The Traumatic Brain Injury Model Systems

A project funded by the U.S. Department of Education
National Institute on Disability and Rehabilitation Research
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 20 years post-injury.
History of TBIMS

• TBIMS is one of three Model Systems programs sponsored by NIDRR
  – 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
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 NIDRR collaborative research grants

• Knowledge Translation
  – Collaborate with the Model Systems Knowledge Translation Center (MSKTC) to provide scientific results and information to stakeholders
TBI Model Systems Leadership

• Federal Project Management
  – National Institute on Disability 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, John D. Corrigan, PhD
<table>
<thead>
<tr>
<th>TBIMS Center</th>
<th>Principal Investigator</th>
<th>State</th>
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<tbody>
<tr>
<td>University of Alabama at Birmingham</td>
<td>Thomas Novack</td>
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<tr>
<td>Santa Clara Valley Medical Center</td>
<td>Tamara Bushnik</td>
<td>CA</td>
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<tr>
<td>Craig Hospital</td>
<td>Gale Whiteneck</td>
<td>CO</td>
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<tr>
<td>Rehabilitation Institute of Chicago (2008)</td>
<td>Elliot Roth</td>
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<tr>
<td>JFK-Johnson Rehabilitation Institute</td>
<td>Keith Cicerone</td>
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<td>Kessler Medical Rehab Research Center</td>
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<td>Institute for Rehab and Research-Baylor</td>
<td>Mark Sherer</td>
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<td>U of Texas Southwest Medical Center</td>
<td>Ramon Diaz-Arrastia</td>
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TBIMS Center-Specific Studies 2007-11

<table>
<thead>
<tr>
<th>Study Type</th>
<th>RCT</th>
<th>Examples of Topics</th>
</tr>
</thead>
</table>
| Drug Intervention (n=5)                 | 4   | ▪ Carbamazepine for irritability/aggression  
▪ Dextroamphetamine for attention/mood/function  
▪ Human growth hormone for function improvement  
▪ Safety and feasibility of minocycline |
| Other Intervention (n=15)               | 14  | ▪ Memory retraining  
▪ Cognitive and neurobehavioral rehabilitation  
▪ Virtual environment and robotic intervention  
▪ Family crisis and support intervention  
▪ Advocacy training  
▪ Work attendance incentive program  
▪ Home Exercise program  
▪ Visual-perceptual training for driving  
▪ Sleep augmentation and fatigue reduction program  
▪ Acupuncture as novel technique for insomnia |
| Assessment and Prediction of Outcomes (n=4) | 0   | ▪ Biomarkers of diffuse axonal injury  
▪ Relationship between fMRI and outcomes  
▪ Statistical models for predictors of function  
▪ Utility of MRI techniques: Prediction of outcome |
## TBIMS Multicenter Research 2007-11*

<table>
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<tr>
<th>Study Type</th>
<th>Study Topics</th>
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<tr>
<td>Intervention</td>
<td>• Amantadine for treatment of post-TBI irritability and aggression (RCT)</td>
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<td>Assessment and Prediction of Outcomes</td>
<td>• Natural history of headache post-TBI</td>
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<td>• Prospective study of the relationship between post-TBI fatigue and insomnia</td>
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<td>• Sexuality after TBI</td>
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<td>• Enhancing core dataset to expand research on environmental influences</td>
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<td></td>
<td>• Individualized planning for the first year following acute rehabilitation</td>
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<td>(Clinical Practice Improvement study)</td>
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* Module Studies and Collaboratives Grants
TBIMS Collaborative Studies

• TBI Model System Collaborative Study of Amantadine for Post TBI Irritability and Aggression
  – Approximately 29-71 percent of individuals with traumatic brain injury (TBI) experience the problem of irritability and/or aggression which can interfere with interpersonal interaction, relationships and function. The current medical literature does not support standards or guidelines for the management of TBI irritability or aggression. However, pilot research at Carolinas Rehabilitation has revealed that amantadine may reduce irritability and aggression severity and frequency. Flora Hammond, MD, Carolinas Rehabilitation, is the Principal Investigator
TBIMS Collaborative Studies

• Individualized Planning for the First Year Following Acute Rehabilitation Project
  
  – This Practice Based Evidence (PBE) study will identify individual differences in demographic characteristics, pre-morbid status, injury-related conditions and medical course that differentially predict the effectiveness of rehabilitation interventions on functional independence, participation and subjective well-being up to 1 year following traumatic brain injury (TBI). The proposal incorporates data being collected for an NIH-funded PBE study focusing only on acute rehabilitation and extends the scope to recovery processes occurring after discharge from rehabilitation. John D. Corrigan, PhD, Ohio State University, is the Principal Investigator.
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<td>University of Miami</td>
<td>Doug Johnson-Greene</td>
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## TBIMS Follow-up Centers: 2012-17

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<th>TBIMS Center</th>
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<tr>
<td>The Rehabilitation Research Center/Santa Clara Valley Health and Hospital Systems</td>
<td>Stephanie Kolakowsky-Hayner</td>
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<td>Rehabilitation Institute of Michigan</td>
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<td>Carolinas Rehabilitation/Carolinas HealthCare System</td>
<td>Tami Guerrier</td>
<td>NC</td>
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### TBIMS Center-Specific Studies 2012-17

<table>
<thead>
<tr>
<th>Study Type</th>
<th>n</th>
<th>Topics</th>
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</thead>
</table>
| **Drug Intervention** | 2 | - Sumatriptan for post-traumatic headache  
                          - Buspirone for post-traumatic irritability/aggression                         |
| **Other Intervention** | 12 | - Brief intervention for substance misuse  
                              - Acceptance & Commitment Therapy to decrease distress and improve participation  
                              - Connecting patients, families, and providers to each other and to TBI resources (remotely)  
                              - Processing speed training to improve cognition  
                              - Promoting survivor resilience and adjustment  
                              - Couples skill-building, supportive & ed. training  
                              - Home-based virtual reality treatment for balance problems  
                              - Volunteer activity to improve psychological well being  
                              - Rewarding activity to promote emotional health  
                              - Light therapy for post-TBI fatigue  
                              - Online emotional regulation group treatment  
                              - Treatment of sleep disordered breathing  
                              - Evaluation of a tele-health weight management treatment program |
## TBIMS Center-Specific Studies 2012-17

<table>
<thead>
<tr>
<th>Study Type</th>
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<th>Topics</th>
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| **Instrument Development**         | 4  | - Aggression and Irritability Impact Measure  
- Observational pain scale  
- Assessing responsiveness & sensitivity of TBI Quality of Life (TBI-QOL) computerized adaptive testing  
- Measuring self reported pain |
| **Assessment and Prediction of Outcomes** | 6  | - Neuroimaging to reduce diagnostic error & facilitate communication in persons with DOC  
- Impact of co-morbidities on deterioration 5 years post TBI  
- Dopamine dysfunction  
- Comparative effectiveness research in TBI rehab  
- Imaging dopamine function and impact on outcome  
- Cultural disparities in TBI rehab healthcare |
### Study Type

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Study Topics</th>
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<tr>
<td><strong>Intervention</strong></td>
<td>- Effect of light exposure during acute rehabilitation on sleep after traumatic brain injury.</td>
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<tr>
<td><strong>Assessment and Prediction of Outcomes</strong></td>
<td>- Cognitive testing in the TBI Model Systems</td>
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<td></td>
<td>- Development of an extended measure of global function to support clinical trials originating in acute care</td>
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<td></td>
<td>- Internet use and online social participation among individuals with TBI</td>
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<td>- Long-term medical co-morbidities and functional decline following TBI</td>
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<td>- Evaluating the validity and responsiveness of the TBI-QOL Instrument</td>
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<td>- Resilience after TBI</td>
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<td>- Test-retest reliability of TBIMS Form II measures with persons with TBI</td>
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<td>- Statins and outcomes after TBI: an observational study</td>
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<td>- Weight and traumatic brain injury</td>
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* Module Studies and Collaboratives Grants*
Definition of TBI for the TBIMS National Database

- 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.
NIDRR TBI National Database

- Method: Repeated surveys of individuals post injury at regular intervals
- Form I: Inpatient rehabilitation discharge; administered in-person: 182 variables
- Form II: Follow-up conducted 1, 2, 5, and every 5 years thereafter; administered via telephone (primarily), in-person or mail questionnaire; 145 variables
NIDRR TBI National Database (cont.)

- Form I – 11758 cases (as of 3/31/2013)
- Form II – 38343 follow-ups* - 24% attrition (3%**)
  - Year 1 – 11,204 – 18% attrition (2%**)
  - Year 2 – 9,981 – 21% attrition (4%**)
  - Year 5 – 7,321 – 25% attrition (6%**)
  - Year 10 – 3,361 – 25% attrition (4%**)
  - Year 15 – 883 – 23% attrition (6%**)
  - Year 20 – 307 – 12% 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
NIDRR TBI Interagency Database Collaborations

• IAAs between Centers for Disease Control and Prevention (CDC) and NIDRR (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 NIDRR (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.
NIDRR TBI Interagency Database Collaborations (cont.)

• IAAs between Department of Veterans Affairs (VA) and NIDRR (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 NIDRR, 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
101 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
TBIMS Accomplishments (cont.)

• 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 NIDRR TBI Interagency Collaborations

• Research-based Initiatives to Advance Treatment/Services
  – 3rd Federal Interagency Conference on TBI (Sponsors: NIDRR, DoD, VA, NIH, CDC and others).
  – Guidelines for the Treatment of Disorders of Consciousness post TBI (Sponsors: NIDRR/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 NIDRR TBI Interagency Collaborations (cont.)

• Consensus Initiatives to Advance Research
  – Common Data Elements (CDE) for TBI Research (Sponsors: DoD, NINDS, NIDRR, 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 NIDRR)
  – Cognitive Rehabilitation Therapy Workshop (Sponsor: IOM/DoD)
Categories of NDB content

I. Premorbid history
II. Demographic characteristics of the population
III. Causes and severity of injury
IV. Nature of diagnoses
V. Types of treatment/services
VI. “Costs” of treatment/services
VII. Measurement and prediction of outcomes including impairment, disability and participation
I. Premorbid History

- Drug use
- Alcohol use (NHSDA/BRFSS)
- Tobacco use
- Conditions and limitations
- Psychiatric History
- Arrests/felony incarcerations
- Learning/behavior problems
- Military History
II. Demographic Characteristics

- Age
- Gender
- Race
- Ethnicity
- Marital Status
- Residence
- Zip Code
- Living with
- Level of Education
- Employment
- Height
- Weight
- Primary Language
- Country of Birth
III. Causes of Injury

- Date of injury
- ICD-9 external cause of injury codes
III. Severity of Injury

- Glasgow Coma Scale Score
- Duration of unconsciousness
- Duration of Post Traumatic Amnesia
IV. Diagnoses

- Spinal Cord Injury
- Intracranial CT scan findings
- Intracranial hypertension
- Neuropsychological assessment
- ICD-9 diagnosis codes
- Cause of death
V. Treatments

- Surgical procedures
- Rehospitalizations
VI. “Costs” of Treatment

- Length of stay
- Payer source
VII. Measure and Predict Outcome at Follow-up

- Impairment
  - Mortality
  - Lifetime History of TBI
- Disability
  - Disability Rating Scale (DRS)
  - Functional Independence Measure (FIM)
  - Glasgow Outcome Scale-Extended (GOS-E)
  - Supervision Rating Scale (SRS)
VII. Measure and Predict Outcome at Follow-up (cont.)

• Health/Behavior
  – Height and Weight
  – History of Specific Health Conditions
  – Subjective General Health
  – Drug use
  – Alcohol use (NHSDA/BRFSS)
  – Tobacco use
  – Psychiatric problems
  – Generalized Anxiety Disorder Scale (GAD-7)
  – Patient Health Questionnaire (PHQ-9)
  – Satisfaction with Life Scale (SWLS)
VII. Measure and Predict Outcome at Follow-up (cont.)

• Participation
  – Participation Assessment (PART)
  – Living with
  – Residence (e.g., private home, SNF, AFC, hospital)
  – Address
  – Marital Status
VII. Measure and Predict Outcome at Follow-up (cont.)

• Participation (cont.)
  – Level of education
  – Employment
  – Drug use
  – Alcohol use (NHSDA/BRFSS)
  – Tobacco use
  – Transportation
  – Arrests
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 (TBI NDSC) located at Craig Hospital in Englewood, Colorado, is a central resource for researchers and data collectors within the Traumatic Brain Injury Model Systems (TBI MS) program. The primary purpose of the TBI NDSC 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 TBI NDSC provides technical assistance, training, and methodological consultation to 16 TBI MS 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 TBI MS Presentation and TBI MS Update, which has information about the individual model systems and descriptions of the injury and followup 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
Please 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:

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<td>ICD-9-CM DIAGNOSIS CODES</td>
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<tr>
<td>110</td>
<td>ASCII</td>
<td>ASSOCIATED INJURY - SPINAL CORD INJURY</td>
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<tr>
<td>120</td>
<td>GCS</td>
<td>GLASGOW COMA SCALE</td>
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<tr>
<td>130</td>
<td>FLWL</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>
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<tr>
<td>150</td>
<td>CRANIO</td>
<td>CRANIAL SURGERY - CRANIOTOMY/CRANECTOMY</td>
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</tr>
<tr>
<td>160</td>
<td>PTA</td>
<td>DATE EMERGED FROM PTA</td>
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Model Systems Knowledge Translation Center (MSKTC)

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 2011-2012 Highlights

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

**NDSC**
National Data and Statistical Center
Traumatic Brain Injury Model Systems

**NIDRR**
TBIMS National Database
Descriptive Data Summary

[Includes data from 01/01/1989 – 12/31/2012]
mean = 40.34; n = 11772
Gender

- Male: 74%
- Female: 26%

n = 11771
Race

- White: 67%
- Black: 20%
- Hispanic: 9%
- Asian: 3%
- Others: 1%

n = 11770
Level of Education At Injury

- High School/GED: 35%
- Some College: 23%
- >=Bachelors: 14%
- <High School: 28%

n = 11558
Summary

• Demographic Characteristics of the Population
  – Average age = 40.34
  – Male (74%)
  – Minority population (33%)
  – High school education or less (63%)
Etiology of Injury

- Vehicular: 53%
- Falls: 24%
- Violence: 12%
- Other: 11%

n = 11753
Glasgow Coma Scale Score

At Emergency Department Admission

- Severe: 45%
- Mild: 39%
- Moderate: 16%

mean = 9.52; n = 8916
Duration of Unconsciousness

- \( \leq 1 \) day: 44%
- 2 to 7 days: 26%
- 8 to 14 days: 12%
- 15 to 28 days: 8%
- \( \geq 29 \) days: 8%

mean = 8.23 days; n = 11291
Duration of PTA

mean = 24.17 days; n = 8922
Summary

• Causes of Injury
  – Primary cause is vehicular (53%), followed by falls (24%) and violence (12%)

• Severity of Injury
  – Average duration of LOC is 8.23 days
  – Average duration of PTA is 24.17 days
Mean Length of Stay

* Did not capture leaves of absence this year
Summary

• Costs of Treatment
  – Acute care LOS has remained relatively stable
  – Total LOS in 2012 represents the lowest in the past decade
  – Days of rehabilitation have consistently decreased over the past 5 years.
  – 37% have government-sponsored rehabilitation care (M’caid/M’care)
Disability Rating Scale

None
Vegetative State
Extremely Severe
Severe
Moderately Severe
Moderate
Partial
Mild

Percentage of Patients

Rehab. Admit (n=10954)  Rehab. DC (n=10540)  1 Yr. Post-Injury (n=7166)
Disability Rating Scale

Average DRS Score

<table>
<thead>
<tr>
<th>Time Point</th>
<th>Average Score</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rehab. Admission (n=11540)</td>
<td>12.35</td>
<td>Severe Disability</td>
</tr>
<tr>
<td>Rehab. Discharge (n=11533)</td>
<td>6.41</td>
<td>Moderate Disability</td>
</tr>
<tr>
<td>1 Yr. Post-Injury (n=8506)</td>
<td>2.87</td>
<td>Partial Disability</td>
</tr>
<tr>
<td>2 Yrs. Post-Injury (n=7240)</td>
<td>2.57</td>
<td>Partial Disability</td>
</tr>
</tbody>
</table>
Functional Independence Measure

Average FIM Score

- **Rehab. Admission (n=11386)**
- **Rehab. Discharge (n=11445)**
- **Year 1 (n=8446)**
- **Year 2 (n=7191)**

**Cognitive**
- Year 1: 15
- Year 2: 24
- Year 1: 30
- Year 2: 31

**Motor**
- Year 1: 36
- Year 2: 67
- Year 1: 83
- Year 2: 84

**Total FIM**
- Year 1: 51
- Year 2: 91
- Year 1: 114
- Year 2: 115

*Note: The value of n is reflective of Total FIM measure*
Mean Scores converted to 7-point scale

- Complete Independence: 2.9
- Modified Independence: 5.1
- Supervision: 6.31
- Minimal Assistance: 6.39
- Moderate Assistance: 6.39
- Maximal Assistance: 6.39
- Total Assistance: 6.39

Rehab. Admit. (n=11368)  Rehab. Disch. (n=11445)  1 Yr. (n=8446)  2 Yr. (n=7191)
Glasgow Outcome Scale-Extended

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Year 1 (n=7841)</th>
<th>Year 2 (n=6849)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vegetative State</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Lower Severe Disability</td>
<td>17%</td>
<td>15%</td>
</tr>
<tr>
<td>Upper Severe Disability</td>
<td>16%</td>
<td>13%</td>
</tr>
<tr>
<td>Lower Moderate Disability</td>
<td>11%</td>
<td>12%</td>
</tr>
<tr>
<td>Upper Moderate Disability</td>
<td>21%</td>
<td>22%</td>
</tr>
<tr>
<td>Lower Good Recovery</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>Upper Good Recovery</td>
<td>21%</td>
<td>25%</td>
</tr>
</tbody>
</table>
Supervision Rating Scale

Year 1 (n=7986)  
- Level 1-Independent: 62%  
- Level 2-Overnight supervision: 6%  
- Level 3-Part-time supervision: 19%  
- Level 4- Full-time indirect supervision: 6%  
- Level 5- Full-time direct supervision: 7%

Year 2 (n=6843)  
- Level 1-Independent: 68%  
- Level 2-Overnight supervision: 6%  
- Level 3-Part-time supervision: 16%  
- Level 4- Full-time indirect supervision: 6%  
- Level 5- Full-time direct supervision: 4%
## Satisfaction With Life Scale

<table>
<thead>
<tr>
<th></th>
<th>Year 1</th>
<th>Year 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>6749</td>
<td>5831</td>
</tr>
<tr>
<td>Mean</td>
<td>21.10</td>
<td>21.48</td>
</tr>
<tr>
<td>SD</td>
<td>8.23</td>
<td>8.34</td>
</tr>
<tr>
<td>Min</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Max</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 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 38% of individuals require some level of supervision at 1 yr. post-injury and 32% 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

Private  Other

- **Injury** (n=11764): 98% (Private), 2% (Other)
- **Rehab. Disch.** (n=11753): 83% (Private), 17% (Other)
- **1 Year** (n=9053): 91% (Private), 9% (Other)
- **2 Years** (n=7744): 91% (Private), 9% (Other)
Marital Status

At injury (n=11747)
- Single: 47%
- Married: 33%
- Divorced/Separated: 16%
- Widowed: 5%

Year 1 (n=8961)
- Single: 45%
- Married: 32%
- Divorced/Separated: 18%
- Widowed: 5%

Year 2 (n=7618)
- Single: 45%
- Married: 31%
- Divorced/Separated: 19%
- Widowed: 5%
Living Situation

- Injury (n=11751)
  - Alone: 40%
  - Spouse/S.O.: 24%
  - Parent(s): 9%
  - Other Family/Relatives: 3%
  - Other: 10%

- Discharge (n=11721)
  - Alone: 18%
  - Spouse/S.O.: 31%
  - Parent(s): 13%
  - Other Family/Relatives: 3%
  - Other: 10%

- Year 1 (n=8984)
  - Alone: 12%
  - Spouse/S.O.: 30%
  - Parent(s): 11%
  - Other Family/Relatives: 13%
  - Other: 13%

- Year 2 (n=7658)
  - Alone: 16%
  - Spouse/S.O.: 28%
  - Parent(s): 11%
  - Other Family/Relatives: 13%
  - Other: 13%
Employment Status

- **Employed**
- **Unemployed**
- **Student**
- **Retired**
- **Other**

<table>
<thead>
<tr>
<th>Status</th>
<th>Injury (n=11700)</th>
<th>Year 1 (n=8929)</th>
<th>Year 2 (n=7586)</th>
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<tbody>
<tr>
<td>Employed</td>
<td>62%</td>
<td>28%</td>
<td>31%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>13%</td>
<td>30%</td>
<td>25%</td>
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<tr>
<td>Student</td>
<td>7%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Retired</td>
<td>15%</td>
<td>32%</td>
<td>34%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Summary

• Participation Outcomes
  – Most live in a private residence following rehab. discharge (83%)
  – Few live alone at rehab. discharge (3%), with the highest proportion living with parent(s) (35%), or spouse/SO (31%)
  – 28% are employed at 1 yr. post-injury (62% 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 11,000 cases with up to 20 years of follow-up.