



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 factsheet serves as a quick reference guide on the policies associated with accessing and using data from the Traumatic Brain Injury Model Systems (TBIMS) National Database for those in the general scientific community who are not affiliated with funded TBIMS data collection sites. 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 database that examines the course of recovery and outcomes following the delivery of coordinated acute neurotrauma and inpatient rehabilitative care to people with TBI. As of June 2020, the National Database contained information on more than 18,000 people with TBI who were admitted for inpatient acute rehabilitation. The people included in the National Database are representative of adults in the United States who experience TBIs that are severe enough to require hospitalization and inpatient rehabilitation. The National Database is the largest longitudinal database about TBI in the world and it includes data on pre-injury, injury, acute care, rehabilitation, and outcomes at 1, 2, and 5 years post-injury and every 5 years thereafter. The National Database contains some data on people who are 30 years post-injury. The National Database has been used to inform research, treatment, and policy to benefit individuals with TBI and their families. For further information, please see the [TBIMS National Database Description](#) or visit the Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) website at [www.tbindsc.org](http://www.tbindsc.org).

## Policies and Procedures for Obtaining Data From the National Database

### How Do You Request Data?

Requesters can access the data by sending a formal request as described in steps 1–7 below, or they can obtain the public use dataset by going to <https://www.tbindsc.org/Researchers.aspx> for instructions. This dataset is composed of de-identified data that have been collected up to 2 years prior to the last quarter. To submit a data request, follow the procedures below, which were designed to be simple and to encourage external researchers to use the data while maintaining the integrity of the data and the confidentiality of the database participants.

1. Complete a Data Request and Use Agreement Form, available at <https://www.tbindsc.org/Researchers.aspx>. Once you complete the form, email it to [tbimsdata@craighospital.org](mailto:tbimsdata@craighospital.org) at the TBINDSC.
2. The NDSC and the TBIMS Research Committee will review the completed Data Request and Use Agreement Form for the principal investigator's (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.
3. The NDSC will post the proposal from the data requester and the recommendations from the TBIMS Research Committee to the TBIMS Notification Listserv for further comment by the TBIMS Project Directors.

### Currently, there are 16 TBIMS Centers and 3 TBIMS Longitudinal Follow-Up Centers,\* sponsored by the NIDILRR.

- University of Alabama at Birmingham Traumatic Brain Injury Model System, Birmingham, AL
- \*Northern California TBI Model System, San Jose, CA
- Rocky Mountain Regional Brain Injury System, Englewood, CO
- Indiana University School of Medicine/Rehabilitation Hospital of Indiana TBI, 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 Traumatic Brain Injury Rehabilitation and Research 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 Langone Health and Bellevue Hospital, New York, NY
- Ohio Regional Traumatic Brain Injury Model System, Columbus, OH
- Moss Traumatic Brain Injury 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
- Texas TBI Model System of TIRR, Houston, TX
- The Virginia Commonwealth Traumatic Brain Injury Model System, Richmond, VA
- University of Washington Traumatic Brain Injury Model System, Seattle, WA

4. After the proposal has been posted to the TBIMS Notification Listserv for 10 working days, the NIDILRR TBIMS Centers Program Manager will make the final decision regarding the proposal with feedback from the NDSC, the TBIMS Research Committee, and the TBIMS Project Directors.
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. Before releasing the dataset, the Institutional Review Board (IRB) approval number and expiration date must be received from the requesting institution.
7. Before releasing the dataset, the NDSC will delete the ID code of the contributing center, or, if a center-to-center comparison is part of the objective, or if the center identity is used in statistical analysis, NDSC will replace the standard center identity codes with other randomly selected codes. Analysts are not allowed to “unscramble” these codes, and center identity must always be treated as masked in any reports and in publications, unless all centers involved give written prior approval for identification of their center.
8. Use of the data for this request is limited to **2 years**. After that time, a new External Use Request and Data Use Agreement Form must be sent to the TBINDSC for re-approval.
9. During analysis, applicants should send annual updates to the NDSC that include the name of the PI, the 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 proposed study findings, including manuscripts, posters, presentations, and other products must include the following citation for the TBIMS National Database:
  - Author: Traumatic Brain Injury Model Systems Program
  - Distributor: Traumatic Brain Injury Model Systems National Data and Statistical Center
  - Persistent identifier: DOI 10.17605/OSF.IO/A4XZB
  - Date: 2020
  - URL: <http://www.tbindsc.org>
  - Version: <https://osf.io/a4xzb/>
4. Any dissemination of the study findings including all manuscripts, posters, presentations, and other products must include the following acknowledgment: “The TBI Model Systems National Database is a multicenter study of the TBI Model Systems Centers Program, and is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), a center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). However, these contents do not necessarily reflect the opinions or views of the TBI Model Systems Centers, NIDILRR, ACL or HHS.
5. The PI will submit manuscripts to the TBINDSC for administrative review at least 4 weeks before submission for publication. The NDSC will forward such manuscripts to the TBIMS Research Committee members for review. Abstracts for meeting presentations also need to be submitted for review.
6. The PI will apprise the NDSC of acceptance or rejection of manuscripts, abstracts, and presentations.
7. The PI will provide the NDSC with the URL and complete citation for any published manuscript, abstract, or presentation that uses TBIMS data, when such information is 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 the infraction. If users willfully violate the agreement, NIDILRR 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 that were obtained fraudulently, immediate steps will be taken to end the violation. Such steps 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.

### Source

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