TBI MS SUBJECT:**  1 = No 2 = Yes  
 System ID Unique Subject ID

**515**

- 1) Development of a Systemic Hemorrhage  1 = No/Auto fill A-D,2 N/A  
 2 = Yes  
 9 = Unknown or missing data
- A Hypotension occurred with SBP < 90
- B Transfusion required  1 = No 2 = Yes  
 8 = Not applicable  
 9 = Unknown or missing data
- C No transfusion / treatment required, but HCT falls >5
- D Bleeding caused discontinuation of anticoagulation
- 2) Date of occurrence of systemic hemorrhage      code 08 / 08 / 8888  
 Month Date Year if no systematic complication  
 09 / 09 / 9999  
 if unknown

**516**

- A Death During Rehabilitation  1 = No/Auto fill B-E N/A 2 = Yes  
 9 = Unknown or missing data
- B P.E. likely cause of death  1 = Unlikely 2 = Possible 3 = Probable 4 = Definite\*  
 8 = Not applicable
- C ICH associated with anticoagulant use likely cause of death  1 = Unlikely 2 = Possible 3 = Probable 4 = Definite\*  
 8 = Not applicable  
 \*autopsy verified
- D Date of death     code 08 / 08 / 8888 if no death during rehab  
 Month Date Year 09 / 09 / 9999 if unknown
- E Autopsy confirmed PE cause of death  1 = No 2 = Yes 8 = Not applicable  
 9 = Unknown or missing data

**If Subject is TBI MS subject:  
 If Subject is non TBI MS subject:**

**Stop  
 Complete DVT modified Form I CRF**

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.



# 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  
MARRIED OR LIVING TOGETHER AT LEAST 7 YEARS SEPARATED OTHER \_\_\_\_\_  
(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)  
HUSBAND ROOMMATE OTHER \_\_\_\_\_  
PARENT SIGNIFICANT OTHER (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

CORRECTIONAL

ACUTE CARE HOSPITAL

OTHER \_\_\_\_\_

(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) |
| COMPETITIVELY 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?

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 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?

**NUMBER OF TIMES PER MONTH:**\_\_\_\_\_

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.**

# 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 number: ( \_\_\_\_ ) \_\_\_\_\_

Cell phone number: ( \_\_\_\_ ) \_\_\_\_\_ email address: \_\_\_\_\_

This person is my: (CIRCLE ONE)

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

-----  
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 \_\_\_\_\_  
PARENT SIGNIFICANT OTHER (PLEASE WRITE IN)  
BROTHER/SISTER OTHER PATIENTS

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

PRIVATE RESIDENCE (HOME, APARTMENT, ETC)

NURSING HOME

ADULT HOME

CORRECTIONAL

HOTEL

HOMELESS

ACUTE CARE HOSPITAL

REHABILITATION CENTER

OTHER HOSPITAL

SUB-ACUTE

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)                            | 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 FOR 1st QUARTER 2006 (V10.2)

Var/Topic	Date due	Description
<b>FORM I</b>		
V101	06Q1	Add note that reported LOS may be longer because of a change in inclusion criteria.
V103	06Q1	Add instruction to estimate date of birth if exact date is unknown. If month is known but day is not, enter the mid-date of the month.
V105	06Q1	Add instruction that, if a person has multiple ethnicities/races and has difficulty picking one, select the one that plays the biggest role in h/her daily life.
V108	06Q1	Add instruction that if person lives in a boarding house, to use code 10.
V110a	06Q1	Add instruction to code years of foreign education the same as years of US education (until equivalence is established).
V110a	06Q1	Add note to code "14=Associate" if took a few college courses without intending to earn a BA.
111a	06Q1	Add definition of illegal employment.
111a	06Q1	Add note about collecting data if employment is illegal
111a	06Q1	Change "other" code from 77 to 55.
111a	06Q1	Add code "77=refused"
111a	06Q1	Add to DEFINITION that no distinction is to be made between legal and illegal employment.
111a	06Q1	Add to code 05 that person may be on leave with pay.
111a	06Q1	Add code "16=on leave from work not receiving pay"
111b	06Q1	Add NOTE to code "999=unknown" if question is not asked because employment was illegal.
111b	06Q1	Add to definition that this includes illegal employment.
111b	06Q1	Add code "777=refused"
111b	06Q1	Remove note that this includes only legal employment.
111d	06Q1	Remove note that this includes only legal employment.
111d	06Q1	Add to definition that this includes illegal employment.
111d	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
111d	06Q1	Add code "77=refused"
111i	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
111i	06Q1	Add to definition that this includes illegal employment.
111i	06Q1	Remove note that this includes only legal employment.
112	06Q1	Add to definition that this includes illegal employment.
112	06Q1	Add code "77=refused"
112	06Q1	Remove from characteristics of data that 4 centers have trouble collecting this information. Currently, all centers are meeting the benchmark.
112	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
122	06Q1	Add note to include alcoholism if it interferes with function.
123	06Q1	Add note to include effects of alcoholism.
123	06Q1	Add note that 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."
133a	06Q1	Add instruction to attempt to determine cause of injury for persons who are found "down".
133a	06Q1	Add note about the importance of this variable and be ready to obtain and submit data about cause later if it is not initially available.
133b	06Q1	Change the NA code to 88888. (The new ICD9 manual has made 888.8 a valid code, so 888.8 can no longer be used for NA.)

DETAILED LIST OF SYLLABUS CHANGES FOR 1st QUARTER 2006 (V10.2)

Var/Topic	Date due	Description
133b	06Q1	Change the “unknown” code to 99999. (In order to match the new format of the NA code.)
137	06Q1	Add note that only brain injury codes should be entered.
144a	05Q4	Add clarification to OLog from T Novack: “ I have no problem with someone looking at the calendar or clock in the room, which requires awareness that there is a calendar and some movement on the part of the person to see the calendar. That is a functional response that I employ as well. In my experience, when a person is confused they do not look for a calendar. I do not tell the person there is a calendar in the room or a clock. I do not ask the person to refer to either as a means of cueing.”
144a	06Q1	Remove instruction to not use the Modified GOAT except for determining emergence of PTA.
144a	06Q1	Improve the example.
144a	06Q1	Add instruction to use chart review if person was not consented (and not assessed clinically).
144b	06Q1	Move “Chart review” all the way to the right and add “(acute hospital only)”
146	06Q1	Add note not to use codes from death certificate.
192A1	06Q1	Add definition of “nonprescription” drugs.
<b>FORM II</b>		
20Ab	06Q1	Add code “4=NA-data obtained out of window from secondary source”
20Ab	06Q1	Add code: “6=Variable didn’t exist at the time data was collected.”
20Ab	06Q1	Add instruction in NOTES on using code 4.
20Ac	06Q1	Add code “4=NA-data obtained out of window from secondary source”
20Ac	06Q1	Add code: “6=Variable didn’t exist at the time data was collected.”
20Ac	06Q1	Add instruction in NOTES on using code 4.
20Ad	06Q1	Add code: “66=Variable didn’t exist at the time data was collected.”
201a	06Q1	Add to code 09/09/9999: “, or all data from secondary source”.
210a	06Q1	Add instruction to code years of foreign education the same as years of US education (until get equivalence).
210a	06Q1	Add note to code “14=Associate” if took a few college courses without intending to earn BA.
211a	06Q1	Add definition of illegal employment.
211a	06Q1	Add note about collecting data if employment is illegal
211a	06Q1	Change “other” code from 77 to 55.
211a	06Q1	Add code “77=refused”
211a	06Q1	Add to DEFINITION that no distinction should be made between legal and illegal employment.
211a	06Q1	Add to code 05 that person may be on leave with pay.
211a	06Q1	Add code “16=on leave from work not receiving pay”
211a	06Q1	Add to CHARACTERISTICS OF DATA that cases with “77=other” have been changed to “55=other”.
211b	06Q1	Add note to code “999=unknown” if not asked because employment was illegal.
211b	06Q1	Add to definition that this includes illegal employment.
211b	06Q1	Add code “777=refused”
211c	06Q1	Add code “07/07/7777=refused”
211c	06Q1	Delete instruction to exclude illegal employment
211c	06Q1	Add to DEFINITION that this includes illegal employment
211c	06Q1	Add note to code “09/09/9999=unknown” if not asked because employment was or may have been illegal.
211d	06Q1	Add code “77=refused”

DETAILED LIST OF SYLLABUS CHANGES FOR 1st QUARTER 2006 (V10.2)

Var/Topic	Date due	Description
211d	06Q1	Delete instruction to exclude illegal employment
211d	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
211d	06Q1	Add to DEFINITION that this includes illegal employment
211i	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
211i	06Q1	Add to definition that this includes illegal employment.
211i	06Q1	Remove note that this includes only legal employment.
212	06Q1	Add note to code "99=unknown" if not asked because employment was illegal.
212	06Q1	Add code "77=refused"
212	06Q1	Add to definition that this includes illegal employment.
273	06Q1	LS page shows only 2 variables (in examples, elsewhere?), instead of 5. Correct this.
292a1	06Q1	Add definition of "nonprescription" drugs.
V292g	06Q1	Add instruction to not embellish.
<b>CONTACT INFO</b>		
Phil Beatty	06Q1	Is now project officer for the TBINDC
Phil Beatty	06Q1	Add "PhD"
Phil Beatty	06Q1	Is now project officer for NC.
Kristi Wilson	06Q1	Remove from all lists
Eugene Komaroff	06Q1	Add to TBIDNC
Nancy Diehl	06Q1	Add " MA".
Wayne Gordon	06Q1	Change email address from <a href="mailto:Wayne.Gordon@msnyuhealth.org">Wayne.Gordon@msnyuhealth.org</a> to <a href="mailto:wayne.gordon@mssm.edu">wayne.gordon@mssm.edu</a>
Judy Defeo	06Q1	Add to UPMC "Contact Info".
Ross Zafonte	06Q1	Change phone number from 6848 to 6979.
Joe Ricker	06Q1	Change phone number from 6848 to 6666
Tina Harrison	06Q1	Change phone number to 6927; change address to: 2310 Jane Street, Suite 1200 ;Pittsburgh, PA 15203
<b>LISTSERVER LISTS</b>		
Data		
	06Q1	Add Annika Ginsberg to the data listserver list. <a href="mailto:Annika.Ginsberg@mountsinai.org">Annika.Ginsberg@mountsinai.org</a>
Disseminat		
	06Q1	Add Keith Cicerone to the dissemination listserver list.
Research		
	06Q1	Add Robert Brunner to the Research Cmte and Research Listserver
<b>OTHER DOCS</b>		

DETAILED LIST OF SYLLABUS CHANGES FOR 1st QUARTER 2006 (V10.2)

Var/Topic	Date due	Description
List of databusters	06Q1	Databusters are: Jeff, Ramon, Allen Brown, Gale, and Sureyya. There are no longer specific databuster groups.
4a.Inclusion criteria	06Q1	Add 3 new characteristics that rehab facilities treating participants must have.
9c.Guidelines for fup data collection	06Q1	Update section 8, which specifies how to code participants who are incarcerated. Changes were indicated at the Project Directors meeting Dec 2005. (Because this is a legal matter, these changes are being expedited.)
12b.Mailout Form II	06Q1	Add footnote about answering if person is incarcerated.
15f1.DVTstudy syllabus	06Q1	Add to appendix 15.
15f2.DVTstudy data collec form	06Q1	Add to appendix 15.
15g. Module project peer review procedure	06Q1	Add to appendix 15.
26a. Premorbid Hist-Family	06Q1	In employment status, add categories: "On leave from work, with pay" and "On leave from work, no pay". Reorganize categories so like-categories are together.
26a. Premorbid Hist-Family	06Q1	Primary person living with: emphasize "primary", put "husband" and "wife" in column, add "own" to "child" categories.
26b. Premorbid Hist-Person	06Q1	In employment status, add categories: "On leave from work, with pay" and "On leave from work, no pay". Reorganize categories so like-categories are together.
26b. Premorbid Hist-Person	06Q1	Primary person living with: emphasize "primary", put "husband" and "wife" in column, add "own" to "child" categories.
<b>LIVE SYLLAB FEATURES</b>		
Training & Certification	06Q1	Remove Sondra Koch from all lists. (No longer with UW)
<b>OTHER LIVE SYLLAB.</b>		
Splash page	06Q1	Minor revisions to bring text up to date.
<b>STANDARD UPDATES</b>		
00d.Title page	every quarter	Update the date.
03a.Contact Information	every quarter	Update the date.

DETAILED LIST OF SYLLABUS CHANGES FOR 1st QUARTER 2006 (V10.2)

Var/Topic	Date due	Description
03c.Commit tee list	Every quarter	Update the date.
03e.Listserv subscribers-by center	every quarter	Update the date.
03f.Listserv subscribers-by listserver	every quarter	Update the date.
07a.Form I dcf	Every quarter	Update version and date.
12a.Form II dcf	Every quarter	Update version and date.
12b.Mailout Form II	Every quarter	Update version and date.
26a. Premorbid Hist-Family	Every quarter	Update version number
26b. Premorbid Hist-Patient	Every quarter	Update version number