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A Guide to the Traumatic Brain Injury Model Systems National Database

CRRLD

Center for Rehabilitation Research
using Large Datasets

utmb Health

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The user guide has been developed through the Center for Rehabilitation Research using Large Datasets (CRRLD). The CRRLD is a collaboration between the University of Texas Medical Branch (UTMB) and Cornell University's Employment and Disability Institute (EDI) and is funded through a grant from the National Institute of Health (NIH grant # R24HD065702). The goal of the Center is to build rehabilitation research capacity by increasing the quantity and quality of rehabilitation outcomes research using large administrative and research datasets. The contents of this paper do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal Government (Edgar, 75.620 (b)).

Acknowledgement

Many thanks to the following individuals who provided valuable assistance with the development of this paper: Cindy Harrison-Felix, Gale Whiteneck and David C. Mellick at the Craig Hospital Traumatic Brain Injury Model Systems Data and Statistical Center, Jennifer Marwitz at Virginia Commonwealth University, Cate Miller at NIDRR, William Erickson and Margaret Waelder at Cornell University.

Disclaimer:

The Traumatic Brain Injury (TBI) Model Systems National Database is supported by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) in collaboration with the TBI Model Systems Centers. However, these contents do not necessarily reflect the opinions or views of the TBI Model Systems Centers, NIDRR or the U.S. Department of Education

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Introduction

This User Guide presents information on the Traumatic Brain Injury Model Systems (TBIMS) National Database consisting of longitudinal information on the clinical course of recovery and rehabilitation outcomes for individuals with Traumatic Brain Injury (TBI). The purpose of the User Guide Series is to: (a) provide information on large existing administrative and survey datasets available for rehabilitation research; (b) describe their study designs, including methods and instruments for data collection, data structure, variable descriptions, as well as strengths and limitations; (c) provide descriptive analyses on key variables using the International Classification of Functioning, Disability and Health (ICF) framework; and (d) discuss practical aspects of missing data and data security. In departure from previous User Guides, disability statistics of key variables contained within this User Guide are not derived from nationally-representative survey data, but instead describe the nuances of a research dataset covering a specific population - i.e., people with TBI served within the TBI Model Systems Centers.

The TBIMS program, initiated in 1987, is funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education. The TBIMS is a multi-center nationwide program, studying the course of recovery and rehabilitation among individuals with TBI served at centers with a coordinated system of acute neurotrauma, inpatient rehabilitation and lifetime follow-up care. As of 2011, NIDRR has funded 22 TBI centers nationally¹, 16 of which currently receive active funding support.² In addition to providing care

¹ An interagency agreement between the VA and NIDRR continues to support the development, implementation and management of a mirror database to the TBIMS ND in which the 4 VA Polytrauma Rehabilitation Centers capture similar data in order to support comparative studies of civilian and military populations with TBI.

and treatment within a comprehensive multi-disciplinary system of rehabilitation, these centers are a leading resource for generating new knowledge on effective rehabilitation intervention strategies for individuals with TBI through site-specific research. The centers also collaboratively engage in modular research projects. The focus of both site-specific and module research is in the areas of: (a) health and function, (b) employment, (c) participation and community living, and (d) technology for access and function. Furthermore, these centers also collaborate with the NIDRR-funded Model Systems Knowledge Translation Center for the dissemination of information regarding innovative and best practices originating from their research projects.

All TBIMS programs collect longitudinal follow-up data on individuals served by their centers who meet additional inclusion criteria to study the course of recovery and to document rehabilitation outcomes at one, two and five years post-injury and every five years thereafter for as long as the particular TBIMS center is funded. These data are a rich resource for researchers, enabling the evaluation of long-term recovery patterns for individuals served by these systems of care. The follow-up data are aggregated nationally at the TBIMS National Data and Statistical Center, located currently at the Craig Hospital in Englewood, Colorado. The National Data and Statistical Center coordinates and standardizes the process of data collection across the TBIMS programs forming the TBIMS National Database (TBIMS ND). This database is the only longitudinal long-term follow-up data set that documents pre-injury characteristics, acute care and rehabilitation services, and long-term rehabilitation outcomes for individuals with TBI in the United States. The primary purpose of this User Guide is to describe the TBIMS ND and discuss

² For a list of TBIMS centers that are currently funded, please visit <https://www.tbindsc.org/Centers.aspx>.

its potential uses in rehabilitation research by examining the data structure, key variables, and data trends. This User Guide does not provide specific interpretations of the observed trends, but encourages further exploration by researchers.

Key Limitations

Before researchers consider utilizing the TBIMS ND, it is important to note some key limitations of this data source.

- a. The dataset is comprised of individuals served by the TBIMS Centers. This potentially limits the generalizability of analysis. However, a recent study by Corrigan and colleagues (2012) indicates comparability between patients served in TBIMS centers and the national inpatient rehabilitation TBI population. Readers are encouraged to consult this publication to infer generalizability especially with respect to sub-group analysis (Corrigan, et al., 2012).
- b. Each TBIMS program has unique patient interventions, but the TBIMS ND does not document center-specific intervention details. Hence, understanding the impact of certain rehabilitation interventions across or between centers is not possible. Publications originating from each of the TBIMS programs remain the primary resource for additional information on the nature of center-specific interventions.
- c. The rate of attrition (e.g., the inability to perform follow-up interviews), is an important limitation for follow-along data sets such as the TBIMS ND. However the overall follow-up rate across all follow-up years to date (out to 20 years post-injury at present) is 79%.

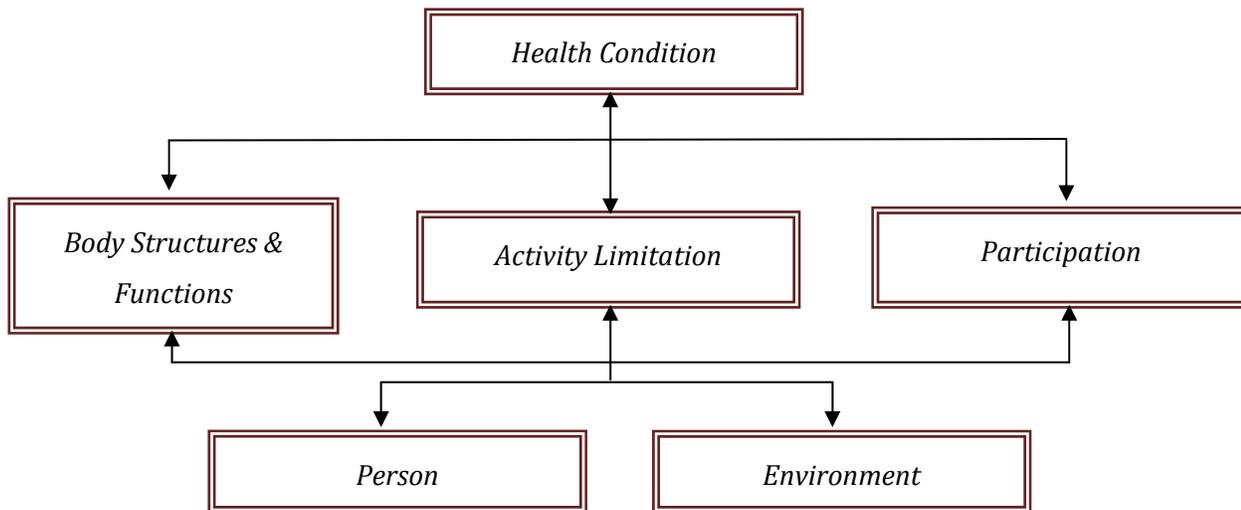
- d. Users must also understand the dynamic nature of the several variables while considering using this data set. Many variables have been modified and discontinued since its inception. The TBIMS ND syllabus provides in-depth information on variable-level changes over time and users must refer to this document to assess potential usefulness of the variables.

Methodology & Data Structure

The ICF Model of Disability

The International Classification of Functioning, Disability and Health (ICF), provides a conceptual framework to describe the state of functioning and health for individuals with disabilities. The ICF defines disability as a manifestation of interaction between the domains of person, environment, body structures and functions, activity limitation, and health condition (Figure 1). The theoretical framework of the ICF provides a method for grouping information on individuals with disabilities in order to understand their needs and assess their recovery and rehabilitation processes by the use of specific instruments. This User Guide employs the ICF framework in describing the variables for demonstrating conceptual connections across different sections of the TBIMS ND data.

Figure 1. ICF Model of Disability



Source: *Towards a Common Language for Functioning, Disability, and Health (ICF)*, World Health Organization, 2002, p. 9 (www.who.int/classifications/icf/trainings/icfbeginnersguide.pdf)

The following tables provide the groupings of variables under each of the ICF domains.

Table 1 consists of variables collected in the pre-injury and acute phase (i.e., from injury through emergency acute hospital admission and inpatient rehabilitation) and Table 2 consists of variables in the post-acute phase (i.e., post-rehabilitation discharge follow-up) for TBIMS patients.

Table 1. Pre-injury and acute variables distributed across the ICF Domains – Form I - Traumatic Brain Injury Model Systems National Database

Personal	Environmental	Body Structure and Function	Activity Limitation	Participation Restriction
<ul style="list-style-type: none"> ➤ Age ➤ Sex ➤ Race/Ethnicity ➤ Education ➤ Pre-injury marital status 	<ul style="list-style-type: none"> ➤ TBI Center Code ➤ Cause of Injury ➤ Payment source for health expenses ➤ Pre-injury incarceration ➤ Primary Language ➤ Time spent in acute care ➤ Time spent in Rehab Care 	<ul style="list-style-type: none"> ➤ Pre-morbid conditions: blindness, deafness, physical limitations ➤ Blood alcohol level in ER ➤ Intracranial CT diagnosis, including intracranial compression, presence of extra-axial collection, and intraparenchymal fragments ➤ Glasgow Coma Scale scores ➤ Revised Trauma Score in ER: Systolic BP ➤ Revised Trauma Score in ER: Respiratory Rate ➤ Neuropsychological Battery – O-log, California Verbal Test-II, Reitan Trail Making Test ➤ Pre-morbid substance use, psychiatric, and alcohol ➤ Pre-injury behavioral disorders ➤ Associated spinal cord injury ➤ ICD-9 Diagnostic Codes ➤ Duration of post-traumatic amnesia ➤ Intracranial hypertension ➤ Cranial surgery ➤ Time between injury and ability to follow commands 	<ul style="list-style-type: none"> ➤ Pre-injury limitations: learning, dressing, going outside home, working ➤ Pre-injury behavioral disorders ➤ Disability Rating Scale at rehabilitation admission & discharge ➤ Functional Independence Measure (FIM) at rehabilitation admission & discharge 	<ul style="list-style-type: none"> ➤ Employment one month prior to injury, including hours and weeks of competitive work ➤ Living situation pre-injury and post-rehabilitation discharge

Table 2. Follow-up variables distributed across the ICF Domains –Form II - Traumatic Brain Injury National Database

Personal	Environmental	Body Structure and Function	Activity Limitation	Participation Restriction
<ul style="list-style-type: none"> ➤ Age ➤ Marital status at follow-up 	<ul style="list-style-type: none"> ➤ TBI Center Code ➤ Incarceration or arrests ➤ Post-injury income 	<ul style="list-style-type: none"> ➤ Patient Health Questionnaire - 9 (PHQ-9) ➤ Generalized Anxiety Disorder - 7 Questionnaire (GAD-7) ➤ Substance use, psychiatric, and alcohol use ➤ Re-hospitalization 	<ul style="list-style-type: none"> ➤ Disability Rating Scale ➤ Functional Independence Measure (FIM) ➤ Glasgow Outcome Scale - Extended (GOS-E) ➤ Supervision Rating Scale 	<ul style="list-style-type: none"> ➤ PART - 18 – item questionnaire measuring participation restriction ➤ Employment post- injury ➤ Living situation at follow-up ➤ Satisfaction with life scale [actually quality of life measures are not part of the ICF]

TBIMS ND Data Collection Process

Identification of Subjects

For the purposes of the TBIMS ND, TBI is defined as “damage to brain tissue caused by an external mechanical force as evidenced by medically documented 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.³” Any individual with a moderate to severe TBI⁴ who is 16 years of age or older at time of injury and presents at a TBIMS center within 72 hours of injury serves as a potential candidate for the TBIMS ND. Further, individuals receiving both acute hospital care and comprehensive rehabilitation services in designated TBIMS programs are eligible to be included in the TBIMS ND. Patients with concurrent injuries or pathologies are not excluded. Individuals, and in some cases their family members, are contacted to secure their consent to participate in the study. The TBIMS ND standard operating procedures offer further details in the process of eligibility determination, inclusion/exclusion criteria, and obtaining informed consent from the potential participants for the study⁵. Either members of the clinical care team or research team at each TBIMS center are responsible for recruiting patients and obtaining informed consent in accordance with the Health Insurance Portability and Accountability Act (HIPAA) and

³ Definition for TBI, including specific inclusion and exclusion criteria can be downloaded from : <https://www.tbindsc.org/SOP/101a%20-%20Identification%20of%20Subjects.pdf>

⁴ Moderate to severe TBI is defined as a person with TBI having post-traumatic amnesia for greater than 24 hours, loss of consciousness of 30 minutes or greater, intracranial abnormalities in brain imaging studies, or a value of 13 or less on the Glasgow Coma Scale at the time of admission in the emergency department.

⁵ Detailed guidelines for obtaining informed consent can be found at: <https://www.tbindsc.org/SOP/102a%20-%20Guidelines%20and%20Strategies%20for%20National%20Database%20Recruitment%20and%20Consent.pdf>

local/individual Institutional Review Board regulations. All TBIMS ND patients are recruited into the study during their inpatient rehabilitation stay (or at the time of IRF admission). After obtaining informed consent, data are collected from the patients using Form I of the data collection forms consisting of variables outlined in Table 1⁶. Broadly, these variables provide background information on patient demographics, their pre-morbid risk factors, clinical conditions at emergency department and/or inpatient rehabilitation admission as well as functional status and disability levels at inpatient rehabilitation admission and discharge.

Follow-up Data Collection

The follow-up data are collected at the intervals of 1, 2, 5 years post-injury and every five years thereafter using Form II⁷. The follow-up in year 1 occurs within a four-month window – 10-to-14 months after the date of the injury; for year 2 this occurs in a six-month window – 21-to-27 months after the date of the injury; and for years 5 and every five years thereafter, it occurs within 6 months before or after the anniversary of injury. The follow-up is conducted by phone, in-person, or mail depending upon the availability of the participant. The TBIMS Standard Operating Protocol 105b⁸ provides additional details on the process of data collection during the follow-up.

⁶ Please see <https://www.tbindsc.org/SOP.aspx> for Form I questionnaire items

⁷ Please see <https://www.tbindsc.org/SOP.aspx> for Form II questionnaire items.

⁸ Please see <https://www.tbindsc.org/SOP.aspx> for additional information.

TBIMS ND Data Structure

The TBIMS ND draws upon various sources of information. Specifically there are two data collection forms: I and II. Form I collects pre-injury data using The Pre-Injury History Questionnaire. This questionnaire collects socio-demographic characteristics, work and school participation, previous history of functional impairments or health conditions, and activity limitations prior to the injury. Form I also collects information from brain imaging studies, medical record data, neuropsychological tests, assessment of activity limitations and health status, as well as ICD-9 codes from acute hospital discharge records. Form II collects information on similar data elements as Form I with the exception of the brain imaging studies and neuropsychological assessments, but also includes several longer term outcome measures at intervals of 1, 2 and 5 years post-injury and every 5 years thereafter. Data, collected in real-time or retrospectively at each TBIMS center, are entered into the live web-based data management system, and are archived quarterly in TBIMS ND for the TBI MSND at the TBIMS National Data and Statistical Center.

Data Request Procedures

A detailed description of the procedure for requesting access to the TBIMS ND is described within the TBI National Data and Statistical Center's standard operating procedure number 602d⁹. This process requires the completion of a Data Request and User Agreement

⁹ Please visit <https://www.tbindsc.org/SOP/602d%20-%20External%20Use%20TBIMS%20National%20Database%20Notification.pdf> for additional information.

Form¹⁰. In addition to institutional affiliations, the individual requesting the data is required to provide a brief summary of the proposed project including study aims, research hypotheses, and methods. This information is reviewed by the TBIMS National Data and Statistical Center and TBIMS Research Committee for PI's affiliation, scientific purpose, and scientific overlap with existing approved projects. Following initial review, the request is posted to the TBIMS Notification Listserv to ensure that the proposal does not duplicate already completed or proposed studies, to solicit collaborators if requestor is interested in collaborating with existing projects, and to invite further comments from TBIMS Project Directors. If the request is approved, data files are made available to the requestor in SAS, SPSS, or tab-delimited text formats.

Description of Key Variables

Key variables from Forms I and II of the TBIMS ND are discussed in the following sections. The ICF framework will be used to describe these variables in order to provide conceptual continuity of the data elements. The TBIMS National Data and Statistical Center provides a complete online data dictionary, "TBIMS MS National Database Syllabus", that can be found at <https://www.tbindsc.org/Syllabus.aspx>. The syllabus provides a listing of all variables, variable names and their corresponding response values. Further, the syllabus also documents any change in the variables and their response categories over time.

¹⁰ Please visit <https://www.tbindsc.org/SOP/602df%20-%20External%20Data%20Request%20and%20Use%20Agreement%20Form.pdf> for additional details.

Traumatic Brain Injury Model Systems National Database - Form I

Variables in the Personal Domain

These variables include personal characteristics that may impact the rehabilitation outcomes of people with TBI.

Participant Socio-Demographic Characteristics. The TBIMS ND has intake information (i.e., Form I) for 10,288 patients across the 20 TBIMS Centers from 1990-2010¹¹. Three-fourths of the population were male, and more than two-thirds were Caucasians. Minority groups consisted primarily of African Americans (20%) and Hispanics (9%). Nearly half of the patients were never married and most were living independently (98%) at the time of injury. Some transition can be observed in living status between pre-injury and post-rehabilitation discharge. It can be observed in Table 3, that about 2% were living in other than private residences at the time of injury and 17% were discharged to other than private residences at discharge, indicating the impact of injury on independent living for TBIMS ND participants. About one-third of the patients were 16 – 25 years old;¹² 34% were 26 – 45 years old; 23% were 46 – 65 years old; and 12% were more than 65 years old at the time of injury. Nearly one third of the patients (29%) had post-secondary education experiences¹³ (i.e., either they were working towards or had

¹¹ Note that TBIMS ND includes data from 1988 to present; only data from 1990 to 2010 were analyzed for the purpose of this user's guide.

¹² It is important to note that the dataset provides users with calculated age at injury and it is therefore possible for users to meaningfully categorize age.

¹³ It is important to note that the dataset collects information on the number of years of education up to high school degree and has categories for higher education where individuals can specifically indicate if they were working towards a degree program or have already attained a post-secondary education degree.

completed a post-secondary degree); 28% had completed high school or had a GED; and 22% had less than a high school degree.

Table 3.

Transition in residence status pre-injury and post-rehabilitation discharge

	At Injury	At Discharge
Private Home	97.9	83.5
Institutional Setting	0.8	15.8
Homeless	0.8	0.1

Variables in the Environmental Domain

This group of variables includes environmental factors that may impact the rehabilitation outcomes of patients.

Cause of Injury. Twenty one known causes of injury are identified by this variable¹⁴. These categories can be collapsed to eight: Assault (includes self-inflicted gunshot wounds), Fall, Motor Vehicle Accidents (MVA), Sports Injury, Striking Injury, Other, and Unknown. Of these groupings, the top three causes of injury include MVA (53%), Fall (23%), and Assault (13%). The trends in cause of injury by year of injury indicate an overall increasing trend in MVA up to the year 2000 and then this trend decreases from 2000 through 2010 (see Figure 2.a). The proportion of fall-related injuries increased over time, especially after year 2000. Further, trends vary by age groups, where trends for Falls increase with the increase in age group

¹⁴ See <https://www.tbindsc.org/SyllabusDetail.aspx?MOD=1&ID=CSEINJ> for detailed codes for cause of injury. Also, note that codes 10, 11, & 12 were used to create “Assault” Category; code 19 was designated “Fall” Category; codes 1, 2, 3, 4, & 5 were grouped for “MVA” Category; and codes 13, 14, 15, 16, 17 & 18 were used to create “Sports” Category.

categories and trends for MVA decrease with an increase in age group categories (Figure 2. b). Trends for other causes of injury remain relatively stable across age group categories.

Figure 2.a. Trends in Causes of Injury for TBIMS ND individuals: 1990 through 2010

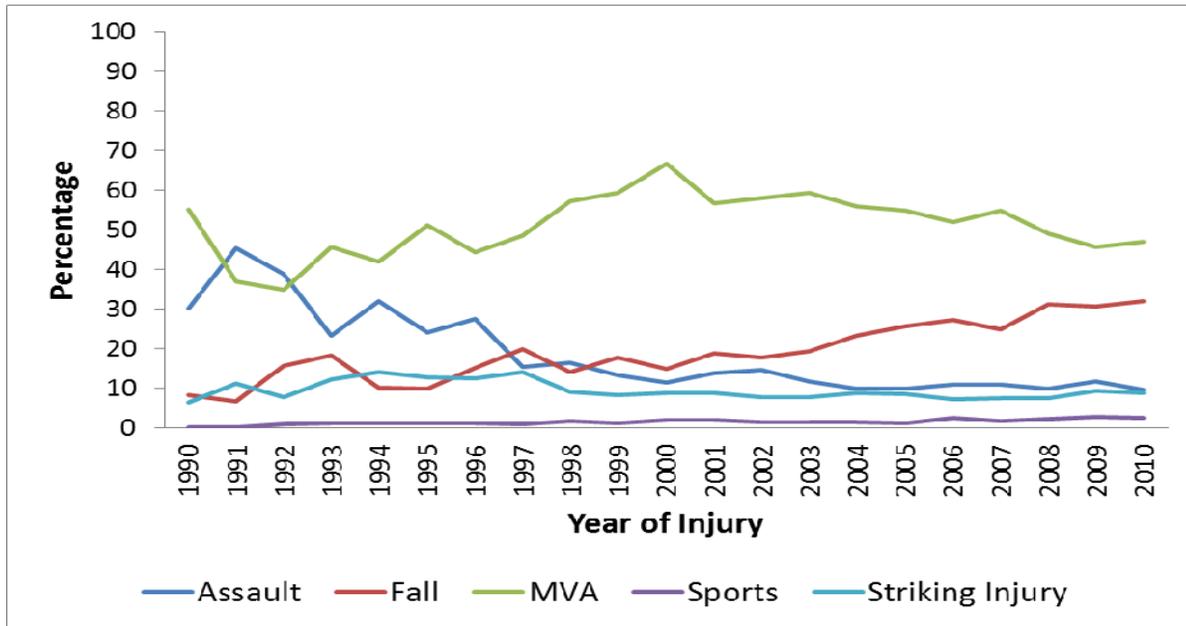
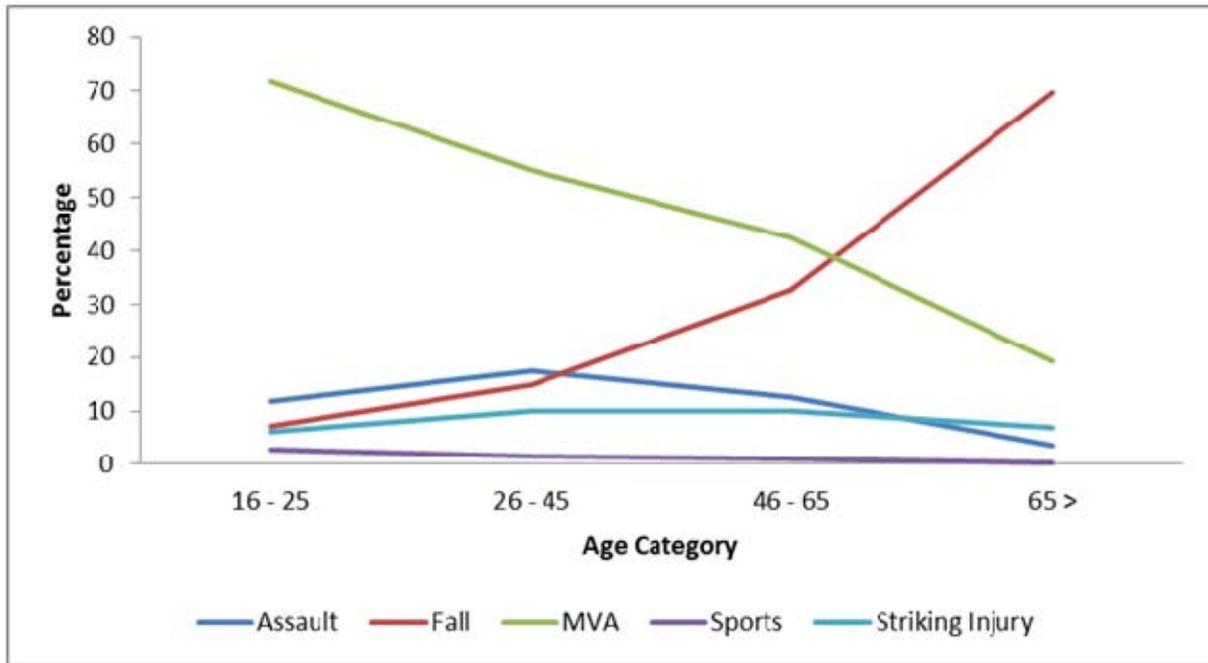


Figure 2. b. Trends in cause of injury by age category for TBIMS ND



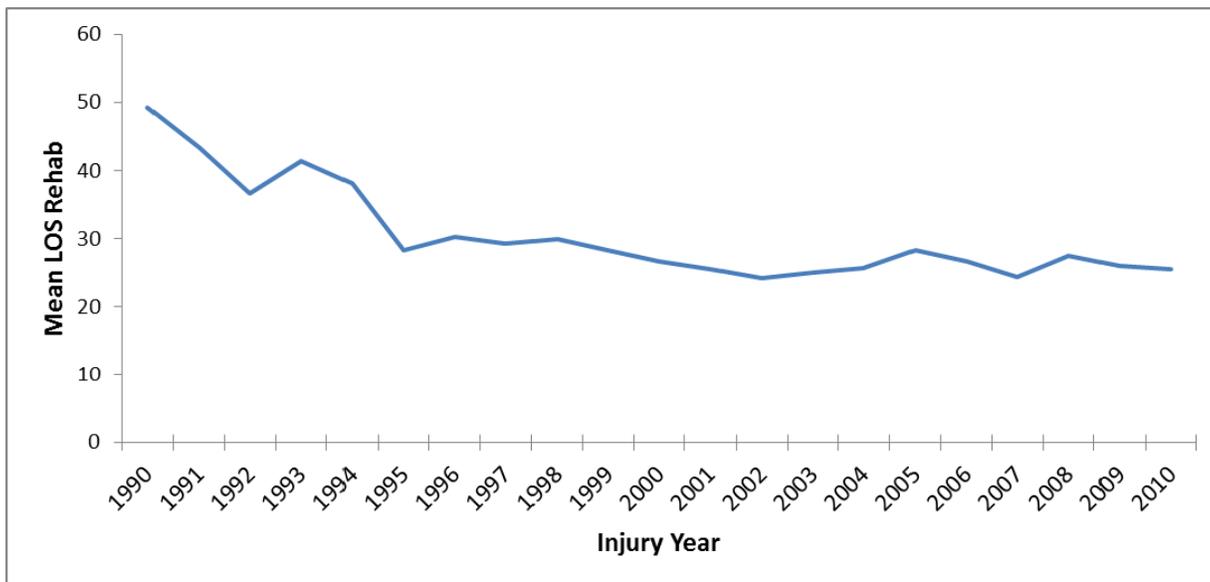
Payer Source for Acute Hospital care and Inpatient Rehabilitation. This variable indicates the primary and secondary payer sources paying for acute care and inpatient rehabilitation services for the participant. This information is collected from the hospital billing/business office¹⁵. This variable was re-categorized in 2011 and four codes were removed. The dataset provided for this analysis reflected the most recent codes for this variable. More than half of the individuals indicated their primary source as private insurance; nearly 37% indicated public insurance as their primary source, and about 6% indicated workers compensation as their primary source of care for acute hospital care and inpatient rehabilitation.

¹⁵ See <https://www.tbindsc.org/SyllabusDetail.aspx?MOD=1&ID=PAY> for detailed categories of Payor Source.

Pre-injury incarceration. Information on previous history of any penal incarcerations with conviction for felony was also collected. About 9% of the patients had a history of incarceration. This variable was added in 1997, however data prior to 1997 are available for some cases as the centers were encouraged to collect data retrospectively.

Inpatient rehabilitation Length of stay (LOS). Inpatient rehabilitation LOS is a calculated variable from admission to discharge from the inpatient rehabilitation facilities. Inpatient rehabilitation LOS is indicated as a marker of underlying brain injury pathology and health status (Arango-Lasparilla et al., 2010). The mean LOS in rehabilitation for TBIMS ND patients is 27.3 days (95% CI: 26.8 – 27.8). This varies substantially by the year of injury where individuals with injuries in years earlier than 1995 had about 40 days of rehabilitation stay; individuals with injuries between 1995 through 2002 had about 30 days of rehabilitation stay; and individuals with injuries after 2002 had about 25 days of rehabilitation stay (Figure 3).

Figure 3. Length Of Stay in Rehabilitation by Year of Injury: 1990 – 2010



Variables in Body Structures & Functions Domain

These variables indicate impairments in body structure and functions that may impact rehabilitation outcomes among TBIMS ND patients.

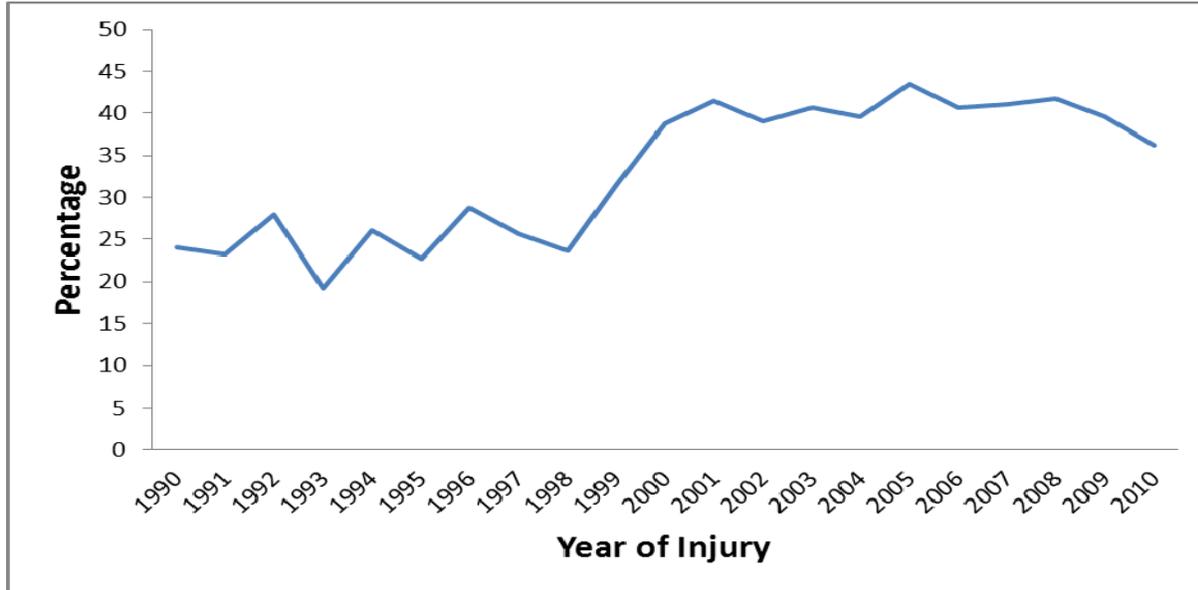
Pre-injury conditions/limitations. This variable was added in 2005 and is based on questions from the long form of the 2000 Decennial Census. Pre-injury conditions visual impairment, hearing impairment, or conditions that limit physical functioning such as walking, climbing stairs, reaching, lifting or carrying. The pre-injury limitations contain information about difficulty in the last 6 months in: (a) learning, remembering or concentration; (b) dressing, bathing, or getting around inside the home; (c) going outside home alone to shop or visit doctor's office; and (d) working at a job or business. Another set of questions inquire about the pre-injury psychiatric history and specifically asks if the participant: (a) received treatment for mental health problems, (b) was hospitalized for a psychiatric problem, or (c) ever attempted suicide. This set of questions in combination with the pre-injury conditions and limitations could be used to identify participants who had disabilities prior to incurring a TBI. Utilizing this approach, 29% of TBIMS ND participants indicate a prior disability, with most indicating mental health and physical disabilities (7% each) followed by sensory and cognitive disabilities (6% each). About 2% indicate work-related disabilities before injury. Users must exercise caution as having a pre-injury condition does not indicate that a person had a disability. Information on activity limitation and participation limitations is important in determining if a person has a disability based on the ICF framework.

Intracranial CT diagnosis. Extensive information on intracranial CT diagnosis is available for each participant in the TBIMS ND. These data are collected from the CT scans

performed within seven days of injury. Only trained TBIMS personnel (in doing CT scans) are authorized to complete this section of the Form I data. Further, it is advisable to use specific brain pathology-related information in determining if an individual had a CT scan-related information rather than the global item variable (CT information available – yes/no) as the latter was added only in 2007 and it could be misleading if one were to examine the global variable only. Information is available on the extent of intracranial compression, presence of intracranial hemorrhage/contusions, subarachnoid hemorrhage, intraventricular hemorrhage, focal cortical/non-cortical parenchymal contusions/hemorrhage, presence of any extra-axial collection, and presence of intraparenchymal fragments. In addition to the intracranial CT diagnosis, information is also collected on the presence of Intracranial Hypertension using data from intracranial pressure (ICP) monitors. However, 43% of the data for this field is marked “unknown” due to patients not having an ICP monitor, limiting its role in evaluating the prevalence of intracranial hypertension.

Pre-injury Alcohol or Drug use. The set of questions about an individual’s alcohol consumption are modeled after the Centers for Disease Control and Prevention’s Behavioral Risk Factor Surveillance System. These variables were added to the database in 1997. A comprehensive indicator of drug and alcohol problem use is established in the TBIMS ND through a set of items on alcohol use and one item about drug use. It is important to note that these are self-reported variables. Based on this constructed variable, nearly 38% of individuals had problems with alcohol or drug use within one year prior to the date of injury. A trend is noted, especially after year 1998, in the proportion of individuals who report pre-injury alcohol or drug use, as indicated in Figure 4.

Figure 4. Trends in Problem Alcohol or Drug Use among TBIMS ND Patients: 1990 – 2010

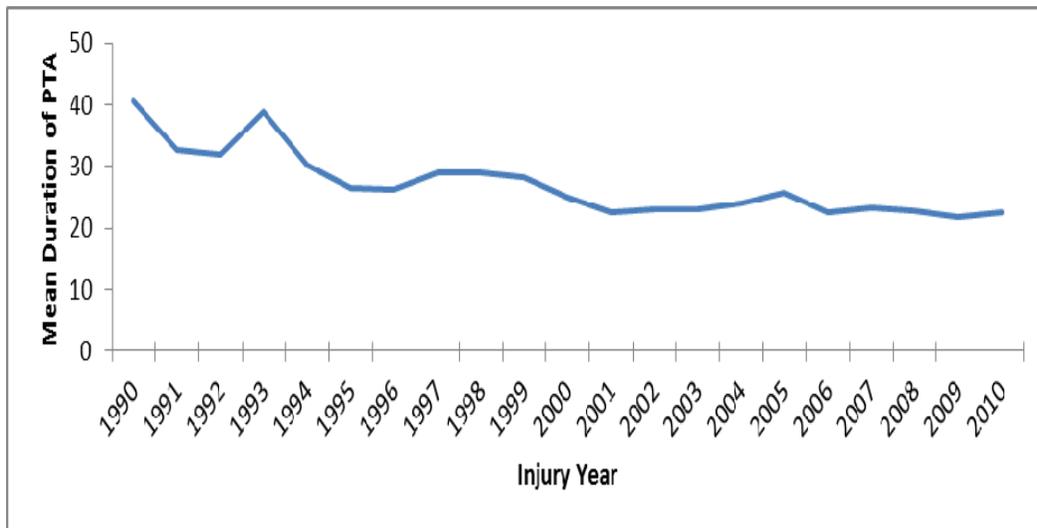


Measures of severity of injury and loss of cognitive functions. These include a battery of instruments meant to evaluate severity of injury as well as the extent of loss of cognitive or higher-order brain functions following TBI. These specifically include: (a) Glasgow Coma Scale (GCS), and (b) Neuropsychological battery. The GCS is administered in the Emergency Department while conducting a post-injury assessment. Neuropsychological batteries, administered between 2 – 4 weeks post injury in rehabilitation facility, are used to identify and monitor cognitive function loss in patients with TBI. Sub-groups of the TBI population can be constructed based on the severity of loss of cognitive function and injury using these metrics. Further, GCS is correlated with long-term outcomes (Zafonte et al., 1996; Cowen et al., 1995).

Duration of Post-traumatic amnesia (PTA). This variable captures the duration of time from the date of injury to the date on which the patient regained orientation and memory. PTA has been used to classify severity of TBI (Rees, 2003) and has been used as a predictor of long-term functional outcomes (Zafonte et al., 1997). The mean duration of PTA was 24.4 days (95%

CI: 23.9 – 24.9). When examined across the year of injury, an overall declining trend in the length of PTA can be observed from 1990 through 2000, with a sharp increase in 1993. The trend stabilizes between 2000 and 2010 (Figure 5)¹⁶.

Figure 5. Duration of Post-Traumatic Amnesia by Year of Injury: 1990 – 2010



Among those with brain injury after 2003, nearly 25% had cranial surgeries. More than half of patients with Assault injuries receive cranial surgery (52%), followed by one-third of patients with Fall and Sports injuries (31% and 32%, respectively). Patients with MVA were least likely to have cranial surgeries (17%).

¹⁶ Note that while computing the mean PTA one needs to set the values 999 and 888 to missing. Results could be erroneous without this minor data manipulation. Further, PTA is tracked only until inpatient rehabilitation discharge and therefore has a truncated distribution. One can potentially address this by calculating PTA as duration from injury to rehabilitation discharge for those cases which were coded 888=still in PTA at rehabilitation discharge.

Variables in the Activity Limitations and Participation Restrictions Domain

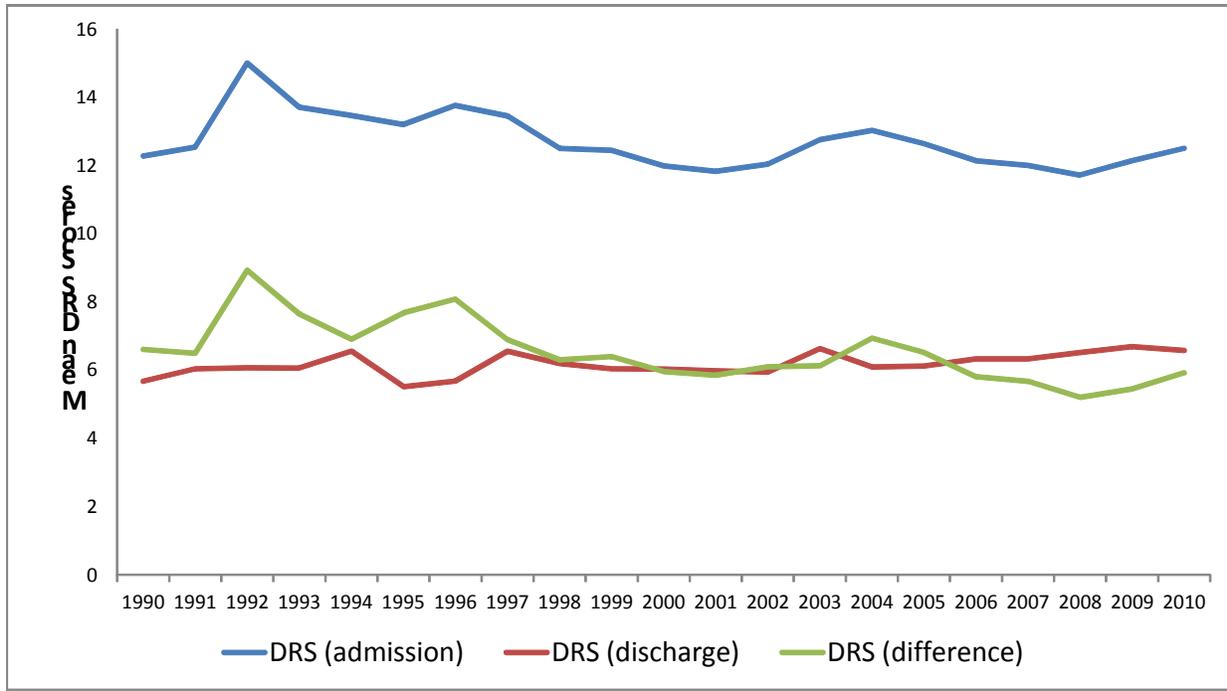
These variables document and measure the extent of activity limitations and participation restrictions in inpatient rehabilitation settings for TBIMS ND patients. Two variables/scales comprise the variables in this domain, the Disability Rating Scale (DRS) and Functional Independence Measure (FIMTM)¹⁷.

Disability Rating Scale (DRS). In brief, the Disability Rating Scale was developed to monitor and track level of disability of individuals with TBI from injury through rehabilitation into community-based settings (Rappaport et al., 1982). The DRS is an eight item scale measuring impairment (3 items), cognitive ability (3 items), level of functioning (1 item), and employability (1 item). The DRS has been studied extensively for its predictive validity and its sensitivity to various severities of TBI (Rao & Kilgore, 1992). Limitations of DRS are discussed elsewhere (Hammond et al., 2001). It is important to note that higher DRS scores indicate greater disability and lower scores (i.e., zero) indicate close to normal function.

Mean DRS score at admission was 12.4 (95% CI: 12.3 – 12.5) and at discharge the mean was 6.3 (95% CI: 6.2 – 6.4). The difference in DRS scores between admission and discharge remains stable for the most part (except for year 1992) across years of injury (Figure 6). Variation in DRS values (as well as other measures) across key demographic variables are provided in Table 4.

¹⁷ Users are urged to review the TBIMS ND syllabus <https://www.tbindsc.org/Syllabus.aspx> to ensure that they set the values such as 66, 77, 888, 999 as missing to avoid errors in computing the averages. The data set does not follow a consistent approach for indicating missing values for variables. Missing values differ across variables and also depend on the variable length (e.g. in some cases, is , and 88 is used instead of 888, etc.)

Figure 6. Mean Disability Rating Scale scores at Admission and Discharge by Year of Injury:
1990 – 2010



Functional Independence Measure (FIMTM). The FIMTM is an instrument developed for planning and monitoring inpatient rehabilitation services and outcomes related to functional independence (Wright, 2000). This 18 item instrument measures cognitive (5 items) and motor functioning (13 items). Each item is rated on a scale of 1 to 7, with 1 indicating “total assistance” and 7 indicating “complete independence” in performing tasks. Though the ability of the FIMTM to predict long-term outcomes continues to be a matter of further research (Whitlock and Hamilton, 1995), several studies have shown the predictive ability of the FIMTM on return to employment one to three years post-injury (Webb et al., 1995). It is important to note that the TBIMS ND dataset consists of individual item-level as well as summation scores across all of the cognitive and motor domains of the FIMTM and also provides the FIMTM total score.

The mean FIMTM Cognitive score at admission was 15.5 (95% CI: 15.4 – 15.7) and at discharge was 23.9 (23.8 – 24.0). The FIMTM Motor score at admission was 36.2 (35.8 – 36.5) and at discharge was 67.8 (67.4 – 68.1). The difference in FIMTM Motor score between admission and discharge is much higher compared to FIMTM Cognitive score. The mean FIMTM total score at admission was 51.7 (95% CI: 51.2 – 52.2) and at discharge was 91.8 (95% CI: 91.3 – 92.2). Figures 7 a, b, and c, illustrate variations in FIM scores across cohorts of individuals injured in a particular year. Variation in FIMTM scores across key demographic variables is provided in Table 4.

Table 4.

Functional Independence MeasureTM and Disability Rating Scale scores across Key Variables

Key Variables	FIMTM Cognitive (admission)	FIMTM Cognitive (discharge)	FIMTM Motor (admission)	FIMTM Motor (discharge)	DRS (Admission)	DRS (Discharge)
Female	16.2	24.4	35.0	65.4	12.2	6.4
Male	15.3	23.8	36.9	68.6	12.5	6.3
White	15.6	24.1	36.2	67.7	12.3	6.2
Black	15.3	23.1	37.0	67.1	12.6	6.7
Asian/Pacific Islander	16.3	25.2	38.0	68.8	11.9	6.0
Native American	17.7	26.0	41.9	72.6	11.4	5.8
Hispanic	15.1	23.7	35.3	68.3	12.5	6.2
Other	16.0	25.0	38.6	71.1	12.4	5.6
16 – 25	15.3	24.5	36.5	69.3	12.7	6.2
26 - 45	15.4	24.1	37.8	69.7	12.4	6.1
46 - 65	15.4	23.4	35.7	67.1	12.3	6.5
65 >	16.4	22.9	33.6	59.2	11.8	7.1
< HS Diploma	15.2	23.2	35.4	66.4	12.6	6.7
GED	14.7	23.5	34.7	67.3	12.6	6.5
HS Diploma	15.6	23.7	35.5	66.3	12.4	6.5
College	15.8	24.5	37.5	69.4	12.2	6.0
Assault	15.1	23.2	40.3	70.8	12.4	6.3
Fall	15.8	23.4	37.1	66.3	11.8	6.5
MVA	15.5	24.3	35.2	67.6	12.6	6.2
Sports	16.5	25.8	42.8	75.2	11.3	5.4
Striking Injury	15.5	23.7	34.1	66.1	12.6	6.6

Figure 7.a. Functional Independence Measure (FIM)TM Cognitive scores at Admission and Discharge by Year of Injury: 1990 – 2010

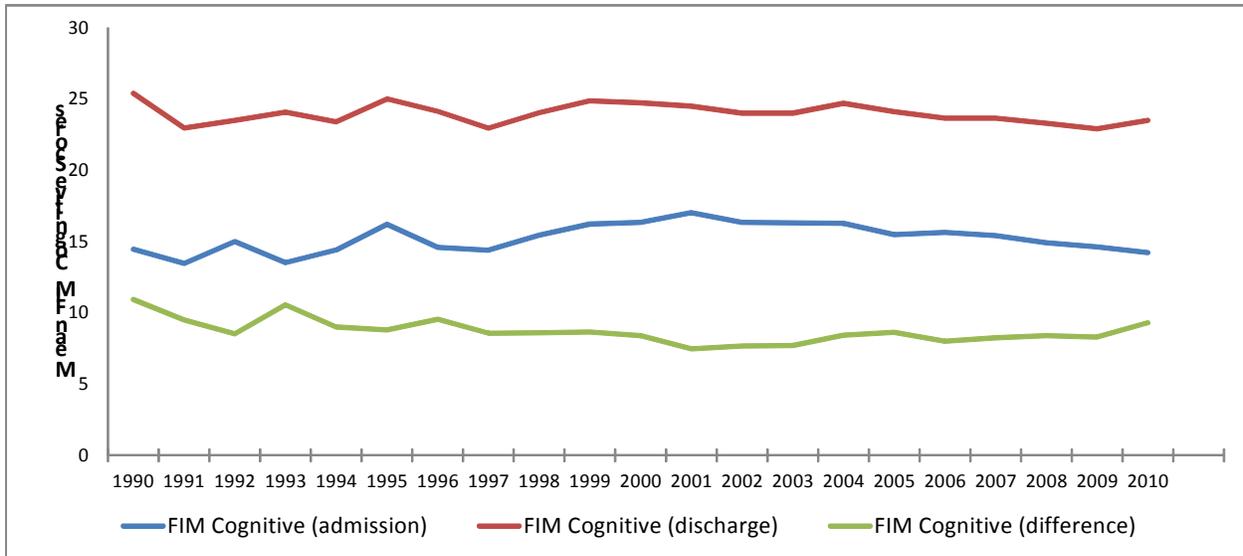


Figure 7.b. FIMTM Motor scores at Admission and Discharge by Year of Injury: 1990 – 2010

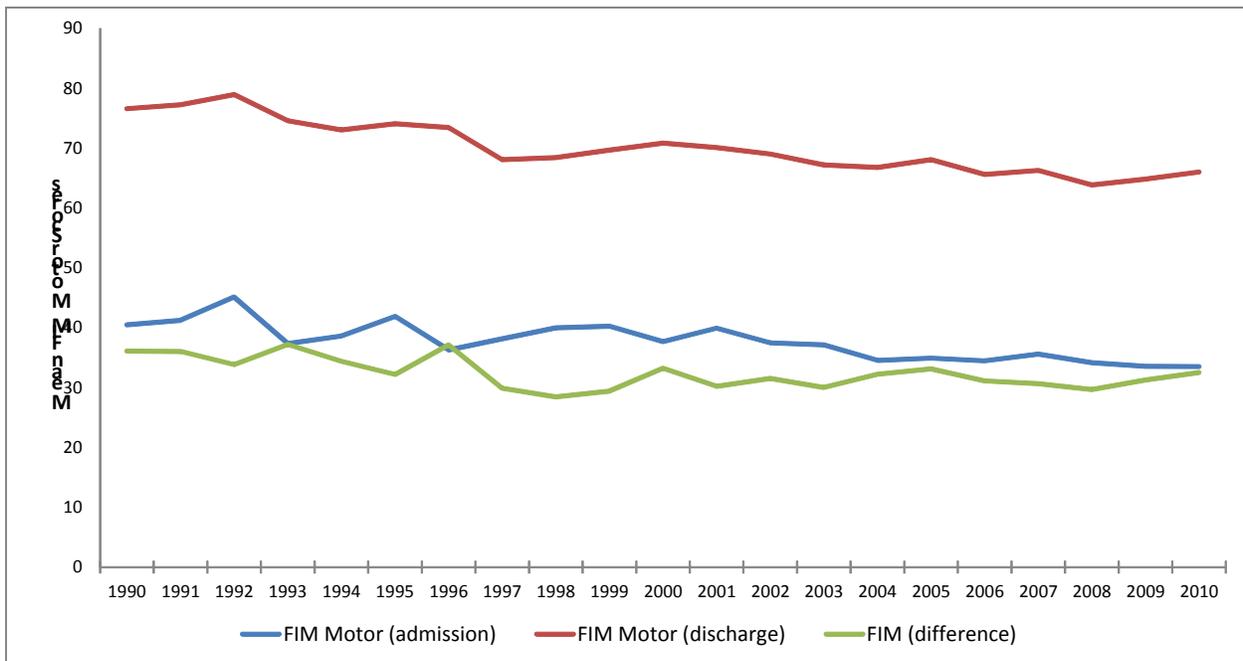
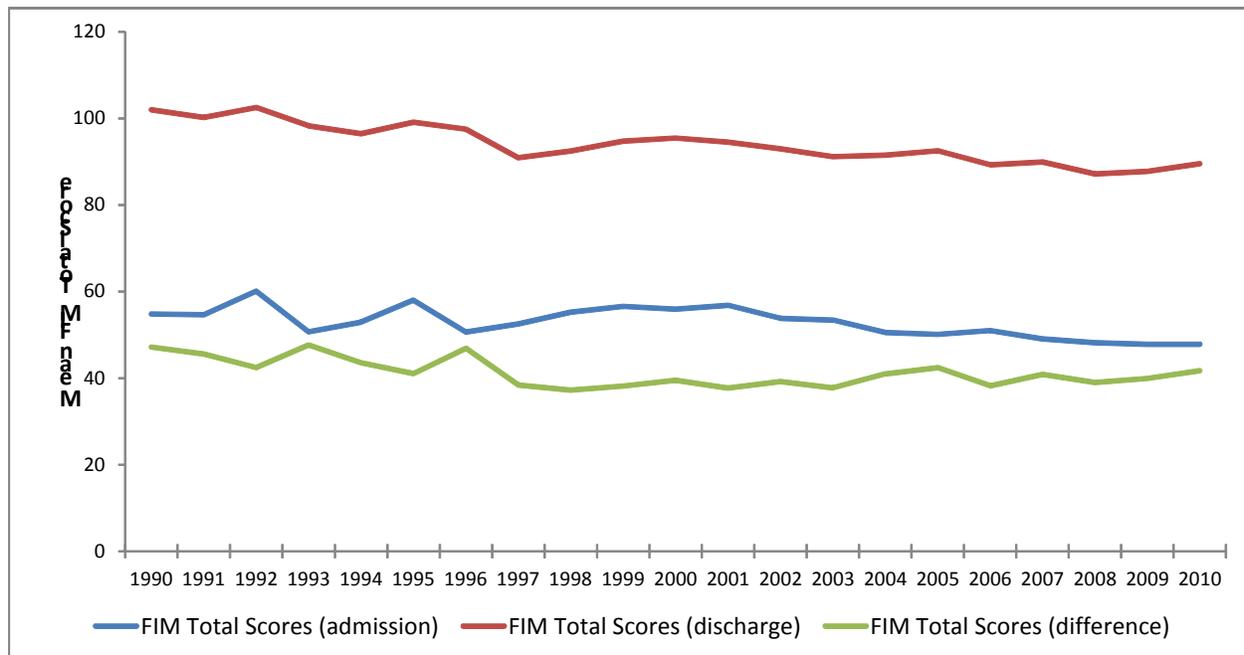


Figure 7.c. Functional Independence Measure™ Total scores at Admission and Discharge by Year of Injury: 1990 -2010



Employment and Earnings at Injury. The TBIMS ND collects information on employment status of patients in the month prior to the date of injury. Prior to 1994, three employment variables were collected (i.e., primary, secondary and tertiary). In 1994, the tertiary employment status was dropped and the current dataset has information on primary and secondary employment status for patients in the month prior to injury. Specific categories of responses for employment status variables are provided in the syllabus¹⁸. Employment, besides indicating financial capital, indicates the extent of physical activities and productive engagement

¹⁸ See <https://www.tbindsc.org/SyllabusDetail.aspx?MOD=1&ID=EMP> for employment status categories.

prior to the injury. Employment prior to injury has also been demonstrated to predict post-injury rehabilitation outcomes (Crepeau & Scherzer, 1993; Shames et al., 2007).

In addition to the employment status, the TBIMS ND collects information on the average number of hours of paid work (minimum wages and above) across all jobs as well as specific occupation categories (the major occupational category using 1990 Census Occupation Codes) for primary employment. Annual earnings¹⁹ from all jobs and the number of weeks of competitive employment for the year prior to the injury were added to the data base beginning in 2001.

In the TBIMS ND data, 51% of individuals were employed (includes individual who were competitively employed, volunteered, looking for work and special employment), 6% were unemployed, and 5% were students one month prior to injury. Data were missing for nearly one quarter of individuals. Among those competitively employed, 78% worked full-time and 17% worked part-time one month prior to injury. Also, among those competitively employed, the majority (60%) earned less than \$40,000 a year prior to injury. Earnings data were missing for 11% of individuals who were competitively employed. This variable was added to the TBIMS ND in 2001.

Traumatic Brain Injury Model Systems - Form II

Form II is utilized for collecting follow-up data on rehabilitation outcomes for TBIMS ND patients at 1, 2, and 5 years post-injury and every 5 years thereafter as long as the TBIMS center is funded to do so. Table 5 provides the percentage of TBIMS ND participants having

¹⁹ Annual earnings were reported as categories.

follow-up information across all follow-up time-points to date where either the person with TBI or their proxies (typically family members) were interviewed. Initial examinations indicate that follow-up data are available for a large proportion of TBIMS ND participants 5 years post-injury (ranging from 80 – 60%). However, the number of missing records increases with each follow-up time-point due in part to sample attrition and as data for later years for many patients are yet to be collected. As is evident in Table 7, researchers may have the ability to conduct research on longitudinal follow-up 5 to 10 years post rehabilitation discharge with a reasonable sample size. However, the heterogeneity in missingness of the specific outcome variable could potentially limit the overall power of the study to detect differences or test hypotheses.

Table 5.

Percentage of Follow-up Records available by Year of Injury

Injury Year	N	Y1	Y2	Y5	Y10	Y15	Y20
1990	93	60.6	42.6	58.5	73.4	67	59.6
1991	105	54.3	57.1	64.8	70.5	76.2	15.2
1992	126	47.6	51.6	64.3	69.8	66.7	0
1993	97	63.9	65	62.9	85.6	58.8	0
1994	97	61.2	65.3	60.2	70.4	59.2	0
1995	140	69.5	63.1	70.9	68.1	60.3	0
1996	149	52.4	50.3	72.5	73.2	14.1	0
1997	134	64.2	59.7	78.4	67.2	0	0
1998	237	80.2	74.3	84.4	69.6	0	0
1999	577	84.1	80	80.2	70.2	0	0
2000	592	83.1	81.9	80.2	59.6	0	0
2001	674	83.2	90.1	80	16.5	0	0
2002	559	94.1	83.2	80.1	0	0	0
2003	737	83.6	78.7	78.7	0	0	0
2004	768	82.2	81	77.1	0	0	0
2005	811	81.5	80.3	63	0	0	0
2006	872	85	81.2	20	0	0	0
2007	863	86.2	84.6	0	0	0	0
2008	872	86.2	74.4	0	0	0	0
2009	890	81.8	13.5	0	0	0	0
2010	802	12.1	0	0	0	0	0

It must also be noted that 926 patients died during the course of the follow-up and the percentage of deaths reported across the follow-up years indicates a higher percentage of deaths in the later follow-up time points (Figure 8.a.). One can also observe that proportion of deaths varies between 2% to 4% for most cohorts and increases markedly for those injured in more recent years. This variation could be attributable to higher risk of deaths in post acute phase of TBI (Figure 8.b.). It must be noted that the percentage values displayed in the charts represent average trends across the follow-up timepoints and do not represent individual-level changes.

The higher proportion of deaths in the Y20 cohort as well as those in 2010 are primarily due to the overall lower sample size of the populations (N = 141 and 110 respectively).

Figure 8.a. Percentage of Deaths across Follow-up Time Points

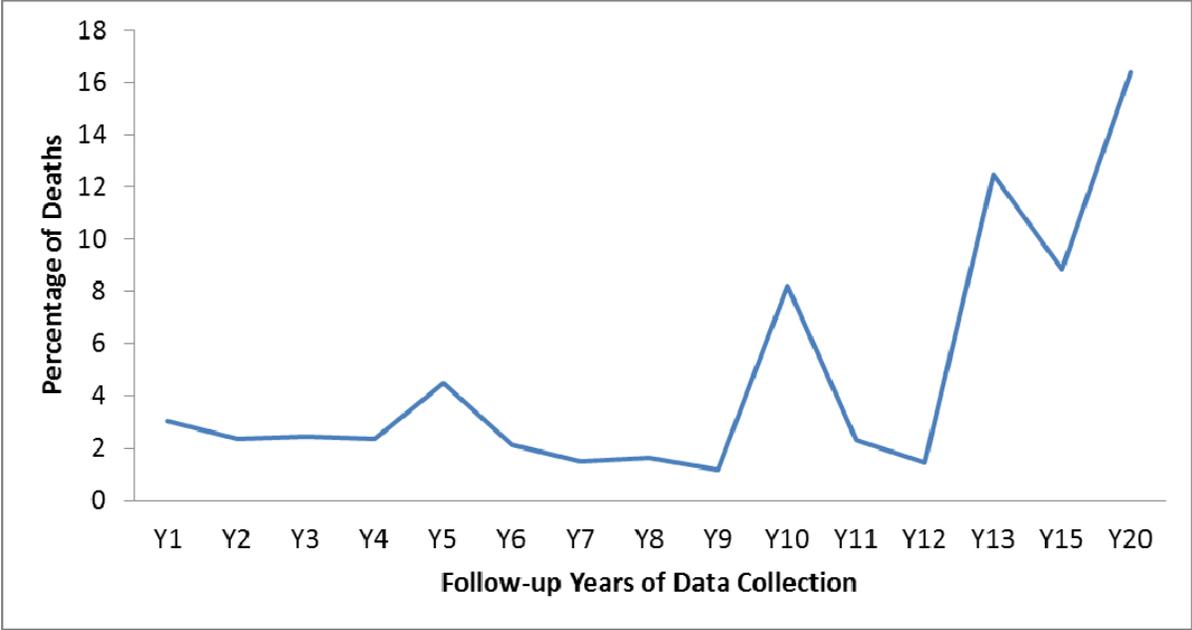
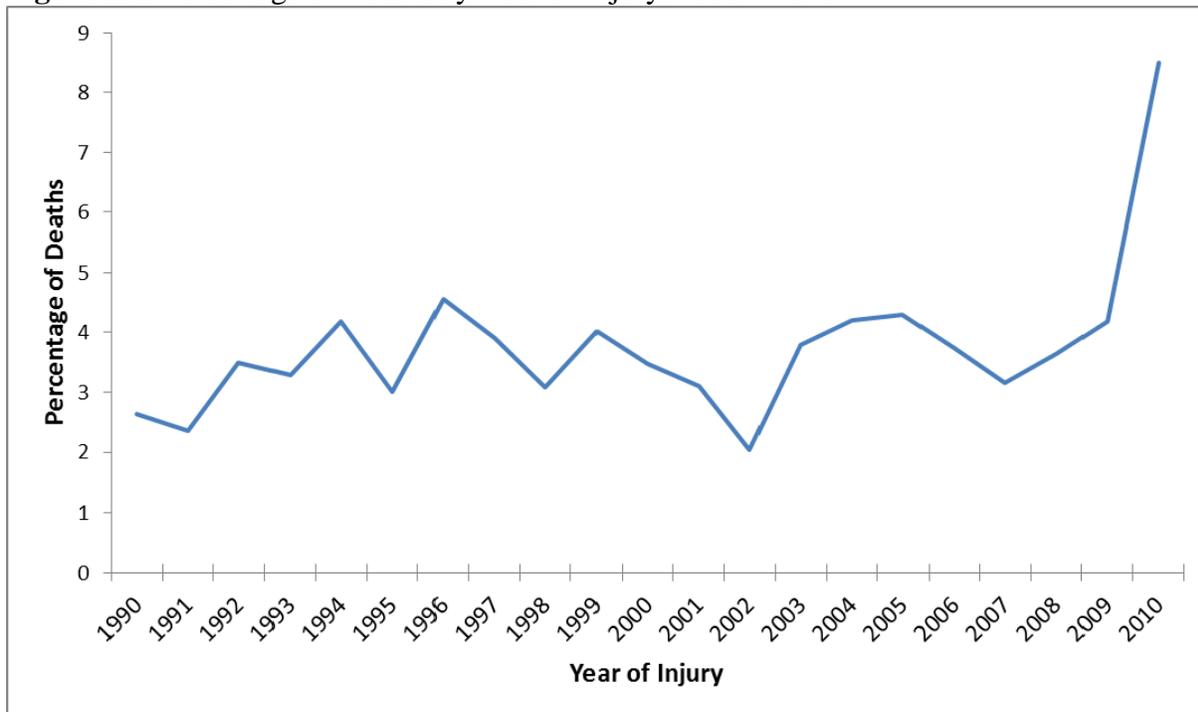


Figure 8.b. Percentage of Deaths by Year of Injury: 1990 – 2010

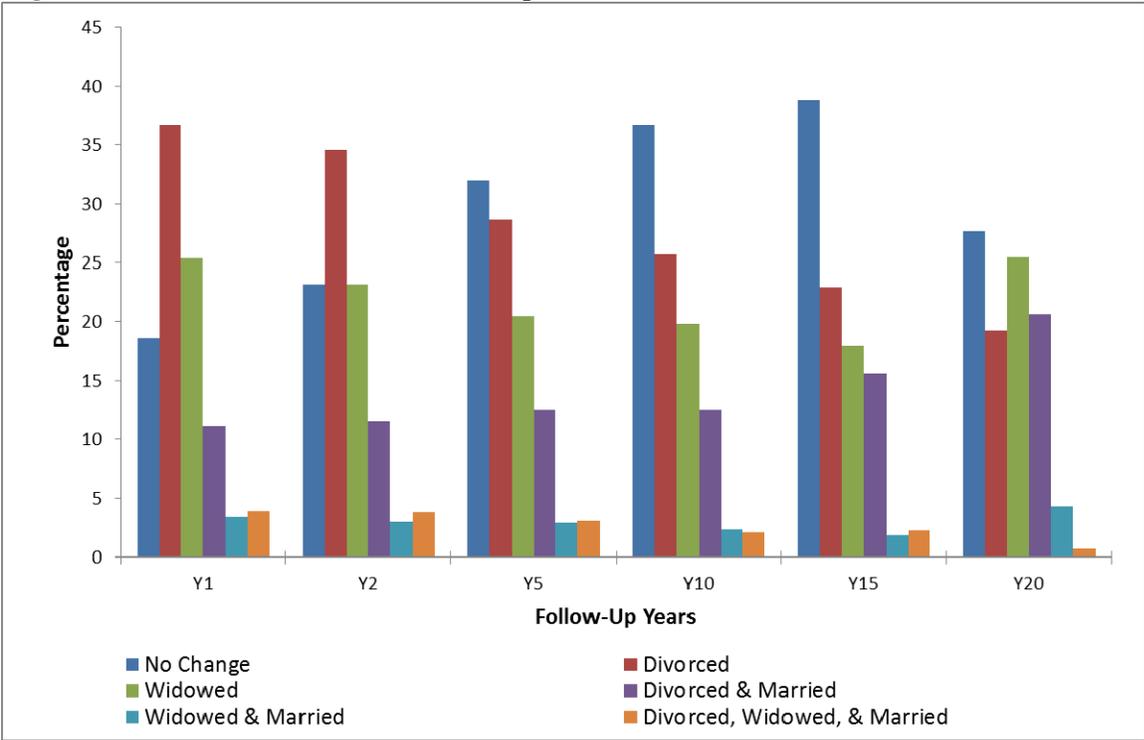


Variables in the Personal Domain

These variables include any change in an individual's personal characteristics that may have an impact on rehabilitation outcomes. Only those variables with a likelihood of changing/varying over time are presented in the following sections.

Marital status. Figure 9 presents trends in the change of marital status of the TBIMS ND follow-up participants compared with their pre-injury status. In the first year of follow-up, more than one-third of individuals indicated that they were divorced; nearly one-quarter were widowed; 11 % were divorced and married and about 3% to 4% indicated they were divorced, widowed, and married (events in no specific order). These personal-level changes in family structure could have an impact on long-term rehabilitation outcomes (Bay, Blow, & Yan, 2011).

Figure 9. Marital Status across Follow-up Time Points



Variables in the Body Structure and Function Domain

These variables are comprised of indicators of loss or improvement in specific body structure and/or functions that impact long-term recovery and rehabilitation outcomes for individuals with TBI. These include self-rated measures of psychiatric symptoms as well as alcohol and substance use history.

Patient Health Questionnaire 9 (PHQ-9) and Generalized Anxiety Disorder – 7 (GAD-7). PHQ-9 is a nine-item self-rated depression screening instrument. Each item in PHQ-9 is rated on a scale from 0 – 3. The scores can be used to indicate minimal, mild, moderate, moderately severe and severe depression (for details see Kroenke, Spitzer, & Williams, 2001). This variable was added to the TBIMS ND data base in 2007.

The Generalized Anxiety Disorder – 7 (GAD-7) is a seven-item self-rated questionnaire developed to identify Generalized Anxiety Disorders (Spitzer et al., 2006). The GAD-7 scores can be used to indicate minimal, mild, moderate, and severe anxiety disorders. This variable was added to the TBIMS ND database in 2010. Figures 10.a. and 10.b. provide trends in depression and generalized anxiety disorders for TBIMS ND patients across the follow-up years.

Figure 10.a. Prevalence of Depression by Follow-up Time Points

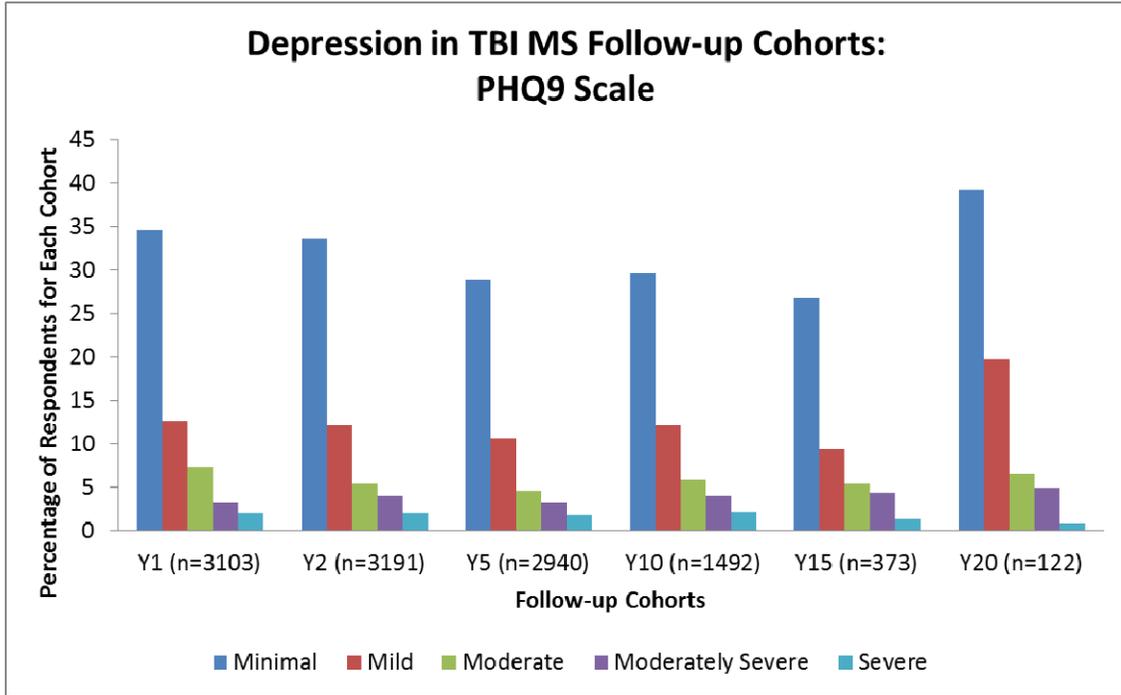
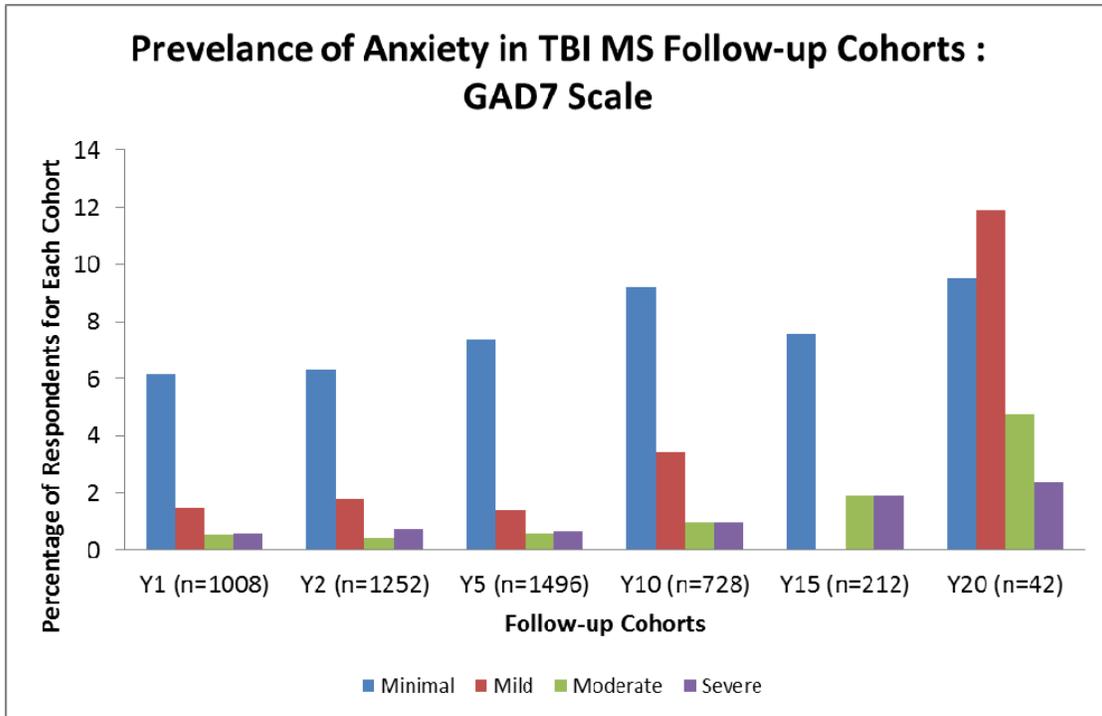
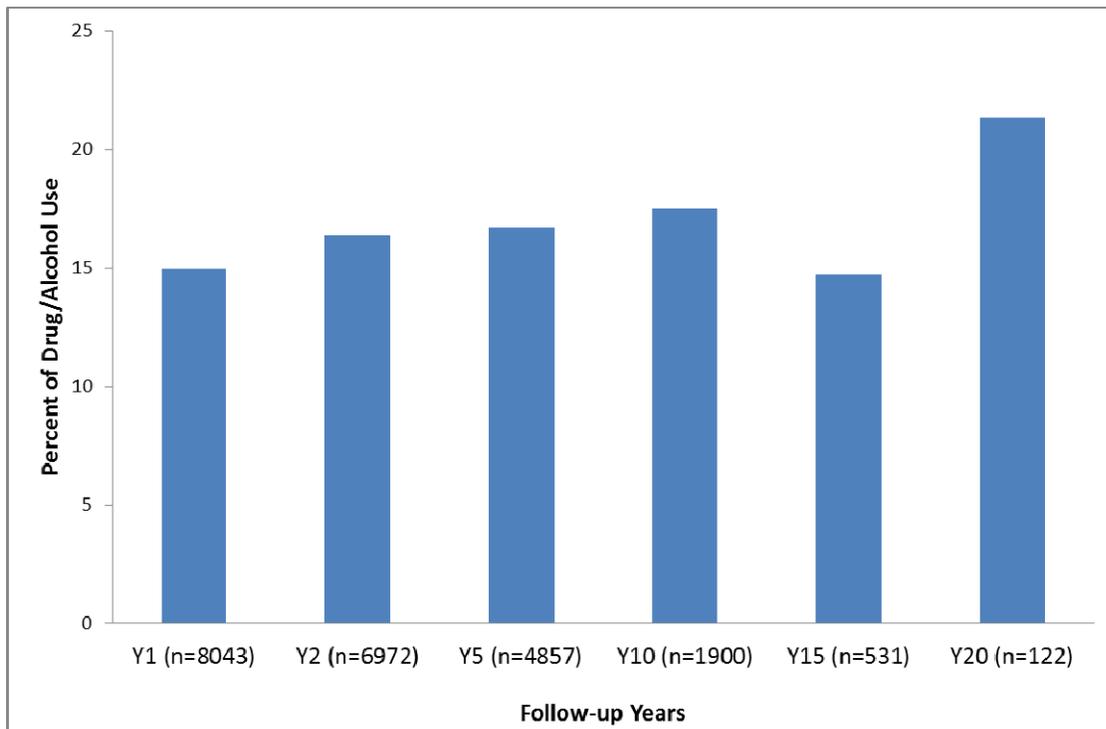


Figure 10.b. Prevalence of Generalized Anxiety Disorder by Follow-up Time Points



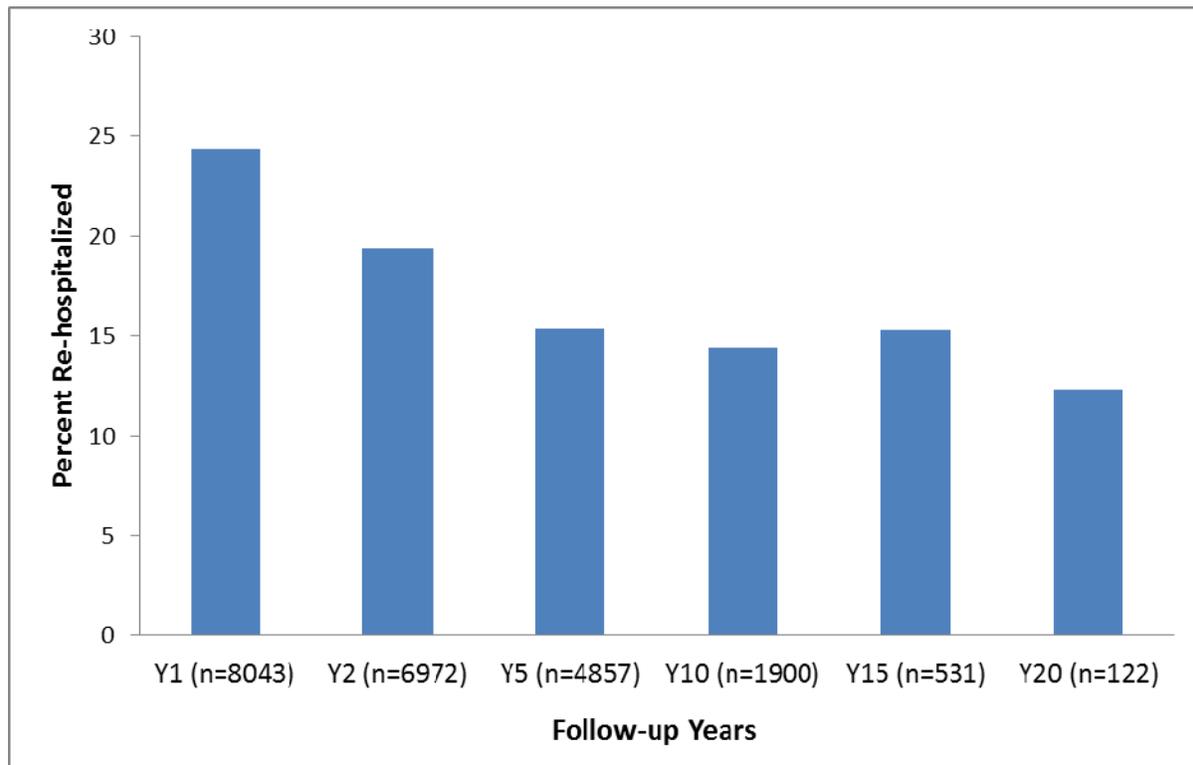
History of Drug and Alcohol Use. Figure 11 displays the prevalence of drug and alcohol use among the TBIMS ND patients. A moderately increasing trend in prevalence of drug or alcohol use can be observed across the follow-up years. The observed increase in the trends for Y20 could be also due to lower Ns.

Figure 11. Prevalence of Drug/Alcohol Use across Follow-up Time Points



Re-hospitalization. The TBIMS ND also collects information on re-hospitalization in the year prior to the follow-up time point of data collection (prior to 2004 the timeframe was “since the last evaluation” instead of “last year”). The prevalence of re-hospitalization decreases over the follow-up period until the 10th year post-injury, when the prevalence of re-hospitalizations increases before trending downward again after the 15th year (Figure 12).

Figure 12. Prevalence of Re-hospitalization by Follow-up Time Points



Variables in the Activity Limitation and Participation Restriction Domains

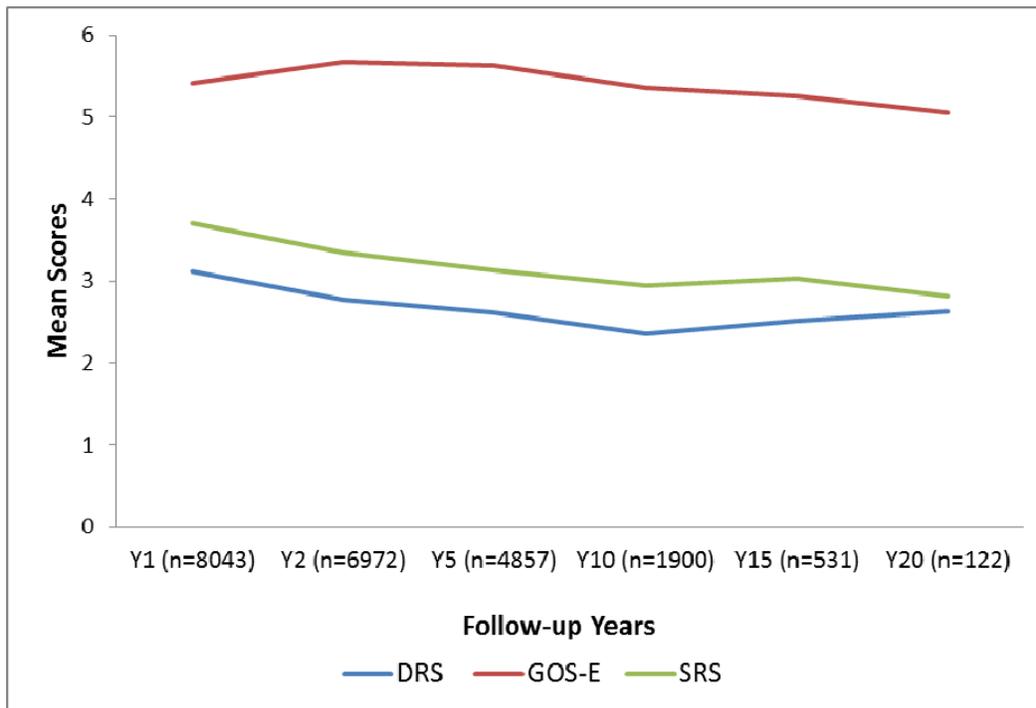
These variables include the standardized assessment of activity limitation for the TBIMS ND patients using the Disability Rating Scale, Functional Independence Measure, Glasgow Outcome Scale – Extended, and Supervision Rating Scale. These also include variables indicating restrictions in participation in home, community, school, work and leisure activities among TBIMS ND patients.

Disability Rating Scale (DRS), Glasgow Outcome Scale – Extended (GOS-E), and Supervision Rating Scale (SRS). The DRS, described within the Form I section, is an eight-item instrument that helps in tracking the improvement in rehabilitation outcomes. Lower scores indicate less disability, while higher scores indicate greater disability (DRS scores range from 0

– 29). The GOS-E, is an eight-level measure intended to measure functional recovery among TBI patients (Jennett, Snoek, & Bond, 1981; Pettigrew, Wilson, & Teasdale, 1998). Contrary to DRS, lower scores in GOS-E indicate worse outcomes compared to higher scores (GOS-E scores range from 1 – 8). The SRS is a 13-level measure that bases measurement of functional recovery on the extent of supervision one may need (SRS scores range from 1 – 13). A higher score indicates dependence and lower scores indicating independence (Boake, 1996).

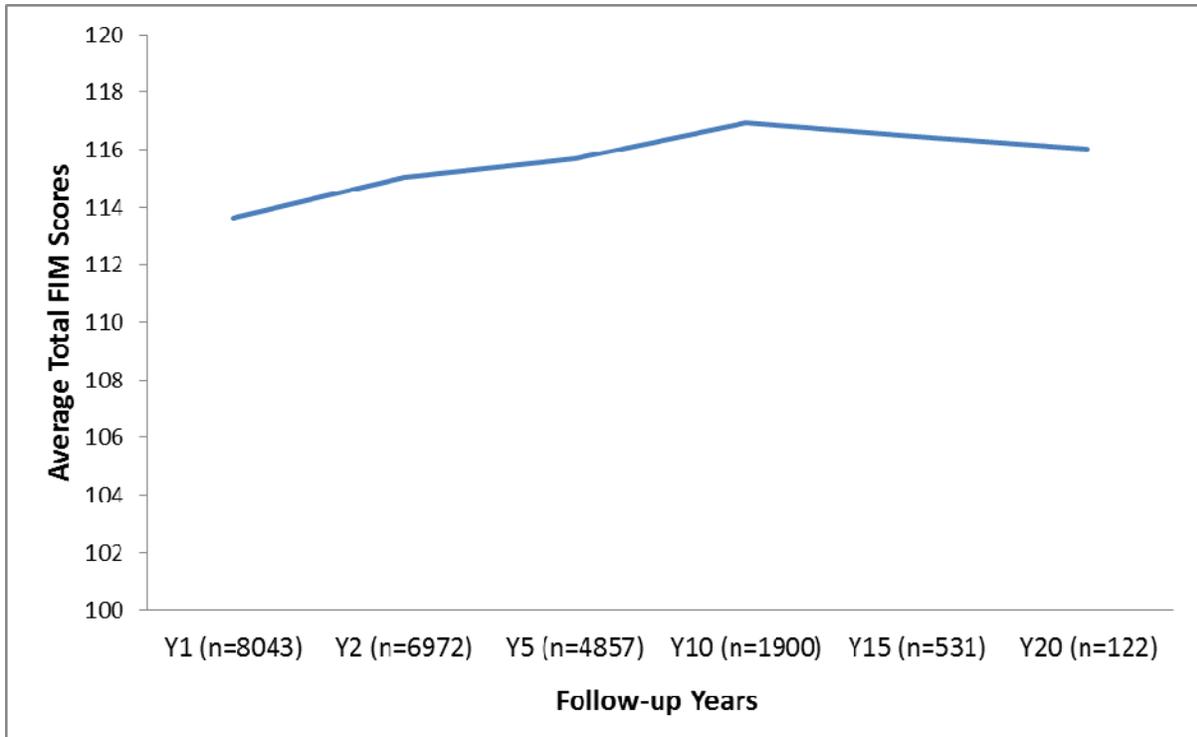
Figure 13 illustrates the mean DRS, GOS-E and SRS scores across the follow-up years for the TBIMS ND patients. Changes in the DRS, GOS-E, and SRS scores remain comparatively stable across the follow-up years with a slightly declining trend.

Figure 13. DRS, GOS-E and SRS Scores across Follow-up Time Points



Functional Independence Measure (FIMTM). The FIMTM (described within the Form I section) is another instrument measuring functional recovery based on activities of daily living among TBIMS ND patients. Figure 14 illustrates the patterns in mean FIMTM Total scores.

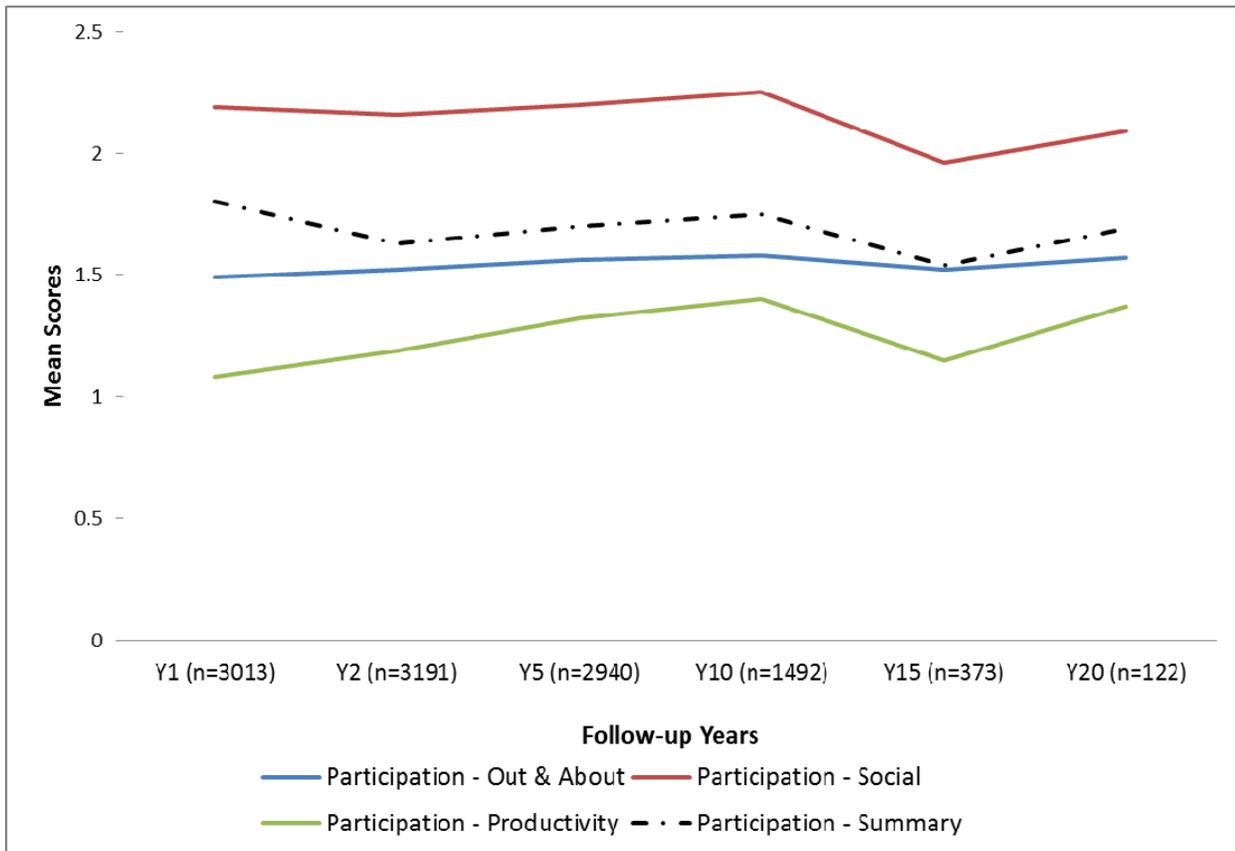
Figure 14. FIMTM Total Scores across Follow-up Time Points



PART-O. This 18-item instrument was developed by the Participation Special Interest Group within TBIMS to understand participation restrictions using telephone interview methodology. This instrument is a combination of other instruments measuring participation in TBI (Whiteneck et al., 2011). The TBIMS ND provides mean scores across the domains of productivity, social relations and community involvement (also referred to as being “out and about”). Figure 15 illustrates the mean scores across the three domains of the PART-O and displays the summary score. In general, TBIMS ND patients had high scores for the social domain, followed by “out and about,” and productivity. It is important to note that this variable

was introduced in the dataset in 2007. A general increasing trend exists across all of the domains in participation which indicates an improved situation for TBIMS patients measured at the successive time points. There is a drop in participation scores between year 10 and year 15, with an increase in year 20.

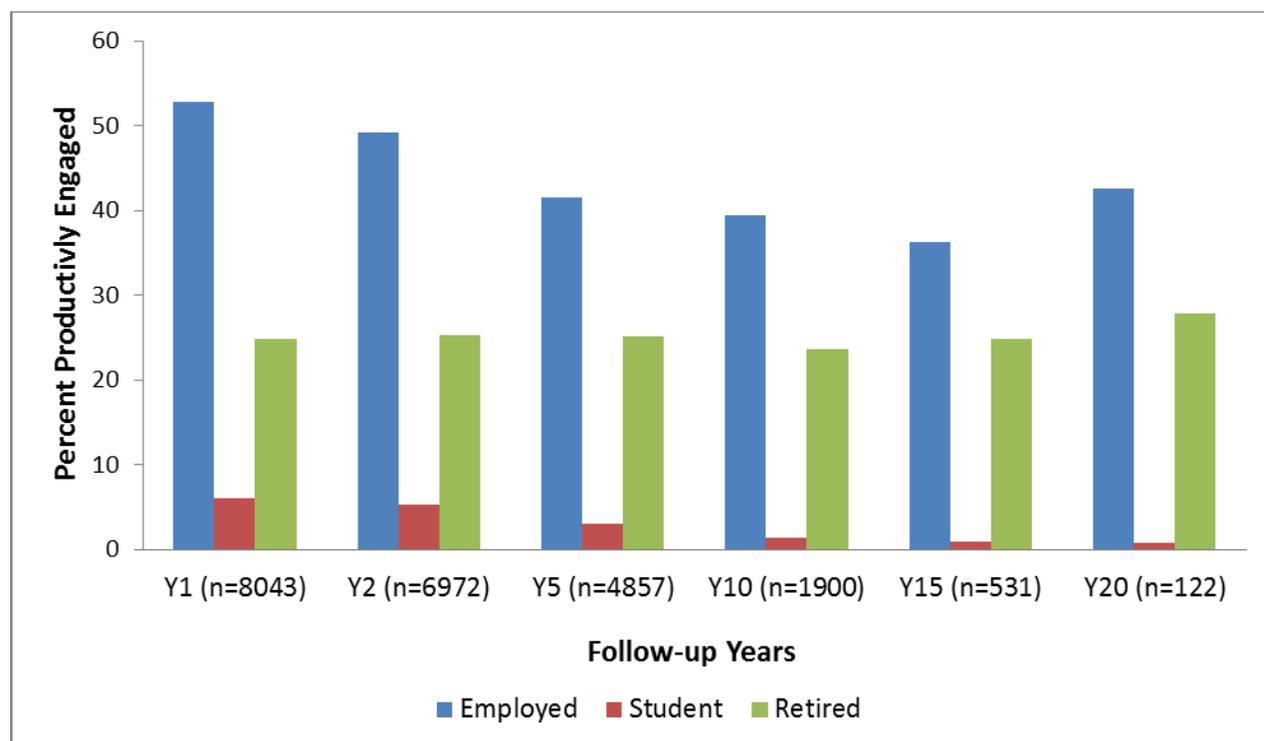
Figure 15. Participation Scores by Follow-up Time Points



Productive Engagement. This variable measures productive engagement (i.e., participation in work and/or education) for TBIMS ND participants. We observe a declining trend in employment (includes competitive employment, special employment, unemployed looking for work, volunteering, and on unpaid leave from work) across all the follow-up time points with the exception of 20 years post-injury and trends in retirement increase substantially at

15 and 20 years post-injury (Figure 16). It is important to note that data were missing for about 15-35% of individuals in each follow-up year and, therefore, should be used with caution.

Figure 16. Productive Engagement across Follow-up Time Points

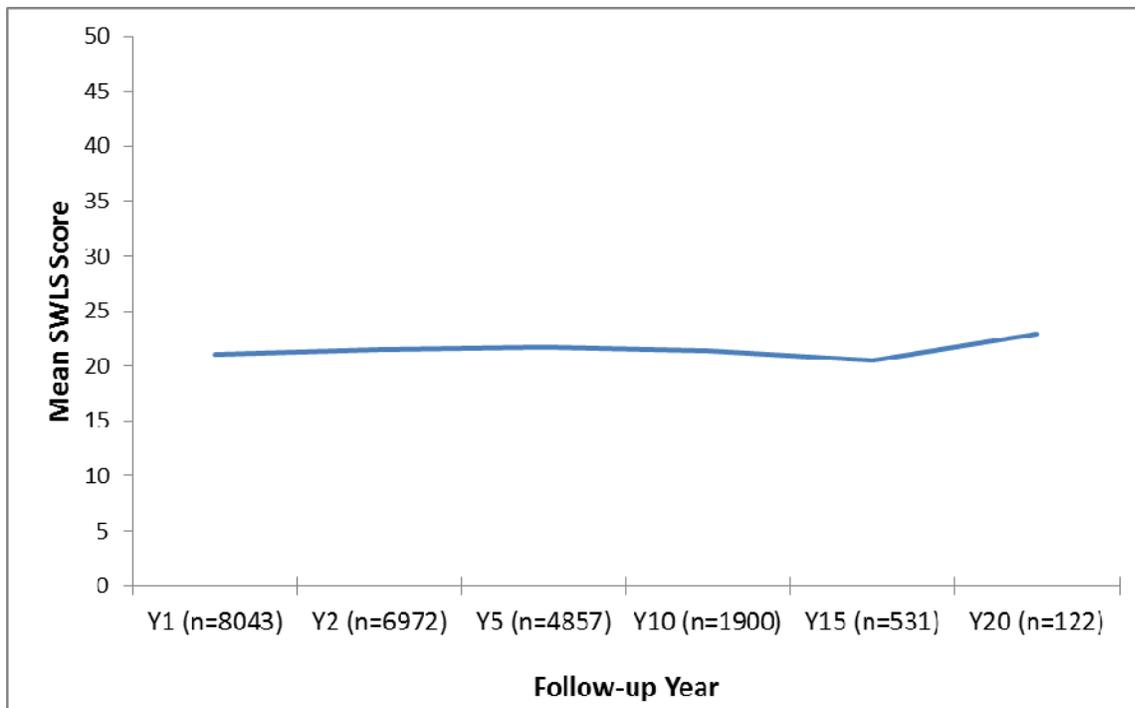


Annual Earnings. This variable collects information on annual income from competitive employment across all jobs during the previous 12 months from the date of interview for TBIMS ND patients. This variable was added to the data collection system in 2001. In preliminary analysis, 75 - 80% of the data were missing, despite restricting the sample to follow-up data collected after 2001. This lack of data may be due to the fact that earnings are only reported for those who are competitively employed. No results of preliminary analysis are reported here and users are cautioned about the extent to which this variable is missing data.

Satisfaction With Life Scale (SWLS). Developed by Diener and colleagues in 1985, the SWLS is an instrument used to measure one's satisfaction with life based on one's comparison of one's own life circumstances to self-established standards. Pavot and Diener (1993) provide a full review of psychometric properties of SWLS. Satisfaction with life is not only a marker of subjective sense of recovery among individuals with TBI (Cicerone et al., 2004), but also forms a key construct of an individual's quality of life after TBI (Dijkers, 2004). The SWLS was added to the TBIMS ND in 1998.

Figure 18 illustrates trends in the SWLS for TBIMS NDC participants during the follow-up years. The trends in SWLS have remained consistent across the time points around the average score of 20 - a neutral point where respondents are equally satisfied or dissatisfied.

Figure 17. Satisfaction With Life Scale Mean Scores by Follow-up Time Points



Conclusion

TBIMS ND offers a rich array of follow-up data for researchers to track short-term and long-term clinical, psychosocial, and functional outcomes post-injury. However, appropriate caution must be exercised before its usage and interpretation. Users are encouraged to review this User's Guide to consider the scope of their research questions. Further, they must refer to the TBIMS ND online syllabus document (<https://www.tbindsc.org/Syllabus.aspx>) for specific information on variables and to understand changes in the patterns of response overtime. Users are encouraged to contact the TBI Model Systems National Data and Statistical Center and to seek their feedback on the ability and feasibility of using the TBIMS ND to investigate their research questions.

References

- Arango-Lasprilla, J. C., Ketchum, J. M., Cifu, D., Hammond, F., Castilo, C., Nicholls, E., Wantnabe, T., & Lequerica, A. (2010). Predictors of extended rehabilitation length of stay after traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*, 91, 1495 – 1504.
- Bay, E. H., Blow, A. J., & Yan, X. (2011). Interpersonal relatedness and psychological functioning following traumatic brain injury: Implications for marital and family therapists. *Journal of Marital & Family Therapy*, 38 (3), 556 – 567.
- Boake, C. (1996). Supervisory Rating Scale: A measure of functional outcome from brain injury. *Archives of Physical Medicine & Rehabilitation*, 77, 765 – 772.
- Cicerone, K. D., Mott, T., Azulay, J., & Freil, J. C. (2004). Community integration and satisfaction with functioning after intensive cognitive rehabilitation after traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*, 85 (6), 943 – 950.
- Corrigan, J., D., Cuthbert, J., P., Whiteneck, G., G., Dijkers, M., P., Coronado, V., Heinemann, A., W., Harrison-Felix, C., & Graham, J., E. (2012). Representativeness of the Traumatic Brain Injury Model Systems National Database. *Journal of Head Trauma Rehabilitation*, 27(6), 391 – 403.
- Cowen, T. D., Meythaler, J. M., DeVivo, M. J., Ivie, C. S. 3rd, Lebow, J., & Novack, T. A. (1995) Influence of early variables in traumatic brain injury on functional independence measure scores and rehabilitation length of stay and charges. *Archives of Physical Medicine & Rehabilitation*, 76, 797-803.

- Crepeau, F. & Scherzer, P. (1993). Predictors and indicators of work status after traumatic brain injury: A meta-analysis. *Neuropsychological Rehabilitation*, 3 (1), 5 – 35.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment*, 49, 71 – 75.
- Dijkers, M. P. (2004). Quality of life after traumatic brain injury: A review of research approaches and findings. *Archives of Physical Medicine & Rehabilitation*, 85 (S2), 21 – 35.
- Hammond, F. M., Grattan, K. D., Sasser, H., Corrigan, J. D., Bushnik, T., & Zafonte, R. D. (2001). Long-term recovery course after traumatic brain injury: A comparison of the Functional Independence Measure and Disability Rating Scale. *Journal of Head Trauma & Rehabilitation*, 16 (4), 318 – 329.
- Jennett, B., Snoek, J., & Bond, M. R. (1981). Disability after severe head injury: Observations on the use of the Glasgow Outcomes Scale. *Journal of Neurology, Neurosurgery & Psychiatry*, 44, 285 – 293.
- Kreonke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16 (9), 606 – 613.
- Pavot, W. & Diner, E. (1993). Review of the Satisfaction With Life Scale. *Psychology Assessment*, 5 (2), 164 – 172.
- Pettigrew, L.E., Wilson, J.T., & Teasdale, G.M. (1998). Assessing disability after head injury: improved use of the Glasgow Outcome Scale. *Journal of Neurosurgery*, 6, 939–943.

- Rao, N., Kilgore, K. M. (1992) Predicting return to work in traumatic brain injury using assessment scales. *Archives of Physical Medicine & Rehabilitation*, 73, 911–916.
- Rappaport, M., Hall, K. M., Hopkins, K., Belleza, T., & Cope, D. N. (1982) Disability rating scale for severe head trauma: Coma to community. *Archives of Physical Medicine & Rehabilitation*, 63, 118–123.
- Rees, P. M. (2003). Contemporary issues in mild traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*, 84 (12), 1885 – 1894.
- Shames, J., Treger, I., Ring, H., & Giaquinto, S. (2007). Return to work following traumatic brain injury: Trends and challenges. *Disability and Rehabilitation*, 29 (17), 1387 – 1395.
- Spitzer, R. L., Kroenke, K., Williams, J. B. & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder. *Archives of Internal Medicine*, 166, 1092 – 1097.
- Webb, C. R., Wrigley, M., Yoels, W., Fine, P. R. (1995) Explaining quality of life for persons with traumatic brain injuries 2 years after injury. *Archives of Physical Medicine & Rehabilitation*, 76, 1113–1119.
- Whiteneck, G. G., Dijkers, M. P., Heinemann, A. W., Bogner, J. A., Bushnik, T. , Cicerone, K. D., . . . Mills, S. R. (2011). Development of participation assessment with recombined tools – Objective for use after traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*, 92, 542 – 551.
- Whitlock, J. A., & Hamilton, B. B. (1995) Functional outcome after rehabilitation for severe traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*, 76, 1103–1112.

Wright, J. (2000). The FIM™. The Center for Outcome Measurement in Brain Injury.

<http://www.tbims.org/FIM> (accessed on January 30, 2013).

Zafonte, R. D., Hammond, F. M., Mann, N. R., Black, K. L., & Mills, S. R. (1996). Relationship between Glasgow coma scale and functional outcome. *American Journal of Physical Medicine & Rehabilitation*, 75 (5), 364 – 369.

Zafonte, R. D., Mann, N. R., Mills, S. R., Black, K. L., Wood, D. L., & Hammond, F. (1997) Posttraumatic amnesia: Its relation to functional outcome. *Archives of Physical Medicine & Rehabilitation*, 78 (10), 1103 – 1106.

Zafonte, R., Ricker, J., Lobmard, L., Mann, N., & Black, K. (1996). Does the requirement of craniotomy predict outcomes? A preliminary investigation. *Brain Injury*, 13 (1), 31 – 38.



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