

# The Traumatic Brain Injury **Model Systems**

## National Institute on Disability, Independent Living, and Rehabilitation Research

Every year an estimated 2.8 million people in the United States visit an emergency department, are hospitalized or die as a result of a traumatic brain injury. A TBI is defined as damage to the brain caused by an external force as evidenced by altered consciousness and impairment of brain functioning. After the initial medical event, TBI can present significant challenges to the individual, family, and society. An injured person may experience a wide range of physical, cognitive, emotional and behavioral changes that affect everyday function. Financial hardship, reduced physical activity, limited participation in the community, isolation, anxiety and depression are some common problems experienced by individuals following a TBI.

The Traumatic Brain Injury Model System (TBIMS) Program is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the U.S. Department of Health and Human Services. The TBIMS began in 1987 and continues its mission to improve care and outcomes for individuals with TBI. Currently there are 16 TBIMS centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical, and post-acute services. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with TBI, their families, and the communities in which they reside.

Some TBIMS accomplishments include:

- Development of practice guidelines in important areas of medical care for people with TBI (e.g., management of post-traumatic seizures, spasticity, post-traumatic agitation, post traumatic headache, and disorders of consciousness).
- Development of innovative approaches and procedures for rehabilitation throughout recovery.
- Creation of new diagnostic procedures and assessment tools that measure recovery and outcome.
- Characterization and improved understanding of the long-term health and societal impacts of TBI across the lifespan.
- Development and dissemination of information for patients/families, professionals, and policy makers on TBI and its consequences.
- Leadership in collaborative efforts among governmental, professional, and advocacy organizations at the state and national level.

#### Research

More than 100 peer-reviewed publications have resulted from TBIMS-funded research, including 10 special issues of leading journals in the field of rehabilitation. Currently there are 16 active center-specific research projects and 8 multicenter research projects in the TBIMS. Collaboration within the TBIMS and with other research groups has demonstrated the utility of leveraging the infrastructure of the TBIMS.

Each of the 16 centers, as well as previously funded centers, contributes data to the TBIMS National Database, a longitudinal database started in 1988 that currently includes information on more than 19,000 individuals who were admitted for inpatient TBI rehabilitation. This database is the largest longitudinal study of TBI in the world and includes data on pre-injury, acute care, rehabilitation, and outcomes at 1, 2 and 5 years post injury and at every 5 years thereafter. Some participants have been followed for 35 years.

To ensure high data quality in TBIMS research, NIDILRR separately funds the TBIMS National Data and Statistical Center, which manages the TBIMS National Database and other collaborative TBIMS research.

To ensure that research is translated into practice, NIDILRR separately funds a Model Systems Knowledge Translation Center, which promotes the adoption of research findings by stakeholders, including rehabilitation professionals, policy-makers, TBI survivors, and family members of persons with TBI.

Once each 5-year funding cycle, TBIMS Centers may also compete for an additional collaborative grant that supports studies of outcomes, rehabilitation interventions, and service delivery.





Knowledge Translation Center

## National Summary Data on TBI

The TBI Model Systems National Database provides valuable information regarding the short-term consequences of surviving a TBI. It also offers a unique opportunity to study the long-term nature of TBI. The information contained in the National Database largely characterizes moderate to severe TBI, given that persons included in the database were admitted for inpatient rehabilitation.

Recent research co-funded by the Centers for Disease Control and Prevention and NIDILRR has confirmed that the TBIMS National Database is representative of persons receiving inpatient rehabilitation for TBI in the US. The following information is based on weighted, nationally representative data of the TBIMS National Database. For those in the US over the age of 15 with TBI requiring inpatient rehabilitation:

- Demographic characteristics: age 16-25 years (27%), 26-45 years (32%), 46-65 years (25%), age 66+ (16%); male (74%); minority population (34%); high school education or less (60%).
- Cause of injury: vehicular (49%), followed by falls (29%) and violence (11%).
- Employment: 61% employed at time of injury, with 18% retired.
- Level of disability and functional ability: Improvements are most pronounced during inpatient rehabilitation, with continued improvement seen the first year after injury.
- Lifespan: Reduced an average of 9 years.
- Health outcomes at 5 years after injury: 22% have died; 30% have become worse; 22% have stayed the same; 26% have improved.
- Disability and social outcomes at 5 years after injury: Of those still living, 53% are moderately or severely disabled; 15% do not have a job (but were employed at the time of their injury); 21% return to a hospital at least once; 19% rely on others for help with everyday activities; 23% are not satisfied with life; 24% use illicit drugs or misuse alcohol; 9% reside in nursing homes or other institutions.

### **TBI Partnerships**

The TBIMS is engaged in several research initiatives with Federal agencies, including the Department of Veterans Affairs (VA), the Centers for Disease Control and Prevention, the Department of Defense and the National Institutes of Health. For example, the TBIMS functions in close partnership with the 5 Polytrauma Rehabilitation Centers, funded by the VA. Also referred to as the VA TBIMS, these centers collaborate with the NIDILRR-funded TBIMS in research, longitudinal data collection, and development and dissemination of TBI-related information materials to the public. This partnership has increased productivity, decreased redundancy, and strengthened TBI research through leveraging of resources.

### **For More Information**

- Traumatic Brain Injury Model Systems: http://msktc.org/tbi
- Model Systems Knowledge Translation Center (MSKTC): http://msktc.org
- Traumatic Brain Injury Model Systems National Data and Statistical Center: http://www.tbindsc.org
- Center for Outcome Measurement in Brain Injury (COMBI): http://www.tbims.org/combi/index.html

#### Source

The contents of this document were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DP0082 and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). The contents of this document do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

**Copyright** © **2023** Model Systems Knowledge Translation Center (MSKTC). May be reproduced and distributed freely with appropriate attribution. Prior permission must be obtained for inclusion in fee-based materials.





Model Systems Knowledge Translation Center