

**TBI Model Systems National Database
Public Use Request and Terms of Use Form**

Note: This form is for requesting use of the national database by the general public.

Today's date:

Requestor's first name:

Requestor's last name:

Requestor's email address:

Requestor's institution or organization:

Institution Type:

Non-profit organization

Commercial

Academic

Other (specify): _____

Number of years in scientific research:

Less than 5

5 - 10

10+

Study Name:

Describe Request:

Terms of Use:

Please read the Terms of Use below. If you agree to them, sign your name at the bottom of the form. These Terms of Use form an agreement between the Traumatic Brain Injury Model Systems National Data and Statistical Center (“NDSC”) and the person agreeing to these Terms of Use (the “AUTHORIZED USER” as further defined below).

Definitions

AUTHORIZED USER

The individual who completes, signs and agrees to the Terms of Use for the TBIMS NDB Public Use Database.

NDSC

Traumatic Brain Injury Model Systems National Data and Statistical Center

NIDILRR

National Institute on Disability, Independent Living, and Rehabilitation Research

PROMISE OF CONFIDENTIALITY

A promise to a RESEARCH PARTICIPANT that the information the RESEARCH PARTICIPANT provides will not be disseminated without the permission of the RESEARCH PARTICIPANT; that the fact that the RESEARCH PARTICIPANT participated in the study will not be disclosed; and that disseminated information will include no linkages to the identity of the RESEARCH PARTICIPANT. Such a promise encompasses traditional notions of both confidentiality and anonymity. Names and other identifying information regarding RESEARCH PARTICIPANTS, proxies, or other persons on whom the RESEARCH PARTICIPANT or proxy provides information, are presumed to be confidential.

RESEARCH PARTICIPANT

A person or organization observed for purposes of research. Also called a respondent, case or subject. A RESEARCH PARTICIPANT is generally a survey respondent or informant, experimental or observational subject, focus group participant, or any other person providing information to a study or on whose behalf a proxy provides information.

Terms of Use:

The NDSC hosts the TBI Model Systems National Database (“TBIMS NDB”). The NDSC adheres to the principles that require the data consumer to comply with access regulations imposed both by law and by the data repository, and to conform to codes of conduct that are generally accepted in higher education and scientific research for the exchange of knowledge and information.

The NDSC will distribute the TBIMS NDB pursuant to these Terms of Use. By signing this document, you signify your agreement to comply with the Terms of Use stated below.

Use of TBIMS data is restricted to the purpose stated in the request and only for a period of two (2) years from the date of data receipt. New or further use of data requires a new request and signed Terms of Use.

Privacy of RESEARCH PARTICIPANTS

The TBIMS NDB to which you will be given access if you agree to these Terms of Use is de-identified data within the meaning of the Health Insurance Portability and Accountability Act (HIPAA) and its implementing regulations. (See 45 CFR 164.514). Any intentional re-identification of a RESEARCH PARTICIPANT or unauthorized disclosure of his or her confidential information violates the PROMISE OF CONFIDENTIALITY given to the RESEARCH PARTICIPANTS. Therefore, AUTHORIZED USERS agree:

- To use the TBIMS NDB solely for research or statistical purposes and not for investigation of specific RESEARCH PARTICIPANTS
- To make no efforts to re-identify a RESEARCH PARTICIPANT
- TO MAKE no use of the identity of any RESEARCH PARTICIPANT discovered inadvertently, and to advise the NDSC of any such discovery (tbimsdata@craighospital.org).

Redistribution of Data

You agree that you may only share the TBIMS NDB with other AUTHORIZED USERS. Each and every person you intend to share the TBIMS NDB with must complete, sign and submit to the NDSC a duplicate version of this form, and agree to these Terms of Use to become an AUTHORIZED USER. If the intended recipient of the TBIMS NDB data does not submit a duplicate request and agree to these Terms of Use, you may not share the TBIMS NDB with him/her. Your sharing the TBIMS NDB with a person who is not an AUTHORIZED USER is a violation of these Terms of Use. In the event that a person who is not an AUTHORIZED USER obtains the TBIMS NDB, you agree that you will promptly notify the NDSC of the data accessed and the person who received it.

Thus, there is no redistribution or sharing of the TBIMS NDB with anyone or any entity for any reason, except that required for journal publication or by research funding agencies. Journal editors or grant makers may, in certain circumstances, request a copy of the data on which a paper or report is based; in which case, the AUTHORIZED USER must notify the NDSC in writing prior to redistribution/sharing for this purpose.

You further agree not to redistribute the TBIMS NDB unless:

- You are assisting AUTHORIZED USERS with obtaining data, or
- You are collaborating with other AUTHORIZED USERS to analyze the data for research or instructional purposes.

When sharing the TBIMS NDB in these approved ways, you must include all accompanying files with the TBIMS NDB data, including these Terms of Use.

Citing Data

You agree to reference the recommended bibliographic citation* in any publication (epub, digital or hard copy) that employs resources provided by the NDSC.

Authors of publications based on the TBIMS NDB are required to send citations of their published works to the NDSC for inclusion in a database of related publications (tbimsdata@craighospital.org).

*Each citation must include the basic elements that allow a unique dataset to be identified over time:

- Title: Traumatic Brain Injury Model Systems 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
- URL: <http://www.tbindsc.org>
- Date: ____ [insert the year of data release]
- Version: <https://osf.io/a4xzb/>

Acknowledgement:

Any dissemination of the study findings including all manuscripts, posters, presentations, epubS, and other digital or hard copy products must include the following acknowledgement:

“This (insert type of publication; e.g., book, report, film) used the Traumatic Brain Injury Model Systems National Database, which is supported by funding from the National Institute on Disability, Independent Living, and Rehabilitation Research. NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this (insert type of publication; e.g., book, report, film) do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.”

Disclaimer

You acknowledge that the original collector of the TBIMS NDB data, the NDSC and NIDILRR bear no responsibility for your use of the TBIMS NDB data or for interpretations or inferences based upon such uses.

Violations

If the NDSC determines that you have violated these Terms of Use, it can and will impose sanctions. The sanctions it could choose to impose include without limitation:

- NDSC may revoke these Terms of Use, demand the return of the data in question, and deny all future access to TBIMS NDB data.
- The violation may be reported to the Research Integrity Officer, Institutional Review Board, or Human Subjects Review Committee of the AUTHORIZED USER's institution. A range of sanctions are available to institutions, including revocation of tenure and termination.
- If the confidentiality of human subjects has been violated, the case may be reported to the Federal Office for Human Research Protections. This may result in an investigation of the AUTHORIZED USER's institution, which can further result in institution-wide sanctions, including the suspension of all research grants.
- A court may award the payment of damages to any individual(s)/organization(s) harmed by the breach of these Terms of Use.

I agree to abide by and be bound by these Terms of Use.

Printed Name

Date

Signature

(Please sign your name to indicate your intent to be bound by these Terms of Use.)