

# The Traumatic Brain Injury Model Systems

A project funded by the U.S. Department of  
Health and Human Services

National Institute on Disability, Independent Living, and  
Rehabilitation Research (NIDILRR)



Data represents database as of 12/31/2022



## Project Design

- 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
- Includes large-scale, follow-up to 35 years post-injury



# History of the Traumatic Brain Injury Model Systems (TBIMS)

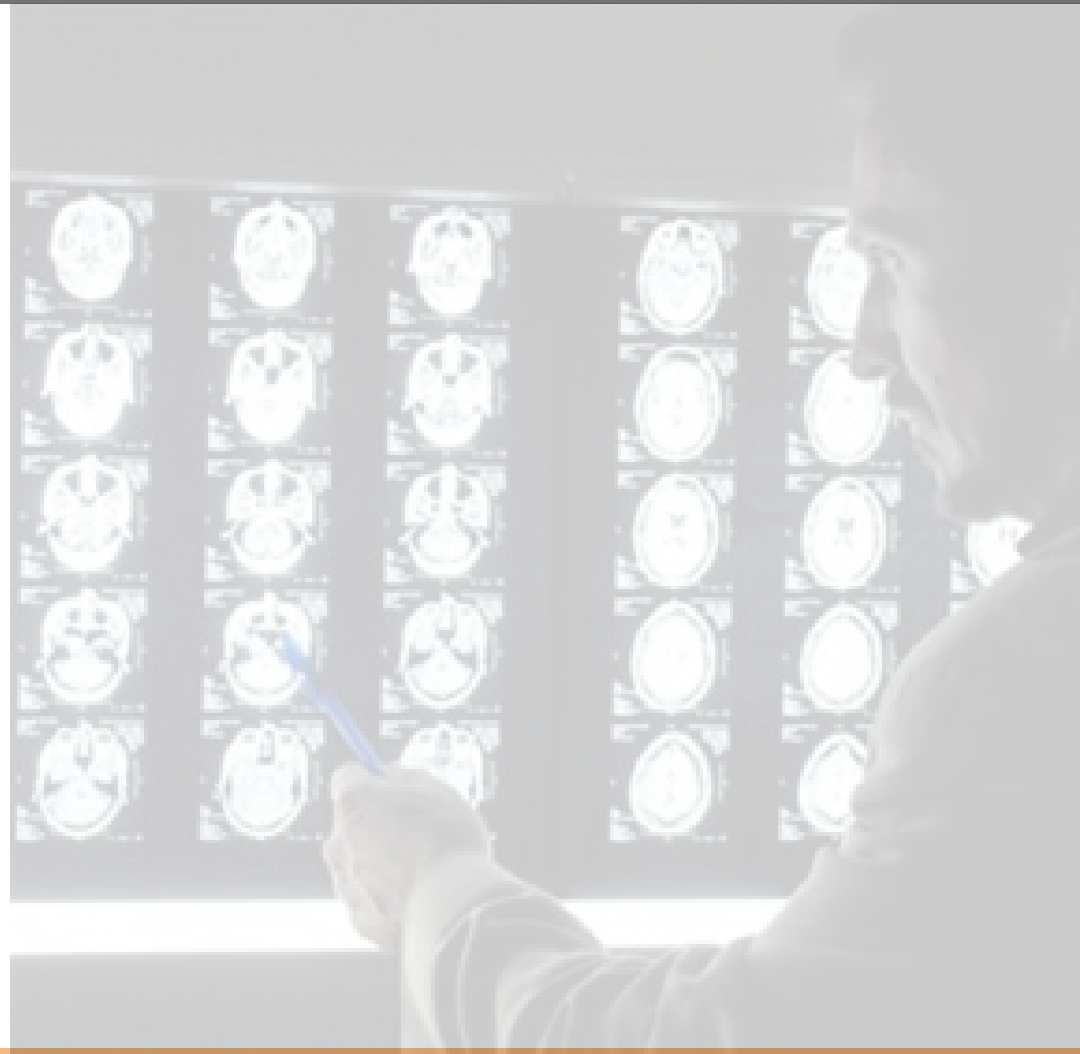
TBIMS is one of three Model Systems programs sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR):

- Spinal Cord Injury Model Systems
  - » 1970: Established with 14 centers
- Traumatic Brain Injury Model Systems
  - » 1987: Established with five centers
  - » 1998: Increased to 17 centers
  - » Currently: 16 centers and four follow-up centers
- Burn Injury Model Systems
  - » 1994: Established with four centers

Conduct research that contributes to evidence-based rehabilitation interventions and clinical and practice guidelines that improve the lives of individuals with traumatic brain injury (TBI).

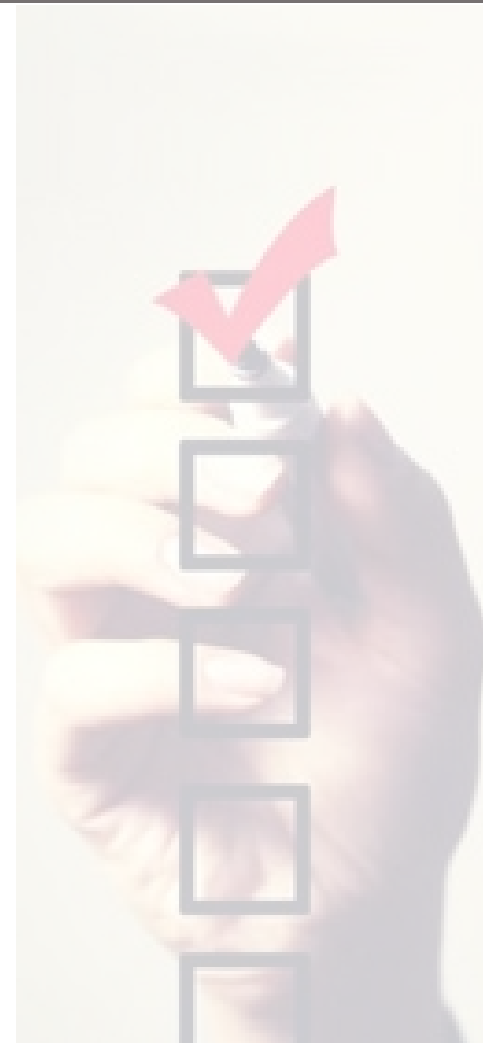
# Requirements of TBIMS Centers

- 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

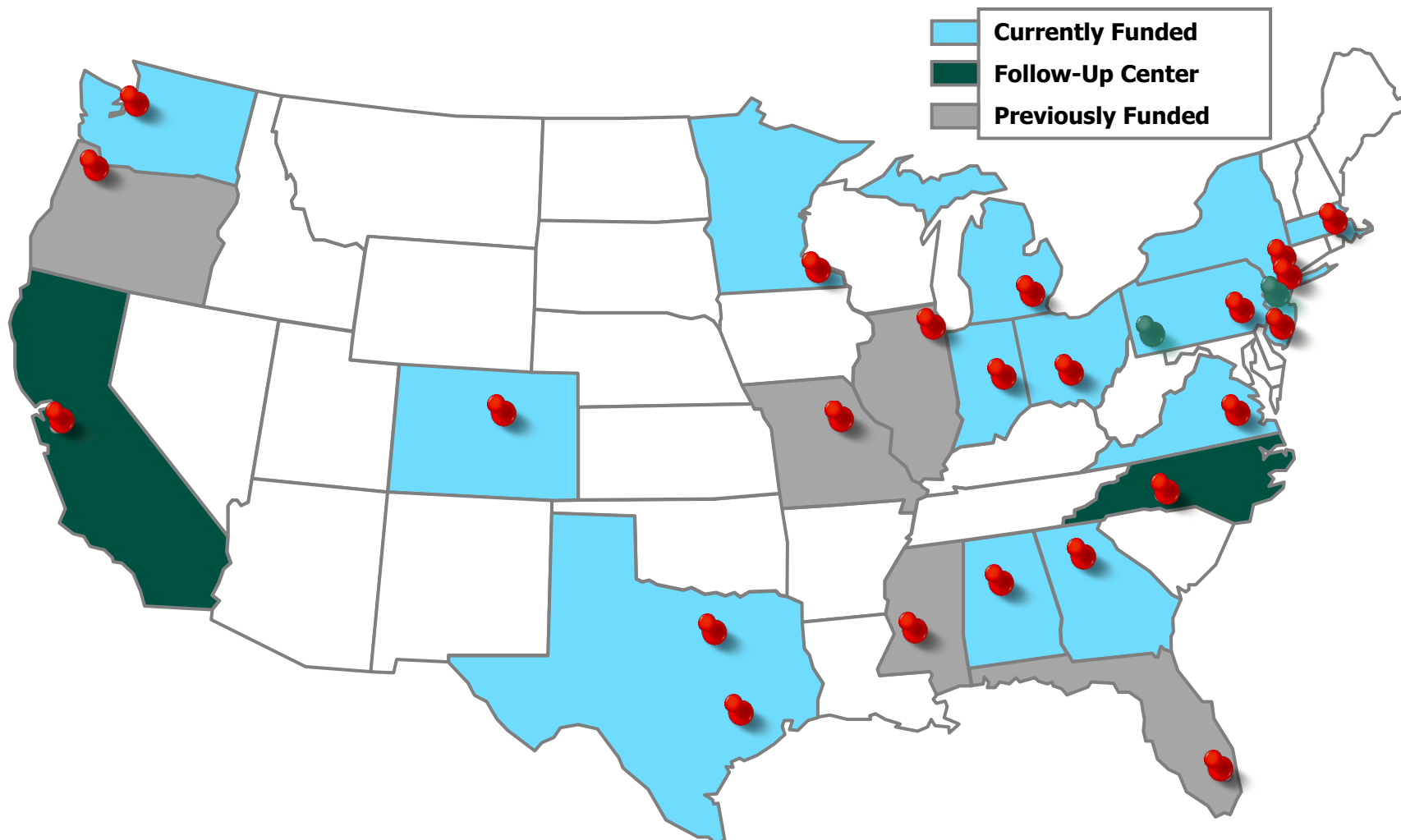


## Requirements of TBIMS Centers (Continued)

- 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 stakeholders



# Current Traumatic Brain Injury Model Systems





# TBI Model Systems Leadership

## Federal Project Management

- National Institute on Disability, Independent Living, and Rehabilitation Research, A. Cate Miller, PhD, Project Manager

## National Data and Statistical Center

- Craig Hospital, Englewood, Colorado, Dave Mellick, PhD, Project Director

## TBI Model Systems Centers

- Executive Committee Chair, Flora Hammond, PhD





## TBIMS Centers: 2022-27

TBIMS Center	Principal Investigator	State
University of Alabama at Birmingham	Robert Brunner	AL
Craig Hospital	Dave Mellick	CO
Rehabilitation Institute of Michigan	Robin Hanks	MI
Indiana University-Rehabilitation Hospital of Indiana	Flora Hammond	IN
Spaulding Rehabilitation-Harvard	Joseph Giacino	MA
Mayo Clinic	Allen Brown	MN
Kessler Foundation Research Center	Nancy Chiaravalloti	NJ
Mount Sinai School of Medicine	Kristen Dams-O'Connor	NY
NYU Medical Center-Rusk Institute	Tamara Bushnik	NY
Ohio State University	Jennifer Bogner	OH
Shepherd Center, Inc.	Brick Johnstone	GA
Albert Einstein Healthcare-Moss Rehab	Amanda Rabinowitz	PA
TIRR Memorial Hermann	Angelle Sander	TX
North Texas TBI Model System	Simon Driver	TX
Virginia Commonwealth University	Ron Seel	VA
University of Washington	Jeanne Hoffman	WA

## TBIMS Follow-up Centers: 2022-27

TBIMS Center	Principal Investigator	State
Santa Clara Valley Health and Hospital Systems	Ben Dirlikov	CA
Carolinas Rehabilitation/Carolinas HealthCare System	Sima Desai	NC
JFK – Johnson Rehabilitation Institute	Monique Tremaine	NJ
University of Pittsburgh	Amy Wagner	PA

## TBIMS Center-Specific Studies 2022-27

Study Type	n	Topics
<b>Intervention</b>	10	<ul style="list-style-type: none"> <li>• Intervention to Change Affect Recognition and Empathy (ICARE)</li> <li>• Improving TBI Rehabilitation Care Transitions with Community Health Services: A Randomized Clinical Trial</li> <li>• Improving Balance and Mobility after Traumatic Brain Injury: A Randomized Controlled Trial Evaluating High Intensity Step Training (TBI-HIST)</li> <li>• Improving Employment Outcomes of Persons with Moderate/Severe TBI</li> <li>• Randomized Controlled Trial of Combined Cognitive Rehabilitation and Aerobic Exercise for New Learning and Memory in Persons with Moderate-to-Severe TBI</li> <li>• Expanding delivery of an evidence-based weight-loss intervention to enhance access and reach underserved groups after TBI</li> <li>• Intervention to Change Affect Recognition and Empathy (ICARE)</li> <li>• Promoting Wellness in Individuals with Moderate to Severe TBI: Effectiveness of the Mindfulness, Exercise, Nutrition To Optimize Recovery (MENTOR) program</li> <li>• Community-based Implementation of an Emotion Regulation Intervention for Individuals with TBI.</li> <li>• GetUp&amp;GO: A Randomized Controlled Trial of a Theory-Based Intervention to Enhance Physical Activity in Chronic, Moderate-Severe TBI</li> </ul>

## TBIMS Center-Specific Studies 2022-27 (Continued)

Study Type	n	Topics
<b>Assessment and Prediction of Outcomes</b>	6	<ul style="list-style-type: none"> <li>• Symptom Trajectories and Evolution of Mental Health Conditions Over the First Year Post-Injury: A Mobile Health Application</li> <li>• Social Determinants of Health and TBI</li> <li>• Validation of Methods to Assess Return to Driving Decisions after TBI and Development of a Driving Intervention Pilot</li> <li>• Whose Outcome Is It Anyway? Characterizing Recovery After Moderate to Severe Traumatic Brain Injury</li> <li>• Ways of Knowing: Listening to Upper Great Lakes Tribal Communities to Characterize Traumatic Brain Injury Incidence, Impact, and Health Inequities</li> <li>• Predictors of financial capacity and risk of exploitation after TBI</li> </ul>

# TBIMS Multi Center Research 2022-27

Study Type	RCT	Topics
<b>Other Intervention (n=1)</b>	1	<ul style="list-style-type: none"> <li>• Telehealth delivered exercise promotion to treat major depression after TBI: A randomized controlled trial.</li> </ul>
<b>Assessment and Prediction of Outcomes (n=7)</b>	7	<ul style="list-style-type: none"> <li>• Multidimensional Health Perceptions Profiles For Personalizing Patient Provider Communication</li> <li>• Financial Vulnerability in Persons with TBI</li> <li>• State Programs and Outcomes from TBI</li> <li>• Engaging Caregivers in Outcome Assessment Across the Lifespan</li> <li>• Predicting Outcome After Moderate-Severe TBI Using A CT Head Deep Learning Model</li> <li>• Understanding the Social Determinants of Healthcare Access After TBI</li> <li>• Associations of Early Life Adversity and Neighborhood Environment with TBI Outcomes in the TBIMS National Database</li> <li>• Pain Trajectory after TBI: Development and treatment of pain from initial injury to 5 years post injury</li> </ul>

## Definition of TBI for the TBIMS National Database

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
- 16 years of age or older at the time of injury
- Receives acute care and comprehensive inpatient rehabilitation within the model system hospitals.
- Informed consent is signed by patient, family or guardian



## Database Objectives

- Aim of the TBIMS National Database (NDB): 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 care and rehabilitation care.
  - Evaluate the recovery and long-term outcome of individuals with TBI.
  - Establish a basis for comparison with other data sources.

# NIDILRR TBI National Database

- **Method:** Repeated surveys of individuals post injury at regular intervals
- **Form 1:** Inpatient rehabilitation discharge; administered in-person: 365 variables
- **Form 2:** Follow-up conducted 1, 2, 5, and every 5 years thereafter; administered via telephone (primarily), in-person or mail questionnaire; 313 variables



## NIDILRR TBI National Database (Continued)

- Form 1 – 19,647 cases (as of 12/31/2022)
- Form 2 – 76,003 follow-ups\* – 16% attrition (5%\*\*)
  - Year 1 – 19,043 – 12% attrition (2%\*\*)
  - Year 2 – 17,656 – 13% attrition (4%\*\*)
  - Year 5 – 14,919 – 15% attrition (7%\*\*)
  - Year 10 – 9,923 – 17% attrition (5%\*\*)
  - Year 15 – 5,811 – 17% attrition (9%\*\*)
  - Year 20 – 2,535 – 21% attrition (8%\*\*)
  - Year 25 – 632 – 21% attrition (0%\*\*)
  - Year 30 – 202 – 19% attrition (0%\*\*)

\*There are some follow-ups in the database that were performed at 3, 4, and 6 years post-injury.

\*\*Additional percent attrition due to loss of center funding.

## TBI NDB Representativeness

- Applicability of TBIMS findings are dependent on the degree to which the TBIMS NDB reflects the larger population of people with TBI
- By definition, the TBI NDB focuses on moderate to severe TBI
- Concern that the TBIMS NDB has a biased sample of cases
- Recent comparison with Uniform Data System for Medical Rehabilitation (UDS) and eRehabData alleviates much of that concern
- Developed ability to weight NDB to represent population of those that receive inpatient rehabilitation to TBI in the US

## Study Limitations

- Lack of control or comparison group
- Lack of uniformity in treatment across all Centers
- Attrition in follow-up
- Inability to systematically track post-acute service utilization
- Limited follow-up evaluations if Center defunded



# NIDILRR TBI Interagency Database Collaborations

## IAAs between Centers for Disease Control and Prevention (CDC) and NIDILRR:

- Extension of the Representativeness of the Traumatic Brain Injury Model Systems National Database: 2001 to 2010.
- US population estimates of health and social outcomes 5 years after rehabilitation for traumatic brain injury.
- Epidemiology of adults receiving acute inpatient rehabilitation for a primary diagnosis of traumatic brain injury in the United States.
- Life Expectancy after Inpatient Rehabilitation for Traumatic Brain Injury in the United States.
- Unemployment in the United States after TBI for working-age individuals: Prevalence and associated factors 2 years postinjury.



## NIDILRR TBI Interagency Database Collaborations (Continued)

### IAAs between Centers for Disease Control and Prevention (CDC) and NIDILRR (Continued):

- Acute Ischemic Stroke After Moderate to Severe Traumatic Brain Injury: Incidence and Impact on Outcome.
- Moderate to Severe Traumatic Brain Injury is a Lifelong Condition.
- Functional Outcome Trajectories following Inpatient Rehabilitation for TBI in the United States: A NIDILRR TBIMS and CDC Interagency Collaboration.
- One and Five Year Outcomes after Traumatic Brain Injury Requiring Inpatient Rehabilitation.
- Return to Productivity Projections for Individuals with Moderate to Severe TBI following Inpatient Rehabilitation.





# NIDILRR TBI Interagency Database Collaborations (Continued)

## IAAs between Department of Veterans Affairs (VA) and NIDILRR (FY2008-2013)

- VA TBI Veterans Health Registry (Congressional mandate)
  - Includes those serving in Operation Enduring Freedom/ Operation Iraqi Freedom who exhibit symptoms associated with TBI, and apply for services or file a disability claim.
  - TBIMS National Data and Statistical Center (NDSC), together with VA and NIDILRR, design studies, conduct analyses, and generate reports
- VA Polytrauma Rehabilitation Centers (PRC) Database
  - Includes those admitted to the VA PRCs with a diagnosis of TBI
  - Includes most variables currently in TBIMS NDB; follows TBIMS NDB procedures and data collection schedules

# NIDILRR TBI Interagency Database Collaborations (Continued)

## Contracts between Department of Veterans Affairs (VA) and NDSC (FY2016-present)

- VA TBI Veterans Health Registry (Congressional mandate)
  - Includes those serving in Operation Enduring Freedom/ Operation Iraqi Freedom who exhibit symptoms associated with TBI, and apply for services or file a disability claim.
  - TBIMS National Data and Statistical Center (NDSC), together with VA and NIDILRR, design studies, conduct analyses, and generate reports
- VA Polytrauma Rehabilitation Centers (PRC) Database
  - Includes those admitted to the VA PRCs with a diagnosis of TBI
  - Includes most variables currently in TBIMS NDB; follows TBIMS NDB procedures and data collection schedules

# Other NIDILRR TBI Interagency Collaborations

## Research-based Initiatives to Advance Treatment/Services

- 3rd Federal Interagency Conference on TBI (Sponsors: NIDILRR, DoD, VA, NIH, CDC and others).
- Guidelines for the Treatment of Disorders of Consciousness post TBI (Sponsors: NIDILRR/American Academy of Neurology/American Congress of Rehabilitation Medicine)
- Guidance for the Acute Diagnosis and Management of Mild Traumatic Brain Injury (mTBI) among Children and Adolescents (Sponsor: CDC)
- Cognitive Rehabilitation for mTBI (Sponsor: DoD)
- Driving evaluations post TBI (Sponsor: DoD)

## Other NIDILRR TBI Interagency Collaborations (Continued)

### Consensus Initiatives to Advance Research

- Common Data Elements (CDE) for TBI Research (Sponsors: DoD, NINDS, NIDILRR, DVBIC, VA)
- FITBIR Federated Database (Sponsors: NIH/DoD)
- Report to Congress on Rehabilitation Post TBI (Sponsor: CDC)
- Future Research Needs for Multidisciplinary Postacute Rehabilitation for Moderate to Severe TBI in Adults (Sponsor: AHRQ)
- State-of-the-Science Report on Sports-related Concussions in Youth (Sponsors: IOM & 10 partners, including NIDILRR)
- Cognitive Rehabilitation Therapy Workshop (Sponsor: IOM/DoD)

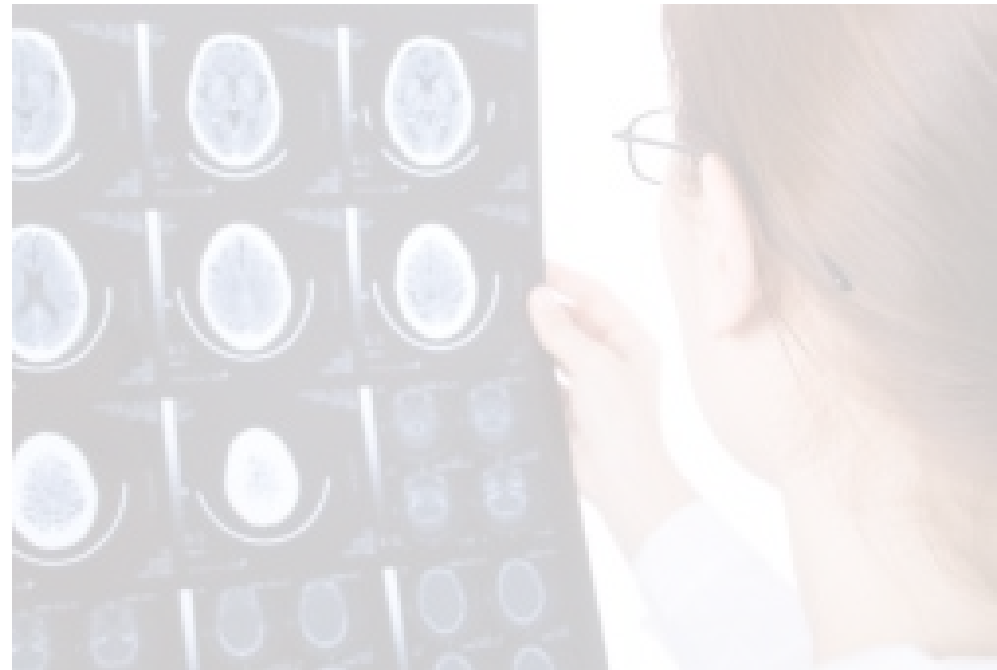
## 266 Studies Use the TBIMS NDB (Internal and External, Excluding Public Use)

### Peer-Reviewed Publications Have Used the TBIMS NDB

- Epidemiology of moderate to severe TBI
- Natural history of TBI outcomes and comorbidities
- Predictors of TBI outcomes and comorbidities
- Validation of severity and outcome measurement
- Longitudinal change over time

## TBIMS Accomplishments (1/7)

- An additional 400-plus peer reviewed publications from TBIMS research include a wide range of topics
  - Patient and injury characteristics
  - Prognostic factors
  - Comorbidities
  - Outcomes research
  - Treatment effectiveness
  - Health service research



## TBIMS Accomplishments (2/7)

- Development of practice parameters in important areas of TBI care
  - Management of post-traumatic seizures
  - Spasticity
  - Post-traumatic agitation
  - Substance misuse
  - Family intervention
  - Driving





## TBIMS Accomplishments (3/7)

- Development of innovative interventions for the acute phase of recovery
  - DVT prophylaxis
  - Amantadine for Disorders of consciousness
  - Amantadine for irritability
  - Adaptation of acute rehab for older adults
  - Care-giver support
  - Telephone follow-up

## TBIMS Accomplishments (4/7)

- Creation of novel diagnostic procedures and measurement instruments
  - Post-traumatic amnesia (O-Log; JFK CRS)
  - Participation (CIQ; PART)
  - Agitation (ABS)
  - Attention (MARS)
  - Disability+ (DRS; MPAI)
  - Neurobehavioral functioning (NFI)
  - Lifetime TBI (OSU-TBI-ID)



## TBIMS Accomplishments (5/7)

- O-Log = The Orientation Log
- JFK CRS = Coma Recovery Scale
- CIQ = Community Integration Questionnaire
- PART = Participation Assessment with Recombined Tools
- ABS = Agitated Behavior Scale
- MARS = Moss Attention Rating Scale
- DRS = Disability Rating Scale
- MPAI = Mayo Portland Adaptability Inventory
- NFI = Neurobehavioral Functioning Inventory
- OSU-TBI-ID = Ohio State University TBI Identification Method

## TBIMS Accomplishments (6/7)

- Identification of adverse rehabilitation outcomes common to TBI and associated risk factors
  - TBIMS research has shown longer PTA, unawareness of deficits, depression, substance abuse, fatigue, minority status, older age to be risk factors for worse outcomes
  - TBIMS research has documented mortality risk after TBI
- Characterization of the recovery trajectory in the years following injury
  - Functional independence, satisfaction with life, cognitive abilities, employment, residence, etc. have all been characterized from the TBIMS data in both the initial two years post-injury and now more than a decade post-injury

## TBIMS Accomplishments (7/7)

- Creation of user-friendly, web-based resources for people with brain injury, their caregivers, and professionals
  - Center on Outcome Measurement in Brain Injury (COMBI)
  - TBIMS NDB syllabus
  - MSKTC fact sheets
  - TIRR web-based materials for care-givers

# Data Categories

- Demographic characteristics of the population
- Causes and severity of injury
- Nature of diagnoses
- Characteristics of treatment/services
- Impairment
- Health and Behavior Measurements
- Disability
- Participation



# I. Demographic Characteristics

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Age	✓	
Gender	✓	
Race / Ethnicity	✓	✓
Height / Weight	✓	
Primary Language	✓	
Country of Birth	✓	
Military History	✓	



## II. Causes / Severity of TBI

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Date of Injury	✓	
ICD External Causes of Injury	✓	
Glasgow Coma Scale Score	✓	
Time to Follow Commands (duration of unconsciousness)	✓	
Duration of Post Traumatic Amnesia	✓	

### III. Diagnoses

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Spinal Cord Injury	✓	
Intracranial CT Scan Reports	✓	
Neuropsychological Assessment (BTACT)	✓	
ICD Diagnosis Codes	✓	

## IV. Treatments

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Lengths of Stay	✓	
Craniotomy	✓	
Rehospitalizations		✓

## V. Impairment

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Mortality	✓	✓
Lifetime History of TBI	✓	✓
Seizures	✓	✓

## VI. Health / Behavior

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Substance use	✓	✓
Psychiatric and Medical History	✓	✓
Arrests/felony incarcerations	✓	✓
Learning/behavior problems	✓	
PHQ 9 – Depression		✓
GAD 7 – Anxiety		✓
Satisfaction With Life Scale (SWLS)		✓

## VII. Disability

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Disability Rating Scale (DRS)	✓	✓
Functional Independence Measure (FIM)	✓	✓
Continuity Assessment Record and Evaluation (CARE)	✓	
Glasgow Outcome Scale-Extended (GOS-E)		✓

## VIII. Participation

	Form 1 (acute injury and hospitalization)	Form 2 (annual follow-up)
Participation Assessment (PART)		✓
Living With	✓	✓
Residence (e.g., private home, SNF, AFC, hospital)	✓	✓
Address (w/consent)	✓	✓
Marital Status	✓	✓
Employment	✓	✓
Education	✓	✓
Transportation		✓

## Sources of Data

- Abstract from medical records
- Pre-existing database
- Specialized data collection forms
- Patient examination/  
interview/testing
- Family interview





## Guidelines for Follow-up

- Follow-up contact attempted with every patient 1st, 2nd, 5th years and then every five years.
- 4 month window for year 1 follow-up, 6 month window for year 2, 1 year window for years 5, 10, 15, . . .
- Patient is primary source of follow-up information; if patient cannot be interviewed, follow-up is attempted with a proxy.
- Methods of follow-up in order of priority: phone/in-person, mail questionnaire.

# Data Quality Checks

- Data entry screens:
  - Checks for valid codes and correct range
  - Logical checks between variables
  - Consistency checks between variables across time



## Data Quality Checks (Continued)

- User-initiated database reports:
  - Identify cases with errors or blanks
  - Notify of follow-ups coming due
  - Warnings about overdue follow-ups
  - Calculate missing data rates
  - Calculate follow-up rates



# Internal Dissemination

- Annual Data Summary
- Quarterly Data Quality Reports
  - Enrollment
  - Retention
  - Missing Data



## External Dissemination

- Internet [[www.tbindsc.org](http://www.tbindsc.org)]
  - Online Database Data Dictionary
  - Annually updated TBI Model Systems PowerPoint Presentation
- National/International Presentations
- Journal Publications



# TBI Model Systems National Data and Statistical Center Website









[www.tbindsc.org](http://www.tbindsc.org)

## 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
-  Moderate to Severe Traumatic Brain Injury is a Lifelong Condition
-  2022 TBI Model Systems Presentation
-  2022 TBI Model Systems National Database Update
-  Using the Traumatic Brain Injury Model Systems National Database
-  Components of the Traumatic Brain Injury Model System Centers
-  The Traumatic Brain Injury Model System Centers Program

### 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 more than 20 papers that utilized data from the NDB. In recognition of his invaluable contributions to the TBIMS and the NDB, the TBIMS established the Rosenthal award in 2008 to keep Mitch's memory alive and to inspire new generations of investigators. Each year, a committee reviews all papers that were published or e-published in the prior calendar year and rates them on 3 criteria: Importance, Technical Quality, and Writing Quality. The top ranked paper is named the Rosenthal awardee for that year.

 Rosenthal Awardees

### Links to other Model Systems Programs

-  National Spinal Cord Injury Statistical Center
-  Burn Model Systems Data Coordinating Center
-  Model Systems Knowledge Translation Center

### Characterization and Treatment of Chronic Pain after Moderate to Severe Traumatic Brain Injury

The TBIMS Collaborative mechanism, funded by NIDILRR, has allowed us to collect more information from our TBIMS participants on their experience with chronic pain and pain treatment after moderate to severe TBI. Our goal is to learn more about how many people continue to have chronic pain over time, for those with pain or who have had pain after their injury, what treatments they have tried, and for those without chronic pain to learn more about common co-occurring conditions like sleep, mood, and quality of life to compare those with and without pain. The ultimate goal of learning more about the experience of pain after moderate to severe TBI is to improve health and function. Our goal is to collect data on 3800 individuals, but along the way we are providing a look at the data we have collected to date through the link below. We will provide an update on a quarterly basis, so please check back regularly.

[Chronic Pain and TBI Public Website](#)

### The Comparing Treatment Approaches to Promote Inpatient Rehabilitation Effectiveness for Traumatic Brain Injury (CARE4TBI)

CARE4TBI project is a pragmatic, stakeholder-driven observational study which aims to: 1) standardize electronic medical record (EMR) documentation of rehabilitation therapy to allow extraction for research and operations, 2) compare the effectiveness of well-defined rehabilitation approaches to improve community participation and functional independence of patients with TBI, and 3) identify patient, provider, setting and post-discharge factors that modify the effect of therapy on key outcomes. In addition to rehabilitation clinicians, persons living with TBI from the Ohio Valley Center Advisory Council will provide input on study implementation and interpretation of findings.

[CARE4TBI Website](#)

# Online TBI Model Systems National Database Data Dictionary

[www.tbindsc.org](http://www.tbindsc.org)

TRAUMATIC BRAIN INJURY MODEL SYSTEMS, National Data and Statistical Center

## Data Dictionary Explorer

[Help](#)

Search:

Include ARCHIVED Variables? ☐ NO

Include These Form Variables

Show Domains Referencing ...

Domain Search Text

Include Variables Referencing ...

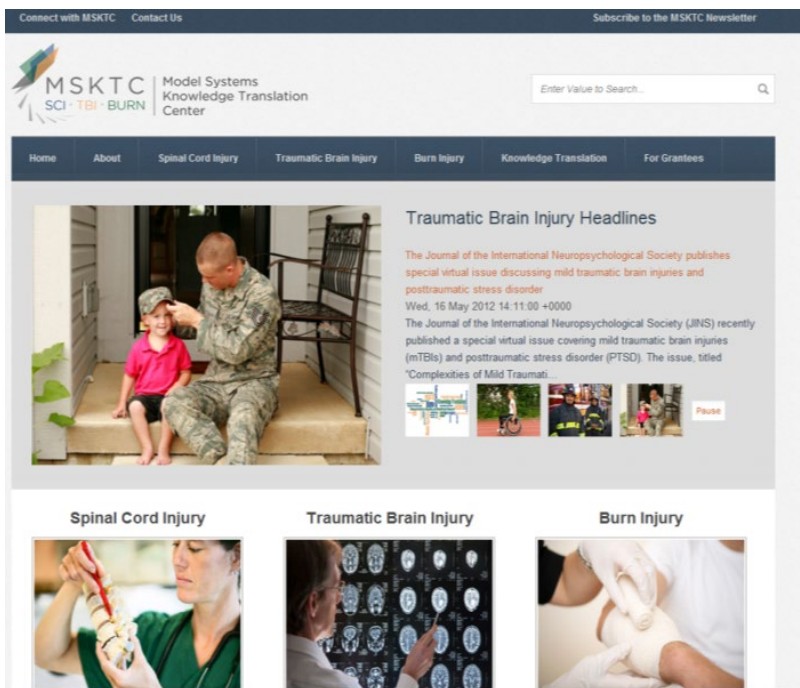
Variable Search Text

## Domains

-  **ANXIETY**  
Subdomains: GAD, GAD - CALCULATED
-  **ASSOCIATED INJURIES**  
Subdomains: SCI
-  **CARE (CONTINUITY ASSESSMENT RECORD AND EVALUATION)**  
Subdomains: MOBILITY, SELF CARE

# Model Systems Knowledge Translation Center (MSKTC)

[www.msktc.org](http://www.msktc.org)



- The Model Systems Knowledge Translation Center (MSKTC) aims to:
  - *Enhance* the relevance and visibility of Model Systems research
  - *Communicate* Model Systems research effectively to stakeholders
- The MSKTC is operated by American Institutes for Research in collaboration with WETA/BrainLine and George Mason University



# MSKTC Goals

## Three overarching goals guide the work of the MSKTC:

- **Goal 1:** Enhance the understanding of the quality and relevance of knowledge among researchers and multiple users on the topics of SCI, TBI, and Burn
- **Goal 2:** Enhance knowledge of advances in SCI, TBI, and Burn research among the diverse audience members who need this information
- **Goal 3:** Create a centralized repository of empirical information and resources on research in SCI, TBI, and Burn areas and actively conduct outreach and dissemination activities to communicate this knowledge

# MSKTC Activities 2011-2014 Highlights

	Completed	In Process
<b>Systematic Reviews</b>		<ul style="list-style-type: none"> <li>TBI &amp; Fatigue</li> <li>TBI &amp; Medical Outcomes</li> </ul>
<b>Consumer Factsheets</b>	<ul style="list-style-type: none"> <li>TBI &amp; Couples' Relationship</li> </ul>	<ul style="list-style-type: none"> <li>TBI &amp; Vocational Rehabilitation</li> <li>TBI &amp; Vision Problems</li> <li>TBI &amp; Spasticity</li> </ul>
<b>Knowledge Translation Products</b>	<p><b>Knowledge Translation Webinar</b></p> <ul style="list-style-type: none"> <li>Planning for Communities of Practice: Model Systems Grantees</li> <li>Getting to Outcomes: A Knowledge Translation Webinar for Model Systems Grantees</li> <li>Engaging with Audiences: A Learning Collaborative</li> </ul> <p><b>Knowledge Translation Toolkit</b></p> <ul style="list-style-type: none"> <li>Newsletter Template and Instructions</li> <li>Press Release Template and Instructions</li> <li>508 Compliance Tip sheet</li> <li>Tips on Presenting facts and figures</li> </ul>	<ul style="list-style-type: none"> <li>Additional Knowledge Translation Webinars</li> <li>Additional tools for the Knowledge Translation tools</li> </ul>
<b>Multimedia Products</b>	<p><b>Slideshows</b></p> <ul style="list-style-type: none"> <li>TBI &amp; Alcohol</li> <li>TBI &amp; Sexuality</li> <li>TBI &amp; Couples' Relationship</li> <li>TBI &amp; Emotional Problems</li> </ul> <p><b>Hot Topics Module</b></p> <ul style="list-style-type: none"> <li>Relationships after TBI</li> </ul>	<p><b>Hot Topics Module</b></p> <ul style="list-style-type: none"> <li>Depression after TBI</li> </ul> <p><b>Slideshows</b></p> <ul style="list-style-type: none"> <li>Depression after TBI</li> </ul>

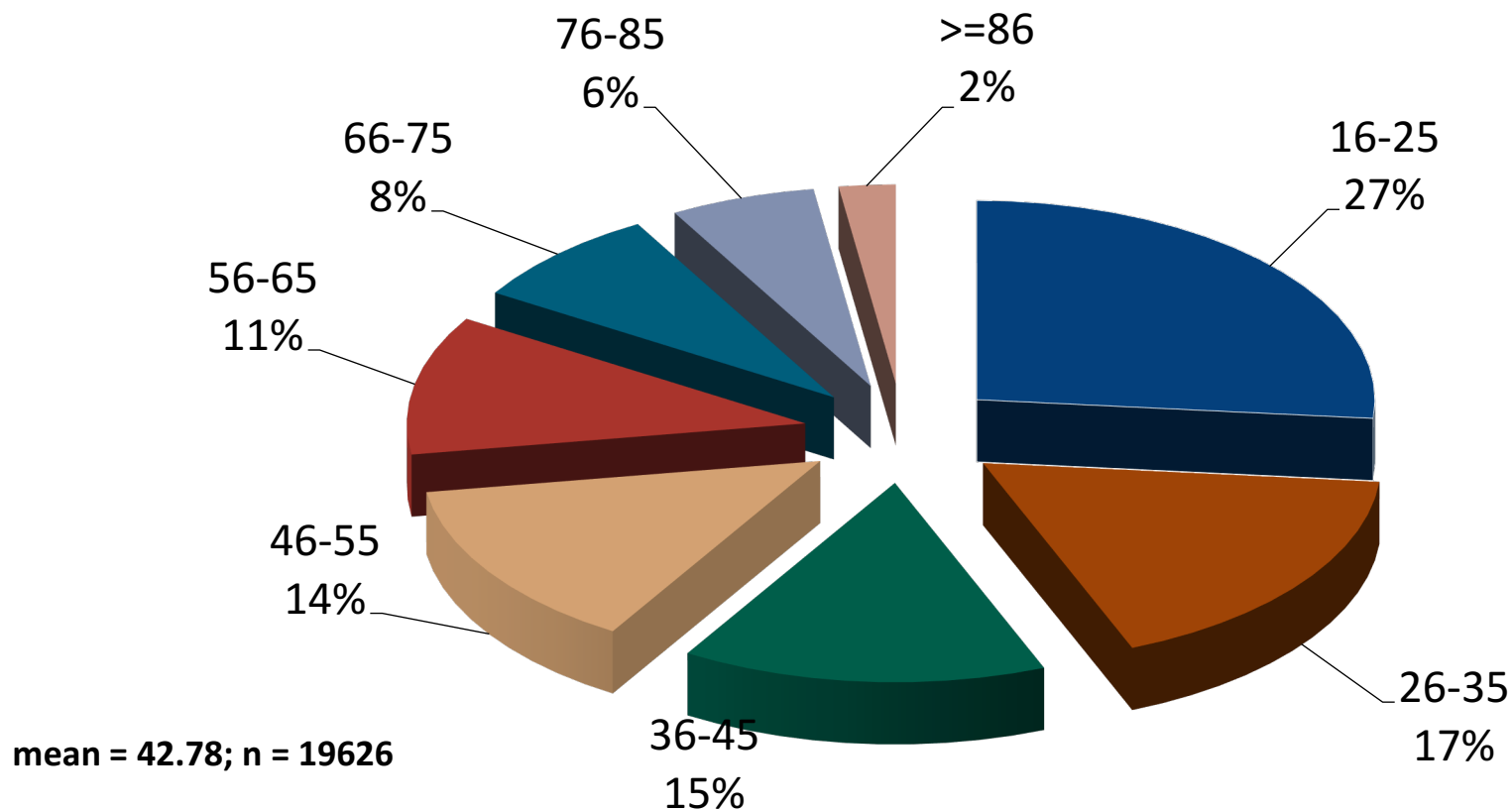
# MSKTC Activities 2015-2019 Highlights

	Completed	In Process
<b>Systematic Reviews</b>	<ul style="list-style-type: none"> <li>Interventions for Fatigue after TBI</li> <li>Screening and Brief Intervention for Substance Misuse Among Patients with TBI</li> <li>TBI and Education (Adult sample)</li> </ul>	<ul style="list-style-type: none"> <li>Treatment for Depression following TBI</li> <li>Interventions for Post Traumatic Headache</li> <li>TBI and Education (Pediatric sample)</li> </ul>
<b>Consumer Factsheets</b>	<ul style="list-style-type: none"> <li>Couples' Relationship after TBI</li> <li>Spasticity and TBI</li> <li>Memory and Moderate to Severe TBI</li> </ul>	<ul style="list-style-type: none"> <li>Vision Problems after TBI</li> <li>Severe TBI: What to Expect in the Trauma Center, Hospital, and Beyond</li> <li>Social Skills after TBI</li> <li>Loss of Smell and Taste after TBI</li> </ul>
<b>Knowledge Translation Tools</b>	<ul style="list-style-type: none"> <li>Disseminate to Your Audiences (9 tools)</li> <li>Develop and Test Products (5 tools)</li> <li>Engage the Media (4 tools)</li> <li>Use social media (5 tools)</li> <li>Charts and Figures (31 tools)</li> </ul>	<ul style="list-style-type: none"> <li>Create User Friendly Website (6 tools)</li> <li>Conduct Systematic Reviews (2 tools)</li> <li>Engage Policymakers (3 tools)</li> <li>Additional Knowledge Translation Tools</li> </ul>
<b>Multimedia Products</b>	<p><b>Slideshows</b></p> <ul style="list-style-type: none"> <li>TBI &amp; Alcohol</li> <li>Relationships after TBI</li> <li>Depression after TBI</li> <li>Emotional problem after TBI</li> <li>Fatigue after TBI</li> <li>TBI &amp; Sexuality</li> </ul>	<ul style="list-style-type: none"> <li>Memory loss after TBI</li> <li>Sleep and TBI</li> <li>Spasticity and TBI</li> </ul> <p><b>Hot Topics Module</b></p> <ul style="list-style-type: none"> <li>TBI &amp; Couples' Relationship</li> <li>TBI and Depression</li> <li>Memory loss after TBI</li> </ul> <p>Additional Multimedia Products</p>

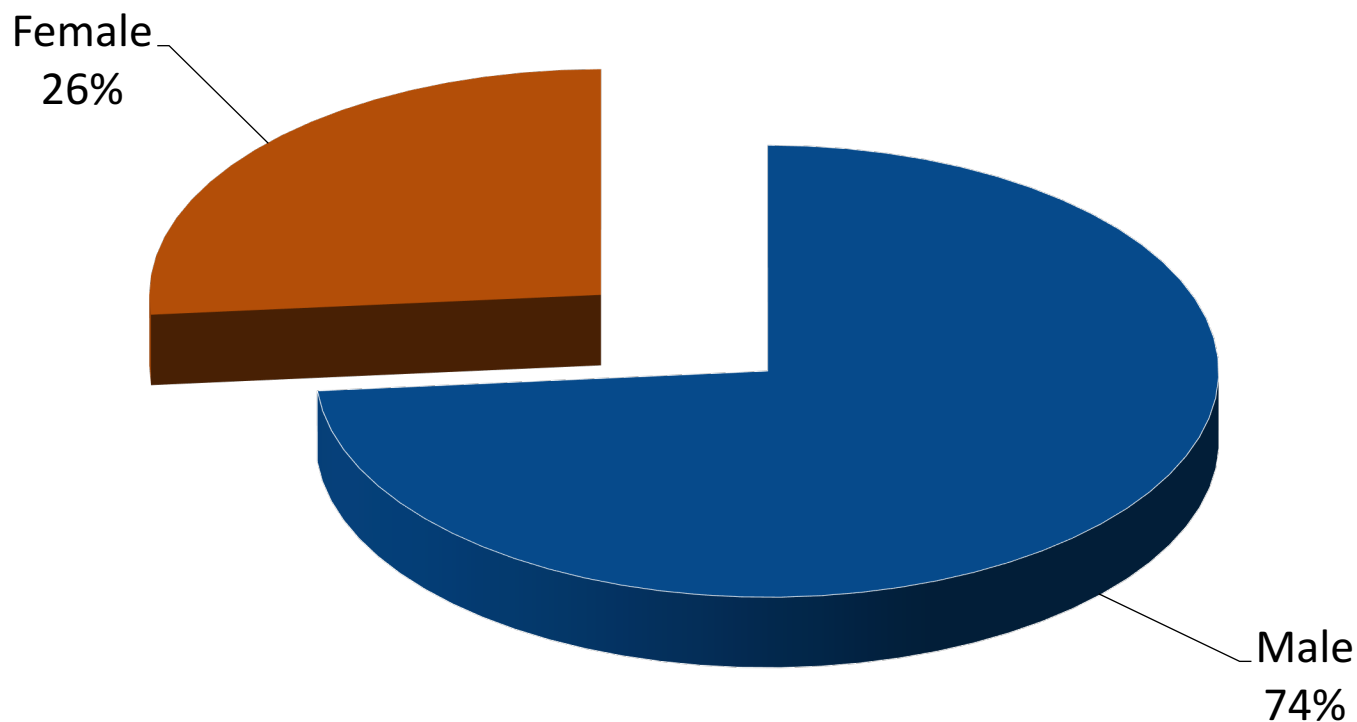
# TBIMS National Database Descriptive Data Summary

Includes data from 1/01/1989-12/31/2022

# Age

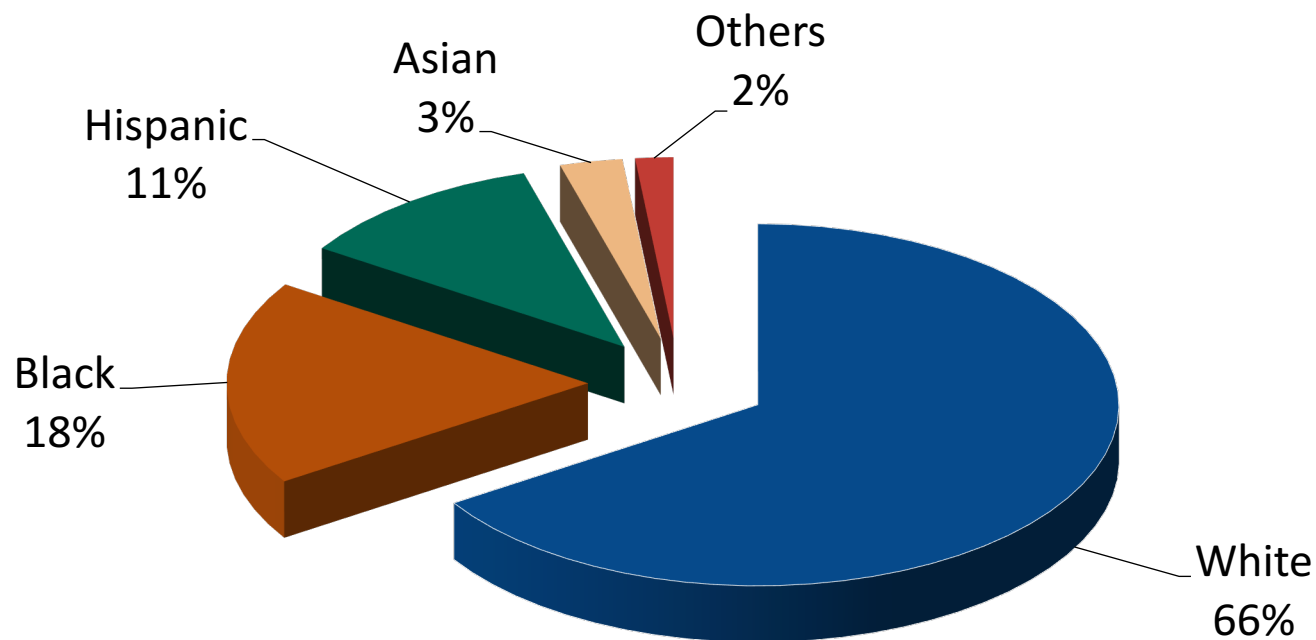


# Gender



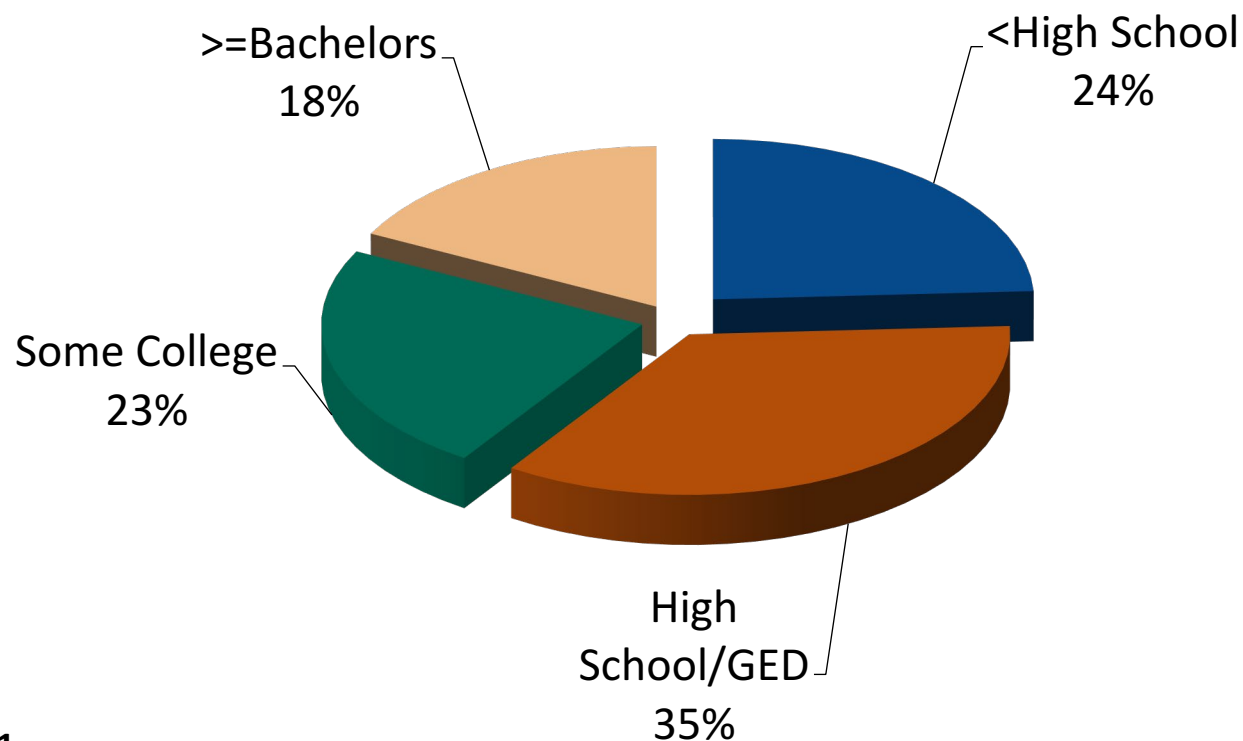
n = 19617

# Race



**n = 19617**

## Level of Education At Injury



**n = 19311**

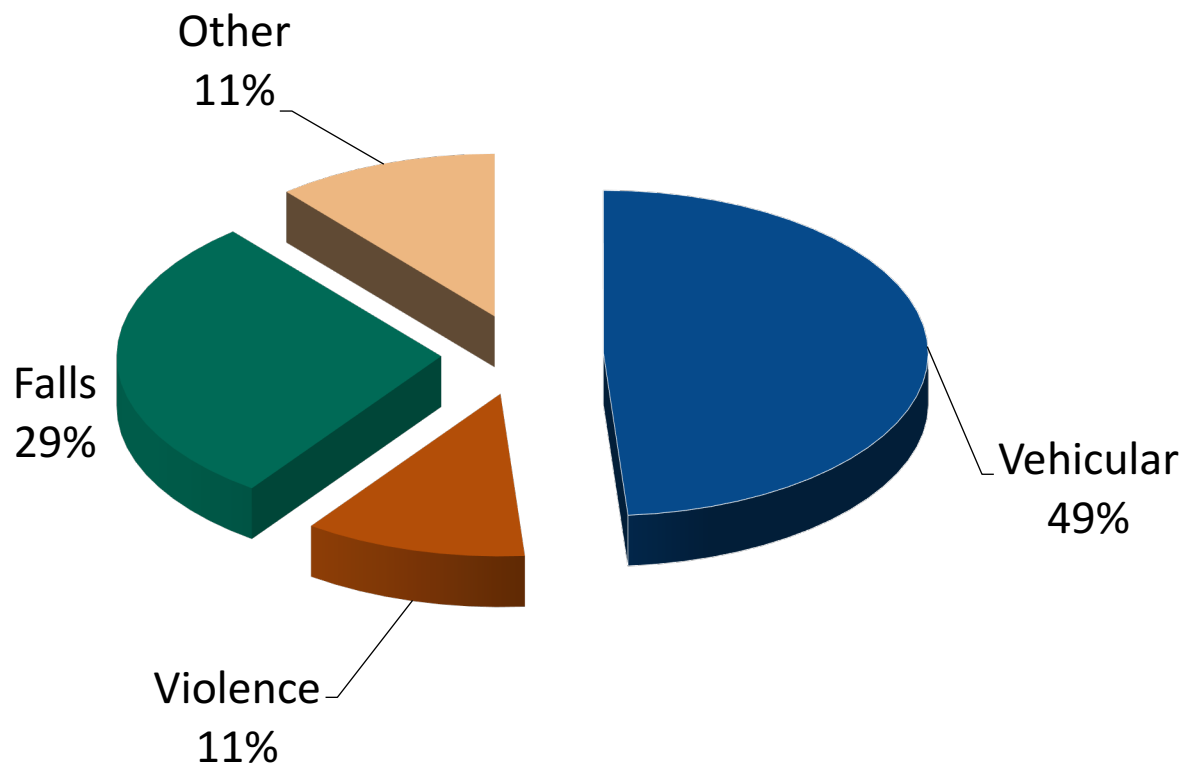


# Summary

## Demographic Characteristics of the Population

- Average age = 42.78
- Male (74%)
- Minority population (34%)
- High school education or less (60%)

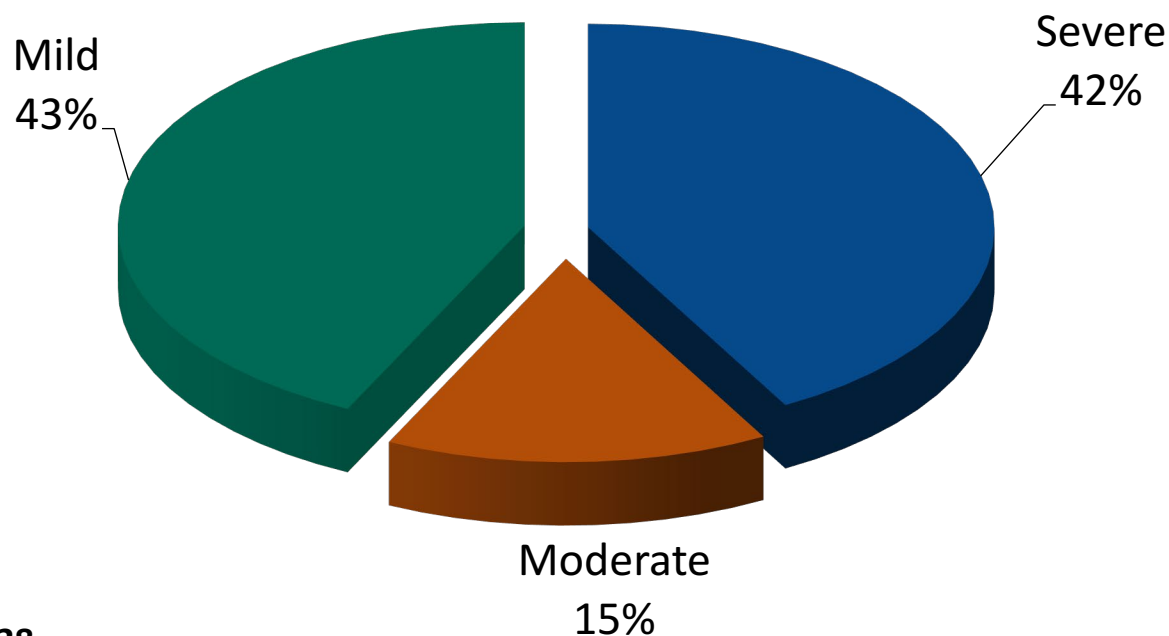
# Etiology of Injury



**n = 19583**

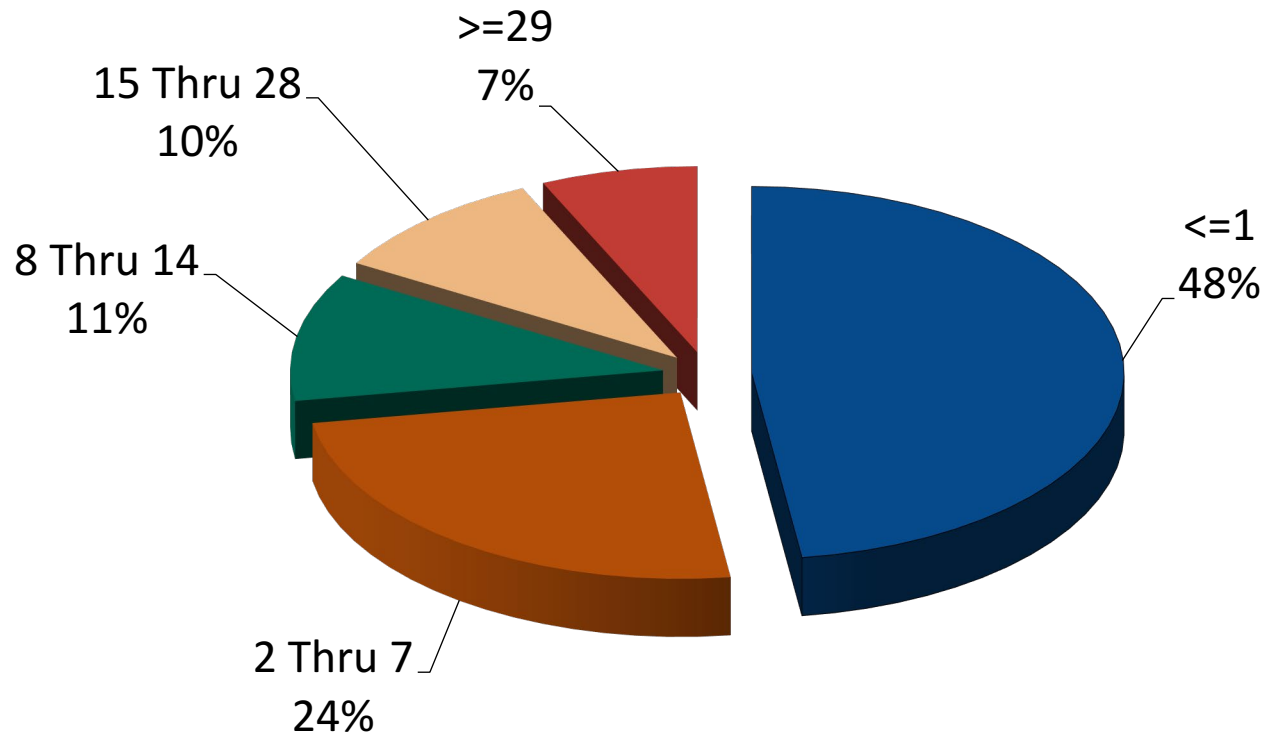
# Glasgow Coma Scale Score

## At Emergency Department Admission



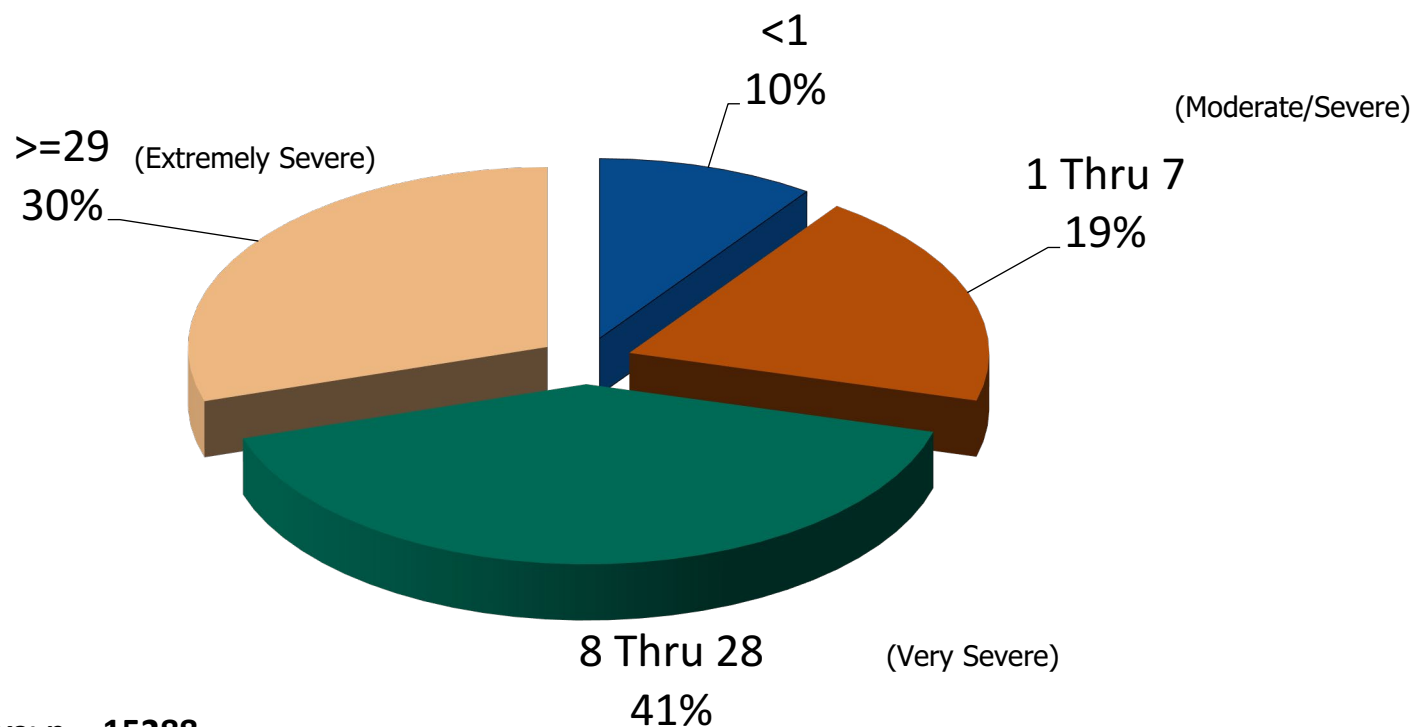
mean = 9.8; n = 15038

## Duration of Unconsciousness



mean = 7.63 days; n = 18881

## Duration of PTA



mean = 22.17 days; n = 15288

# Summary

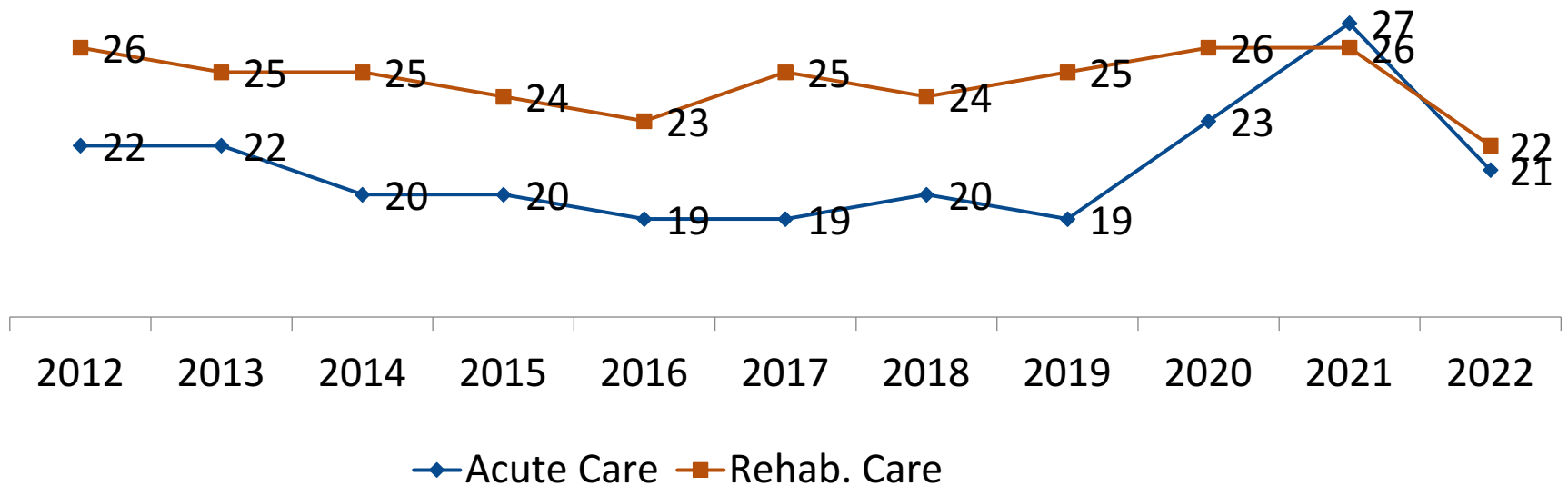
## Causes of Injury

- Primary cause is vehicular (49%), followed by falls (29%) and violence (11%)

## Severity of Injury

- Average duration of LOC is 7.63 days
- Average duration of PTA is 22.17 days

## Mean Length of Stay



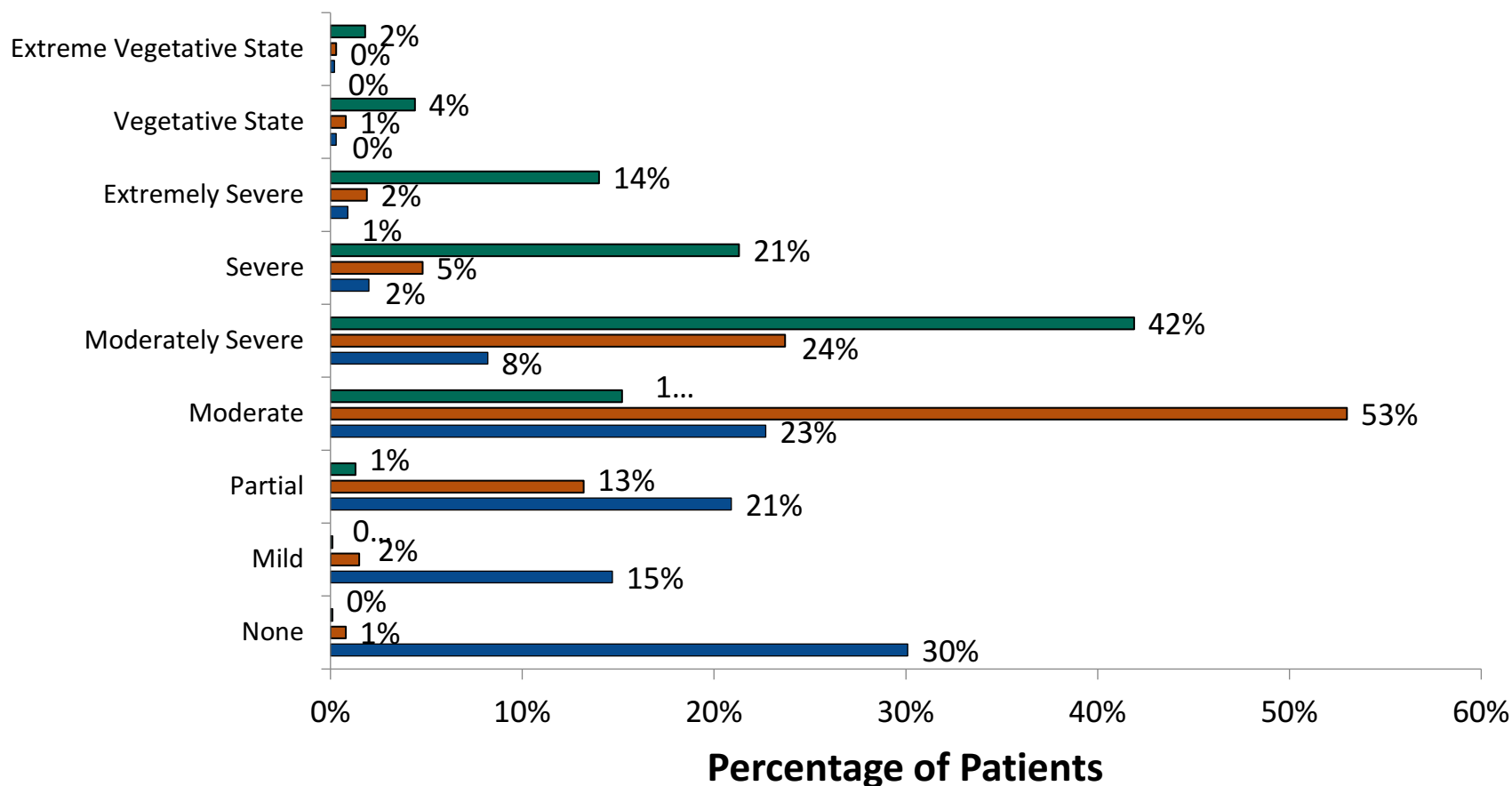
# Summary

## Costs of Treatment

- Total length of stay (LOS) had been steadily decreasing over the last 10 years until 2020 when the COVID pandemic hit, and overall stays began to increase.
- Total acute LOS in 2021 had remained fairly stable over the last 5 years, however during the COVID-19 pandemic of 2020 and 2021, the acute LOS days jumped from 19 days (2019) to 23 in 2020, and 27 in 2021. It declined back to 21 in 2022.
- Total rehab LOS in 2021 represents the highest in the past decade, with 2022 numbers returning to more typical LOS totals.
- Thirty-nine percent have government-sponsored rehabilitation care (Medicaid/Medicare).

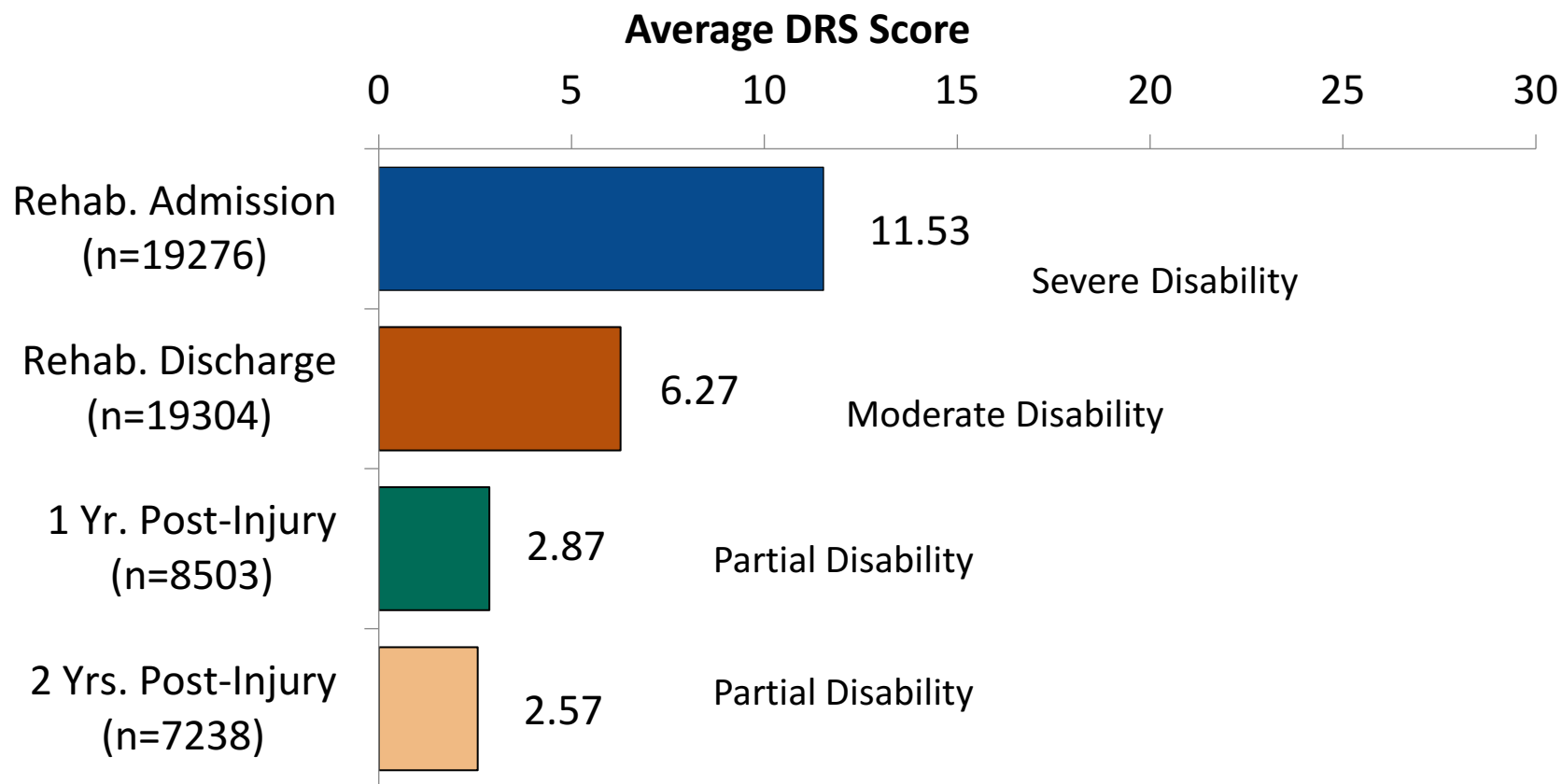


# Disability Rating Scale

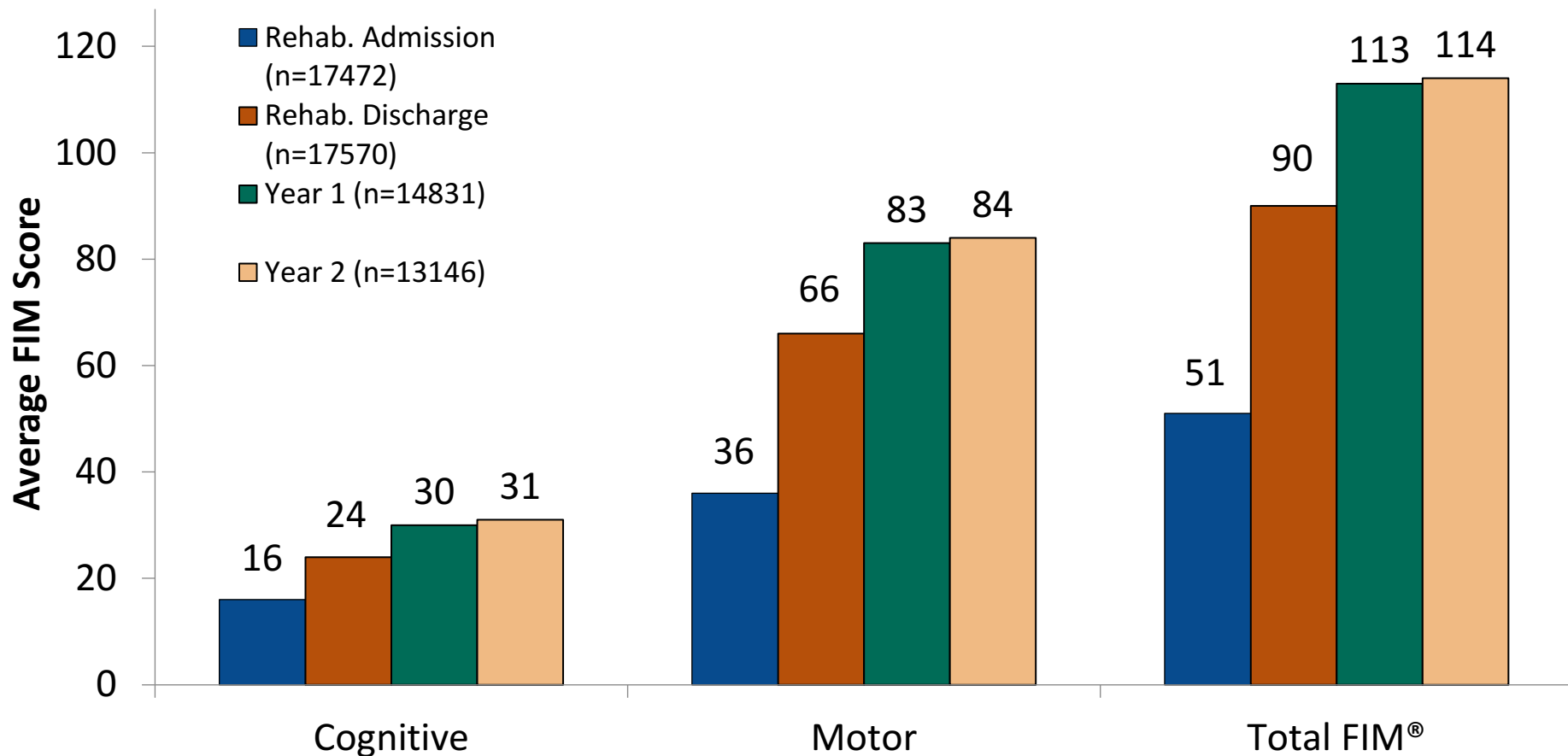


■ Rehab. Admit (n=19259)
 ■ Rehab. DC (n=19287)
 ■ 1 Yr. Post-Injury (n=7163)

## Disability Rating Scale (Continued)



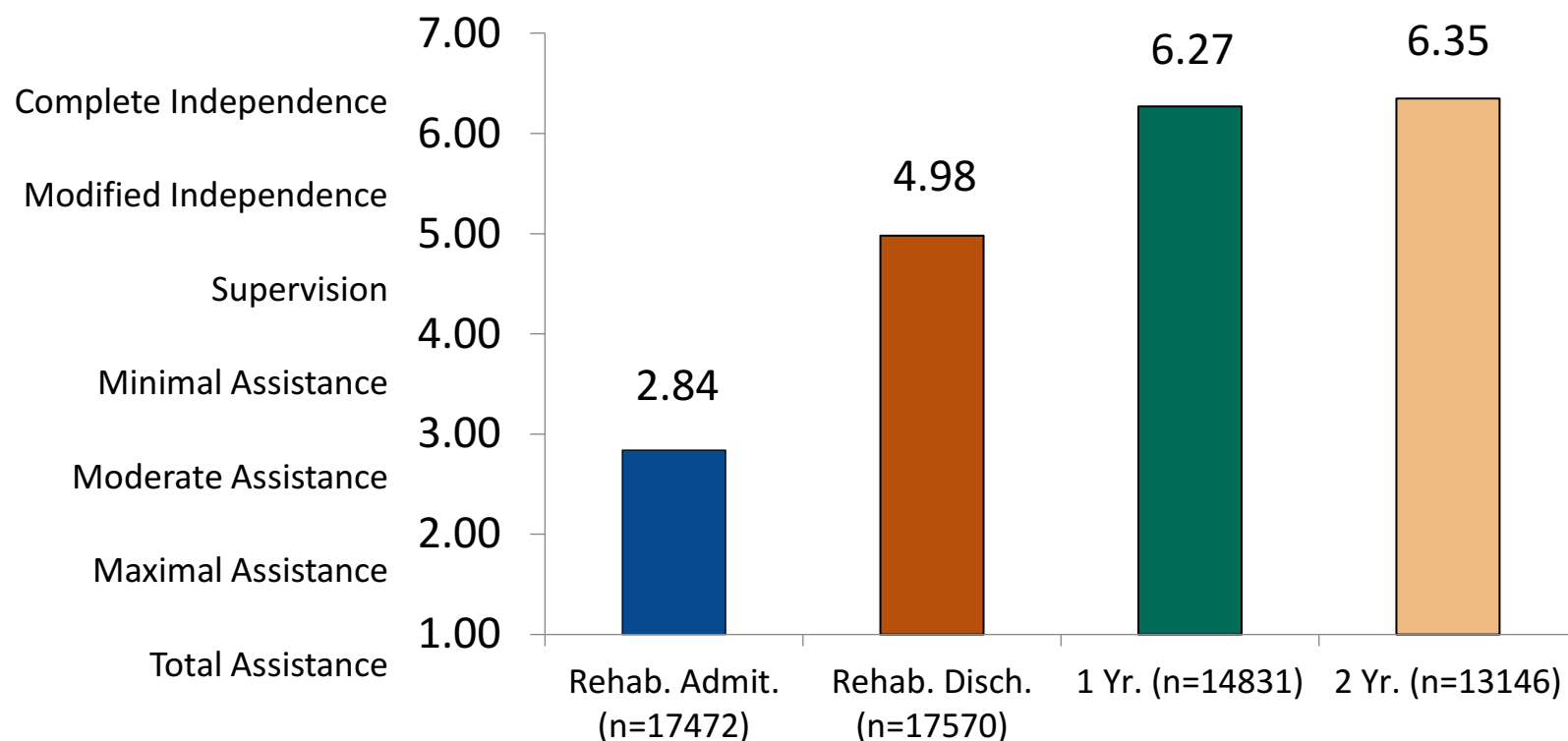
# FIM® Instrument



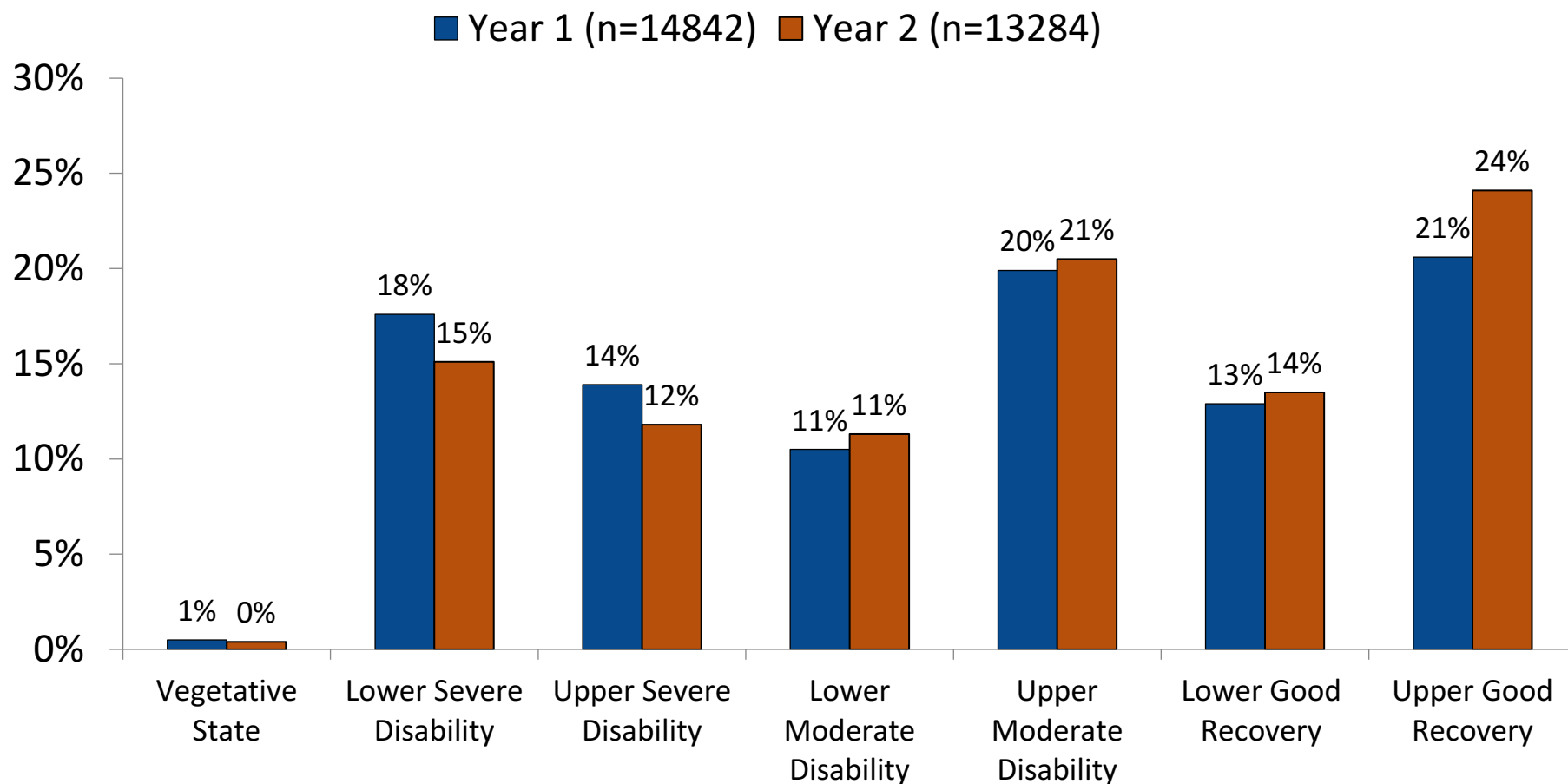
\*Note: The value of n is reflective of Total FIM® measure

## FIM® Instrument (Continued)

Mean Scores converted to 7-point scale



# Glasgow Outcome Scale-Extended

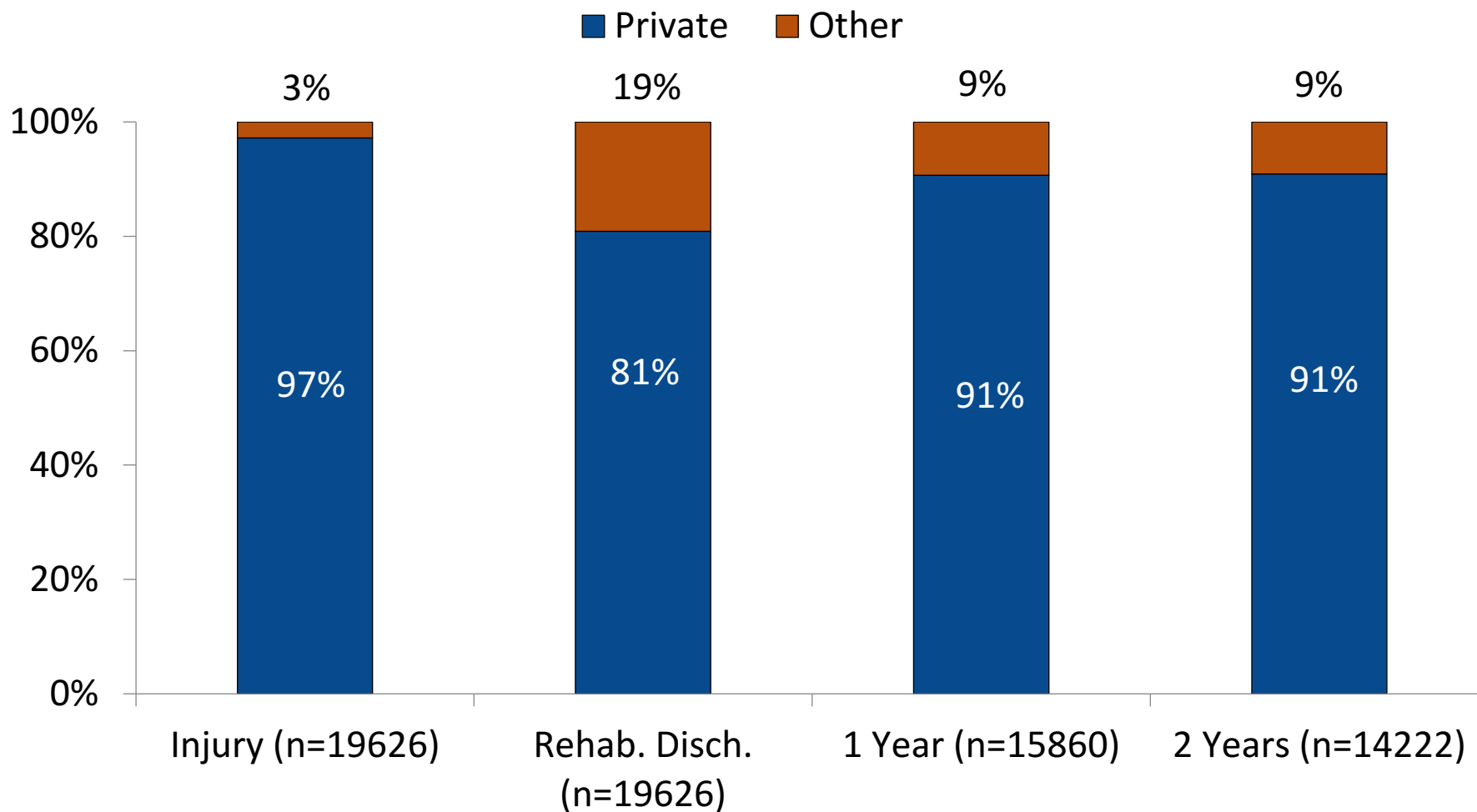


# Summary

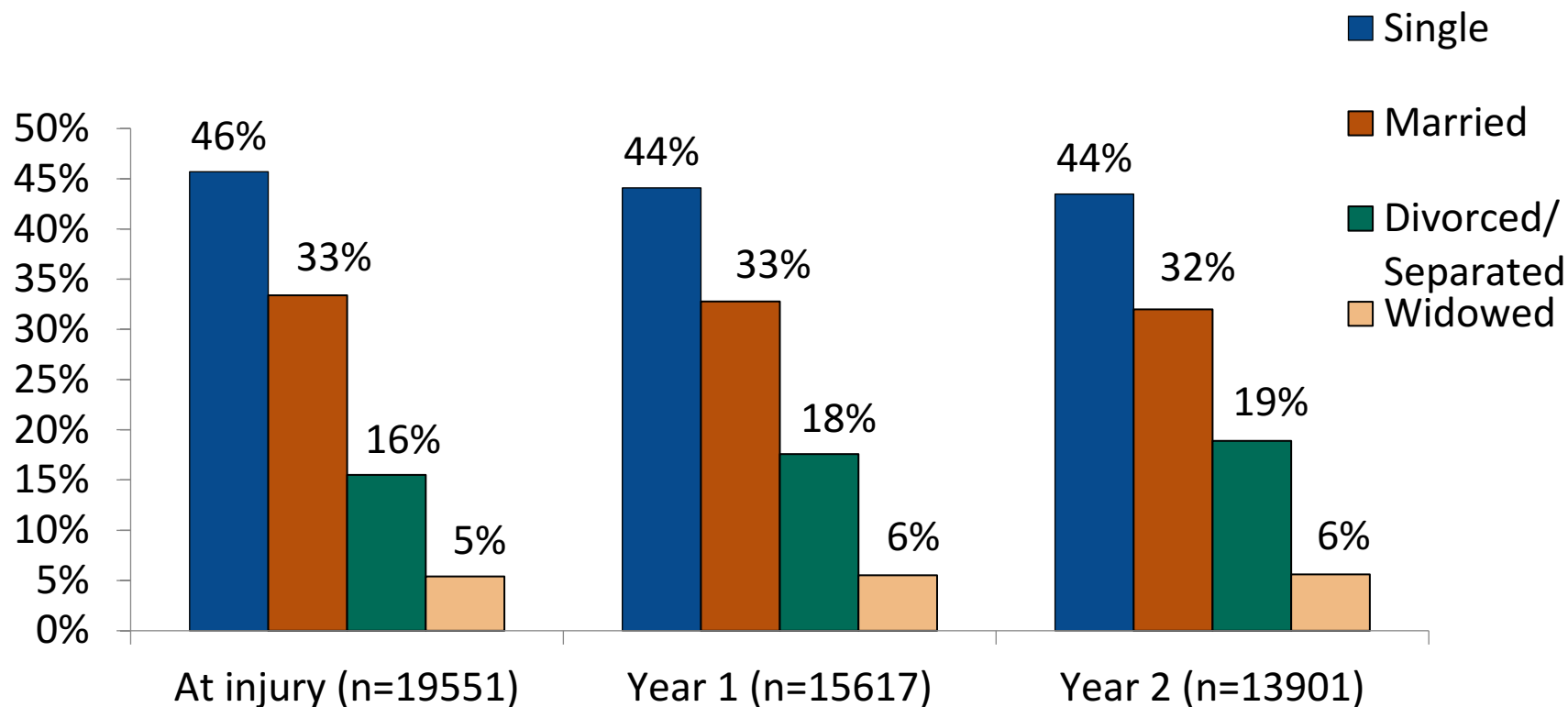
## Disability Outcomes

- DRS indicates improvement in level of disability from SEVERE DISABILITY at rehab. admission to PARTIAL DISABILITY at 1 and 2 years post-injury.
- FIM<sup>®</sup> Instrument indicates improvement in functional ability from level requiring MODERATE ASSISTANCE at rehab. admission to MODIFIED INDEPENDENCE at 1 and 2 years post-injury.
- Most improvement in level of disability and functional ability occurs during inpatient rehabilitation.
- Continued improvement is seen at 1 year post-injury.
- Levels of disability and functional ability appear to plateau between 1 and 2 years post-injury.

## Residence

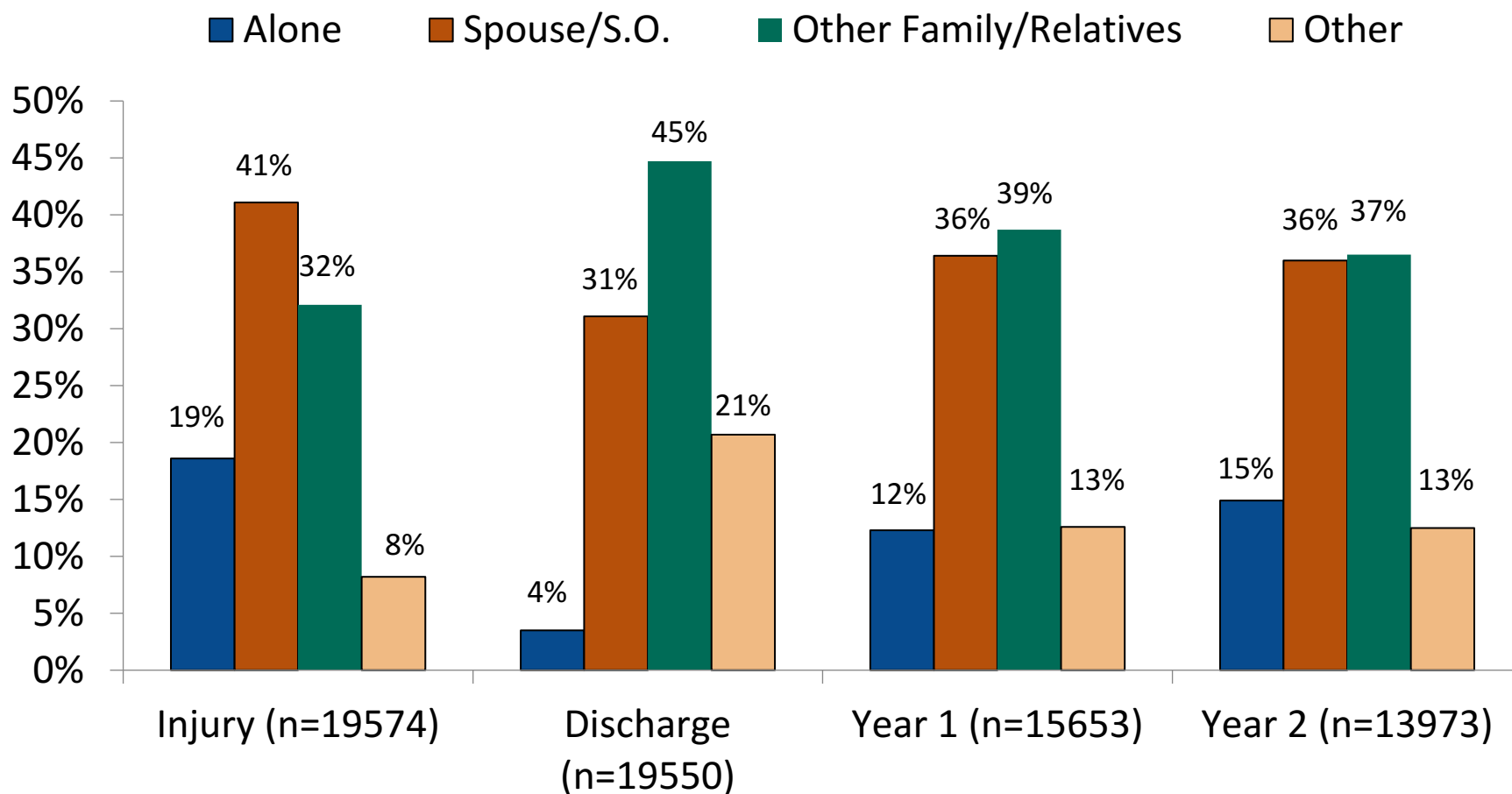


## Marital Status

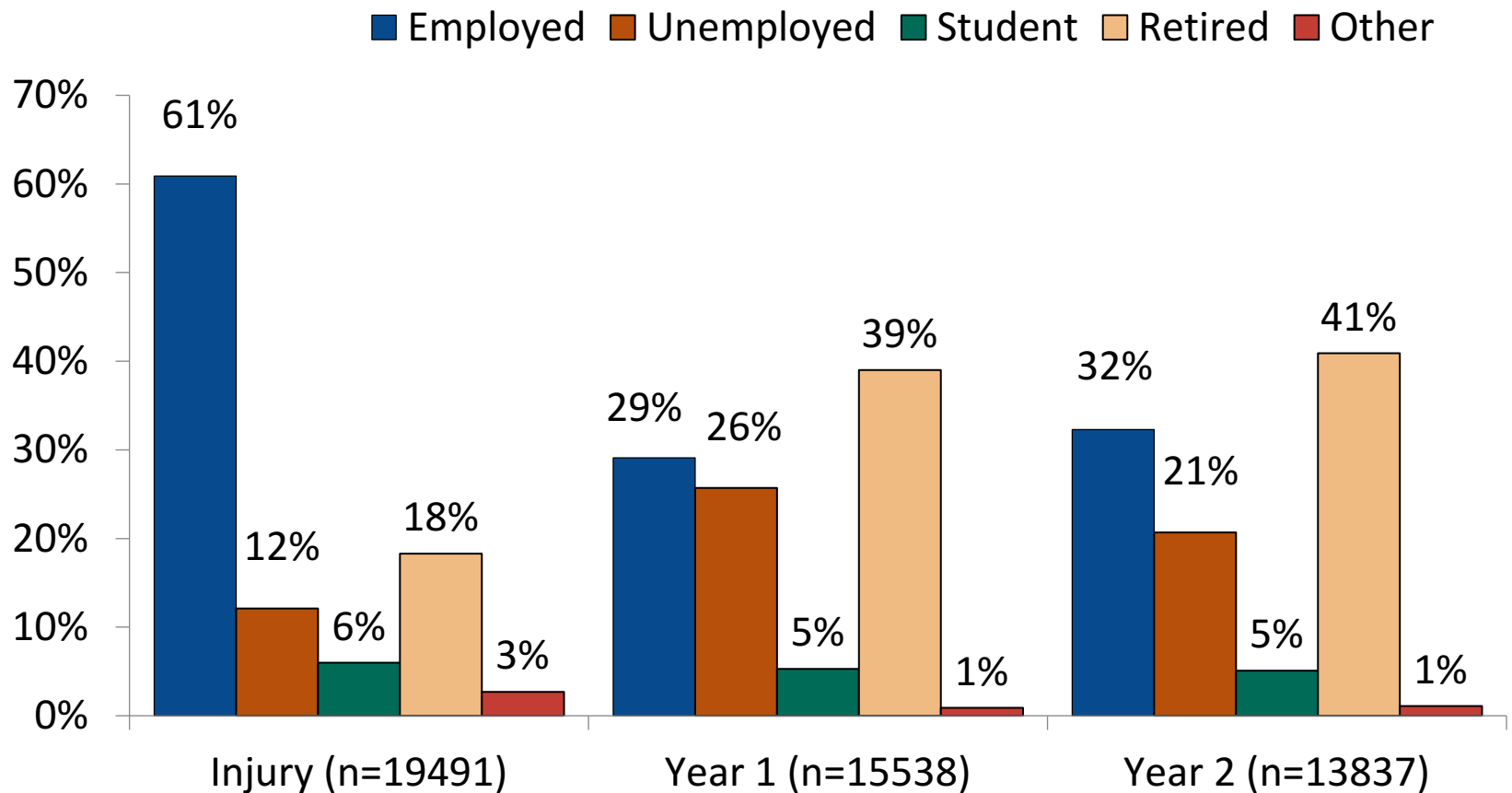




## Living Situation



# Employment Status



# Summary

## Participation Outcomes

- Most live in a private residence following rehab. discharge (81%).
- Few live alone at rehab. discharge (4%), with the highest proportion living with spouse/SO (31%) or other family/relatives (45%).
- Twenty-nine percent are employed at 1 year post-injury (61% employed at injury).

# Conclusions

## The TBI Model Systems Program:

- Demonstrates a system of care for TBI
- Performs several types of research
  - » Several center-specific clinical trials and other types of studies
  - » Innovative module (collaborative) studies
  - » A comprehensive, longitudinal database containing over 19,000 cases with up to 30 years of follow-up

# References

## TBIMS National Database:

- 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
- Date: 2022
- URL: <http://www.tbindsc.org>
- Version: <https://osf.io/a4xzb/>

## TBIMS Annual Presentation:

Traumatic Brain Injury Model Systems National Data and Statistical Center,  
2022 Traumatic Brain Injury Model Systems Annual Presentation [PDF File].  
Retrieved from <https://www.tbindsc.org>

# Acknowledgement

The contents of this presentation were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers: 90DPTB0018; 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.