The Traumatic Brain Injury Model Systems

A project funded by the U.S. Department of Health and Human Services

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Project Design

• The first prospective, longitudinal multi-center study ever conducted which examines the course of recovery and outcomes following the delivery of a coordinated system of acute neurotrauma and inpatient rehabilitation.

• Includes large scale follow-up to 30 years post-injury.
History of TBIMS

• TBIMS is one of three Model Systems programs sponsored by NIDILRR
  – Spinal Cord Injury Model Systems
    ▪ 1970: Established with 14 centers
  – Traumatic Brain Injury Model Systems
    ▪ 1987: Established with 5 centers
    ▪ 1998: Increased to 17 centers
    ▪ Currently: 16 Centers and 3 Follow-up Centers
  – Burn Injury Model Systems
    ▪ 1994: Established with four centers
2017-2022 Project Priorities

Conduct research that contributes to evidence-based rehabilitation interventions and clinical and practice guidelines which improve the lives of individuals with TBI.
Requirements of TBIMS Centers

• Clinical Care: Provide a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with TBI including:
  ▪ Emergency medical services, Level 1 Trauma Center(s)
  ▪ Acute neurosurgical care
  ▪ Comprehensive inpatient rehabilitation services
  ▪ Long-term interdisciplinary follow-up and rehabilitation services
Requirements of TBIMS Centers

• Knowledge Generation
  – Conduct one or two center-specific studies
  – Participate in at least one multicenter (module) study
  – Collect and submit longitudinal data for inclusion in the TBIMS National Database
  – Optional: Participate with other TBIMS Centers in separately funded NIDILRR collaborative research grants

• Knowledge Translation
  – Collaborate with the Model Systems Knowledge Translation Center (MSKTC) to provide scientific results and information to stakeholders
Current Traumatic Brain Injury Model Systems

- **Currently Funded**
- **Follow-up Center**
- **Previously Funded**

[Map of the United States showing the current model systems in blue, follow-up centers in green, and previously funded in orange.]
TBI Model Systems Leadership

• Federal Project Management
  – National Institute on Disability, Independent Living, and Rehabilitation Research, A. Cate Miller, PhD, Project Manager

• National Data and Statistical Center
  – Craig Hospital, Englewood, CO, Cindy Harrison-Felix, PhD, Project Director

• TBI Model Systems Centers
  – Executive Committee Chair, Flora Hammond, PhD
## TBIMS Centers: 2017-22

<table>
<thead>
<tr>
<th>TBIMS Center</th>
<th>Principal Investigator</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Alabama at Birmingham</td>
<td>Thomas Novack</td>
<td>AL</td>
</tr>
<tr>
<td>Craig Hospital</td>
<td>Cindy Harrison-Felix</td>
<td>CO</td>
</tr>
<tr>
<td>Rehabilitation Institute of Michigan</td>
<td>Robin Hanks</td>
<td>MI</td>
</tr>
<tr>
<td>Indiana University-Rehabilitation Hospital of Indiana</td>
<td>Flora Hammond</td>
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<tr>
<td>Spaulding Rehabilitation-Harvard</td>
<td>Joseph Giacino</td>
<td>MA</td>
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<tr>
<td>Mayo Clinic</td>
<td>Allen Brown</td>
<td>MN</td>
</tr>
<tr>
<td>Kessler Foundation Research Center</td>
<td>Nancy Chiaravalloti</td>
<td>NJ</td>
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<tr>
<td>Mount Sinai School of Medicine</td>
<td>Kristen Dams-O’Connor</td>
<td>NY</td>
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<tr>
<td>NYU Medical Center-Rusk Institute</td>
<td>Tamara Bushnik</td>
<td>NY</td>
</tr>
<tr>
<td>Ohio State University</td>
<td>Jennifer Bogner</td>
<td>OH</td>
</tr>
<tr>
<td>JFK – Johnson Rehabilitation Institute</td>
<td>Keith Cicerone</td>
<td>NJ</td>
</tr>
<tr>
<td>Albert Einstein Healthcare-Moss Rehab</td>
<td>Tessa Hart</td>
<td>PA</td>
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<tr>
<td>TIRR Memorial Hermann</td>
<td>Mark Sherer</td>
<td>TX</td>
</tr>
<tr>
<td>Baylor Research Institute</td>
<td>Simon Driver</td>
<td>TX</td>
</tr>
<tr>
<td>Virginia Commonwealth University</td>
<td>Jeffrey Kreutzer</td>
<td>VA</td>
</tr>
<tr>
<td>University of Washington</td>
<td>Jeanne Hoffman</td>
<td>WA</td>
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# TBIMS Follow-up Centers: 2017-22

<table>
<thead>
<tr>
<th>TBIMS Center</th>
<th>Principal Investigator</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Rehabilitation Research Center/Santa Clara Valley Health and Hospital Systems</td>
<td>Thao Duong</td>
<td>CA</td>
</tr>
<tr>
<td>University of Pittsburgh</td>
<td>Amy Wagner</td>
<td>PA</td>
</tr>
<tr>
<td>Carolinas Rehabilitation/Carolinas HealthCare System</td>
<td>Shanti Pinto</td>
<td>NC</td>
</tr>
</tbody>
</table>
TBIMS Collaborative Studies 2012-17

• Multicenter Evaluation of Memory Remediation After TBI with Donepizil

  – This proposed study will definitively establish whether, and to what extent, donepezil is an effective treatment for functionally important TBI-related memory deficit. The project is a four-site, randomized, parallel design, double-blind, placebo-controlled, 10-week trial of donepezil 10 mg daily for verbal memory problems among adults with TBI in the subacute or chronic recovery period. Data will be acquired with which to assess the effects of donepezil on attention, processing speed, neuropsychiatric symptoms, community participation, quality of life, and caregiver experiences. Findings from this study will influence the practices of prescribing healthcare providers and contribute information that will improve lives of persons with TBI and their families. David B. Arciniegas, MD, TIRR Memorial Hermann, is the Principal Investigator.
## Study Type

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Study Topics</th>
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<tbody>
<tr>
<td><strong>Intervention</strong></td>
<td>Problem Solving Training (PST) for Care Partners of Adults with Traumatic Brain Injuries (TBI) during Inpatient Rehabilitation.</td>
</tr>
</tbody>
</table>
| **Assessment and Prediction of Outcomes** | Caregiver Resilience A Longitudinal Investigation  
Health Literacy Following Traumatic Brain Injury and Impact on Health-Related Outcomes  
Menopause in Women with TBI  
Return to Driving after Moderate-Severe TBI  
Partnering with Caregivers to Increase Knowledge of the Post-Acute Phase of Recovery From Severe TBI  
Physical Activity and its relationship with cognition and secondary conditions after TBI  
Trajectories of Cognitive Functioning Years after TBI  
Alexithymia Prevalence & Relationships to Patient Characteristics & Outcome in TBIMS Cohort |
| **Analytical** | Development and Assessment of Crosswalks in the TBIMS Database |

* Module Studies and Collaboratives Grants
Characterization and Treatment of Chronic Pain after Moderate to Severe Traumatic Brain Injury

- The aims of this study are to: 1) Determine chronic pain classification, prevalence, location, duration and associations with demographic, injury severity, functioning, and comorbidities; 2) Identify and compare chronic pain extreme phenotype characteristics across two outcomes – impact of chronic pain on daily life and overall perceptions of improvement.; and 3) Identify treatment practices by clinicians who treat comorbid TBI and chronic pain to determine gaps in availability/accessibility of multidisciplinary pain treatment. Cindy Harrison-Felix, PhD (Craig Hospital), Jeanne Hoffman, PhD (University of Washington) and Kimberley Monden, PhD (Craig Hospital) are the Principal Investigators on the study.
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.
Database Inclusion Criteria

• Moderate to severe TBI (PTA>24 hrs or LOC>30 minutes or GCS in ED<13 or intracranial neuroimaging abnormalities)
• Admitted to system’s hospital emergency department within 72 hours of injury.
• 16 years of age or older at the time of injury
• Receives acute care and comprehensive inpatient rehabilitation within the model system hospitals.
• Informed consent is signed by patient, family or guardian.
Database Objectives

• Aim of the TBIMS National Database (NDB): Generate new and useful knowledge about the short- and long-term outcomes for people with TBI

• Objectives
  – Study the clinical course of individuals with TBI from time of injury through discharge from acute care and rehabilitation care.
  – Evaluate the recovery and long-term outcome of individuals with TBI.
  – Establish a basis for comparison with other data sources.
NIDILRR TBI National Database

- Method: Repeated surveys of individuals post injury at regular intervals
- Form I: Inpatient rehabilitation discharge; administered in-person: 285 variables
- Form II: Follow-up conducted 1, 2, 5, and every 5 years thereafter; administered via telephone (primarily), in-person or mail questionnaire; 243 variables
NIDILRR TBI National Database (cont.)

- Form I – 16,495 cases (as of 3/31/2018)
- Form II – 57,498 follow-ups* - 17% attrition (4%**)
  - Year 1 – 15,892 – 13% attrition (2%**)
  - Year 2 – 14,278 – 14% attrition (4%**)
  - Year 5 – 11,608 – 16% attrition (9%**)
  - Year 10 – 6,877 – 18% attrition (7%**)
  - Year 15 – 3,034 – 17% attrition (10%**)
  - Year 20 – 794 – 15% attrition (0%**)
  - Year 25 – 274 – 15% attrition (0%**)

*There are some follow-ups in database that were performed at 3, 4, and 6 years post-injury.

**Additional percent attrition due to loss of center funding.
TBI NDB Representativeness

- Applicability of TBIMS findings are dependent on the degree to which the TBIMS NDB reflects the larger population of people with TBI
- By definition, the TBI NDB focuses on moderate to severe TBI
- Concern that the TBIMS NDB has a biased sample of cases
- Recent comparison with Uniform Data System for Medical Rehabilitation (UDS) and eRehabData alleviates much of that concern
- Developed ability to weight NDB to represent population of those that receive inpatient rehabilitation to TBI in the US
Study Limitations

• Lack of control or comparison group
• Lack of uniformity in treatment across all Centers
• Attrition in follow-up
• Inability to systematically track post-acute service utilization
• Limited follow-up evaluations if Center defunded
NIDILRR TBI Interagency Database Collaborations

• IAAs between Centers for Disease Control and Prevention (CDC) and NIDILRR (FY2011-FY2012)
  – Population Estimates of Health and Social Outcomes 5 Years after Rehabilitation for Traumatic Brain Injury
  – Epidemiology of Adults Receiving Acute Inpatient Rehabilitation for a Primary Diagnosis of Traumatic Brain Injury in the United States
  – Effect of Alcohol Misuse on Outcomes 5 Years Following Acute Rehabilitation for Traumatic Brain Injury

• IAAs between Centers for Disease Control and Prevention (CDC) and NIDILRR (FY2012-FY2013)
  – Life Expectancy following inpatient rehabilitation for a primary diagnosis of TBI in the US.
  – Factors influencing 2 year employment post-TBI.
  – Predictors of deterioration and improvement 5 years post TBI.
NIDILRR TBI Interagency Database Collaborations (cont.)

- IAAs between Department of Veterans Affairs (VA) and NIDILRR (FY2008-2013)
- VA TBI Veterans Health Registry (Congressional mandate)
  - Includes those serving in Operation Enduring Freedom/Operation Iraqi Freedom who exhibit symptoms associated with TBI, and apply for services or file a disability claim.
  - TBIMS National Data and Statistical Center (NDSC), together with VA and NIDILRR, design studies, conduct analyses, and generate reports
- VA Polytrauma Rehabilitation Centers (PRC) Database
  - Includes those admitted to the VA PRCs with a diagnosis of TBI
  - Includes most variables currently in TBIMS NDB; follows TBIMS NDB procedures and data collection schedules
NIDILRR TBI Interagency Database Collaborations (cont.)

• Contracts between Department of Veterans Affairs (VA) and NDSC (FY2016-present)

• VA TBI Veterans Health Registry (Congressional mandate)
  – Includes those serving in Operation Enduring Freedom/Operation Iraqi Freedom who exhibit symptoms associated with TBI, and apply for services or file a disability claim.
  – TBIMS National Data and Statistical Center (NDSC), together with VA and NIDILRR, design studies, conduct analyses, and generate reports

• VA Polytrauma Rehabilitation Centers (PRC) Database
  – Includes those admitted to the VA PRCs with a diagnosis of TBI
  – Includes most variables currently in TBIMS NDB; follows TBIMS NDB procedures and data collection schedules
155 Studies Use the TBIMS NDB

- Peer reviewed publications have used the TBIMS NDB
  - Epidemiology of moderate to severe TBI
  - Natural history of TBI outcomes and comorbidities
  - Predictors of TBI outcomes and comorbidities
  - Validation of severity and outcome measurement
  - Longitudinal change over time
TBIMS Accomplishments

• An additional 400 peer reviewed publications from TBIMS research include a wide range of topics
  – Patient and injury characteristics
  – Prognostic factors
  – Comorbidities
  – Outcomes research
  – Treatment effectiveness
  – Health service research
TBIMS Accomplishments (cont.)

• Development of practice parameters in important areas of TBI care
  – Management of post-traumatic seizures
  – Spasticity
  – Post-traumatic agitation
  – Substance misuse
  – Family intervention
  – Driving
TBIMS Accomplishments (cont.)

- Development of innovative interventions for the acute phase of recovery
  - DVT prophylaxis
  - Amantadine for Disorders of consciousness
  - Amantadine for irritability
  - Adaptation of acute rehab for older adults
  - Care-giver support
  - Telephone follow-up
• Creation of novel diagnostic procedures and measurement instruments
  – Post-traumatic amnesia (O-Log; JFK CRS)
  – Participation (CIQ; PART)
  – Agitation (ABS)
  – Attention (MARS)
  – Disability+ (DRS; MPAI)
  – Neurobehavioral functioning (NFI)
  – Lifetime TBI (OSU-TBI-ID)
TBIMS Accomplishments (cont.)

- O-Log = The Orientation Log
- JFK CRS = Coma Recovery Scale
- CIQ = Community Integration Questionnaire
- PART = Participation Assessment with Recombined Tools
- ABS = Agitated Behavior Scale
- MARS = Moss Attention Rating Scale
- DRS = Disability Rating Scale
- MPAI = Mayo Portland Adaptability Inventory
- NFI = Neurobehavioral Functioning Inventory
- OSU-TBI-ID = Ohio State University TBI Identification Method
TBIMS Accomplishments (cont.)

• Identification of adverse rehabilitation outcomes common to TBI and associated risk factors
  – TBIMS research has shown longer PTA, unawareness of deficits, depression, substance abuse, fatigue, minority status, older age to be risk factors for worse outcomes
  – TBIMS research has documented mortality risk after TBI
TBIMS Accomplishments (cont.)

• Characterization of the recovery trajectory in the years following injury
  – Functional independence, satisfaction with life, cognitive abilities, employment, residence, etc. have all been characterized from the TBIMS data in both the initial two years post-injury and now more than a decade post-injury
TBIMS Accomplishments (cont.)

• Creation of user-friendly, web-based resources for people with brain injury, their caregivers, and professionals
  – Center on Outcome Measurement in Brain Injury (COMBI)
  – TBIMS NDB syllabus
  – MSKTC fact sheets
  – TIRR web-based materials for care-givers
Other NIDILRR TBI Interagency Collaborations

• Research-based Initiatives to Advance Treatment/Services
  – 3rd Federal Interagency Conference on TBI (Sponsors: NIDILRR, DoD, VA, NIH, CDC and others).
  – Guidelines for the Treatment of Disorders of Consciousness post TBI (Sponsors: NIDILRR/American Academy of Neurology/American Congress of Rehabilitation Medicine)
  – Guidance for the Acute Diagnosis and Management of Mild Traumatic Brain Injury (mTBI) among Children and Adolescents (Sponsor: CDC)
  – Cognitive Rehabilitation for mTBI (Sponsor: DoD)
  – Driving evaluations post TBI (Sponsor: DoD)
Other NIDILRR TBI Interagency Collaborations (cont.)

- Consensus Initiatives to Advance Research
  - Common Data Elements (CDE) for TBI Research (Sponsors: DoD, NINDS, NIDILRR, DVBIC, VA)
  - FITBIR Federated Database (Sponsors: NIH/DoD)
  - Report to Congress on Rehabilitation Post TBI (Sponsor: CDC)
  - Future Research Needs for Multidisciplinary Postacute Rehabilitation for Moderate to Severe TBI in Adults (Sponsor: AHRQ)
  - State-of-the-Science Report on Sports-related Concussions in Youth (Sponsors: IOM & 10 partners, including NIDILRR)
  - Cognitive Rehabilitation Therapy Workshop (Sponsor: IOM/DoD)
Data Categories

• Demographic characteristics of the population
• Causes and severity of injury
• Nature of diagnoses
• Characteristics of treatment/services
• Impairment
• Health and Behavior Measurements
• Disability
• Participation
### I. Demographic Characteristics

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Form 1 (acute injury and hospitalization)</th>
<th>Form 2 (annual follow-up)</th>
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<tr>
<td>Age</td>
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</tr>
<tr>
<td>Gender</td>
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<td></td>
</tr>
<tr>
<td>Race / Ethnicity</td>
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<td>✓</td>
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<tr>
<td>Height / Weight</td>
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<tr>
<td>Primary Language</td>
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<tr>
<td>Country of Birth</td>
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<tr>
<td>Military History</td>
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</table>
## II. Causes / Severity of TBI

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<th>Form 1 (acute injury and hospitalization)</th>
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<tr>
<td>Date of Injury</td>
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<tr>
<td>ICD External Causes of Injury</td>
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<tr>
<td>Glasgow Coma Scale Score</td>
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<tr>
<td>Time to Follow Commands (duration of unconsciousness)</td>
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<td></td>
</tr>
<tr>
<td>Duration of Post Traumatic Amnesia</td>
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## III. Diagnoses

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<td>Spinal Cord Injury</td>
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<tr>
<td>Intracranial CT Scan Reports</td>
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<td>Neuropsychological Assessment (BTACT)</td>
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<td>ICD Diagnosis Codes</td>
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## IV. Treatments

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<td>Lengths of Stay</td>
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<td>Craniotomy</td>
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<td>Rehospitalizations</td>
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<td>Lifetime History of TBI</td>
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<tr>
<td>Seizures</td>
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## VI. Health / Behavior

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<th>Form 1 (acute injury and hospitalization)</th>
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<td>Arrests/felony incarcerations</td>
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<td>Learning/behavior problems</td>
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<td>PHQ 9 – Depression</td>
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<td>GAD 7 – Anxiety</td>
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<td>Satisfaction with Life Scale (SWLS)</td>
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## VII. Disability

<table>
<thead>
<tr>
<th>Measure</th>
<th>Form 1 (acute injury and hospitalization)</th>
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<tr>
<td>Functional Independence Measure (FIM)</td>
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<tr>
<td>Glasgow Outcome Scale-Extended (GOS-E)</td>
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## VIII. Participation

<table>
<thead>
<tr>
<th>Participation Assessment (PART)</th>
<th>Form 1 (acute injury and hospitalization)</th>
<th>Form 2 (annual follow-up)</th>
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<td>Living with</td>
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<tr>
<td>Residence (e.g., private home, SNF, AFC, hospital)</td>
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<td>Address (w/consent)</td>
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<tr>
<td>Marital Status</td>
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<td>Employment</td>
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<tr>
<td>Education</td>
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<tr>
<td>Transportation</td>
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</tbody>
</table>
Sources of Data

- Abstract from medical records
- Pre-existing database
- Specialized data collection forms
- Patient examination/interview/testing
- Family interview
Guidelines for Follow-up

• Follow-up contact attempted with every patient 1st, 2nd, 5th years and then every five years.

• 4 month window for year 1 follow-up, 6 month window for year 2, 1 year window for years 5, 10, 15, . . .

• Patient is primary source of follow-up information; if patient cannot be interviewed, follow-up is attempted with a proxy.

• Methods of follow-up in order of priority: phone/in-person, mail questionnaire.
Data Quality Checks

• Data entry screens:
  – Checks for valid codes and correct range
  – Logical checks between variables
  – Consistency checks between variables across time
Data Quality Checks (cont.)

• User-initiated database reports:
  – Identify cases with errors or blanks
  – Notify of follow-ups coming due
  – Warnings about overdue follow-ups
  – Calculate missing data rates
  – Calculate follow-up rates
Internal Dissemination

• Annual Data Summary
• Quarterly Data Quality Reports
  – Enrollment
  – Retention
  – Missing Data
External Dissemination

- Internet [www.tbindsc.org]
  - Online Database Syllabus
  - Annually updated TBI Model Systems PowerPoint Presentation
- National/International Presentations
- Journal Publications
Welcome to the NDSC

The Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) located at Craig Hospital in Englewood, Colorado, is a central resource for researchers and data collectors within the Traumatic Brain Injury Model Systems (TBIMS) program. The primary purpose of the TBINDSC is to advance medical rehabilitation by increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of individuals with traumatic brain injury (TBI). The TBINDSC provides technical assistance, training, and methodological consultation to 16 TBIMS centers as they collect and analyze longitudinal data from people with TBI in their communities, and as they conduct research toward evidence-based TBI rehabilitation interventions.

Below are links to the TBIMS Presentation and TBIMS Update, which has information about the individual model systems and descriptions of the injury and follow-up data that are being collected.

### Publications
- 2012 TBI Model Systems Presentation
- 2012 TBI Model Systems National Database Update
- 2010 TBI Model Systems Brochure

### Links to other Model Systems Programs
- National Spinal Cord Injury Statistical Center
- Burn Model Systems Data Coordinating Center
- Model Systems Knowledge Translation Center
Online TBI Model Systems National Database Syllabus

### Syllabus


### Printed Syllabus

#### Online TBI Model Systems National Database Syllabus

Select which Form Variables you would like to see. Form I variables are the variables asked about the initial rehabilitation stay. Form II variables are questions asked to an individual at follow-up. Once you select Form I or Form II you have a choice of viewing either the actual fields that the variable group has ("Show Fields"). or you can view the data dictionary page ("Select") for the selected variable group.

**Select which form you want to see:** Form 1

<table>
<thead>
<tr>
<th>Order</th>
<th>Group ID</th>
<th>Variable Group Name</th>
<th># of Variables</th>
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<tbody>
<tr>
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<td>INJURY DATE</td>
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<tr>
<td>60</td>
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<td>PAYOR SOURCE</td>
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<tr>
<td>80</td>
<td>CSEINJ</td>
<td>CAUSE OF INJURY</td>
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<tr>
<td>90</td>
<td>CSEICD</td>
<td>ICD-9 CM EXTERNAL CAUSE OF INJURY CODE</td>
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<tr>
<td>100</td>
<td>DIAGICD</td>
<td>ICD-9 CM DIAGNOSIS CODES</td>
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<tr>
<td>110</td>
<td>AISCN</td>
<td>ASSOCIATED INJURY - SPINAL CORD INJURY</td>
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<tr>
<td>120</td>
<td>GCS</td>
<td>GLASGOW COMA SCALE</td>
<td>4</td>
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<tr>
<td>130</td>
<td>FLW</td>
<td>DATE ABLE TO FOLLOW COMMANDS</td>
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<tr>
<td>140</td>
<td>ICP</td>
<td>CRANIAL COMPLICATIONS - INTRACRANIAL HYPERTENSION</td>
<td>1</td>
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<tr>
<td>150</td>
<td>CRANIO</td>
<td>CRANIAL SURGERY - CRANIOTOMY/CRANECTOMY</td>
<td>1</td>
</tr>
<tr>
<td>160</td>
<td>PTA</td>
<td>DATE EMERGED FROM PTA</td>
<td>2</td>
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</tbody>
</table>
The Model Systems Knowledge Translation Center (MSKTC) aims to:

- **Enhance** the relevance and visibility of Model Systems research
- **Communicate** Model Systems research effectively to stakeholders

The MSKTC is operated by American Institutes for Research in collaboration with WETA/BrainLine and George Mason University
Three overarching goals guide the work of the MSKTC:

**Goal 1**: Enhance the understanding of the quality and relevance of knowledge among researchers and multiple users on the topics of SCI, TBI, and Burn

**Goal 2**: Enhance knowledge of advances in SCI, TBI, and Burn research among the diverse audience members who need this information

**Goal 3**: Create a centralized repository of empirical information and resources on research in SCI, TBI, and Burn areas and actively conduct outreach and dissemination activities to communicate this knowledge
### MSKTC Activities
#### 2011-2014 Highlights

<table>
<thead>
<tr>
<th>Completed</th>
<th>In Process</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Systematic Reviews</strong></td>
<td>• TBI &amp; Fatigue</td>
</tr>
<tr>
<td></td>
<td>• TBI &amp; Medical Outcomes</td>
</tr>
<tr>
<td><strong>Consumer Factsheets</strong></td>
<td>• TBI &amp; Couples’ Relationship</td>
</tr>
<tr>
<td><strong>Knowledge Translation Webinar</strong></td>
<td>• TBI &amp; Vocational Rehabilitation</td>
</tr>
<tr>
<td>• Planning for Communities of Practice: Model Systems Grantees</td>
<td>• TBI &amp; Vision Problems</td>
</tr>
<tr>
<td>• Getting to Outcomes: A Knowledge Translation Webinar for Model Systems Grantees</td>
<td>• TBI &amp; Spasticity</td>
</tr>
<tr>
<td>• Engaging with Audiences: A Learning Collaborative</td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge Translation Toolkit</strong></td>
<td>• Additional Knowledge Translation Webinars</td>
</tr>
<tr>
<td>• Newsletter Template and Instructions</td>
<td>• Additional tools for the Knowledge Translation tools</td>
</tr>
<tr>
<td>• Press Release Template and Instructions</td>
<td></td>
</tr>
<tr>
<td>• 508 Compliance Tip sheet</td>
<td></td>
</tr>
<tr>
<td>• Tips on Presenting facts and figures</td>
<td></td>
</tr>
<tr>
<td><strong>Multimedia Products</strong></td>
<td>• Hot Topics Module</td>
</tr>
<tr>
<td><strong>Slideshows</strong></td>
<td>• Depression after TBI</td>
</tr>
<tr>
<td>• TBI &amp; Alcohol</td>
<td><strong>Slideshows</strong></td>
</tr>
<tr>
<td>• TBI &amp; Sexuality</td>
<td>• Depression after TBI</td>
</tr>
<tr>
<td>• TBI &amp; Couples’ Relationship</td>
<td></td>
</tr>
<tr>
<td>• TBI &amp; Emotional Problems</td>
<td></td>
</tr>
<tr>
<td><strong>Hot Topics Module</strong></td>
<td></td>
</tr>
<tr>
<td>• Relationships after TBI</td>
<td></td>
</tr>
</tbody>
</table>
TBIMS National Database
Descriptive Data Summary

[Includes data from 01/01/1989 – 12/31/2017]
Age

mean = 41.87; n = 16497
Gender

Male: 74%
Female: 26%

n = 16490
Race

- White: 67%
- Black: 18%
- Hispanic: 11%
- Asian: 3%
- Others: 1%

n = 16486
Level of Education At Injury

- High School/GED: 35%
- Some College: 23%
- Greater than Bachelors: 16%
- Less than High School: 26%

n = 16237
Summary

- Demographic Characteristics of the Population
  - Average age = 41.87
  - Male (74%)
  - Minority population (33%)
  - High school education or less (61%)
Etiology of Injury

- Vehicular: 51%
- Falls: 27%
- Violence: 11%
- Other: 11%

n = 16453
Glasgow Coma Scale Score

At Emergency Department Admission

- **Severe**: 44%
- **Mild**: 41%
- **Moderate**: 15%

mean = 9.67; n = 12710
Duration of Unconsciousness

- <=1: 46%
- >29: 7%
- 15 Thru 28: 10%
- 8 Thru 14: 12%
- 2 Thru 7: 25%
- n = 15846

mean = 7.86 days
Duration of PTA

- Mean = 22.89 days; n = 12835

- 1 Thru 7 (Moderate/Severe) 18%
- 8 Thru 28 (Very Severe) 42%
- >=29 (Extremely Severe) 31%
- <1 9%

(Moderate/Severe) (Very Severe)
Summary

• Causes of Injury
  – Primary cause is vehicular (51%), followed by falls (27%) and violence (11%)

• Severity of Injury
  – Average duration of LOC is 7.86 days
  – Average duration of PTA is 22.89 days
Mean Length of Stay

Acute Care

Rehab. Care


29 27 27 26 26 25 25 24 23 23

22 20 20 22 22 22 20 20 19 18
Summary

• Costs of Treatment
  – Total LOS has consistently decreased over the last 5 years for both acute and rehab.
  – Total acute LOS in 2017 represents the lowest in the past decade.
  – Total rehab LOS in 2017 represents the lowest in the past decade.
  – 37% have government-sponsored rehabilitation care (M’caid/M’care)
## Disability Rating Scale

<table>
<thead>
<tr>
<th>Disability Level</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>0%</td>
</tr>
<tr>
<td>Mild</td>
<td>2%</td>
</tr>
<tr>
<td>Partial</td>
<td>12%</td>
</tr>
<tr>
<td>Moderate</td>
<td>23%</td>
</tr>
<tr>
<td>Moderately Severe</td>
<td>24%</td>
</tr>
<tr>
<td>Severe</td>
<td>23%</td>
</tr>
<tr>
<td>Extremely Severe</td>
<td>16%</td>
</tr>
<tr>
<td>Vegetative State</td>
<td>5%</td>
</tr>
<tr>
<td>Extreme Vegetative State</td>
<td>2%</td>
</tr>
</tbody>
</table>

### Rehabilitation Admission (n=16197)
- None: 0%
- Mild: 2%
- Partial: 12%
- Moderate: 23%
- Moderately Severe: 24%
- Severe: 23%
- Extremely Severe: 16%
- Vegetative State: 5%
- Extreme Vegetative State: 2%

### Rehabilitation Discharge (n=16202)
- None: 0%
- Mild: 2%
- Partial: 15%
- Moderate: 23%
- Moderately Severe: 24%
- Severe: 23%
- Extremely Severe: 16%
- Vegetative State: 5%
- Extreme Vegetative State: 2%

### 1 Year Post-Injury (n=10903)
- None: 0%
- Mild: 2%
- Partial: 15%
- Moderate: 23%
- Moderately Severe: 24%
- Severe: 23%
- Extremely Severe: 16%
- Vegetative State: 5%
- Extreme Vegetative State: 2%
Disability Rating Scale

Average DRS Score

0 5 10 15 20 25 30

Rehab. Admission (n=16197) 11.85 Severe Disability
Rehab. Discharge (n=16202) 6.41 Moderate Disability
1 Yr. Post-Injury (n=10903) 2.93 Partial Disability
2 Yrs. Post-Injury (n=9386) 2.65 Partial Disability
**FIM® Instrument**

- **Rehab. Admission (n=16031)**
- **Rehab. Discharge (n=16110)**
- **Year 1 (n=12204)**
- **Year 2 (n=10467)**

*Note: The value of n is reflective of Total FIM® measure*
FIM® Instrument

Mean Scores converted to 7-point scale

Complete Independence
Modified Independence
Supervision
Minimal Assistance
Moderate Assistance
Maximal Assistance
Total Assistance

Rehab. Admit. (n=16031) 2.82
Rehab. Disch. (n=16110) 4.99
1 Yr. (n=12204) 6.29
2 Yr. (n=10467) 6.38

[national data and statistical center logo]
Glasgow Outcome Scale-Extended

Year 1 (n=11652)  Year 2 (n=10183)

Vegetative State: 1% 1%
Lower Severe Disability: 18% 15%
Upper Severe Disability: 15% 12%
Lower Moderate Disability: 11% 11%
Upper Moderate Disability: 21% 22%
Lower Good Recovery: 13% 14%
Upper Good Recovery: 21% 25%
Supervision Rating Scale

Year 1 (n=11823)
- Level 1-Independent: 63%
- Level 2-Overnight supervision: 18%
- Level 3-Part-time supervision: 6%
- Level 4- Full-time indirect supervision: 8%
- Level 5- Full-time direct supervision: 5%

Year 2 (n=10186)
- Level 1-Independent: 69%
- Level 2-Overnight supervision: 15%
- Level 3-Part-time supervision: 4%
- Level 4- Full-time indirect supervision: 7%
- Level 5- Full-time direct supervision: 5%
## Satisfaction With Life Scale

<table>
<thead>
<tr>
<th></th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 5</th>
</tr>
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<tbody>
<tr>
<td><strong>Number</strong></td>
<td>9627</td>
<td>8455</td>
<td>6222</td>
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<tr>
<td><strong>Mean</strong></td>
<td>21.26</td>
<td>21.57</td>
<td>21.90</td>
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<tr>
<td><strong>SD</strong></td>
<td>8.24</td>
<td>8.39</td>
<td>8.32</td>
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<tr>
<td><strong>Min</strong></td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Max</strong></td>
<td>35</td>
<td>35</td>
<td>35</td>
</tr>
</tbody>
</table>
Summary

• Disability Outcomes
  – DRS indicates improvement in level of disability from SEVERE DISABILITY at rehab. admission to PARTIAL DISABILITY at 1 and 2 yrs. post-injury
  – FIM® Instrument indicates improvement in functional ability from level requiring MODERATE ASSISTANCE at rehab. admission to MODIFIED INDEPENDENCE at 1 and 2 yrs. post-injury
  – SRS indicates that 37% of individuals require some level of supervision at 1 yr. post-injury and 31% at 2 yrs. post-injury.
Summary

• Disability Outcomes (cont.)
  – Most improvement in level of disability and functional ability occurs during inpatient rehabilitation
  – Continued improvement is seen at 1 yr. post-injury
  – Level of disability and functional ability appear to plateau between 1 and 2 yrs. post-injury
Residence

<table>
<thead>
<tr>
<th>Residence</th>
<th>Injury (n=16489)</th>
<th>Rehab. Disch. (n=16474)</th>
<th>1 Year (n=13038)</th>
<th>2 Years (n=11285)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private</td>
<td>98%</td>
<td>82%</td>
<td>91%</td>
<td>91%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>18%</td>
<td>9%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Marital Status

At injury (n=16451)  
- Single: 46%  
- Married: 33%  
- Divorced/ Separated: 16%  
- Widowed: 5%

Year 1 (n=12876)  
- Single: 44%  
- Married: 32%  
- Divorced/ Separated: 18%  
- Widowed: 6%

Year 2 (n=11081)  
- Single: 44%  
- Married: 31%  
- Divorced/ Separated: 19%  
- Widowed: 6%
Living Situation

Injury (n=16464)  Discharge (n=16428)  Year 1 (n=12906)  Year 2 (n=11132)

- Alone
- Spouse/S.O.
- Parent(s)
- Other Family/Relatives
- Other

% Distribution:

- Injury:
  - Alone: 18%
  - Spouse/S.O.: 41%
  - Parent(s): 11%
  - Other Family/Relatives: 8%
- Discharge:
  - Alone: 31%
  - Spouse/S.O.: 33%
  - Parent(s): 13%
  - Other Family/Relatives: 20%
- Year 1:
  - Alone: 36%
  - Spouse/S.O.: 28%
  - Parent(s): 11%
  - Other Family/Relatives: 13%
- Year 2:
  - Alone: 15%
  - Spouse/S.O.: 27%
  - Parent(s): 11%
  - Other Family/Relatives: 12%
Employment Status

- **Employed**: 61%
- **Unemployed**: 13%
- **Student**: 3%
- **Retired**: 22%
- **Other**: 6%

Injury (n=16402) Year 1 (n=12830) Year 2 (n=11035)
Summary

• Participation Outcomes
  – Most live in a private residence following rehab. discharge (82%)
  – Few live alone at rehab. discharge (3%), with the highest proportion living with parent(s) (33%), or spouse/SO (31%)
  – 29% are employed at 1 yr. post-injury (61% employed at injury)
Conclusions

• The TBI Model Systems Program:
  – Demonstrates a system of care for TBI
  – Performs several types of research
    ▪ Several center-specific clinical trials and other types of studies
    ▪ Innovative module (collaborative) studies
    ▪ A comprehensive longitudinal database already containing over 16,000 cases with up to 30 years of follow-up.