



February 2017

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) supports the collection of data from participants in the Traumatic Brain Injury (TBI) Model System Centers Program, a network of institutions across the country collecting data for research on outcomes after a TBI.

The result of this collaboration is a unique, well-characterized population of subjects with uniformly collected data compiled in the National Database.

Currently, there are 16 TBIMS Centers and 3 TBIMS Longitudinal Follow-up Centers sponsored by NIDILRR.

The Traumatic Brain Injury Model System (TBIMS) Centers program, begun in 1987, currently consists of 16 centers across the US that are competitively funded for 5 years by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The TBIMS Centers are situated in centers of excellence for clinical care and innovative research focused on improving the lives of people with TBI, their families, and close others. The primary focus is on moderate to severe TBI, as patients are recruited from inpatient rehabilitation to participate in research; however, many TBIMS investigators are also interested in mild TBI, or concussion.

The National Database (NDB), managed by the [TBIMS National Data and Statistical Center](#), is at the core of the TBIMS Centers program. More than 15,000 individuals are currently enrolled in the NDB. Each TBIMS center collects and enters into the NDB an identical data set on each individual, which captures:

- Emergency and acute care information such as CT scan findings and depth/ duration of loss or alteration of consciousness;
- Status and progress during inpatient rehabilitation;
- Pre-injury social and demographic data;
- Findings from a battery of measures assessing functional, social, emotional, and medical outcomes at 1, 2, 5, 10, 15 years after the TBI and every five years thereafter. The TBIMS is unique in the scope of its longitudinal data on the outcomes of persons with complex mild/ moderate/ severe TBI.

Recent research has confirmed that the TBIMS NDB is representative of persons receiving inpatient rehabilitation for TBI in the US.

In addition to the enrollment and data capture for the NDB, NIDILRR funding supports the following types of TBI research within TBIMS Centers:

- Data mining studies, which examine relationships among existing data elements in the NDB;
- Local research projects, which are site-specific studies proposed for each 5-year grant cycle;
- Module research projects, which are time-limited, multi-center studies designed to capitalize on the TBIMS infrastructure to address focused research questions that cannot feasibly be answered by a single center. In each 5-year cycle, centers propose and participate in modular studies of interest to them. Module projects have produced new knowledge on (e.g.) the natural history and typology of headache after TBI, the prevalence and outcomes of treatments for deep venous thrombosis, and the feasibility and utility of assessing cognitive function via telephone.

The TBIMS centers work in collaboration with the separately-funded [Model Systems Knowledge Translation Center](#) to provide scientific results and information for dissemination to stakeholders, including persons with TBI and their families, researchers, clinicians, and policymakers.

Source

This is a publication of the TBIMS Centers and the Model Systems Knowledge Translation Center at American Institutes for Research, Washington, DC (Grant Number 90DP0082). These centers are funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, an agency within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).