



April 2020

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.

This factsheet is a quick reference on the policies associated with accessing and using data from the Traumatic Brain Injury Model Systems (TBIMS) National Database for the general public. It covers the following topics:

- What is the TBIMS National Database?
- How Can the General Public Request Data from the TBIMS National Database?

What Is the TBIMS National Database?

The TBIMS National Database (NDB) 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 January 2020, the NDB contained information on nearly 18,000 individuals admitted for inpatient, acute TBI rehabilitation. The people included in the NDB are representative of adults in the United States who experience TBIs severe enough to require hospitalization and inpatient rehabilitation. The TBIMS NDB is the largest longitudinal database about TBI in the world and includes data on pre-injury, injury, acute care, rehabilitation, and lifelong outcomes. Participants are followed at 1, 2, 5 and 10 years post-injury and every 5 years thereafter. The NDB contains information on some people who are 30 years post-injury. TBIMS NDB has been used to inform research, treatment, and policy to benefit individuals with TBI and their families. For further information, please see the [TBIMS NDB Description](#) and visit www.tbinsc.org.

How Can the General Public Request Data from the TBIMS National Database?

The Health Insurance Portability and Accountability Act (HIPAA) establishes the conditions under which protected health information may or may not be used or disclosed. The dataset that the TBIMS National Data and Statistical Center (NDSC) provides to the general public does not contain any health information of individuals and does not include the most recent two years of data.

To request data from the TBIMS National Database for general public use, the requestors should:

1. Complete a Data Request and Use Agreement Form, available from <https://www.tbinsc.org/Researchers.aspx>.
2. Email or fax the completed form to the Project Director (tbimsdata@craighospital.org) of the TBIMS National Data and Statistical Center (NDSC).

After receiving the request form, the NDSC will record the requestor's information and will then send the Public Use Database to the requestor.

Source

This is a publication of the TBI Model Systems National Data and Statistical Center, Craig Hospital, Englewood, CO (Grant Number 90DP0013) 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 (NIDILRR), Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.