

Introduction to the Traumatic Brain Injury Model Systems

The TBIMS is funded by the National Institutes on Disability, Independent Living, and Rehabilitation Research (NIDILRR), A Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS)

Goals

To provide an introduction and overview of

- The Traumatic Brain Injury Model Systems (TBIMS) Program
- The TBIMS National Database (NDB)
- The TBIMS National Data and Statistical Center (NDSC)

What is the TBIMS?

The TBIMS program is funded by the National Institutes on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to support innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with traumatic brain injury (TBI).

NIDILRR awards TBIMS grants to institutions (“centers”) that are national leaders in medical research and patient care; these institutions provide the highest level of comprehensive specialty services from the point of injury through eventual re-entry into full community life.

In addition, each TBIMS center conducts research and contributes data to the TBIMS National Database (NDB)

Requirement of TBIMS Centers

Clinical Care: Provide a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with TBI, including:

- Emergency medical services, Level 1 Trauma Center(s)
- Acute neurosurgical care
- Comprehensive inpatient rehabilitation services
- Long-term, interdisciplinary follow-up and rehabilitation services

Knowledge Generation

- Conduct one or two center-specific studies
- Participate in at least one multicenter (“module”) study
- Collect and submit longitudinal data for inclusion in the TBIMS National Database
- Optional: Participate with other TBIMS Centers in separately funded NIDILRR collaborative research grants

Knowledge Translation

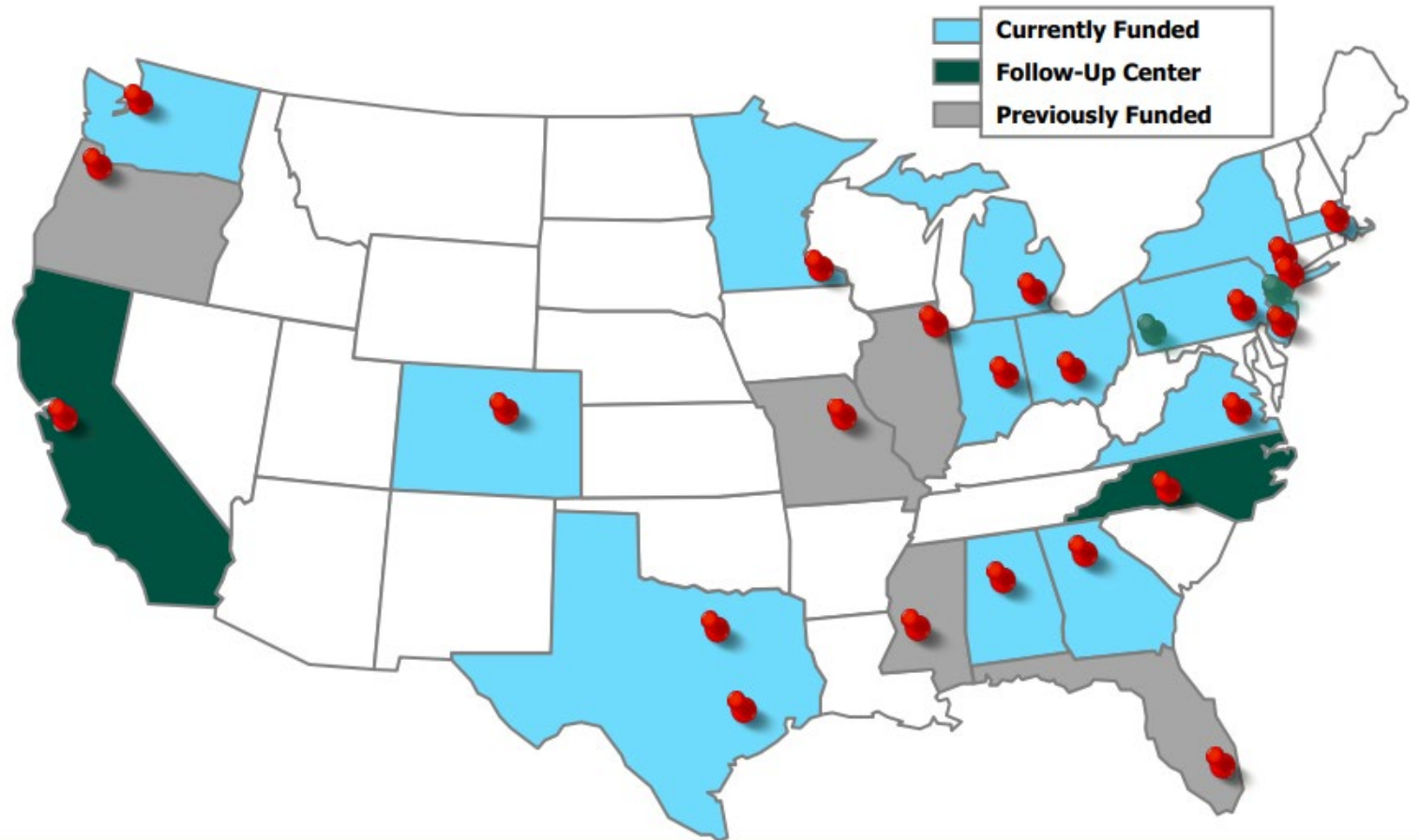
- Collaborate with the Model Systems Knowledge Translation Center (MSKTC) to provide scientific results and information to individuals with TBI; their families, caregivers, and friends; health care professionals; policy makers; and the general public

Current TBIMS Centers

1987: Established with 5 Centers

1998: Increased to 17 centers each 5 year funding cycle

Currently: 16 centers and 4 follow-up centers



The TBIMS National Database

The first prospective, longitudinal, multicenter study ever conducted which examines the course of recovery and outcomes following the delivery of a coordinated system of acute neurotrauma and inpatient rehabilitation for TBI.

Participants are enrolled at TBIMS Centers during inpatient rehabilitation and followed by interview over time at 1, 2, and 5 years post-injury, and every 5 years thereafter.

Currently (2024), the TBIMS National Database (NDB) contains data from over 20,000 participants and more than 80,000 follow-up interviews out to 35 years post-injury making it the largest longitudinal study on moderate to severe TBI in the world!

The TBIMS National Database

The aim of the TBIMS NDB is to generate new and useful knowledge about the short- and long-term outcomes for people with TBI.

Objectives

- Study the clinical course of individuals with TBI from time of injury through discharge from acute and rehabilitation care
- Evaluate the recovery and long-term outcomes of individuals with TBI
- Establish a basis for comparison with other data sources

TBIMS National Data and Statistical Center

The TBIMS National Data and Statistical Center (NDSC) is funded by NIDILRR to develop and manage the infrastructure for the TBIMS to collect, enter, store, and view their data

- Data collection and management
- Data checks and quality control
- Database reports and visualization tools

The TBIMS NDSC provide technical assistance, training, and statistical consultation to the TBIMS centers as they collect and analyze these data

- Support for database access
- Training and technical assistance
- Statistical and analytical expertise

The NDSC provides access and support to external users of the TBIMS NDB including the public

TBI Definition and Inclusion Criteria

Definition of TBI for the TBIMS NDB

- TBI is defined as damage to brain tissue caused by an external mechanical force as evidenced by medically documented loss of consciousness or post traumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination

Database Inclusion Criteria

- Moderate to severe TBI (PTA>24 hours or LOC>30 minutes or GCS in ED<13 or intracranial neuroimaging abnormalities)
- Admitted to system's hospital emergency department within 72 hours of injury
- Receives acute care and comprehensive inpatient rehabilitation within the model system hospitals
- 16 years of age or older at the time of injury
- Informed consent is signed by patient, family, or guardian

TBIMS Resources

The TBIMS NDSC website contains helpful information for researchers interested in understanding and utilizing the TBIMS NDB

<https://www.tbindsc.org>

**NDSC**
National Data and Statistical Center
Traumatic Brain Injury Model System

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Traumatic Brain Injury Model Systems National Data and Statistical Center

The Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) located at Craig Hospital in Englewood, Colorado, is a central resource for researchers and data collectors within the Traumatic Brain Injury Model Systems (TBIMS) program. The primary purpose of the TBINDSC is to advance medical rehabilitation by increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of individuals with traumatic brain injury (TBI). The TBINDSC provides technical assistance, training, and methodological consultation to 16 TBIMS centers as they collect and analyze longitudinal data from people with TBI in their communities, and as they conduct research toward evidence-based TBI rehabilitation interventions.

Below are links to the TBIMS Presentation and TBIMS Update, which has information about the individual model systems and descriptions of the injury and followup data that are being collected.

Publications

-  [Traumatic Brain Injury Model Systems National Database - Info Sheet](#)
-  [Traumatic Brain Injury Model Systems National Database - Info Sheet Brochure](#)

Rosenthal Award

Mitchell Rosenthal, PhD (1949-2007), played a significant role in the development and refinement of the TBIMS National Database (NDB). He implemented initiatives to improve the quality of the data, increase the visibility and usability of the NDB, and facilitate collaborative research utilizing the NDB. Dr. Rosenthal authored or co-authored

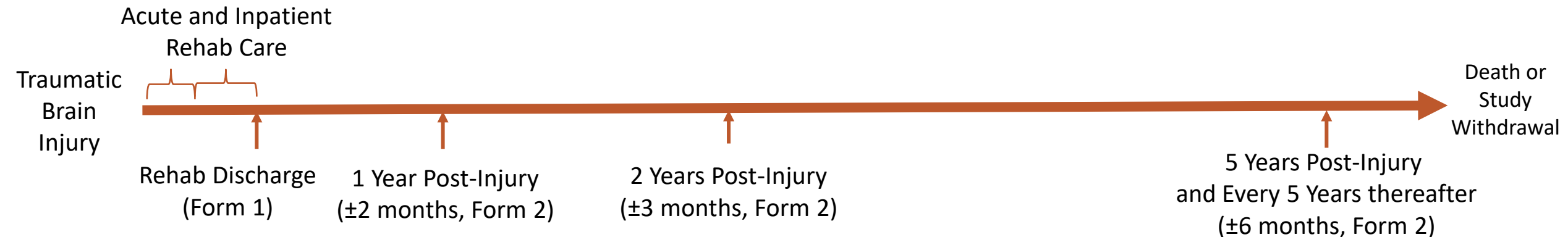
Data Collection

Participants are enrolled during inpatient rehabilitation at participating centers

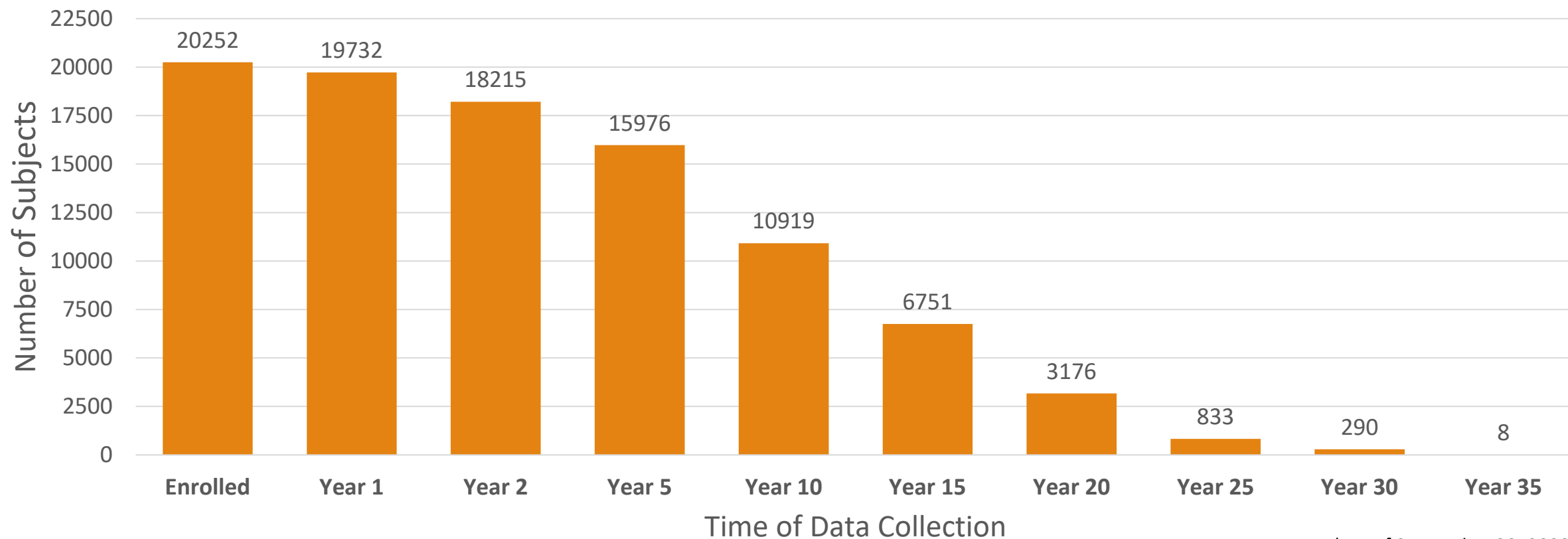
- Data on demographic, pre-injury, injury, and rehabilitation characteristics are collected through medical record abstraction and patient (or proxy) interview during inpatient rehabilitation (Form 1 interview)

Participants are followed-up by interview at 1, 2, 5 years post-injury, and every 5 years thereafter over their lifetime

- Follow-up Interviews are conducted by phone, in-person, or mail out, with the participant (or proxy) to collect updated demographic characteristics and outcome measures such as health, impairment, disability, and participation (Form 2 interview)



Participants Enrolled and Followed in the TBIMS NDB*



* As of September 30, 2023

Attrition ranges from 12-13% at years 1 and 2, 15-17% in Years 5-15, and 19-21% in years 20+

Domains

Demographic Characteristics	Form 1	Form 2
Age	X	
Sex	X	
Race/Ethnicity	X	
Height & Weight	X	X
Primary Language	X	
Country of Birth	X	
Military History	X	

Causes and Severity of TBI	Form 1	Form 2
Date of Injury	X	
ICD External Causes of Injury	X	
Glasgow Coma Scale	X	
Time to Follow Commands	X	
Duration of Post-Traumatic Amnesia	X	

Diagnoses	Form 1	Form 2
Spinal Cord Injury	X	
Intracranial CT Scan Reports	X	
Neuropsychological Assessment	X	
ICD Diagnosis Codes	X	

Domains

Treatments	Form 1	Form 2
Length of Acute and Rehabilitation Stay	X	
Craniotomy/Craniectomy	X	
Re-Hospitalizations		X

Impairment	Form 1	Form 2
Mortality (Date and Cause of Death)	X	X
Lifetime History of TBI	X	X
Seizure	X	X

Health and Behavior	Form 1	Form 2
Substance Use	X	X
Psychiatric and Medical History	X	X
Arrests/Felony	X	X
Learning/Behavior Problems	X	
Depression (PHQ-9)		X
Anxiety (GAD-7)		X
Satisfaction with Life Scale (SWLS)		X

Domains

Disability	Form 1	Form 2
Disability Rating Scale (DRS)		X
Functional Independence Measure (FIM)		X
Continuity Assessment Record and Evaluation (CARE)	X	
Glasgow Outcome Scale-Extended (GOS-E)		X

Participation	Form 1	Form 2
Participation Assessment (PART-O)		X
Living With	X	X
Residence	X	X
Address (with consent)	X	X
Marital Status	X	X
Employment	X	X
Education	X	X
Transportation		X

Resources

The TBIMS NDB and the NDSC website are valuable resources for TBI researchers:

<https://www.tbindsc.org/>

The Data Dictionary Explorer is your best friend

<https://hub.tbindsc.org/tbimsdatadictionary/Home>

The NDSC is your second best friend

<https://www.tbindsc.org/Contact.aspx>

Data are made readily available for internal researchers of the TBIMS, external researchers, and to the larger public free of charge – see the For Researchers page for Data Request Forms

<https://www.tbindsc.org/Researchers.aspx>

Available on the “For Researchers” page of the NDSC website is a notification list of ongoing studies and a list of publications using the TBIMS NDB

Ongoing training presentations for working with and analyzing the TBIMS NDB will be made available on the For Researchers page – stay tuned!

Thank You