



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 Systems 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.

Introduction

This fact sheet is a quick reference on the policies associated with accessing and using data from the Traumatic Brain Injury Model Systems (TBIMS) National Database for those who are not a funded data collection site for the TBIMS (i.e., the general scientific community). Topics covered include the following:

- What Is the TBIMS National Database?
- Policies and Procedures for Obtaining Data From the National Database
- Publication Policies When Using the National Database
- Failure To Follow Policies and Procedures

What Is the TBIMS National Database?

The TBIMS National Database is a prospective, longitudinal, multicenter study that examines the course of recovery and outcomes following the delivery of coordinated acute neurotrauma and inpatient rehabilitation care. As of December 2018, the database contained information on 16,000 individuals admitted for inpatient acute TBI rehabilitation, and was representative of the over 150,000 adults who experienced TBIs severe enough to require hospitalization and inpatient physical rehabilitation in the United States. The TBIMS National Database (ND) is the largest longitudinal database of TBI in the world and includes data on pre-injury, injury, acute care, rehabilitation, and outcomes at 1, 2, and 5 years post-injury and every 5 years with information on persons, so far, up to 30 years post-injury. TBIMS ND has been used to inform research, treatment, and policy to benefit individuals with TBI and their families. For further information, visit our Web site at www.tbindsc.org.

Policies and Procedures for Obtaining Data From the National Database

Who Can Use This Database?

The TBIMS National Database welcomes the use of the data by external researchers who share our goal of improving lives of persons with TBI. Anyone from the scientific community who wishes to use data from the TBIMS National Database can use this database.

How Do You Request Data?

Requesters can either access the data by sending a formal request as described by steps 1-7 below or they can obtain the Public Use dataset by contacting us at tbimsdata@craighospital.org. This dataset is comprised of de-identified data that has been collected up to 2 years prior to the last quarter. The following procedures have been designed to be simple and invite participation by external researchers while maintaining the integrity of the data use and confidentiality of the participants.

1. Requestors should complete a Data Request and Use Agreement Form, available from <https://www.tbindsc.org/Researchers.aspx>. Once you complete the form, email or fax it to the Project Director (contact information is available from <https://www.tbindsc.org/Contact.aspx>) of the TBIMS National Data and Statistical Center (NDSC).
2. The NDSC and the TBIMS Research Committee will review the Data Request and Use Agreement Form for PI's affiliation, scientific purpose, and scientific overlap with existing approved projects.
3. The NDSC will post the proposal and the recommendations from the TBIMS Research Committee to the TBIMS Notification Listserv for further comment by the TBIMS Project Directors.
4. After the proposal has been posted to the TBIMS Notification Listserv for 10 working days, the NIDRR TBIMS Centers Program Manager will make the final decision regarding approval of the proposal with feedback from the NDSC, the TBIMS Research Committee, and the TBIMS Project Directors.

Currently, there are 16 TBIMS Centers and 3 TBIMS Longitudinal Follow-up Centers* sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research.

- University of Alabama at Birmingham Traumatic Brain Injury Care System, Birmingham, AL
- *Northern California TBI Model System, San Jose, CA
- Rocky Mountain Regional Brain Injury System, Englewood, CO
- Indiana University/Rehabilitation Hospital of Indiana, Indianapolis, IN
- JFK Johnson Rehabilitation Institute Traumatic Brain Injury Model System, Edison, NJ
- Spaulding-Harvard Traumatic Brain Injury Model System, Boston, MA
- Southeastern Michigan Traumatic Brain Injury System, Detroit, MI
- Mayo Clinic Traumatic Brain Injury Model System, Rochester, MN
- *Carolinas Rehabilitation/Carolinas HealthCare System, Charlotte, NC
- Northern New Jersey Traumatic Brain Injury System, West Orange, NJ
- New York Traumatic Brain Injury Model System, New York, NY
- Rusk Rehabilitation TBIMS at NYU, New York, NY
- The Ohio Regional TBI Model System, Columbus, OH
- Moss TBI Model System, Elkins Park, PA
- *University of Pittsburgh Medical Center Traumatic Brain Injury Model System, Pittsburgh, PA
- North Texas Traumatic Brain Injury Model System, Dallas, TX
- The Institute for Rehabilitation and Research, Houston, TX
- The Virginia Commonwealth TBI Model System, Richmond, VA
- University of Washington Traumatic Brain Injury Model System, Seattle, WA

Source

This is a publication of the TBI Model Systems National Data and Statistical Center, Craig Hospital, Englewood, CO (Grant Number H133A110006) and the Model Systems Knowledge Translation Center at American Institutes for Research, Washington, DC (Grant Number 90DP0012). Both 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).

5. After approval, the PI will work with NDSC staff to detail the proposal so that an appropriate de-identified dataset can be released to the PI.
6. Applicants are given the option to have as a consultant a TBIMS researcher who is familiar with the data and how they were collected.
7. Applicants are required to send annual updates to the NDSC, including the name of the PI, title of the project, progress on the project, and an updated anticipated completion date.

Publication Policies When Using the National Database

1. At no time should a researcher who has been given access to the data attempt to identify individual patients.
2. All manuscripts should accurately describe the methods of data collection for the TBIMS National Database.
3. Any dissemination of the study findings (including manuscripts, posters and presentations) should include proper acknowledgment of the TBIMS and NIDRR support.
4. The PI will submit manuscripts to the TBIMS NDSC for administrative review at least 4 weeks before submission for publication. Abstracts for meeting presentations similarly need to be submitted for review.
5. The PI will apprise NDSC of acceptance or rejection of manuscripts, abstracts, and presentations.
6. The PI will provide the URL and complete citation for any published manuscript, abstract, or presentation using the TBIMS data to the NDSC when available.

Failure To Follow Policies and Procedures

Failure To Follow the Data Use Agreement

If users violate the agreement, they should take corrective action as soon as they discover infractions. If users willfully violate the agreement, NIDRR and/or NDSC may revoke current and future access to the TBIMS National Database.

Fraudulent Use of Data

Should the TBIMS Research Committee or NDSC discover an attempt to publish data obtained fraudulently, immediate steps will be taken to end the violation. This may include discontinuing the user's data access, reporting the violation, and reporting scientific misconduct to the violator's institution, relevant professional organizations and/or scientific institutions.