

# 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 12/31/2020

# 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 30 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 three follow-up centers
- Burn Injury Model Systems
  - » 1994: Established with four centers

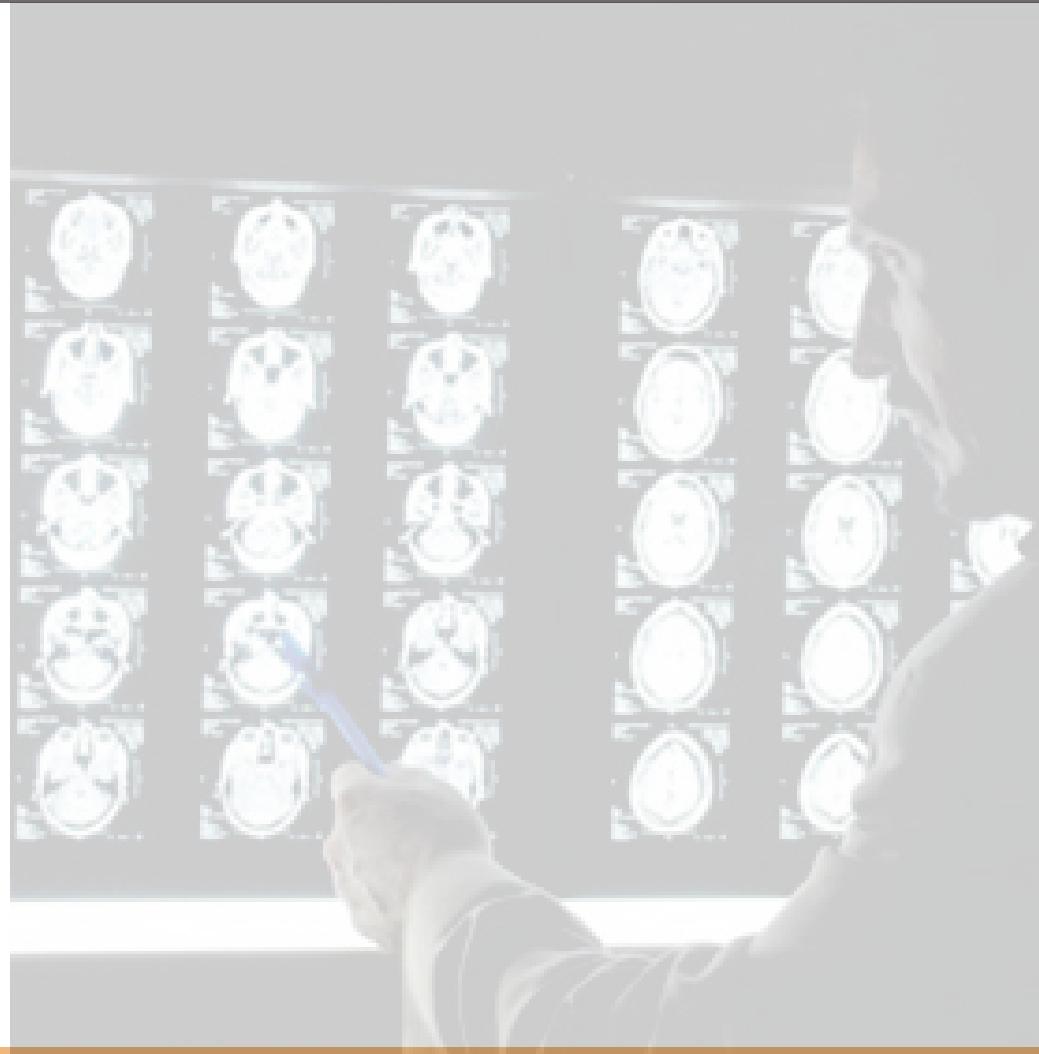


Conduct research that contributes to evidence-based rehabilitation interventions and clinical and practice guidelines that improve the lives of individuals with traumatic brain injury (TBI).



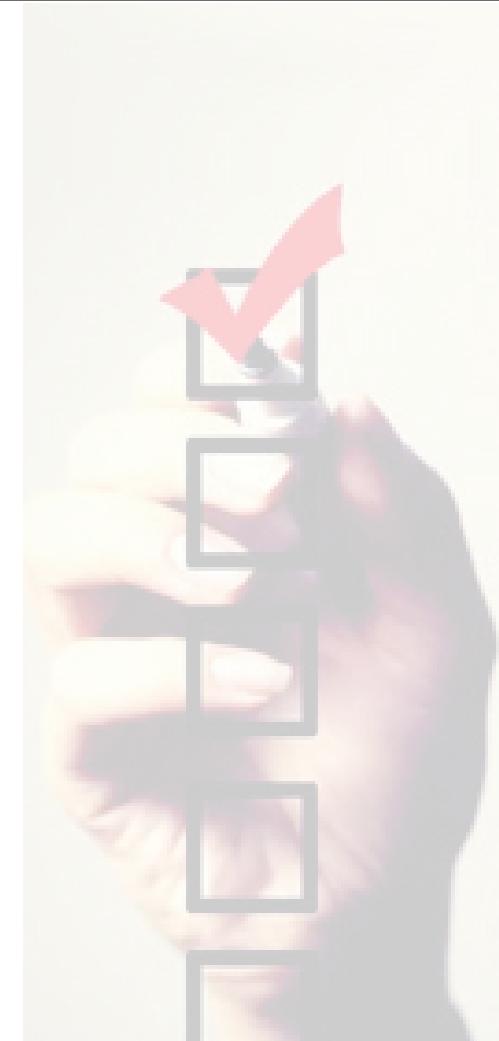
# Requirements of TBIMS Centers

- 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

- 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



**TBIMS**

Traumatic Brain Injury Model System

Since 1987



**NDSC**

National Data and Statistical Center

Traumatic Brain Injury Model System



**NiDILRR**

National Institute on Disability, Independent Living,  
and Rehabilitation Research

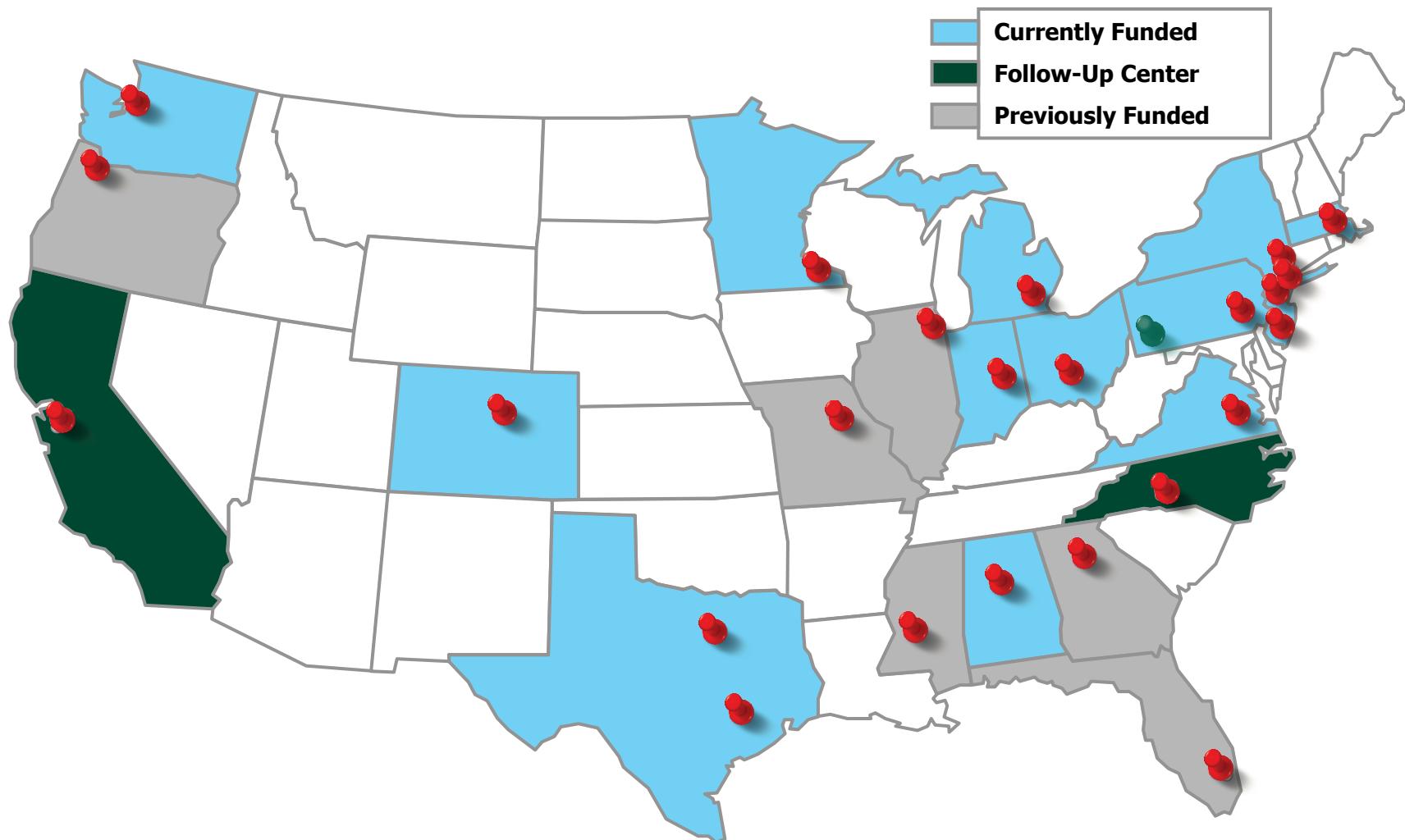


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# Current Traumatic Brain Injury Model Systems



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# TBI Model Systems Leadership

## Federal Project Management

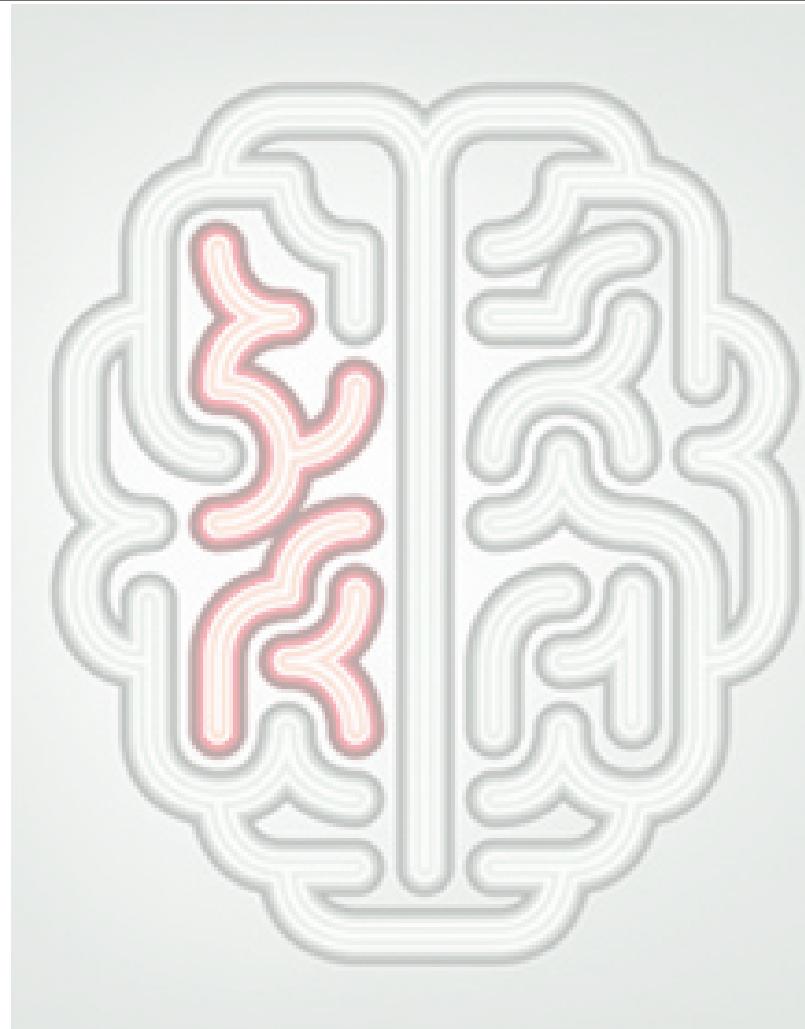
- National Institute on Disability, Independent Living, and Rehabilitation Research, A. Cate Miller, PhD, Project Manager

## National Data and Statistical Center

- Craig Hospital, Englewood, Colorado, Dave Mellick, PhD, Co-Project Director; Cindy Harrison-Felix, PhD, Co-Project Director

## TBI Model Systems Centers

- Executive Committee Chair, Flora Hammond, PhD



# TBIMS Centers: 2017-22

TBIMS Center	Principal Investigator	State
University of Alabama at Birmingham	Robert Brunner	AL
Craig Hospital	Cindy Harrison-Felix/Candy Tefertiller	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
JFK – Johnson Rehabilitation Institute	Yelena Goldin	NJ
Albert Einstein Healthcare-Moss Rehab	Amanda Rabinowitz	PA
TIRR Memorial Hermann	Mark Sherer/Angelle Sander	TX
Baylor Research Institute	Simon Driver	TX
Virginia Commonwealth University	Jenny Marwitz	VA
University of Washington	Jeanne Hoffman	WA



# TBIMS Follow-up Centers: 2017-22

TBIMS Center	Principal Investigator	State
The Rehabilitation Research Center/Santa Clara Valley Health and Hospital Systems	Ben Dirlkov	CA
University of Pittsburgh	Amy Wagner	PA
Carolinas Rehabilitation/Carolinas HealthCare System	Shanti Pinto	NC

# TBIMS Center-Specific Studies 2017-22

Study Type	RCT	Examples of Topics
<b>Other Intervention (n=10)</b>	10	<ul style="list-style-type: none"><li>▪ Resilience and Adjustment Intervention</li><li>▪ Mood Tracking Application</li><li>▪ Resilience and Social Support in Family Members</li><li>▪ Self-Advocacy for Independent Life</li><li>▪ Delivery of Medical and Social Services</li><li>▪ Cognitive Rehabilitation for Learning and Memory Deficits</li><li>▪ Reduction of Interference of Pain</li><li>▪ Weight Loss</li><li>▪ Emotional Dysregulation</li><li>▪ Alexithymia</li></ul>
<b>Assessment and Prediction of Outcomes (n=6)</b>	6	<ul style="list-style-type: none"><li>▪ TBI as a Chronic Health Condition</li><li>▪ Behavioral Activation/Ecological Momentary Assessment</li><li>▪ Impact of Healthy Lifestyle Decisions</li><li>▪ Recovery of Consciousness in the ICU</li><li>▪ Improve Assessment of Outcomes</li><li>▪ Quality of Life</li></ul>



# TBIMS Multicenter Research 2017-22 \*

Study Type	Study Topics
<b>Intervention</b>	<ul style="list-style-type: none"><li>▪ Problem Solving Training (PST) for Care Partners of Adults with Traumatic Brain Injuries (TBI) during Inpatient Rehabilitation.</li></ul>
<b>Assessment and Prediction of Outcomes</b>	<ul style="list-style-type: none"><li>▪ Caregiver Resilience A Longitudinal Investigation</li><li>▪ Health Literacy Following Traumatic Brain Injury and Impact on Health-Related Outcomes</li><li>▪ Menopause in Women with TBI</li><li>▪ Return to Driving after Moderate-Severe TBI</li><li>▪ Partnering with Caregivers to Increase Knowledge of the Post-Acute Phase of Recovery From Severe TBI</li><li>▪ Physical Activity and its relationship with cognition and secondary conditions after TBI</li><li>▪ Trajectories of Cognitive Functioning Years after TBI</li><li>▪ Alexithymia Prevalence &amp; Relationships to Patient Characteristics &amp; Outcome in TBIMS Cohort</li></ul>
<b>Analytical</b>	<ul style="list-style-type: none"><li>▪ Development and Assessment of Crosswalks in the TBIMS Database</li></ul>

\* Module Studies and Collaboratives Grants

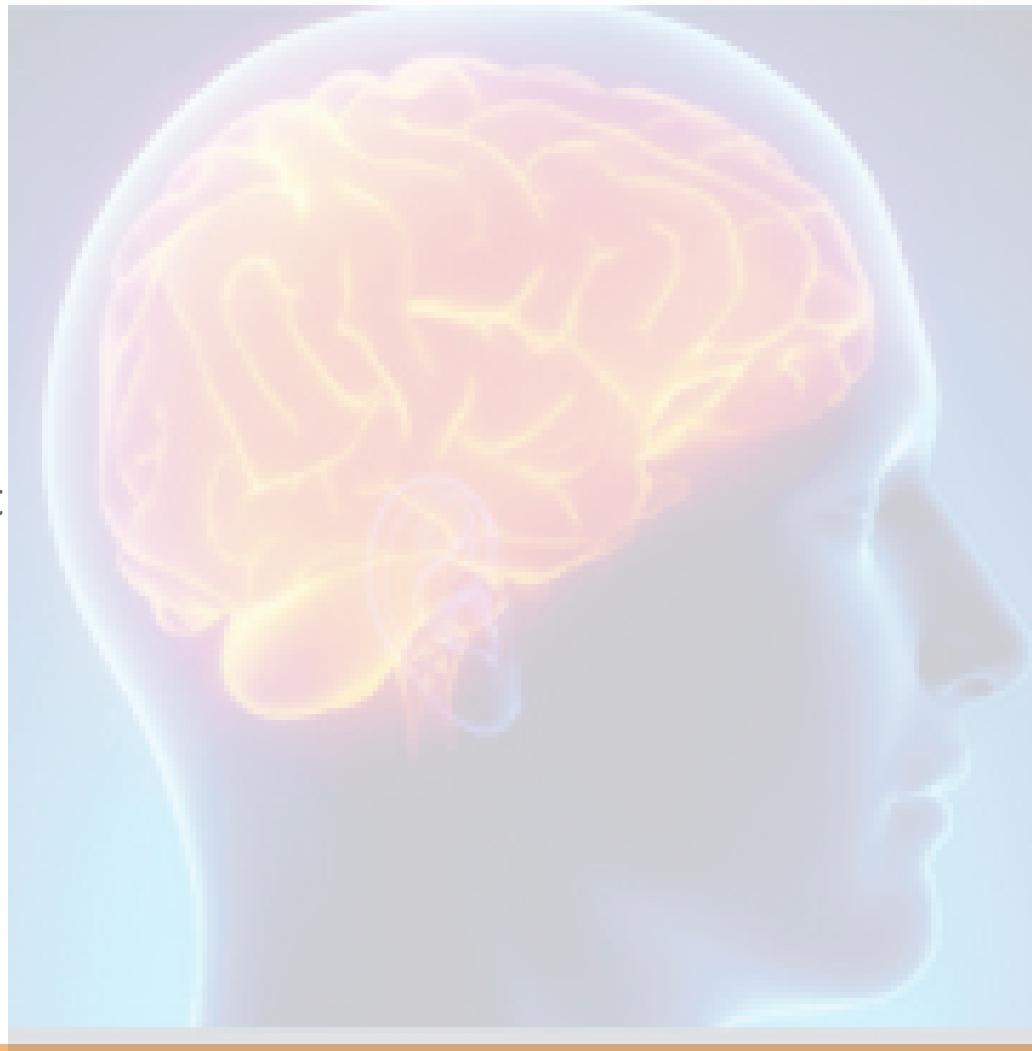
# TBIMS Collaborative Study 2017-22

- **Characterization and Treatment of Chronic Pain after Moderate to Severe Traumatic Brain Injury**
  - The aims of this study are to: 1) Determine chronic pain classification, prevalence, location, duration and associations with demographic, injury severity, functioning, and comorbidities; 2) Identify and compare chronic pain extreme phenotype characteristics across two outcomes – impact of chronic pain on daily life and overall perceptions of improvement.; and 3) Identify treatment practices by clinicians who treat comorbid TBI and chronic pain to determine gaps in availability/accessibility of multidisciplinary pain treatment. Cindy Harrison-Felix, PhD (Craig Hospital), Jeanne Hoffman, PhD (University of Washington) and Kimberley Monden, PhD (Craig Hospital) are the Principal Investigators on the study.



# 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: 285 variables
- **Form 2:** Follow-up conducted 1, 2, 5, and every 5 years thereafter; administered via telephone (primarily), in-person or mail questionnaire; 243 variables



## NIDILRR TBI National Database (Continued)

- Form 1 – 18,557 cases (as of 3/31/2021)
- Form 2 – 70,632 follow-ups\* – 17% attrition (5%\*\*)
  - Year 1 – 18,286 – 13% attrition (2%\*\*)
  - Year 2 – 16,810 – 14% attrition (4%\*\*)
  - Year 5 – 13,808 – 16% attrition (7%\*\*)
  - Year 10 – 9,059 – 17% attrition (5%\*\*)
  - Year 15 – 4,906 – 17% attrition (9%\*\*)
  - Year 20 – 1,868 – 17% attrition (6%\*\*)
  - Year 25 – 497 – 21% attrition (0%\*\*)
  - Year 30 – 116 – 14% 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

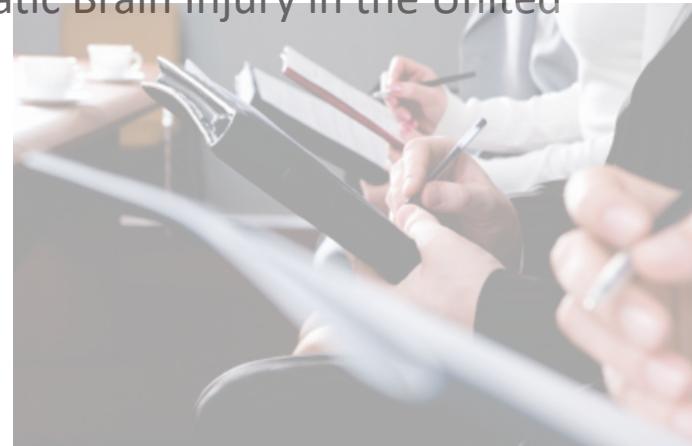
- Lack of control or comparison group
- Lack of uniformity in treatment across all Centers
- Attrition in follow-up
- Inability to systematically track post-acute service utilization
- Limited follow-up evaluations if Center defunded



# 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.



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# 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
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# 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)

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

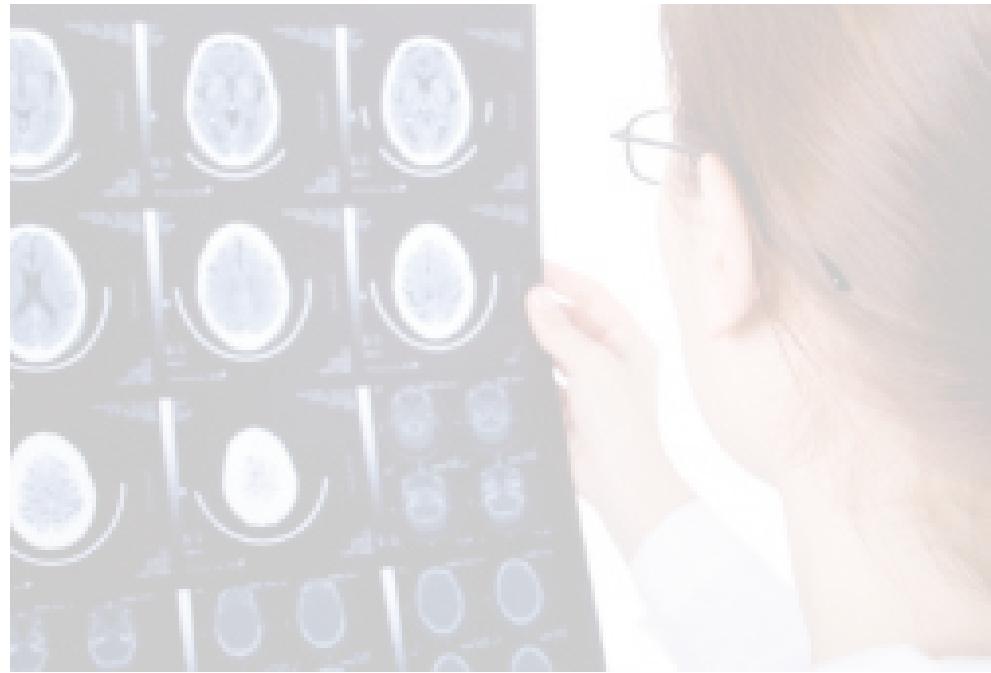
## Peer-Reviewed Publications Have Used the TBIMS NDB

- 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



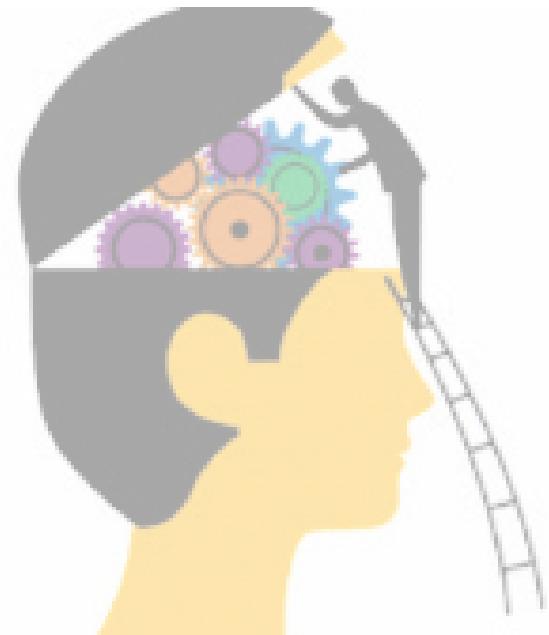
## TBIMS Accomplishments (3/7)

- 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

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



## II. Causes / Severity of TBI

	<b>Form 1</b> (acute injury and hospitalization)	<b>Form 2</b> (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

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



## IV. Treatments

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



## V. Impairment

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



## VI. Health / Behavior

	<b>Form 1</b> (acute injury and hospitalization)	<b>Form 2</b> (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

	<b>Form 1</b> (acute injury and hospitalization)	<b>Form 2</b> (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

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



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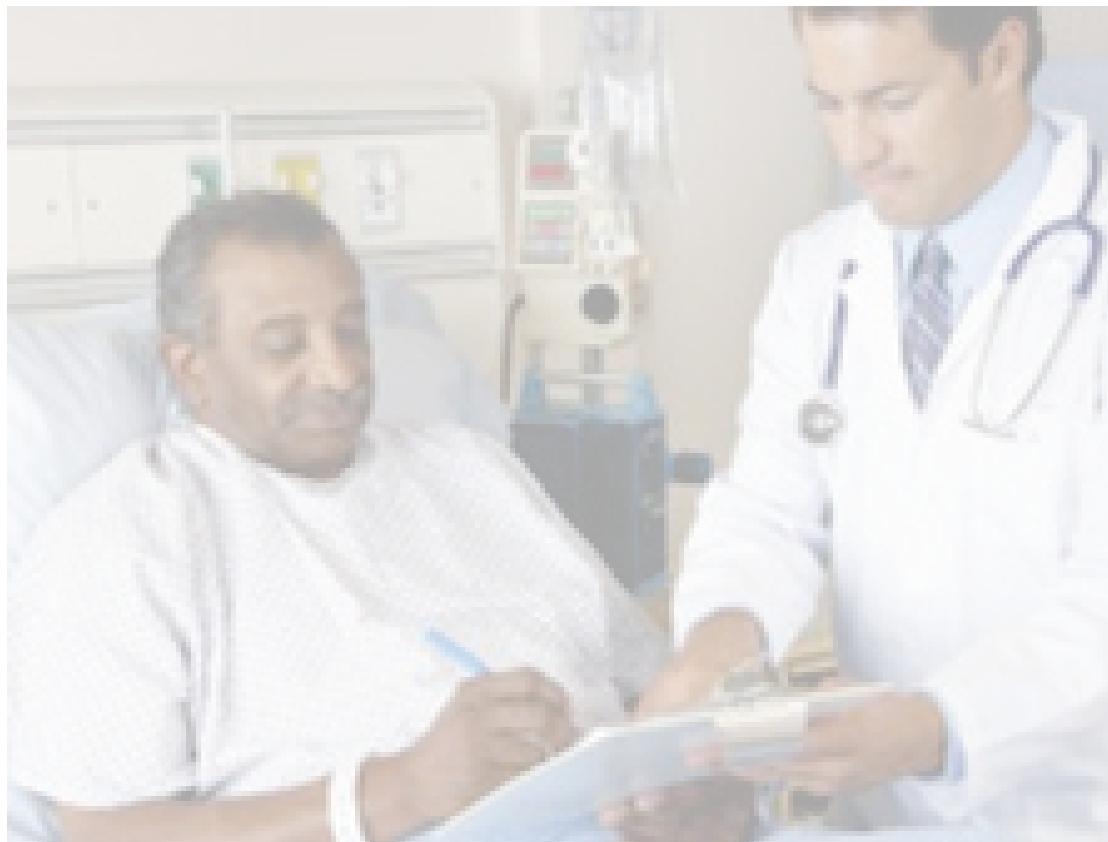


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# Sources of Data

- 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



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## 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



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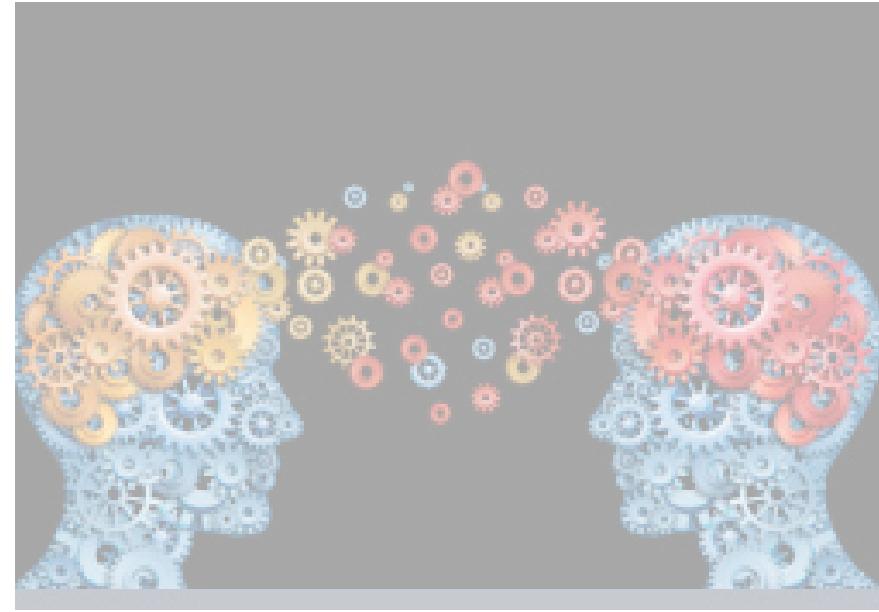
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# External Dissemination

- 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)

 **NATIONAL DATA AND STATISTICAL CENTER**  
TRAUMATIC BRAIN INJURY MODEL SYSTEMS

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**Welcome to the NDSC**

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**

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-  [2012 TBI Model Systems Presentation](#)
-  [2012 TBI Model Systems National Database Update](#)
-  [2010 TBI Model Systems Brochure](#)

**Links to other Model Systems Programs**

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-  [National Spinal Cord Injury Statistical Center](#)
-  [Burn Model Systems Data Coordinating Center](#)
-  [Model Systems Knowledge Translation Center](#)



# 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

Search Question and Description:

Filter by Module:

## Domains



### ANXIETY

Sub Domains: GAD, GAD - CALCULATED, QOL ANXIETY - CALCULATED



### ASSOCIATED INJURIES

Sub Domains: SCI



### CARE (CONTINUITY ASSESSMENT RECORD AND EVALUATION)

Sub Domains: MOBILITY, SELF CARE



### COLLECTION METHODS

Sub Domains: None

Count of Variables in Domain: 25



### CRANIAL COMPLICATIONS

Sub Domains: ICP - INTRACRANIAL HYPERTENSION, SEIZURES



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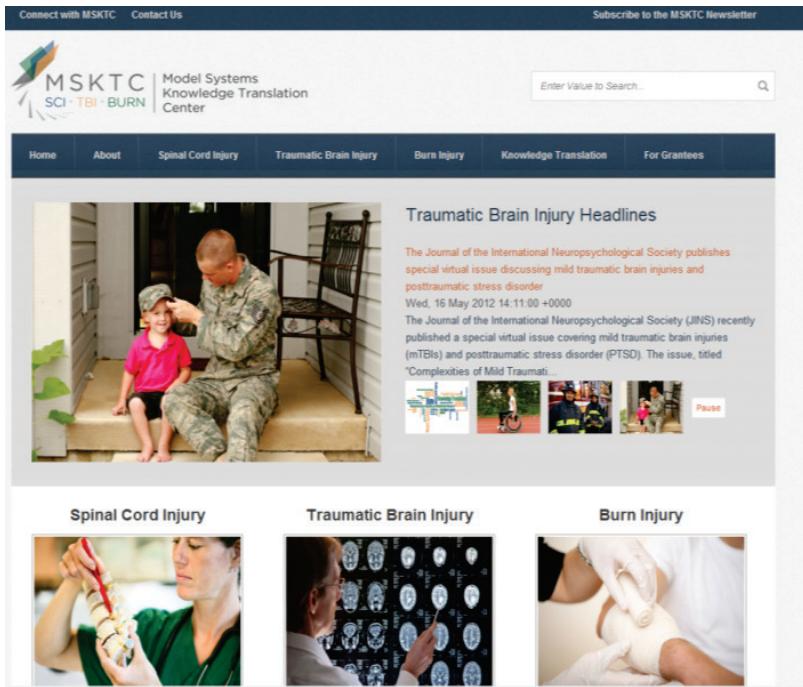


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# Model Systems Knowledge Translation Center (MSKTC)

[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>			
<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; Fatigue</li><li>TBI &amp; Medical Outcomes</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>TBI &amp; Vocational Rehabilitation</li><li>TBI &amp; Vision Problems</li><li>TBI &amp; Spasticity</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> </ul>	<ul style="list-style-type: none"> <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> </ul>	<ul style="list-style-type: none"> <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> </ul>	<ul style="list-style-type: none"> <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>	<ul style="list-style-type: none"> <li>Additional Multimedia Products</li> </ul>



# TBIMS National Database Descriptive Data Summary

Includes data from 1/01/1989-12/31/2020



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Traumatic Brain Injury Model System

Since 1987



**NDSC**

National Data and Statistical Center

Traumatic Brain Injury Model System



**NiDILRR**

National Institute on Disability, Independent Living,  
and Rehabilitation Research

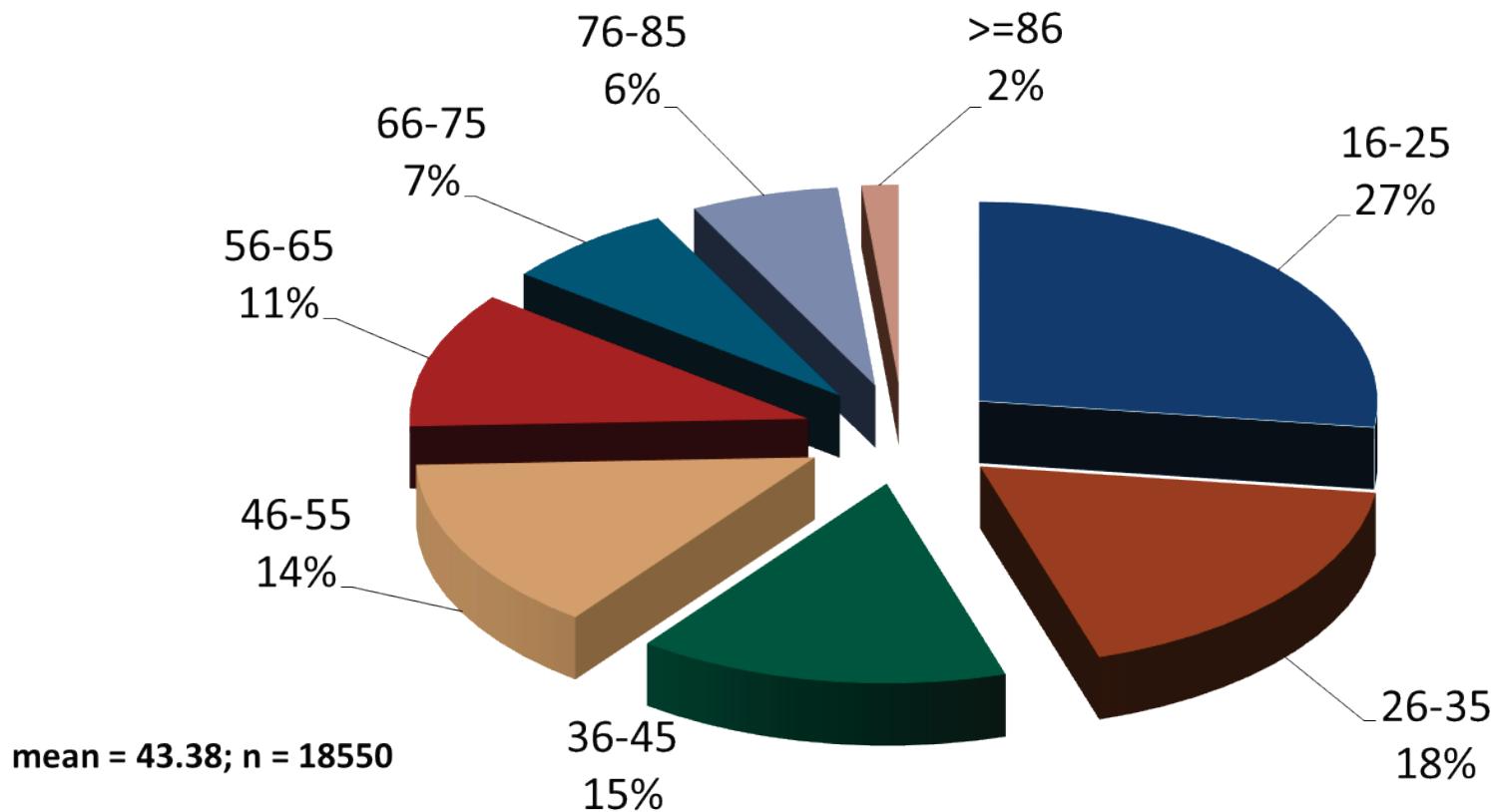


**MSKTC.org**

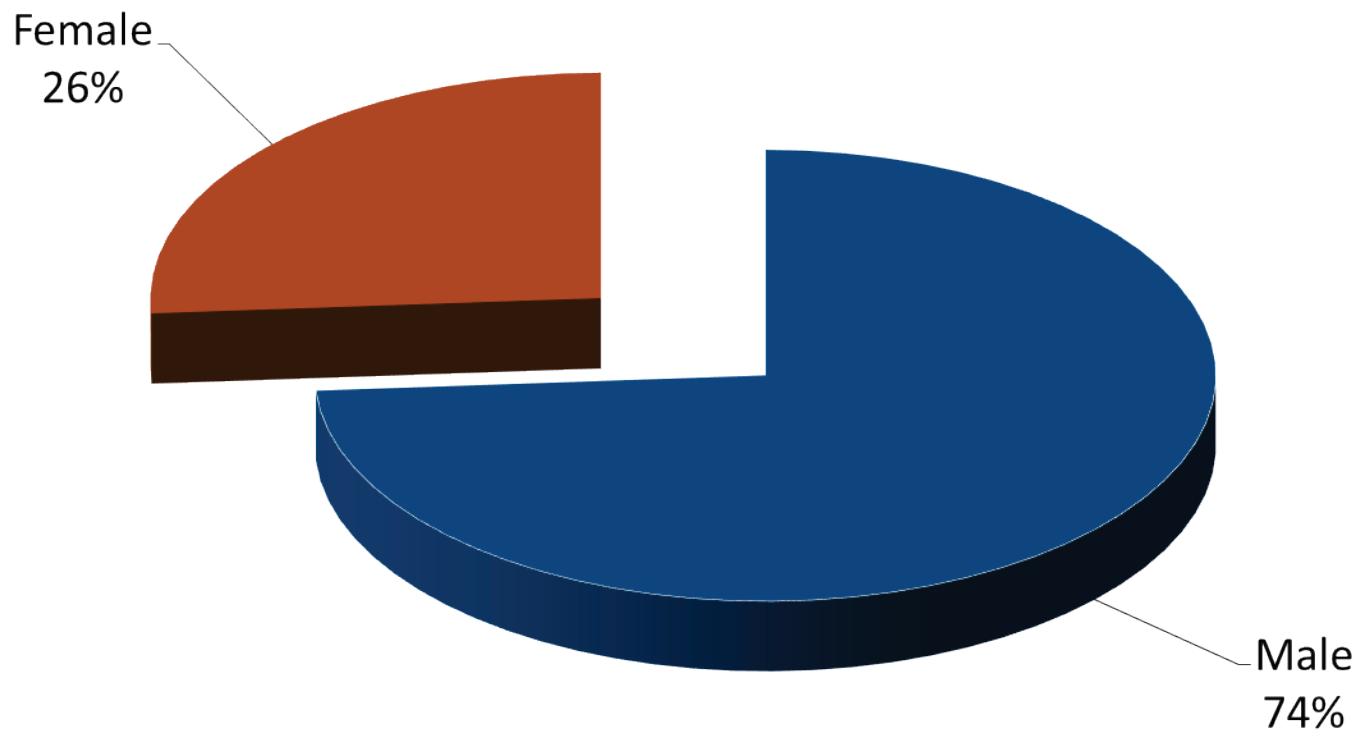
SCI • TBI • BURN

Model Systems  
Knowledge Translation  
Center

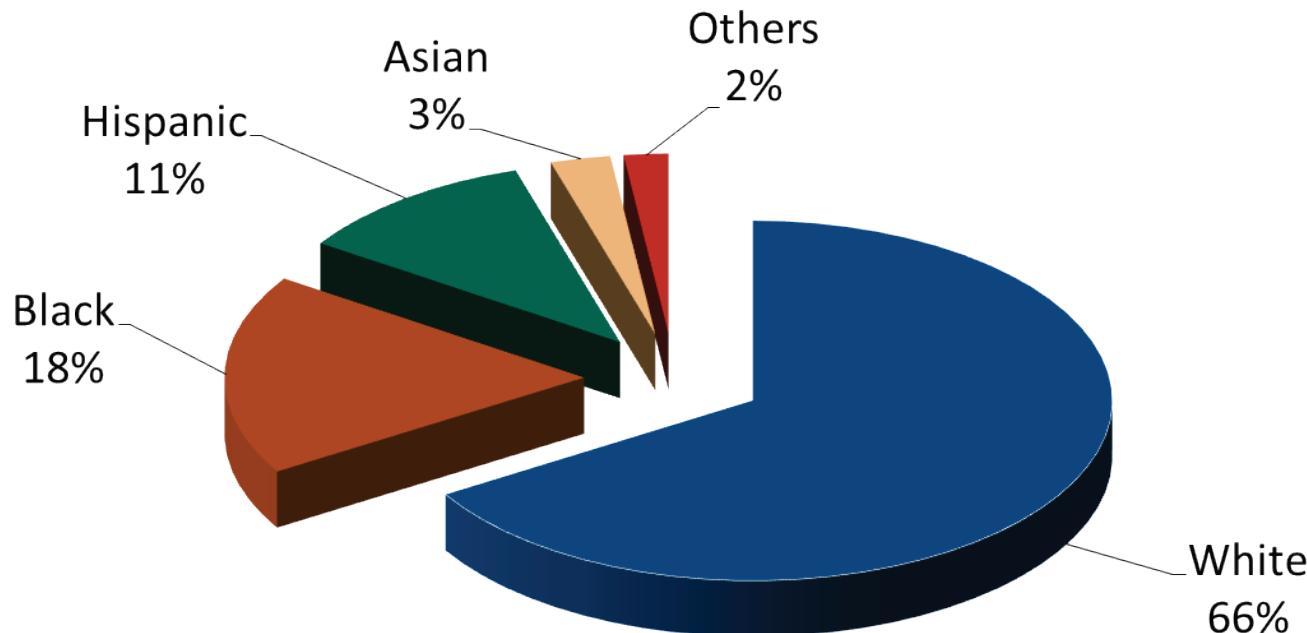
# Age



## Gender



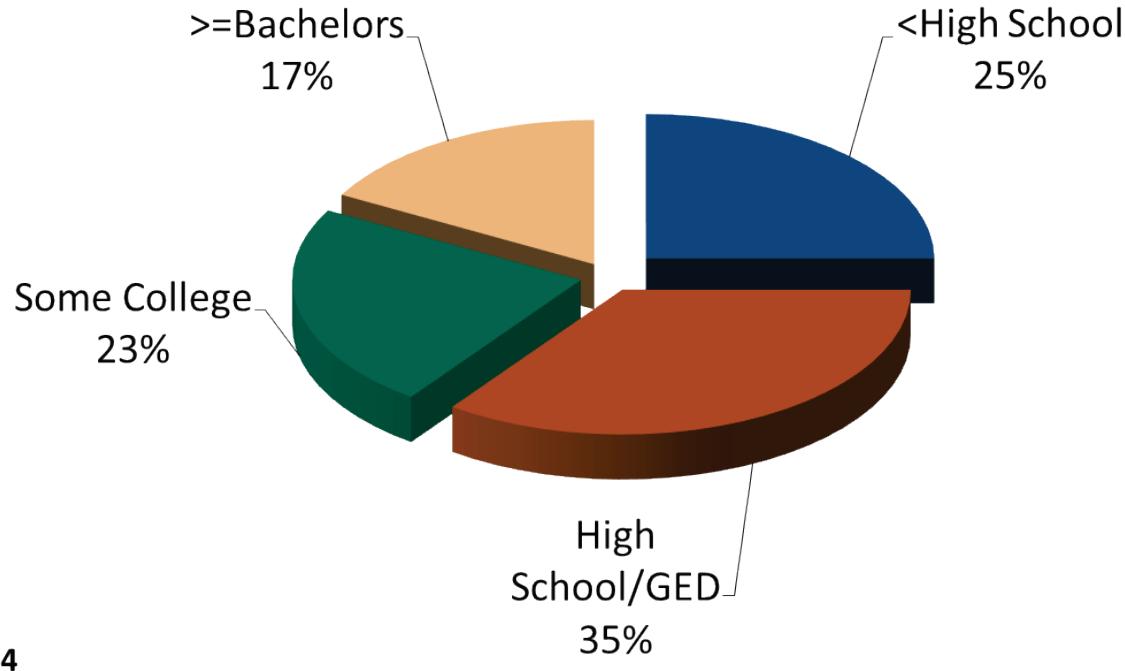
## Race



n = 18543



## Level of Education at Injury



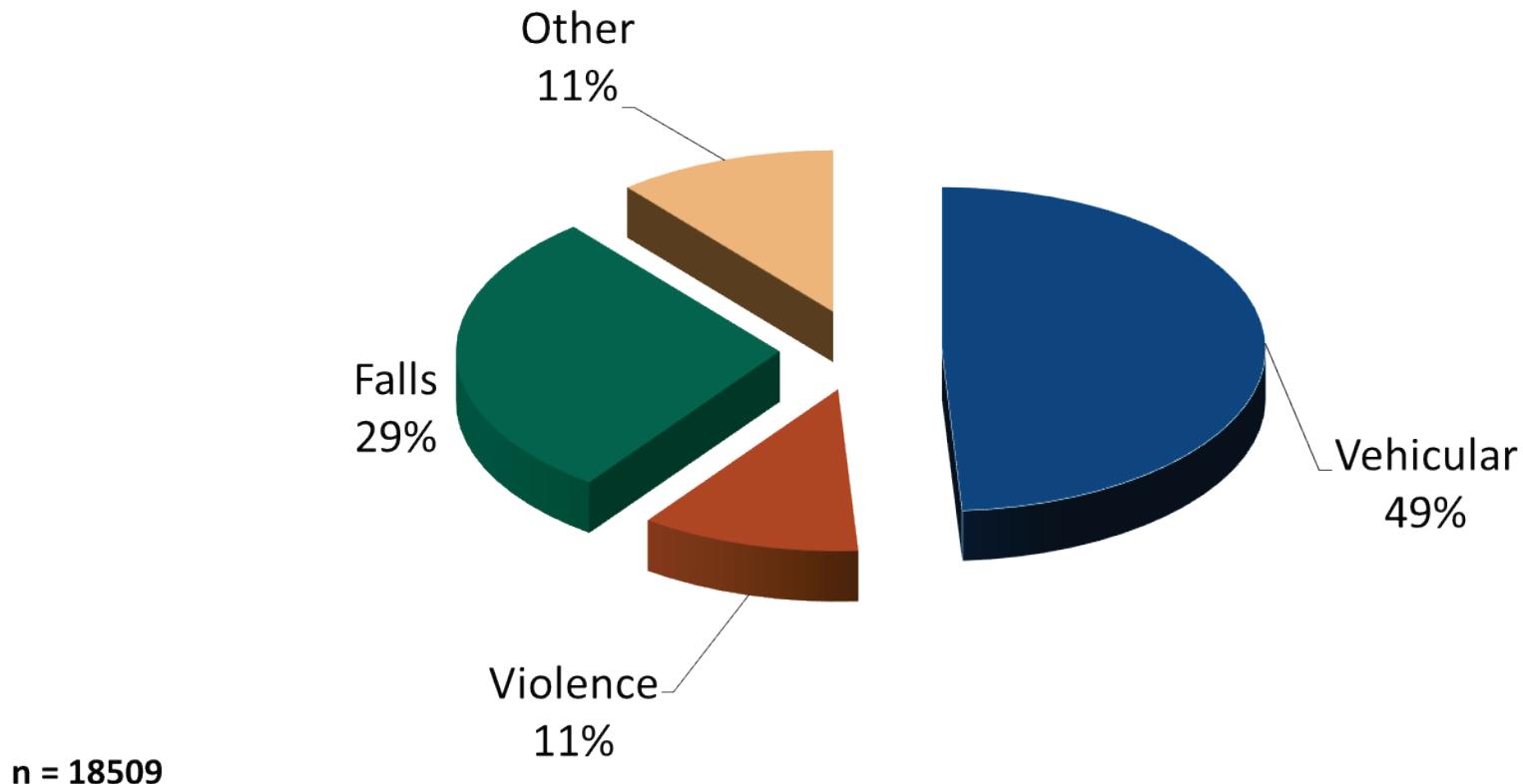
# Summary

## Demographic Characteristics of the Population

- Average age = 43.38
- Male (74%)
- Minority population (34%)
- High school education or less (60%)

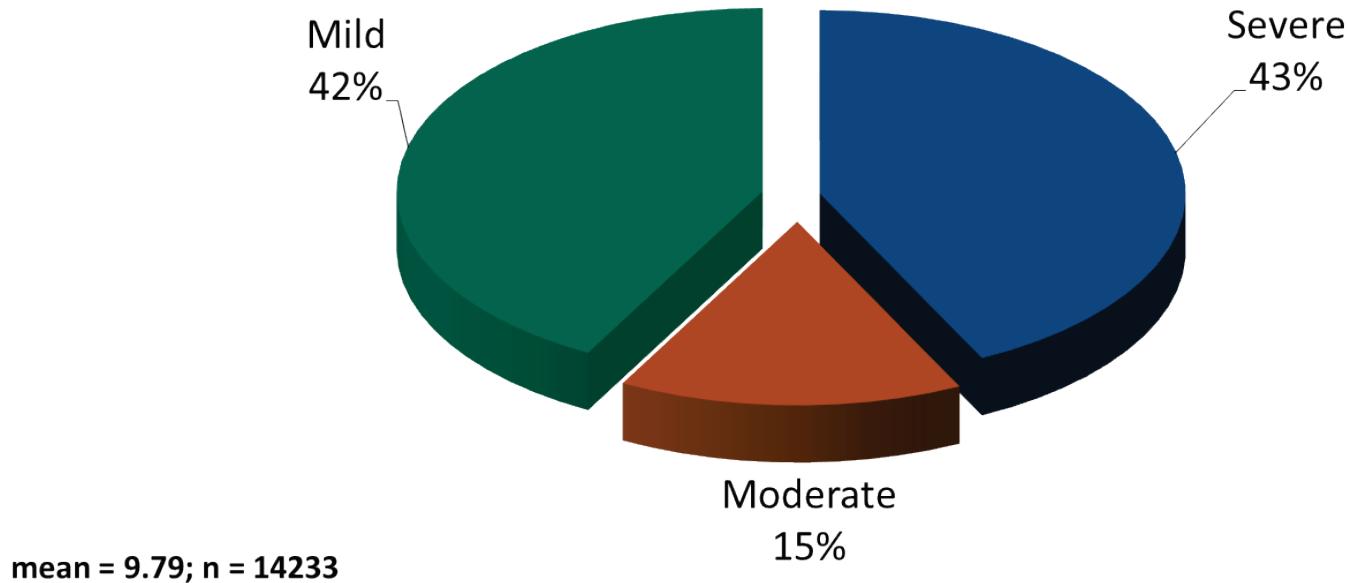


# Etiology of Injury



# Glasgow Coma Scale Score

**At Emergency Department Admission**



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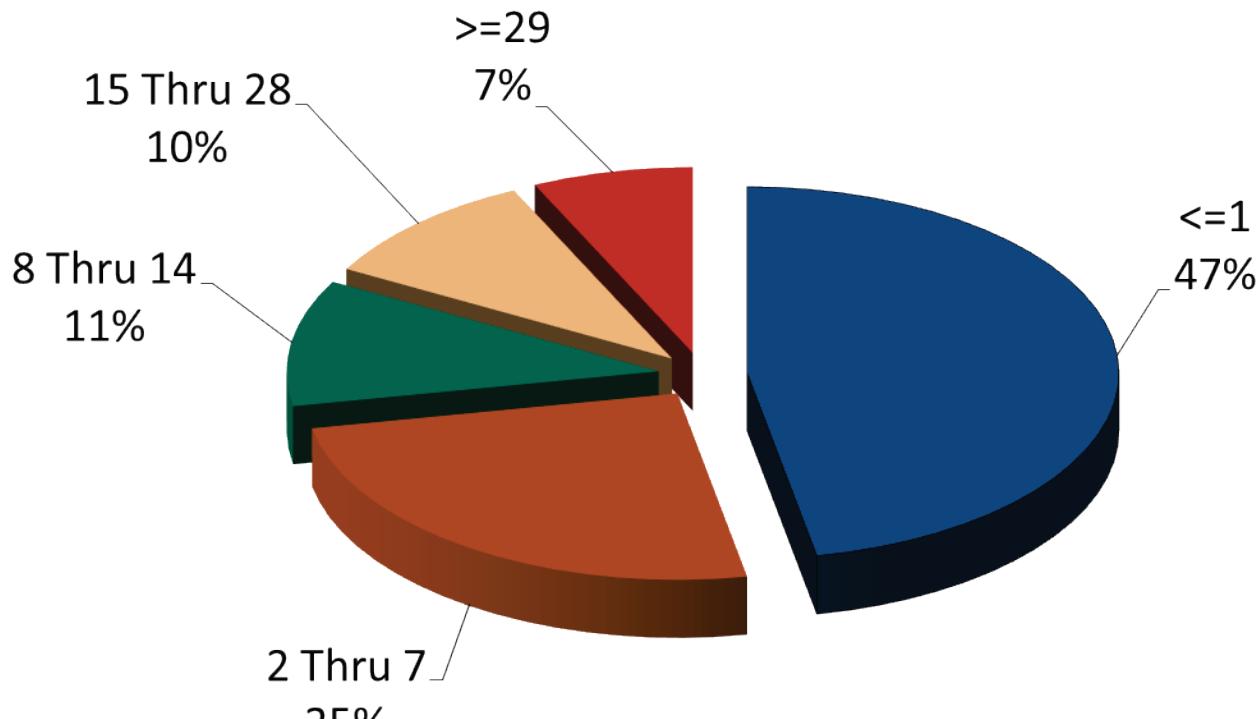


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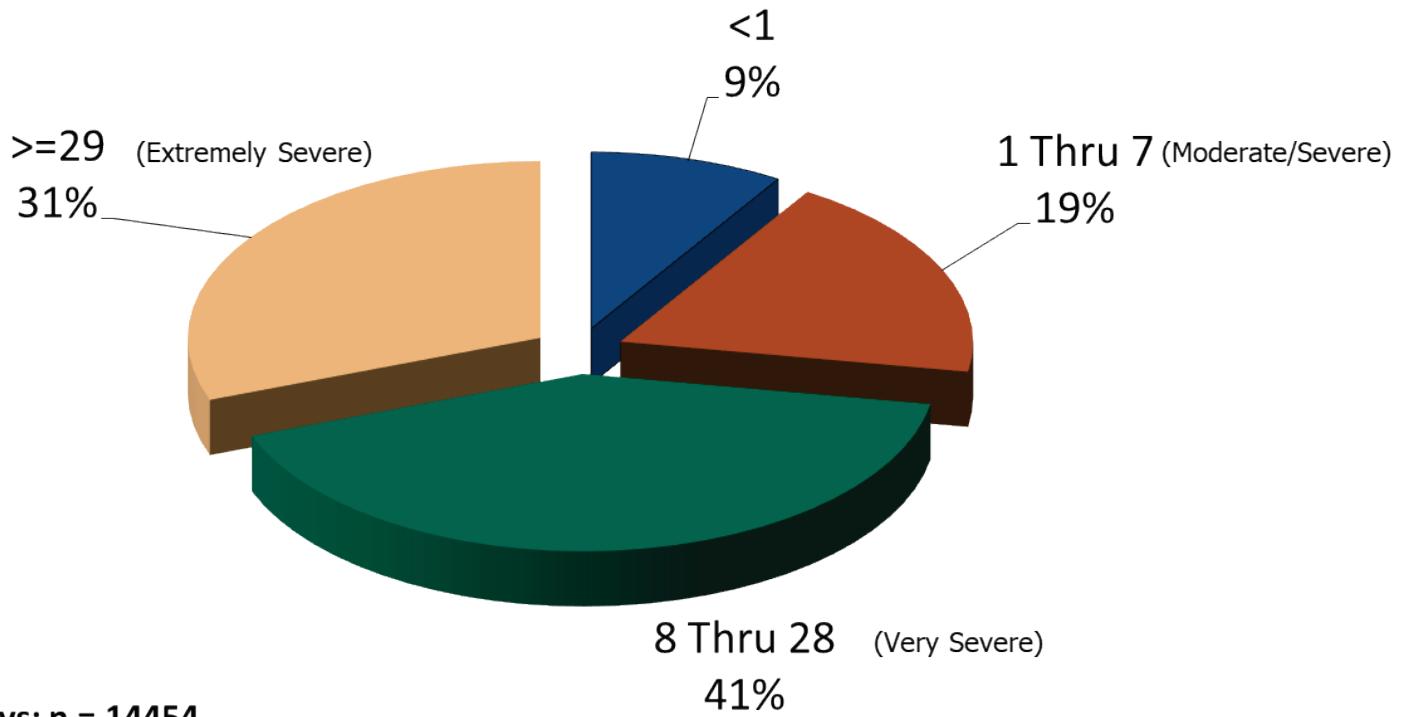
## Duration of Unconsciousness



mean = 7.65 days; n = 17833



## Duration of PTA



# Summary

## Causes of Injury

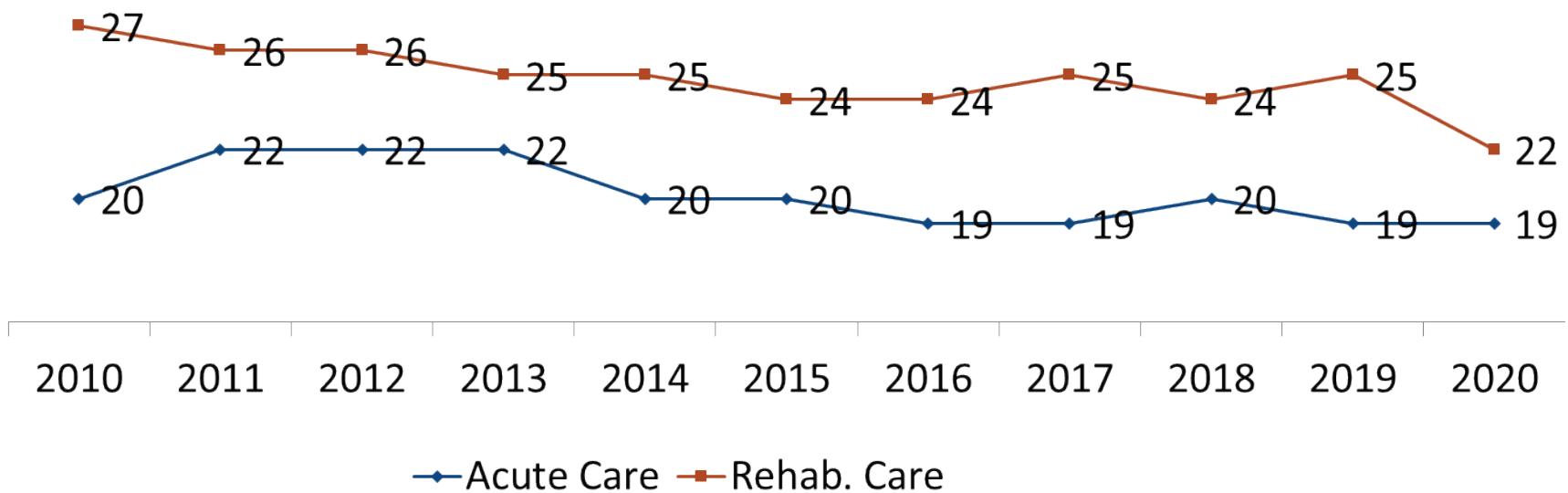
- Primary cause is vehicular (49%), followed by falls (29%) and violence (11%)

## Severity of Injury

- Average duration of LOC is 7.65 days
- Average duration of PTA is 22.32 days



## Mean Length of Stay



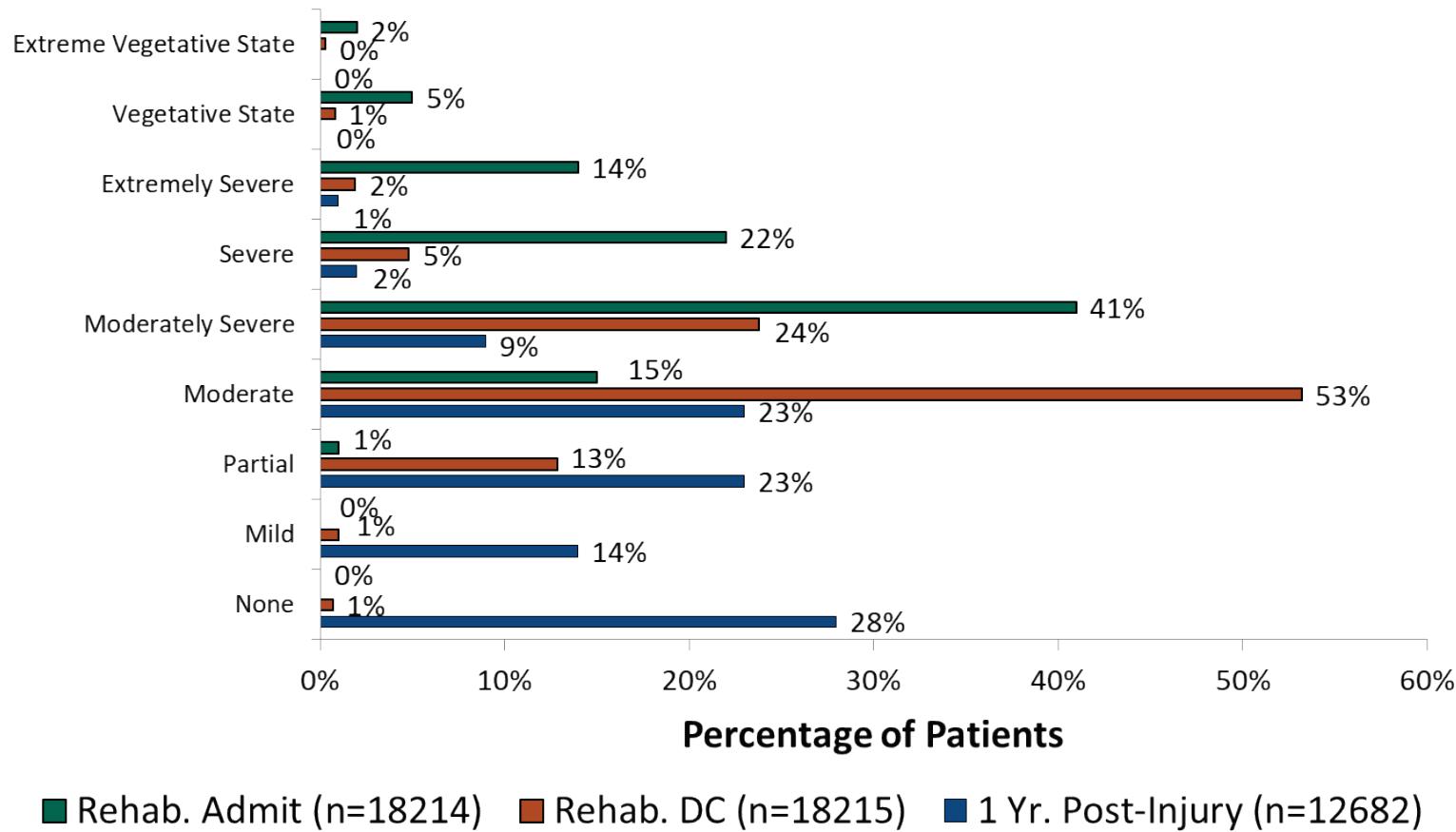
# Summary

## Costs of Treatment

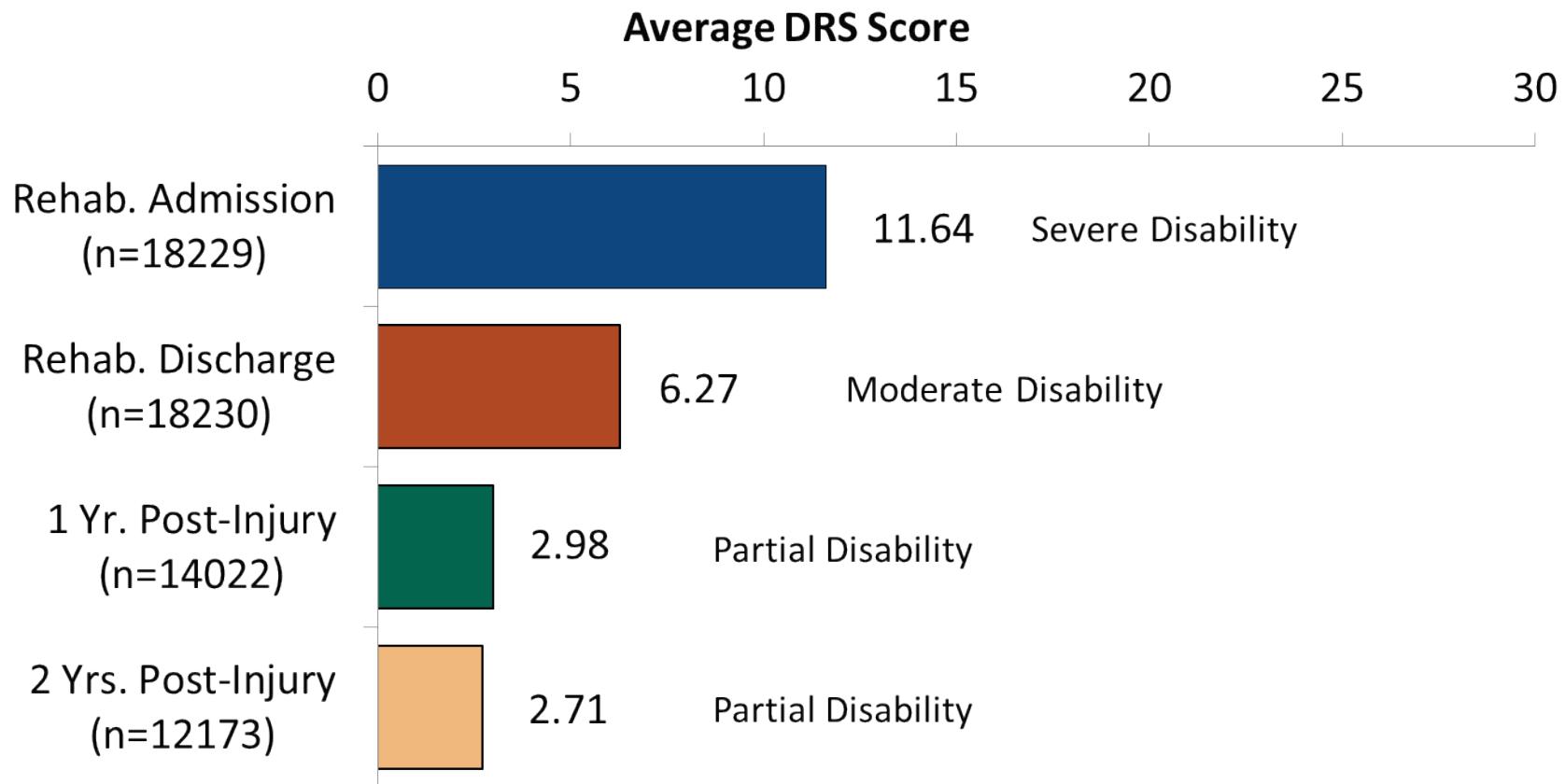
- Total length of stay (LOS) has decreased over the last 10 years for rehab.
- Total acute LOS in 2020 has remained fairly stable over the last 5 years.
- Total rehab LOS in 2020 represents the lowest in the past decade.
- Thirty-eight percent have government-sponsored rehabilitation care (Medicaid/Medicare).



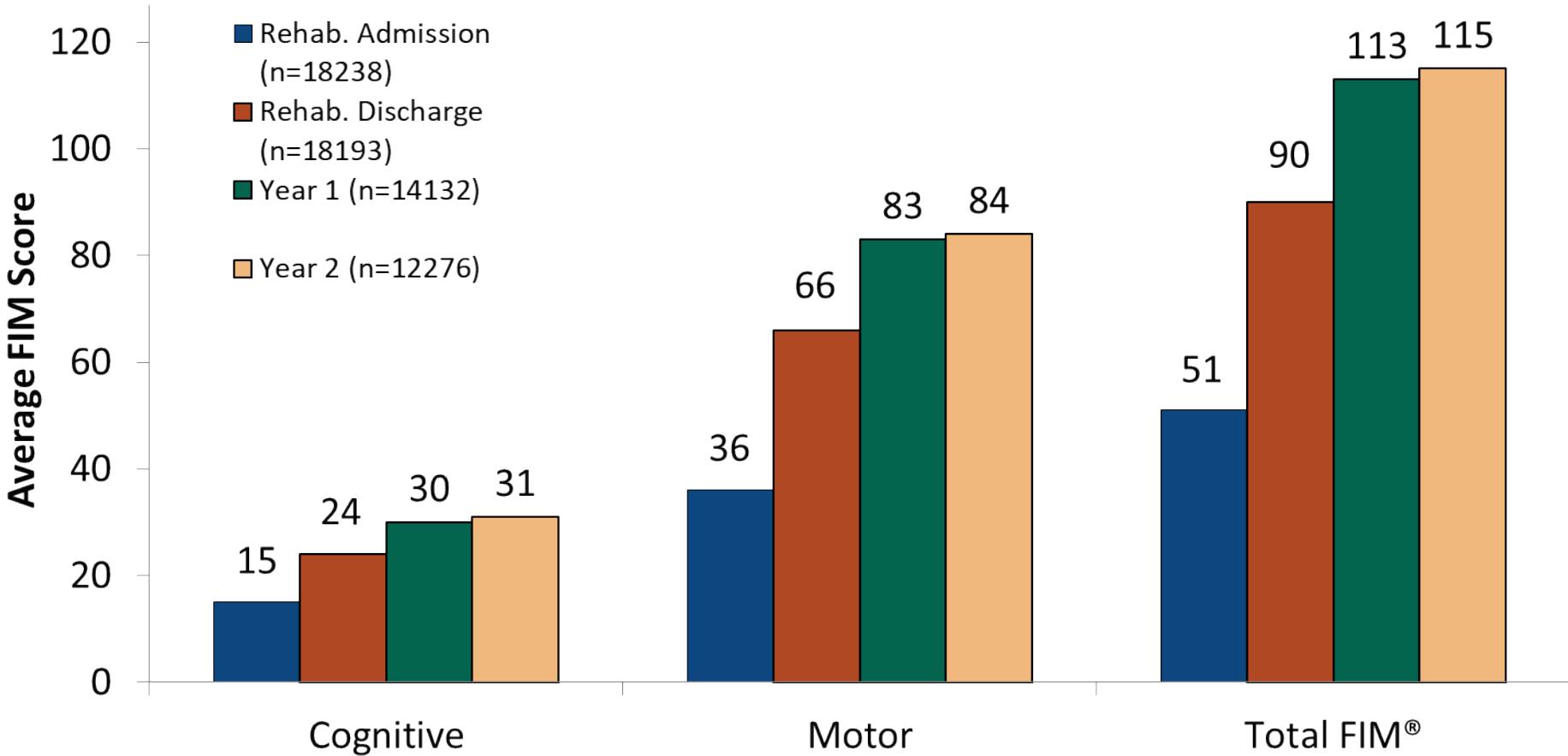
# Disability Rating Scale



# Disability Rating Scale



# FIM® Instrument



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



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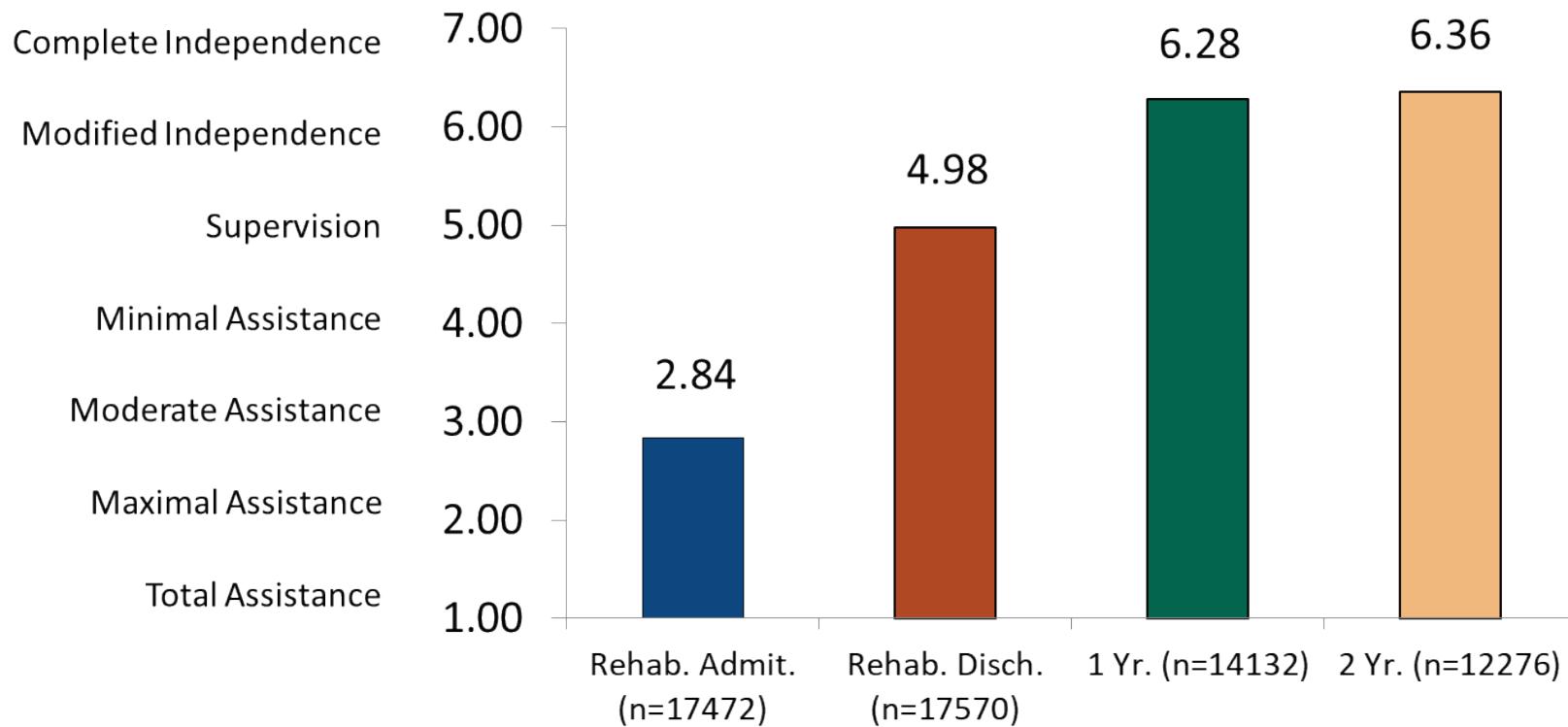


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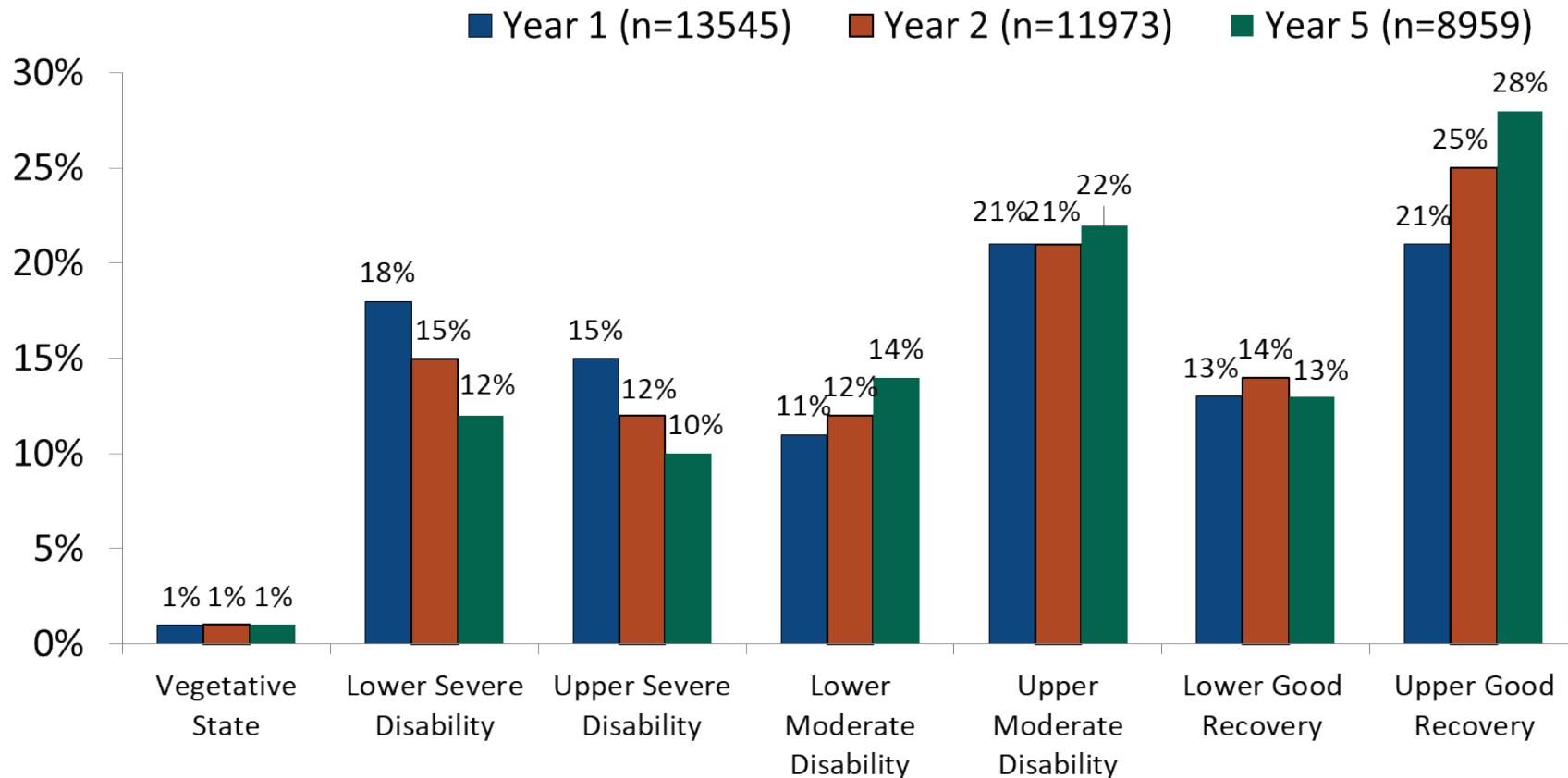
Model Systems  
Knowledge Translation  
Center

# FIM® Instrument

Mean scores converted to a 7-point scale



# Glasgow Outcome Scale-Extended



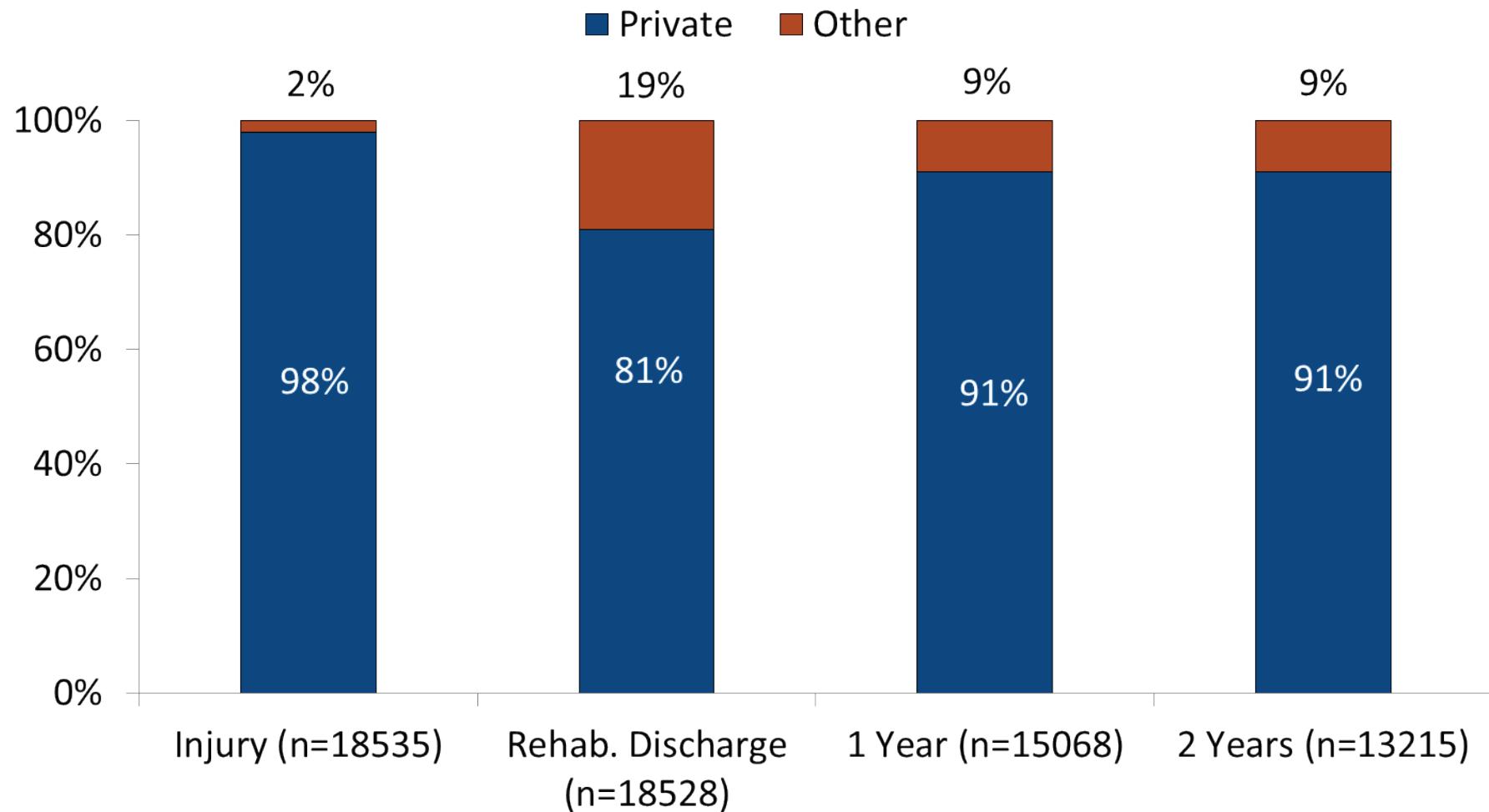
# Summary

## Disability Outcomes

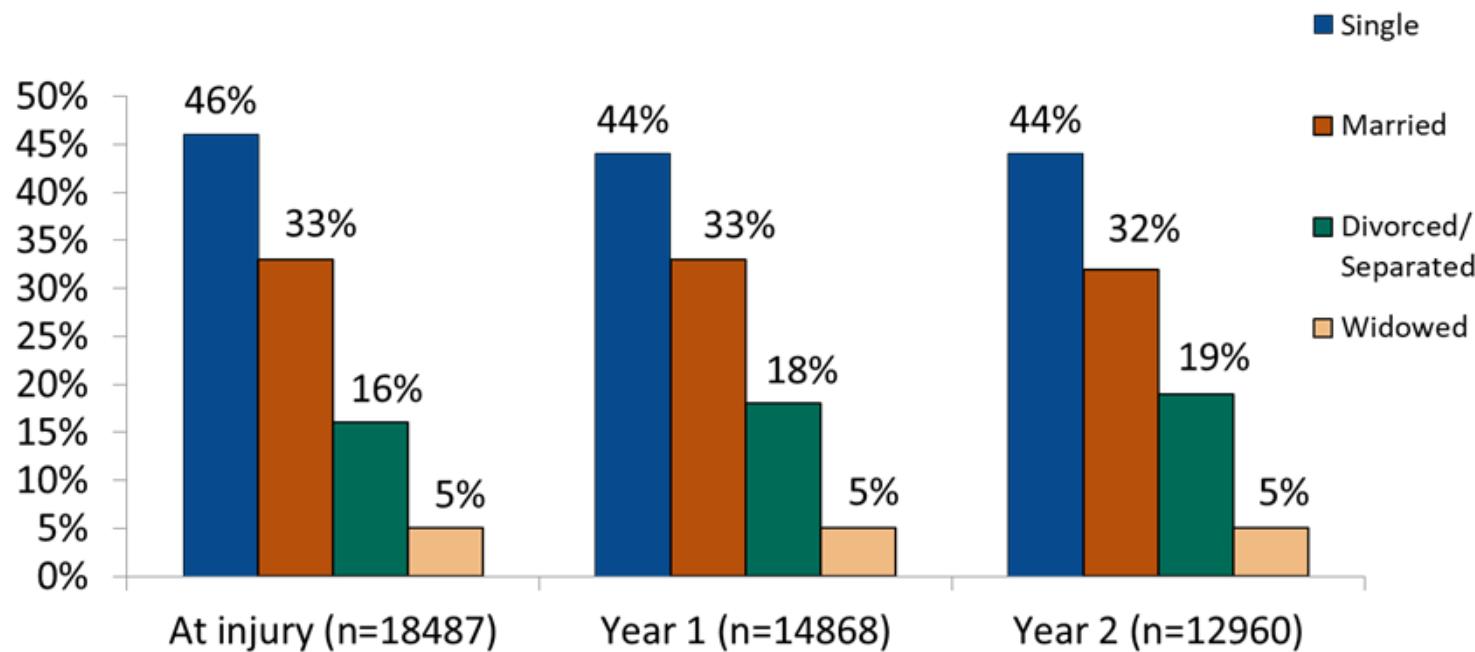
- DRS indicates improvement in level of disability from SEVERE DISABILITY at rehab. admission to PARTIAL DISABILITY at 1 and 2 years post-injury.
- FIM® Instrument indicates improvement in functional ability from level requiring MODERATE ASSISTANCE at rehab. admission to MODIFIED INDEPENDENCE at 1 and 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.



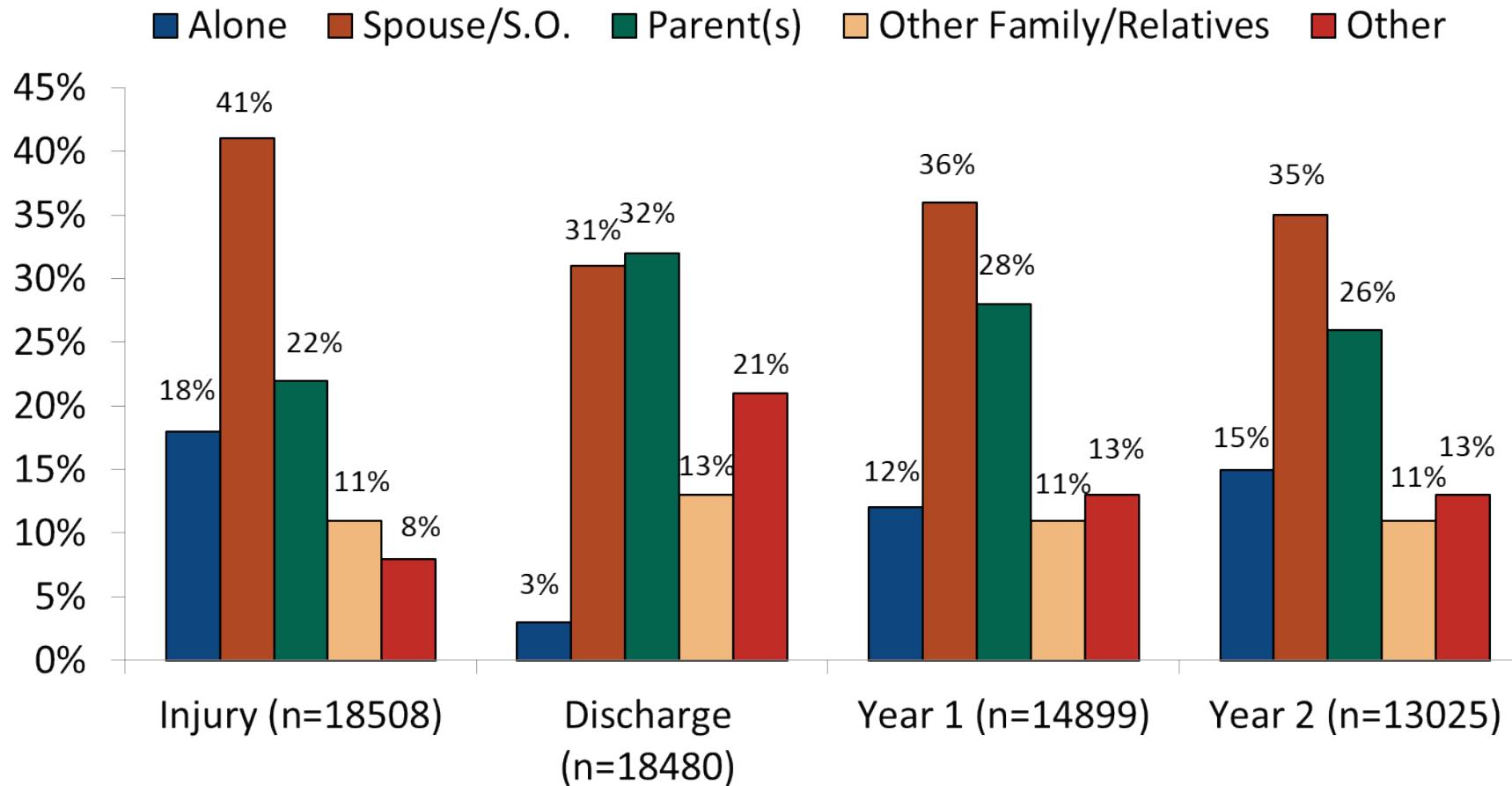
## Residence



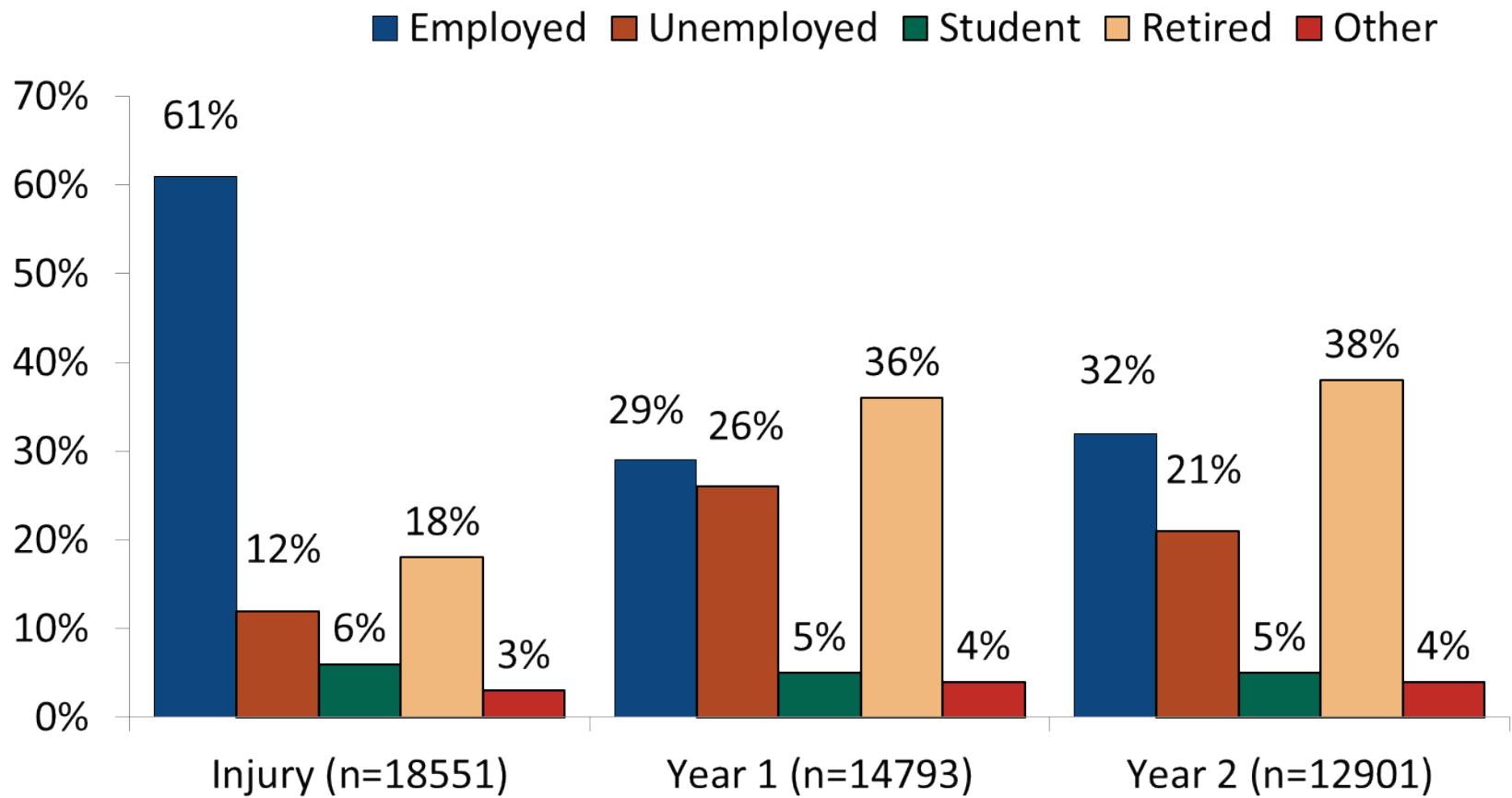
# Marital Status



## Living Situation



# Employment Status



# Summary

## Participation Outcomes

- Most live in a private residence following rehab. discharge (81%).
- Few live alone at rehab. discharge (3%), with the highest proportion living with parent(s) (32%), or spouse/SO (31%).
- 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 18,000 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: 2020
- URL: <http://www.tbindsc.org>
- Version: <https://osf.io/a4xzb/>

## TBIMS Annual Presentation:

Traumatic Brain Injury Model Systems National Data and Statistical Center,  
2020 Traumatic Brain Injury Model Systems Annual Presentation [PDF File].  
Retrieved from <https://www.tbindsc.org>