# 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)

NDSC
National Data and Statistical Center
Traumatic Brain Injury Model Systems

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

MSKTC
SCI · TBI · BURN
Model Systems Knowledge Translation Center

# Project Design

- The first prospective, longitudinal multi-center 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 TBIMS

- TBIMS is one of three Model Systems programs sponsored by NIDILRR
  - Spinal Cord Injury Model Systems
    - 1970: Established with 14 centers
  - Traumatic Brain Injury Model Systems
    - 1987: Established with 5 centers
    - 1998: Increased to 17 centers
    - Currently: 16 Centers and 3 Follow-up Centers
  - Burn Injury Model Systems
    - 1994: Established with four centers

# 2017-2022 Project Priorities

Conduct research that contributes to evidence-based rehabilitation interventions and clinical and practice guidelines which improve the lives of individuals with TBI.

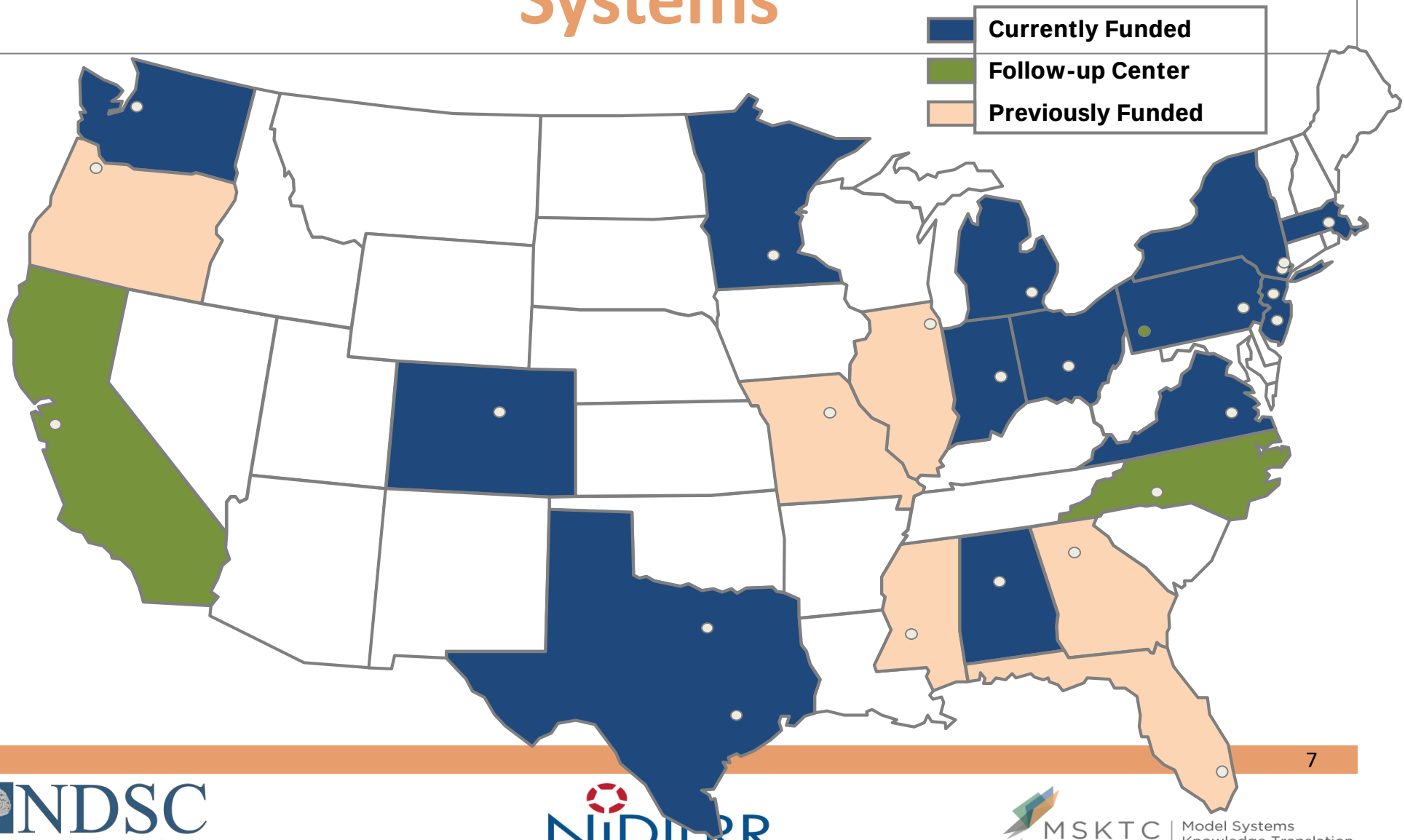
# Requirements of TBIMS Centers

- 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

# Current Traumatic Brain Injury Model Systems






NDSC
National Data and Statistical Center
Traumatic Brain Injury Model Systems

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

MSKTC
SCI · TBI · BURN
Model Systems Knowledge Translation Center

# 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, CO, Cindy Harrison-Felix, PhD, Project Director
- TBI Model Systems Centers
  - Executive Committee Chair, Flora Hammond, PhD

# TBIMS Collaborative Studies

- Multicenter Evaluation of Memory Remediation After TBI with Donepizil
  - This proposed study will definitively establish whether, and to what extent, donepezil is an effective treatment for functionally important TBI-related memory deficit. The project is a four-site, randomized, parallel design, double-blind, placebo-controlled, 10-week trial of donepezil 10 mg daily for verbal memory problems among adults with TBI in the subacute or chronic recovery period. Data will be acquired with which to assess the effects of donepezil on attention, processing speed, neuropsychiatric symptoms, community participation, quality of life, and caregiver experiences. Findings from this study will influence the practices of prescribing healthcare providers and contribute information that will improve lives of persons with TBI and their families. David B. Arciniegas, MD , TIRR Memorial Hermann, is the Principal Investigator.

# TBIMS Centers: 2017-22

| TBIMS Center | Principal Investigator | State |
|---|---|---|
| University of Alabama at Birmingham | Thomas Novack | AL |
| Craig Hospital | Cindy Harrison-Felix | 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 | Keith Cicerone | NJ |
| Albert Einstein Healthcare-Moss Rehab | Tessa Hart | PA |
| TIRR Memorial Hermann | Mark Sherer | TX |
| Baylor Research Institute | Simon Driver | TX |
| Virginia Commonwealth University | Jeffrey Kreutzer | 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 Dirlikov | CA |
| University of Pittsburgh | Amy Wagner | PA |
| Carolinas Rehabilitation/Carolinas HealthCare System | Shanti Pinto | NC |

# TBIMS Multicenter Research 2017-22 *

| Study Type | Study Topics |
|---|---|
| **Intervention** | ▪ Problem Solving Training (PST) for Care Partners of Adults with Traumatic Brain Injuries (TBI) during Inpatient Rehabilitation. |
| **Assessment and Prediction of Outcomes** | ▪ Caregiver Resilience A Longitudinal Investigation<br>▪ Health Literacy Following Traumatic Brain Injury and Impact on Health-Related Outcomes<br>▪ Menopause in Women with TBI<br>▪ Return to Driving after Moderate-Severe TBI<br>▪ Partnering with Caregivers to Increase Knowledge of the Post-Acute Phase of Recovery From Severe TBI<br>▪ Physical Activity and its relationship with cognition and secondary conditions after TBI<br>▪ Trajectories of Cognitive Functioning Years after TBI<br>▪ Alexithymia Prevalence & Relationships to Patient Characteristics & Outcome in TBIMS Cohort |
| **Analytical** | ▪ Development and Assessment of Crosswalks in the TBIMS Database |

* Module Studies and Collaboratives Grants

# 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 hrs 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 I: Inpatient rehabilitation discharge; administered in-person: 285 variables
- Form II: 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 (cont.)

- Form I – 16,495 cases (as of 3/31/2018)
- Form II – 57,498 follow-ups* - 17% attrition (4%**)
  - Year 1 – 15,892 – 13% attrition (2%**)
  - Year 2 – 14,278 – 14% attrition (4%**)
  - Year 5 – 11,608 – 16% attrition (9%**)
  - Year 10 – 6,877 – 18% attrition (7%**)
  - Year 15 – 3,034 – 17% attrition (10%**)
  - Year 20 – 794 – 15% attrition (0%**)
  - Year 25 – 274 – 15% attrition (0%**)

*There are some follow-ups in 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 (FY2011-FY2012)
  - 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
  - Extension of the Representativeness of the Traumatic Brain Injury Model Systems National Database: 2001 to 2010
  - Effect of Alcohol Misuse on Outcomes 5 Years Following Acute Rehabilitation for Traumatic Brain Injury
- IAAs between Centers for Disease Control and Prevention (CDC) and NIDILRR (FY2012-FY2013)
  - Life Expectancy following inpatient rehabilitation for a primary diagnosis of TBI in the US.
  - Factors influencing 2 year employment post-TBI.
  - Predictors of deterioration and improvement 5 years post TBI.

# NIDILRR TBI Interagency Database Collaborations (cont.)

- 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

# 155 Studies Use the TBIMS NDB

- 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

- An additional 400 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 (cont.)

- 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 (cont.)

- 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 (cont.)

- 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 (cont.)

- 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 (cont.)

- 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

# TBIMS Accomplishments (cont.)

- 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 (cont.)

- 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

# 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 (cont.)

- 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)

# 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 / TBI - QOL | | √ |
| GAD 7 – Anxiety / TBI QOL | | √ |
| 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) | √ | √ |
| Glasgow Outcome Scale-Extended (GOS-E) | | √ |
| Supervision Rating Scale (SRS) | √ | √ |

# 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 (cont.)

- 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

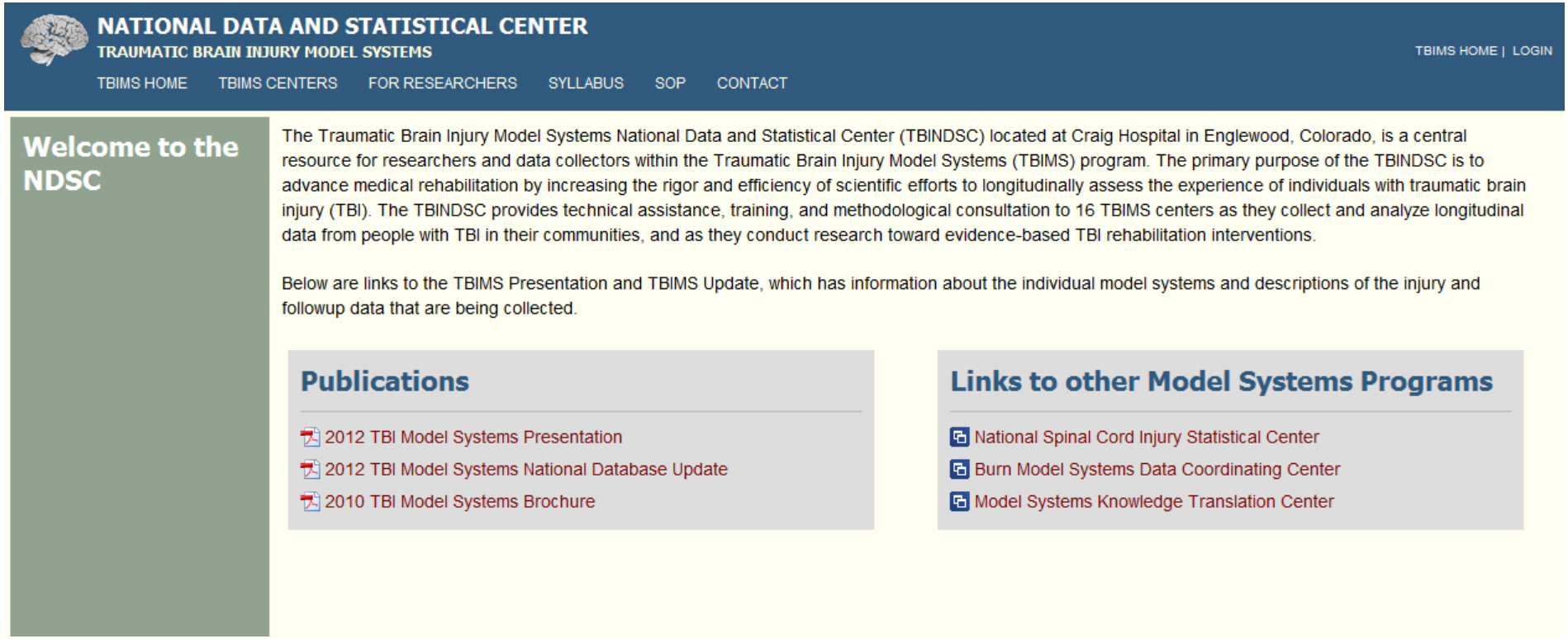
# Internal Dissemination

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

# External Dissemination

- Internet [www.tbindsc.org]
  - Online Database Syllabus
  - Annually updated TBI Model Systems PowerPoint Presentation
- National/International Presentations
- Journal Publications

# TBI Model Systems National Data and Statistical Center Website www.tbindsc.org



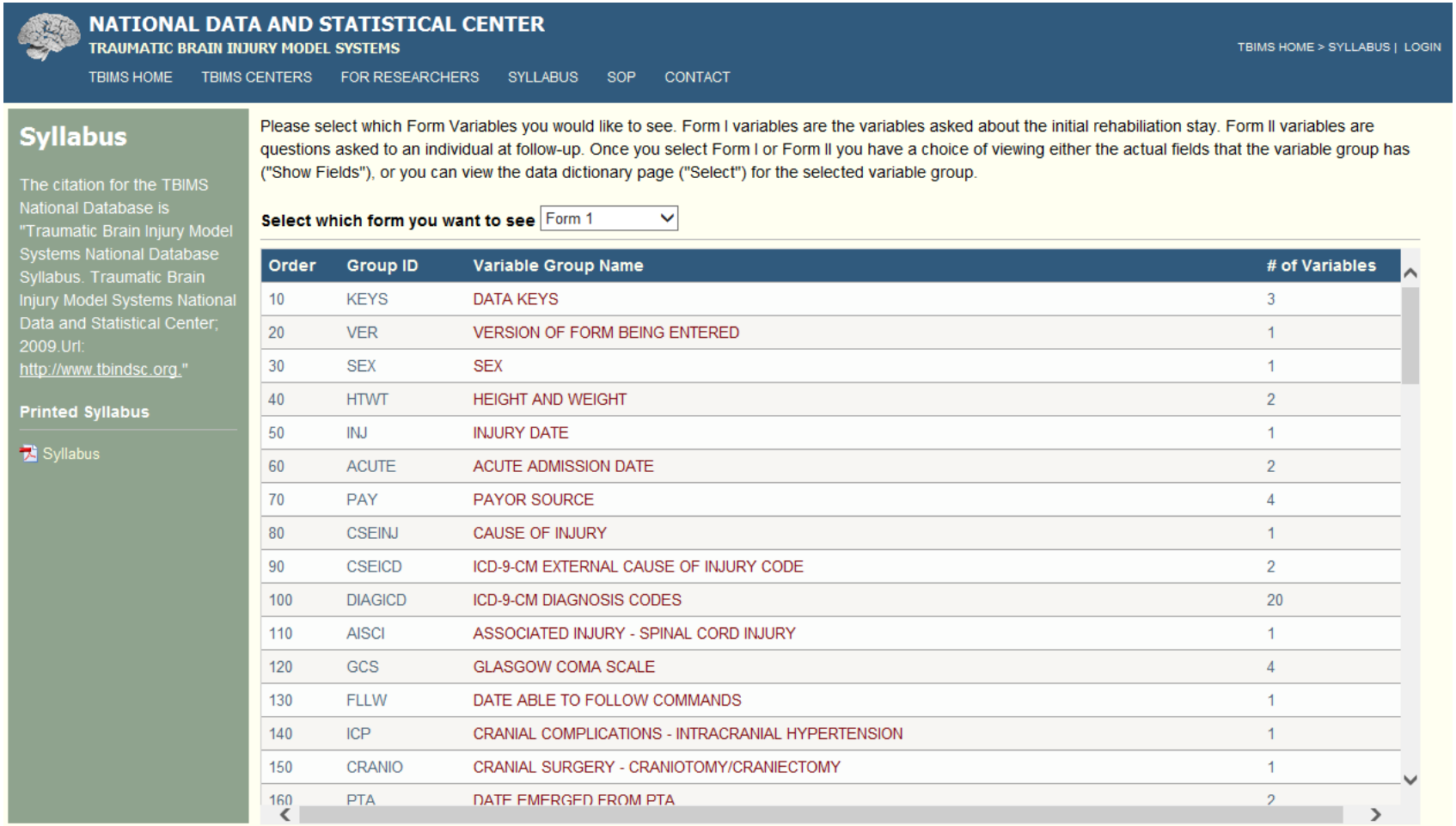



NDSC National Data and Statistical Center Traumatic Brain Injury Model Systems

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

MSKTC SCI · TBI · BURN Model Systems Knowledge Translation Center

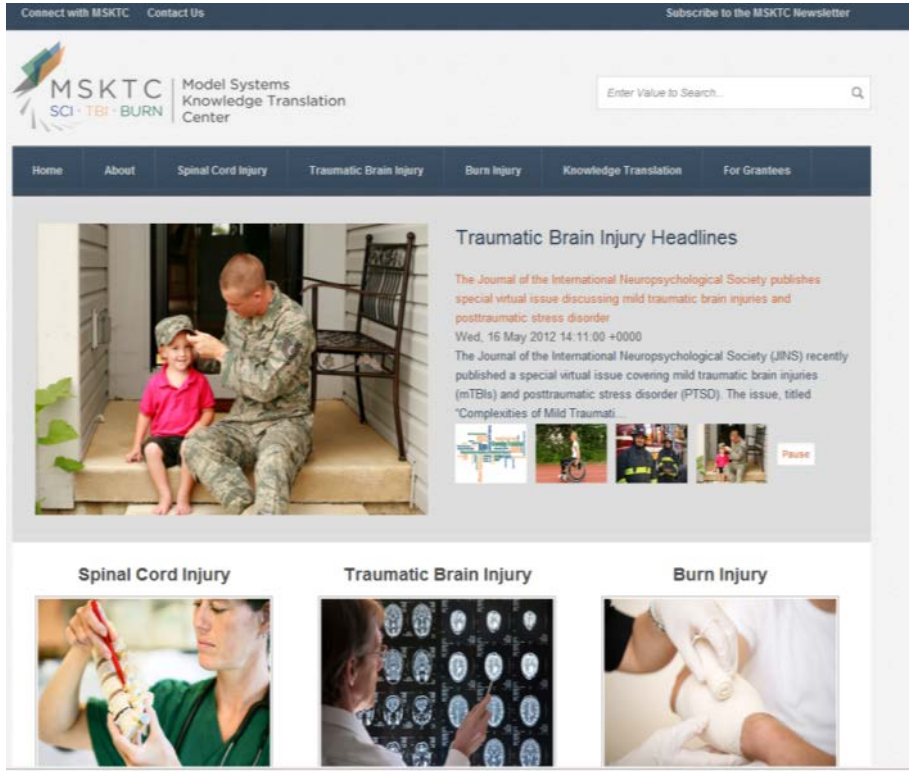
# Online TBI Model Systems National Database Syllabus




| Order | Group ID | Variable Group Name | # of Variables |
|---|---|---|---|
| 10 | KEYS | DATA KEYS | 3 |
| 20 | VER | VERSION OF FORM BEING ENTERED | 1 |
| 30 | SEX | SEX | 1 |
| 40 | HTWT | HEIGHT AND WEIGHT | 2 |
| 50 | INJ | INJURY DATE | 1 |
| 60 | ACUTE | ACUTE ADMISSION DATE | 2 |
| 70 | PAY | PAYOR SOURCE | 4 |
| 80 | CSEINJ | CAUSE OF INJURY | 1 |
| 90 | CSEICD | ICD-9-CM EXTERNAL CAUSE OF INJURY CODE | 2 |
| 100 | DIAGICD | ICD-9-CM DIAGNOSIS CODES | 20 |
| 110 | AISCI | ASSOCIATED INJURY - SPINAL CORD INJURY | 1 |
| 120 | GCS | GLASGOW COMA SCALE | 4 |
| 130 | FLLW | DATE ABLE TO FOLLOW COMMANDS | 1 |
| 140 | ICP | CRANIAL COMPLICATIONS - INTRACRANIAL HYPERTENSION | 1 |
| 150 | CRANIO | CRANIAL SURGERY - CRANIOTOMY/CRANIECTOMY | 1 |
| 160 | PTA | DATE EMERGED FROM PTA | 2 |

# Model Systems Knowledge Translation Center (MSKTC)

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 |
|---|---|---|
| **Systematic Reviews** | | • TBI & Fatigue<br>• TBI & Medical Outcomes |
| **Consumer Factsheets** | • TBI & Couples' Relationship | • TBI & Vocational Rehabilitation<br>• TBI & Vision Problems<br>• TBI & Spasticity |
| **Knowledge Translation Products** | **Knowledge Translation Webinar**<br>• Planning for Communities of Practice: Model Systems Grantees<br>• Getting to Outcomes: A Knowledge Translation Webinar for Model Systems Grantees<br>• Engaging with Audiences: A Learning Collaborative<br>**Knowledge Translation Toolkit**<br>• Newsletter Template and Instructions<br>• Press Release Template and Instructions<br>• 508 Compliance Tip sheet<br>• Tips on Presenting facts and figures | • Additional Knowledge Translation Webinars<br>• Additional tools for the Knowledge Translation tools |
| **Multimedia Products** | **Slideshows**<br>• TBI & Alcohol<br>• TBI & Sexuality<br>• TBI & Couples' Relationship<br>• TBI & Emotional Problems<br>**Hot Topics Module**<br>• Relationships after TBI | **Hot Topics Module**<br>• Depression after TBI<br>**Slideshows**<br>• Depression after TBI |

# TBIMS National Database
# Descriptive Data Summary

## [Includes data from 01/01/1989 – 12/31/2017]

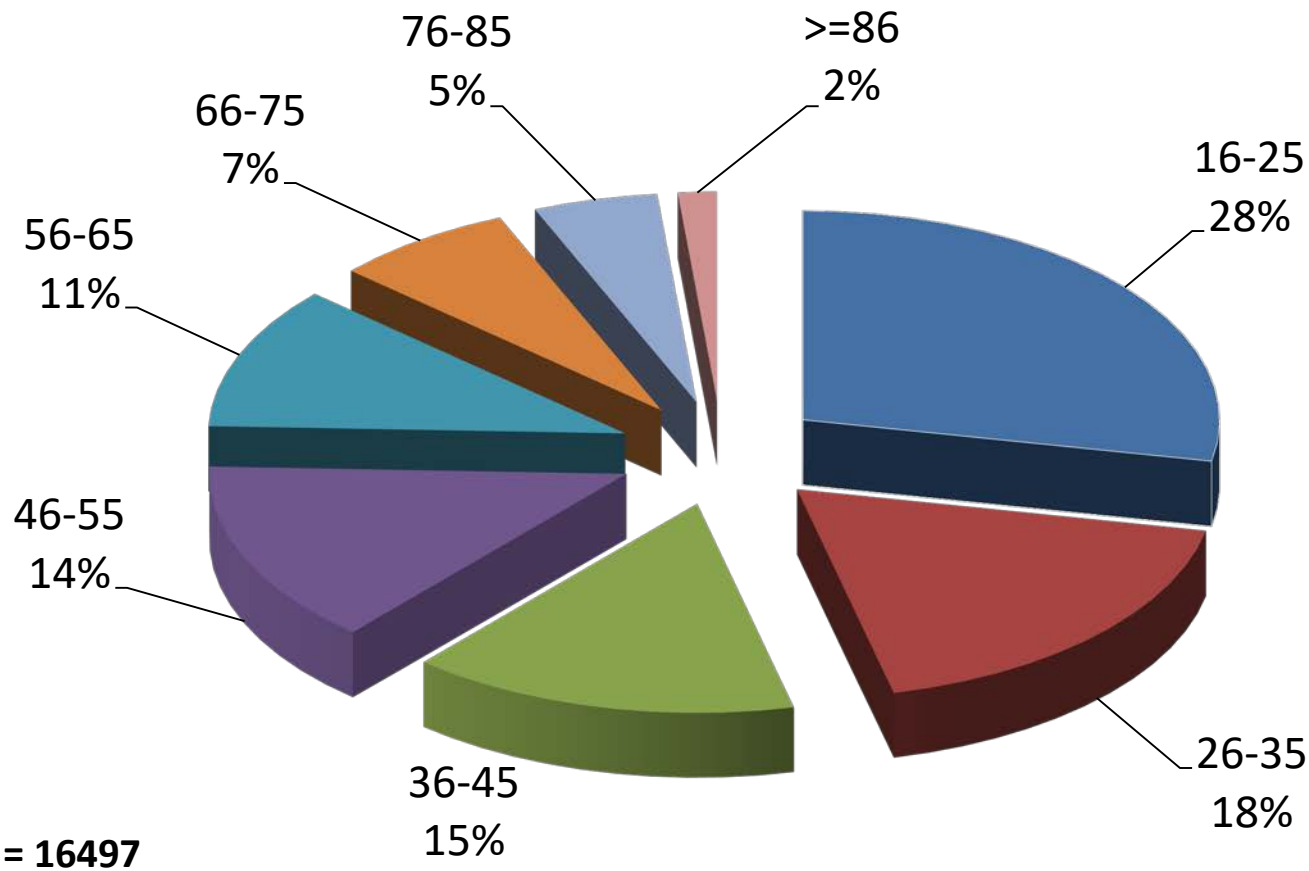


NDSC
National Data and Statistical Center
Traumatic Brain Injury Model Systems

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

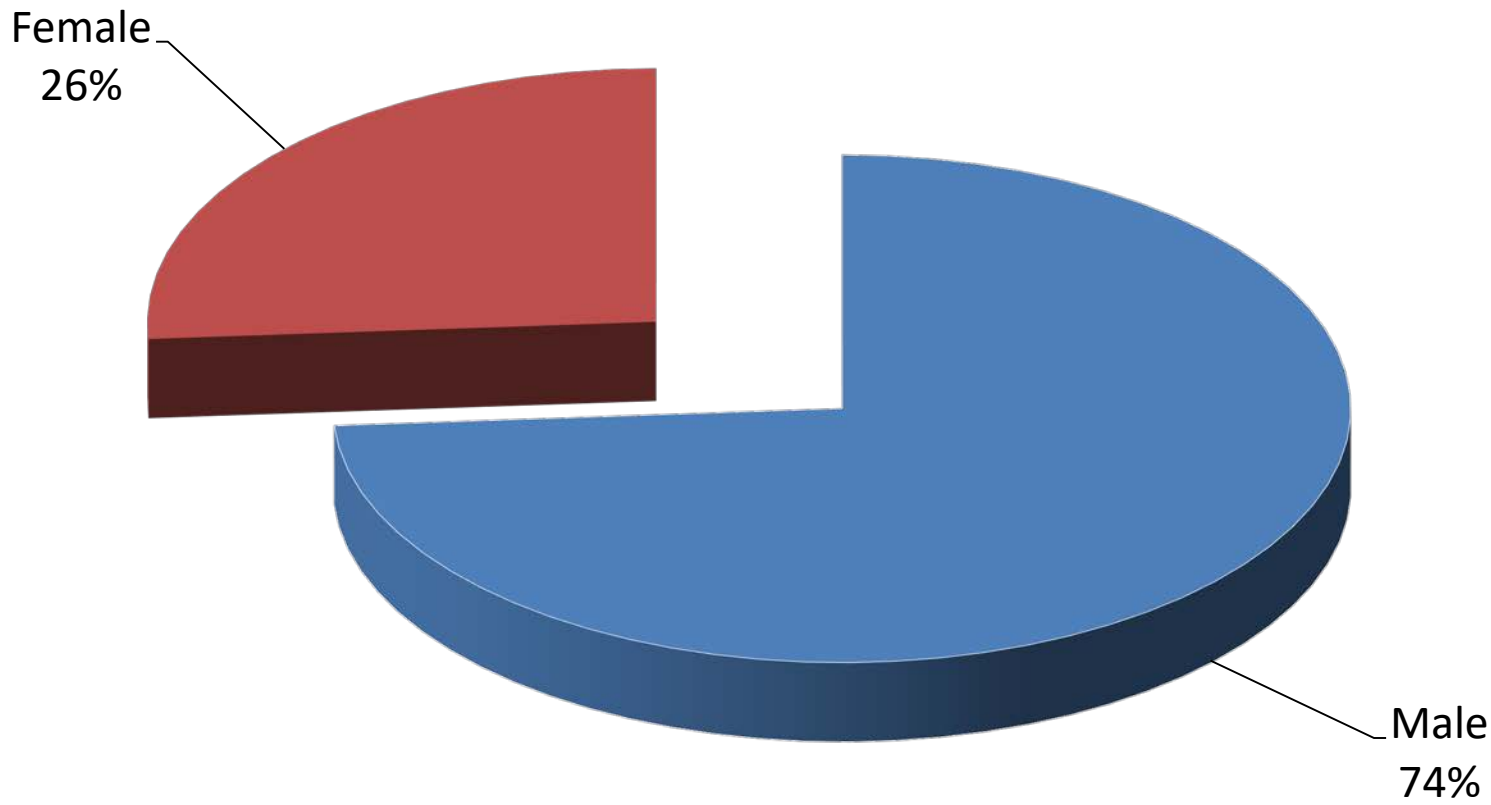
MSKTC
SCI · TBI · BURN
Model Systems Knowledge Translation Center

# Age



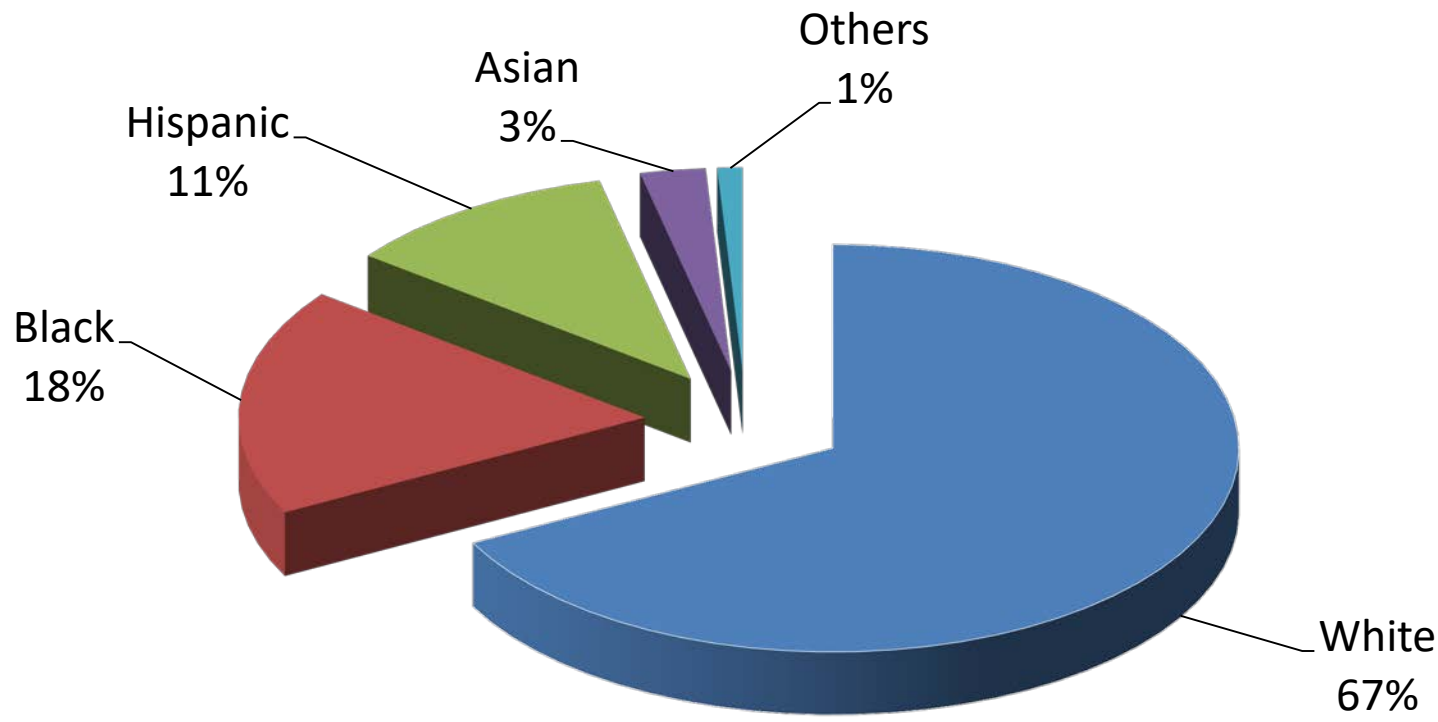

**mean = 41.87; n = 16497**

# Gender



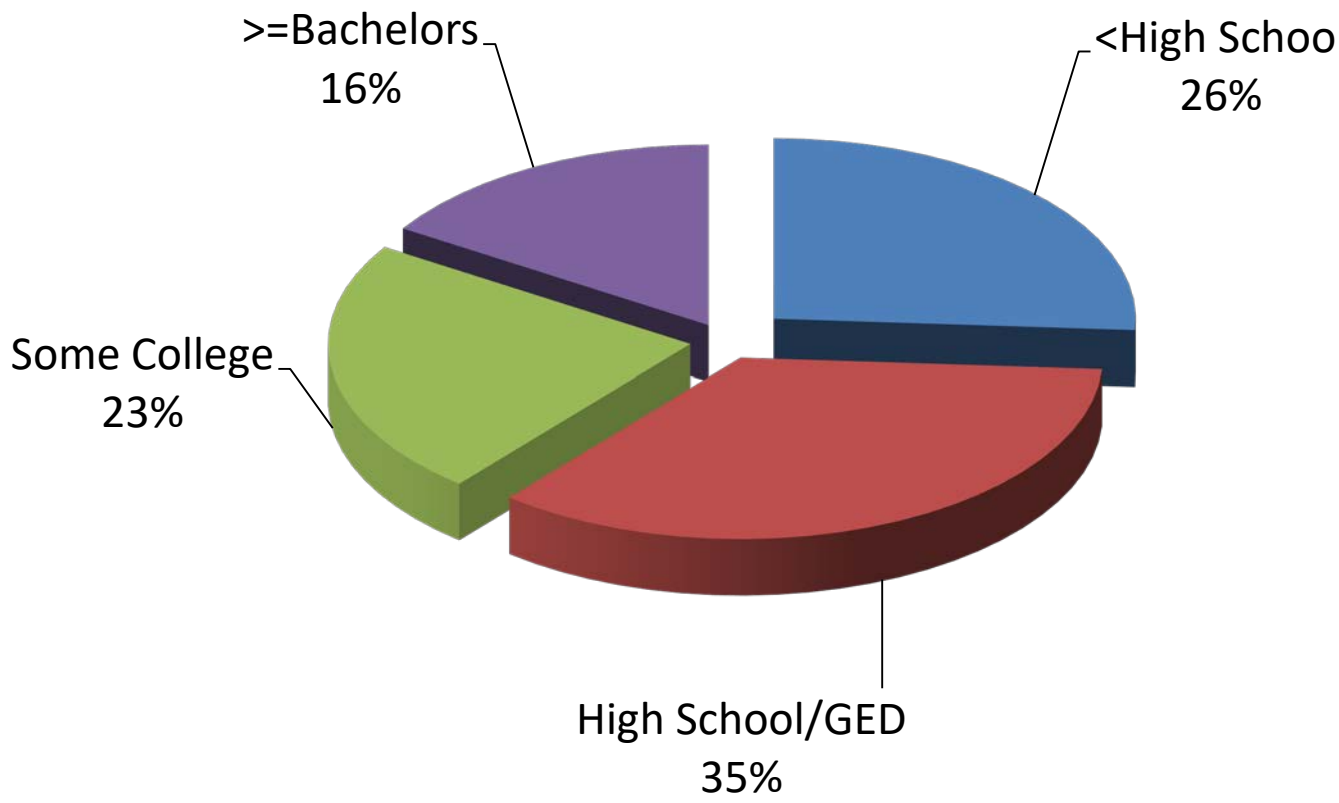

**n = 16490**

# Race




**n = 16486**

# Level of Education At Injury

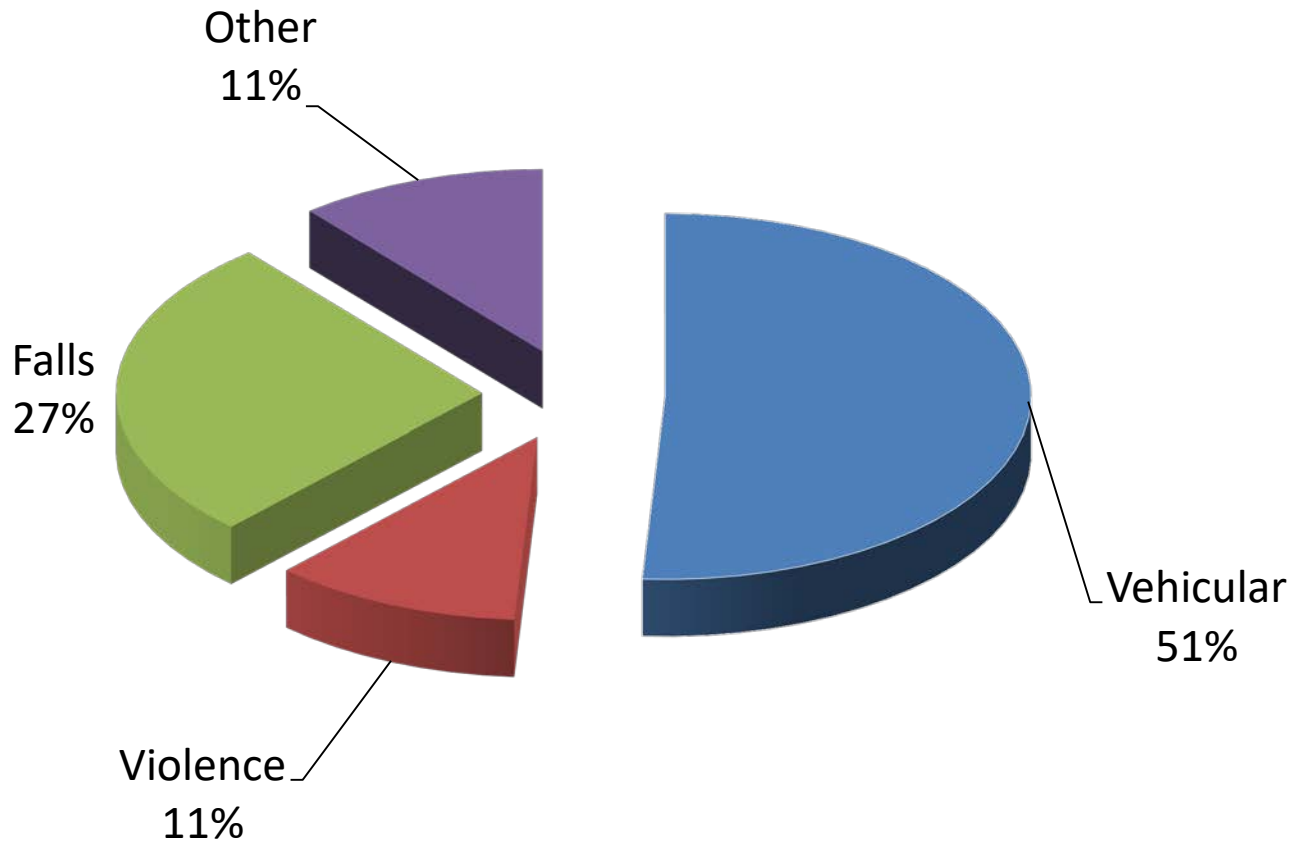



**n = 16237**

# Summary

- Demographic Characteristics of the Population
  - Average age = 41.87
  - Male (74%)
  - Minority population (33%)
  - High school education or less (61%)

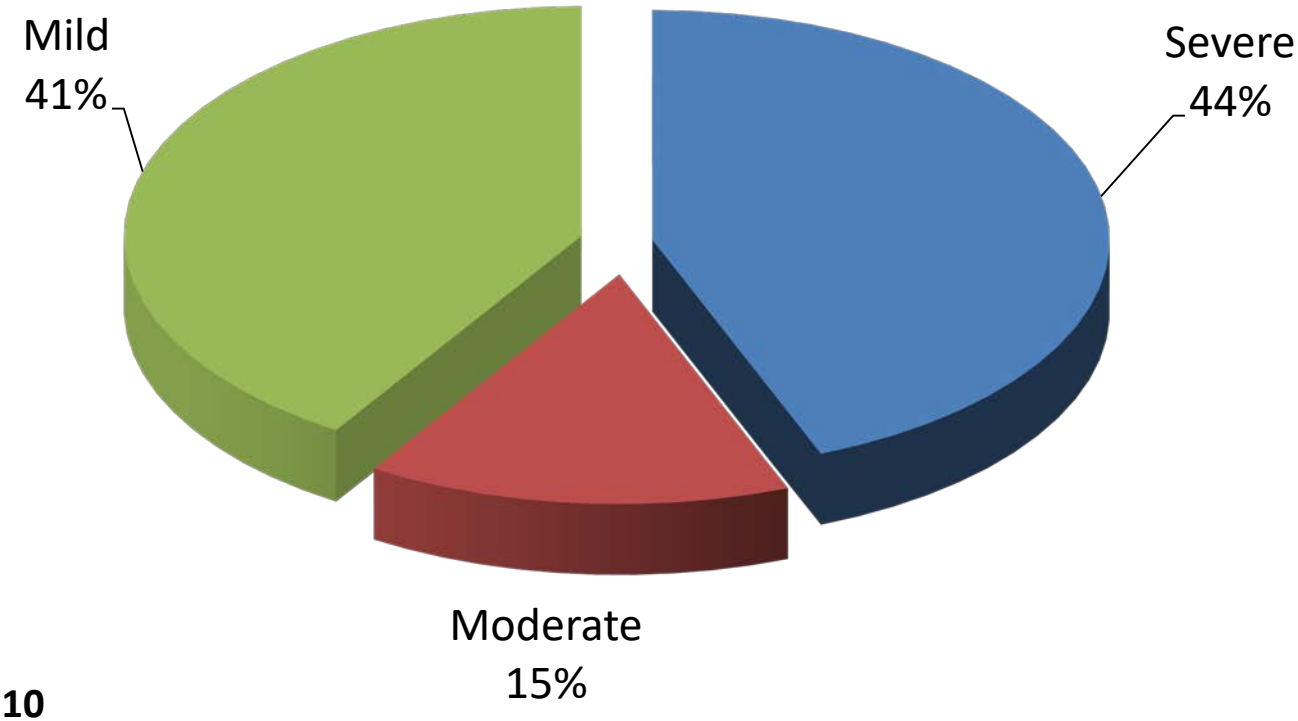
# Etiology of Injury




**n = 16453**

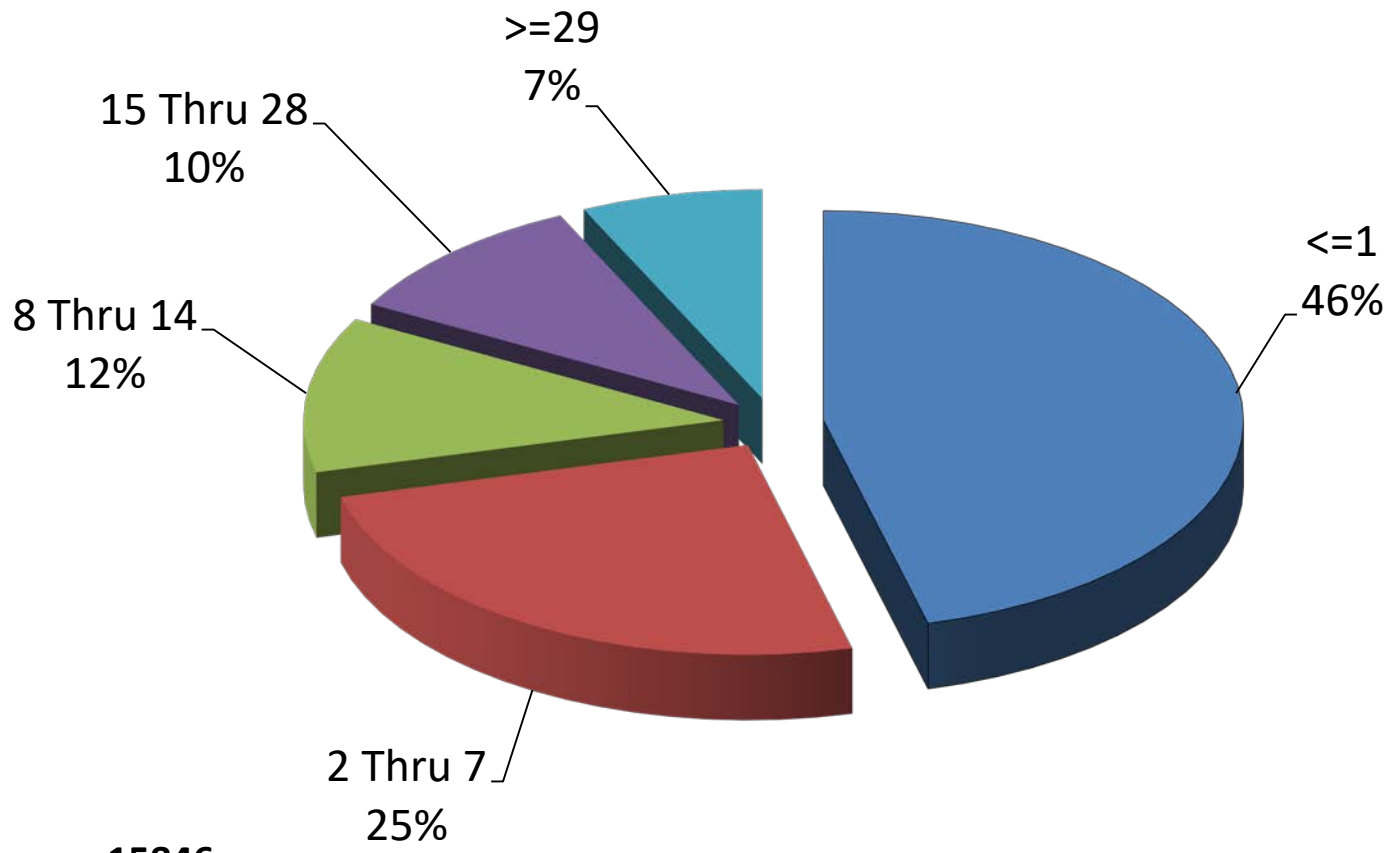
# Glasgow Coma Scale Score

**At Emergency Department Admission**



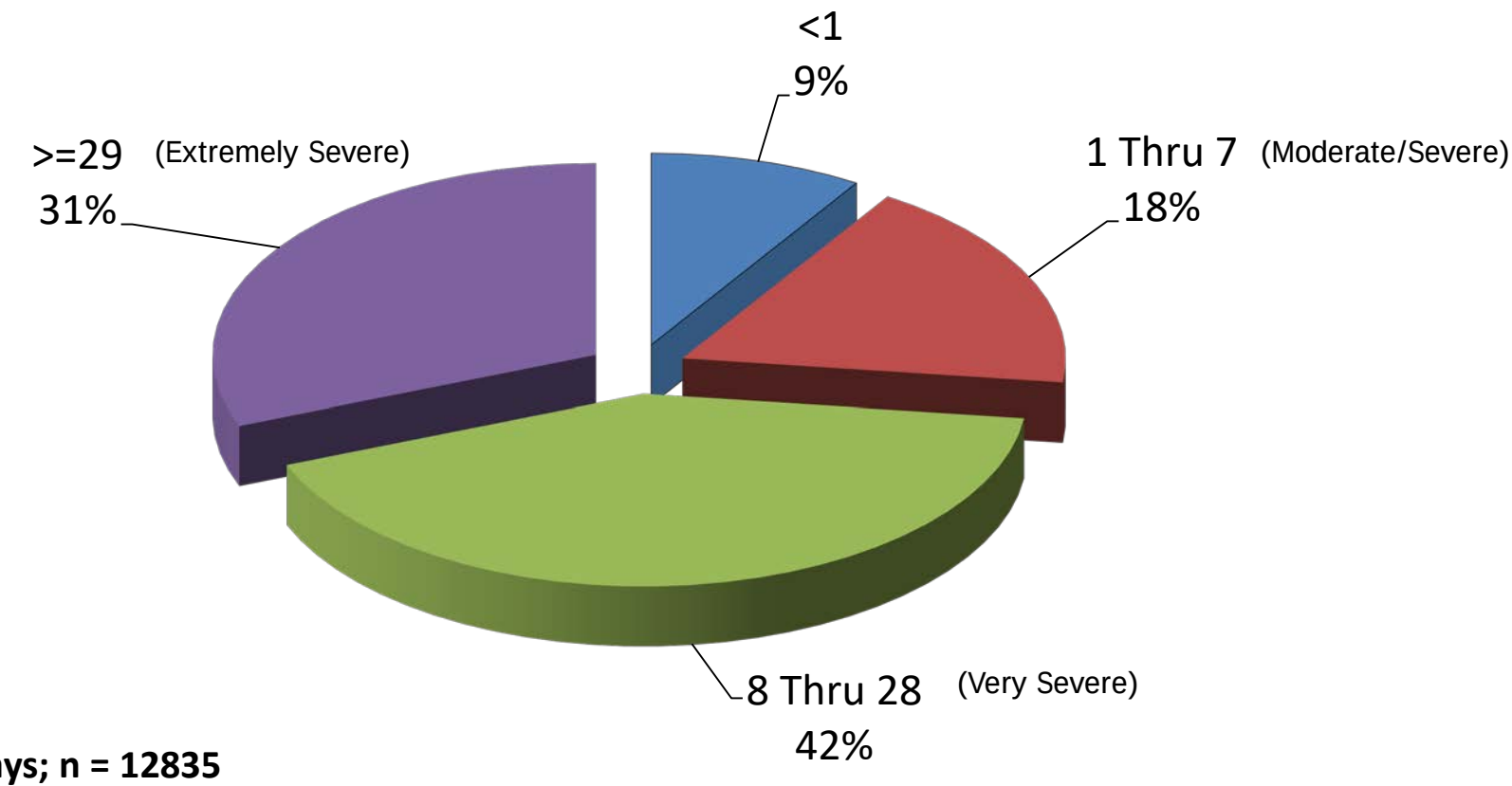

**mean = 9.67; n = 12710**

# Duration of Unconsciousness




**mean = 7.86 days; n = 15846**

# Duration of PTA



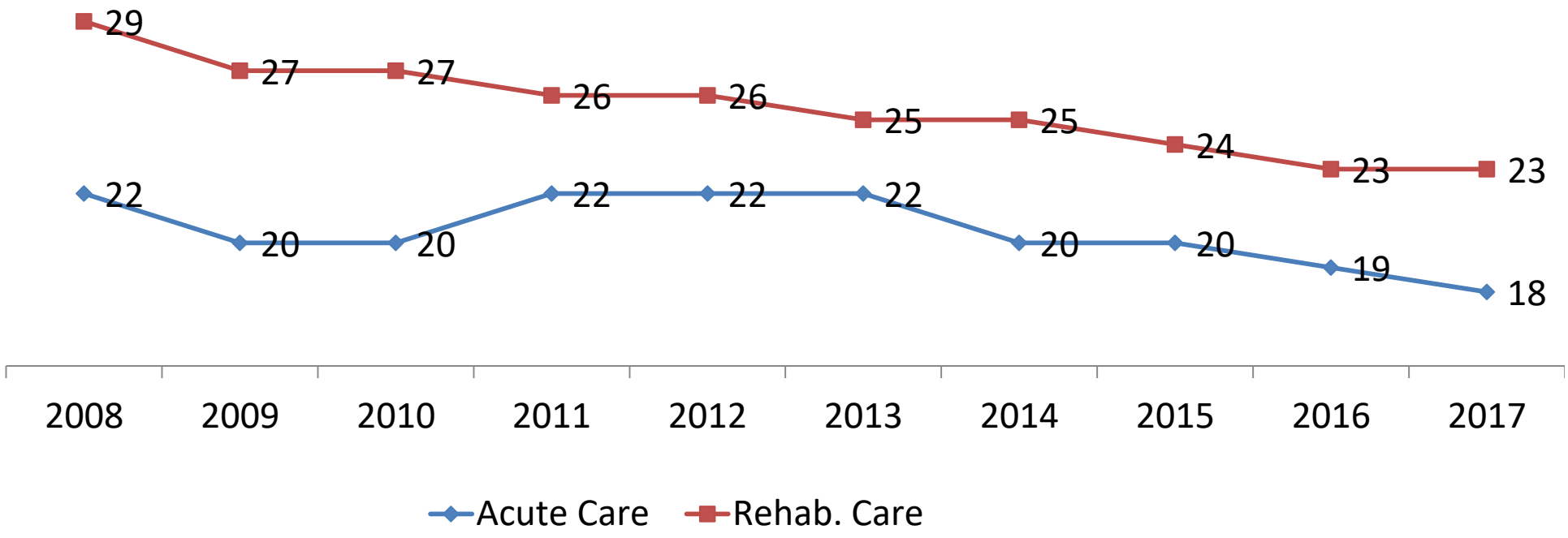

**mean = 22.89 days; n = 12835**

# Summary

- Causes of Injury
  - Primary cause is vehicular (51%), followed by falls (27%) and violence (11%)

- Severity of Injury
  - Average duration of LOC is 7.86 days
  - Average duration of PTA is 22.89 days

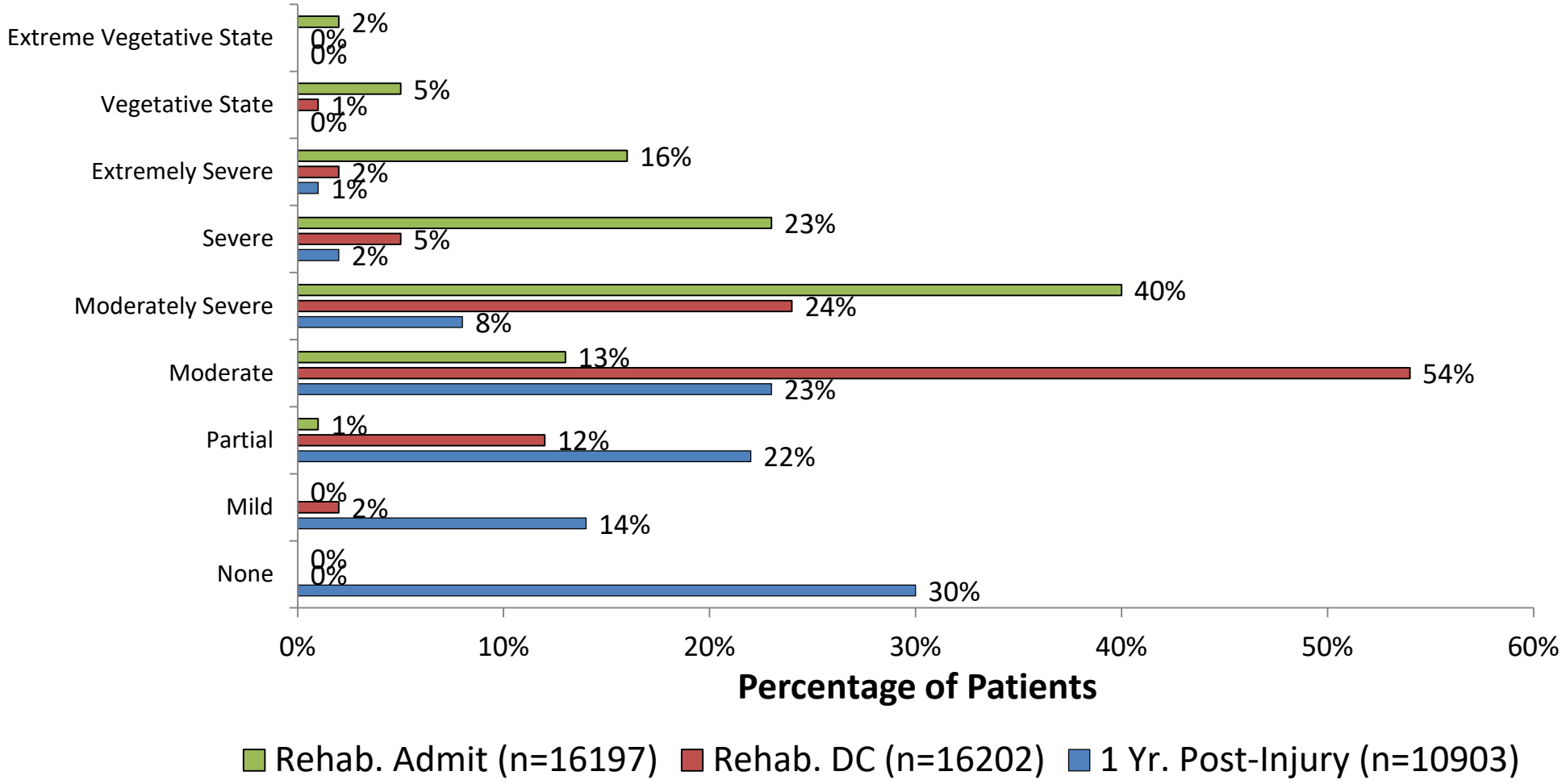
# Mean Length of Stay



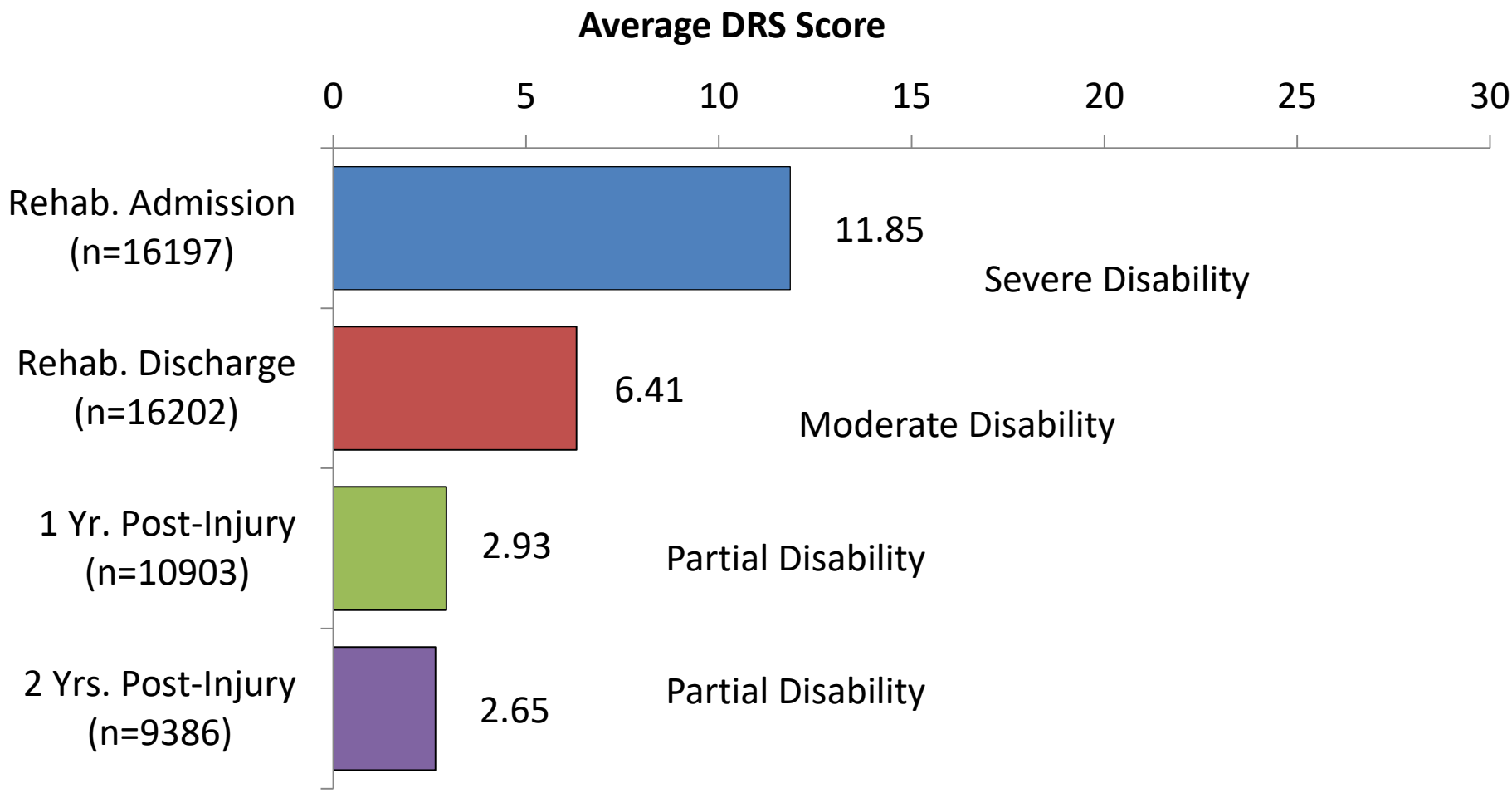
# Summary

- Costs of Treatment
  - Total LOS has consistently decreased over the last 5 years for both acute and rehab.
  - Total acute LOS in 2017 represents the lowest in the past decade.
  - Total rehab LOS in 2017 represents the lowest in the past decade.
  - 37% have government-sponsored rehabilitation care (M'caid/M'care)

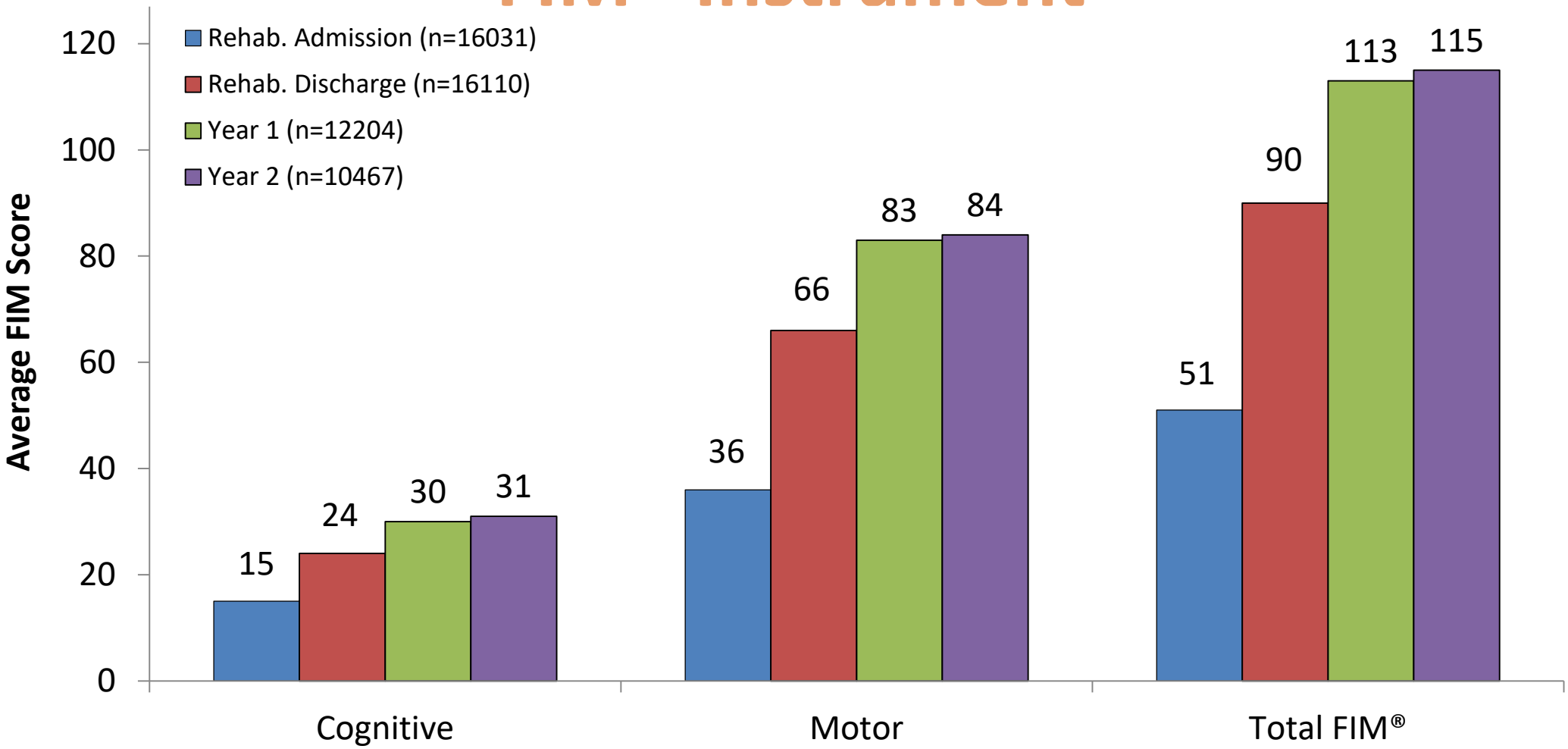
# Disability Rating Scale



# Disability Rating Scale



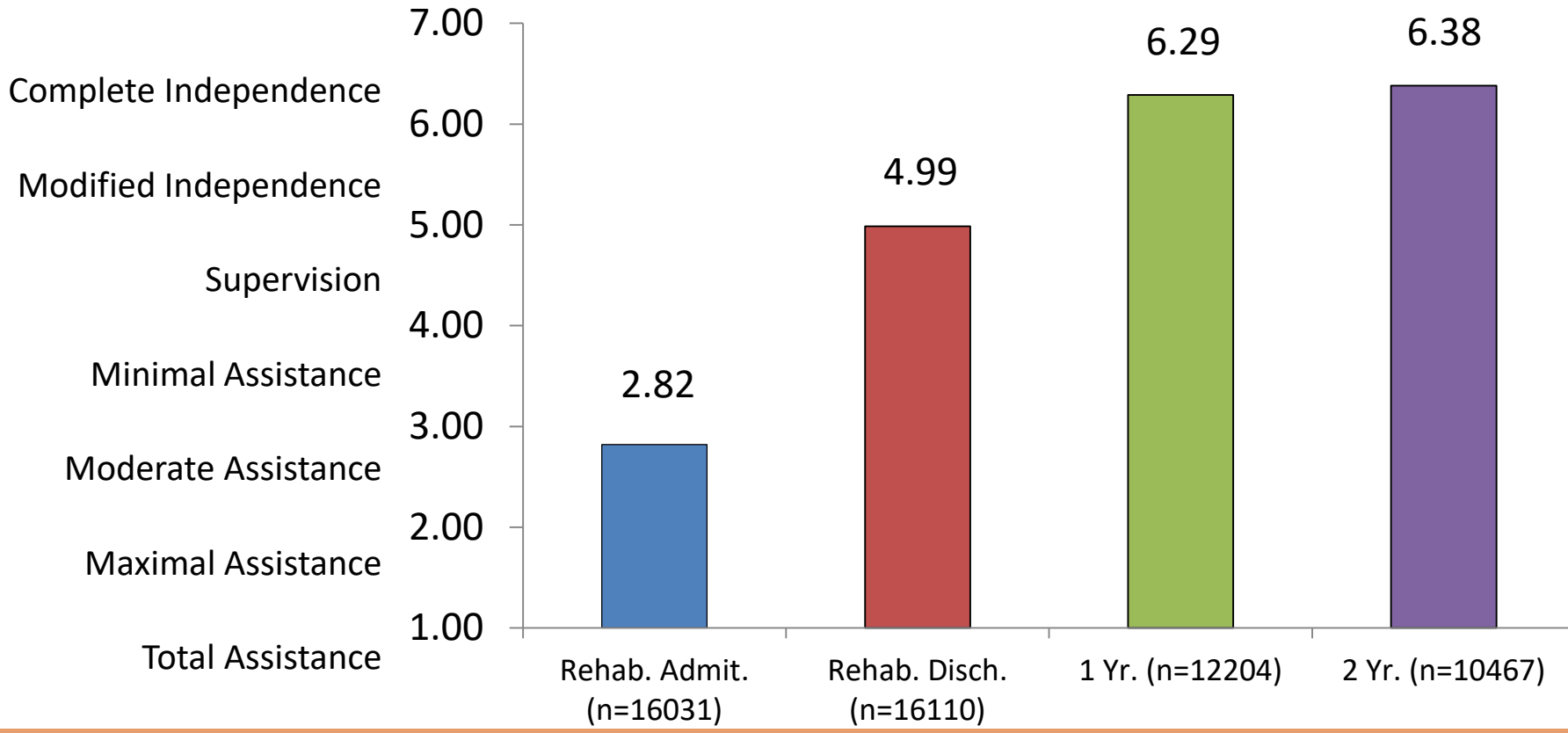
# FIM® Instrument



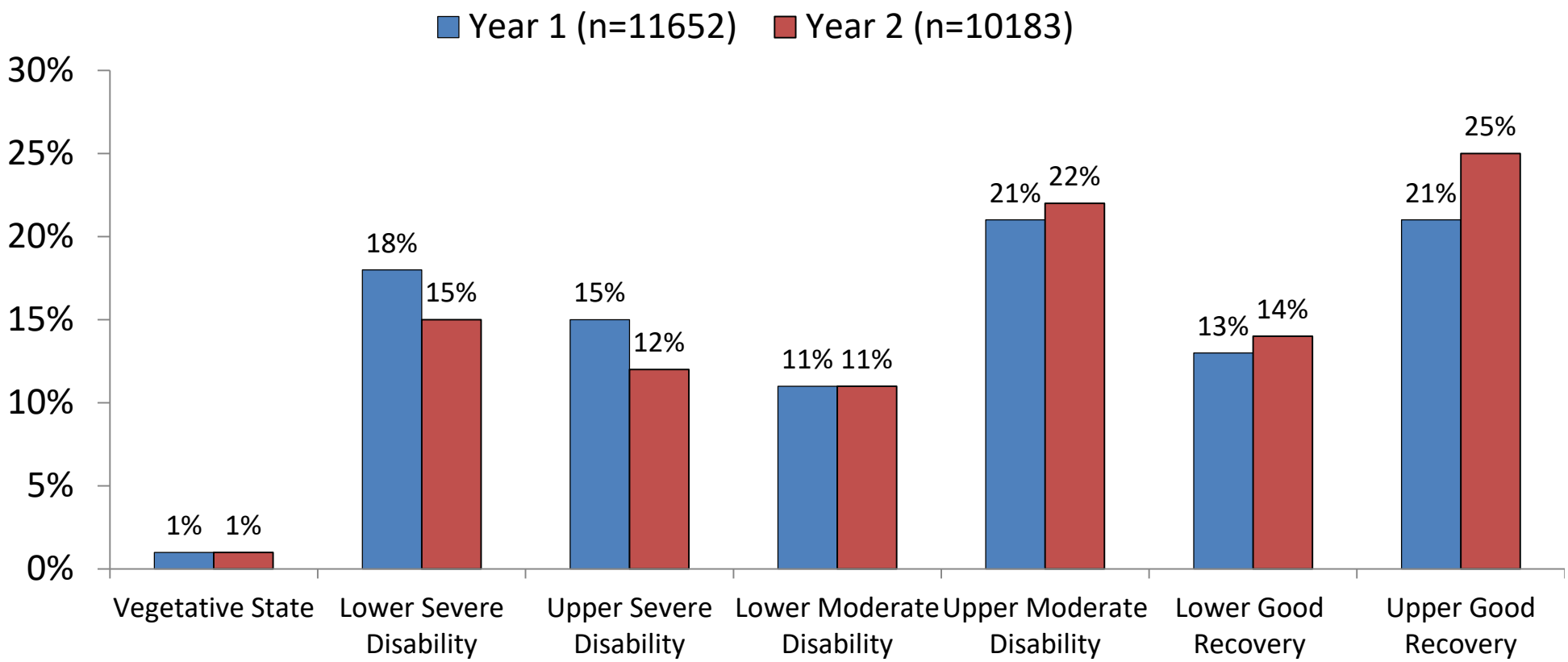

*Note: The value of n is reflective of Total FIM® measure

# FIM® Instrument

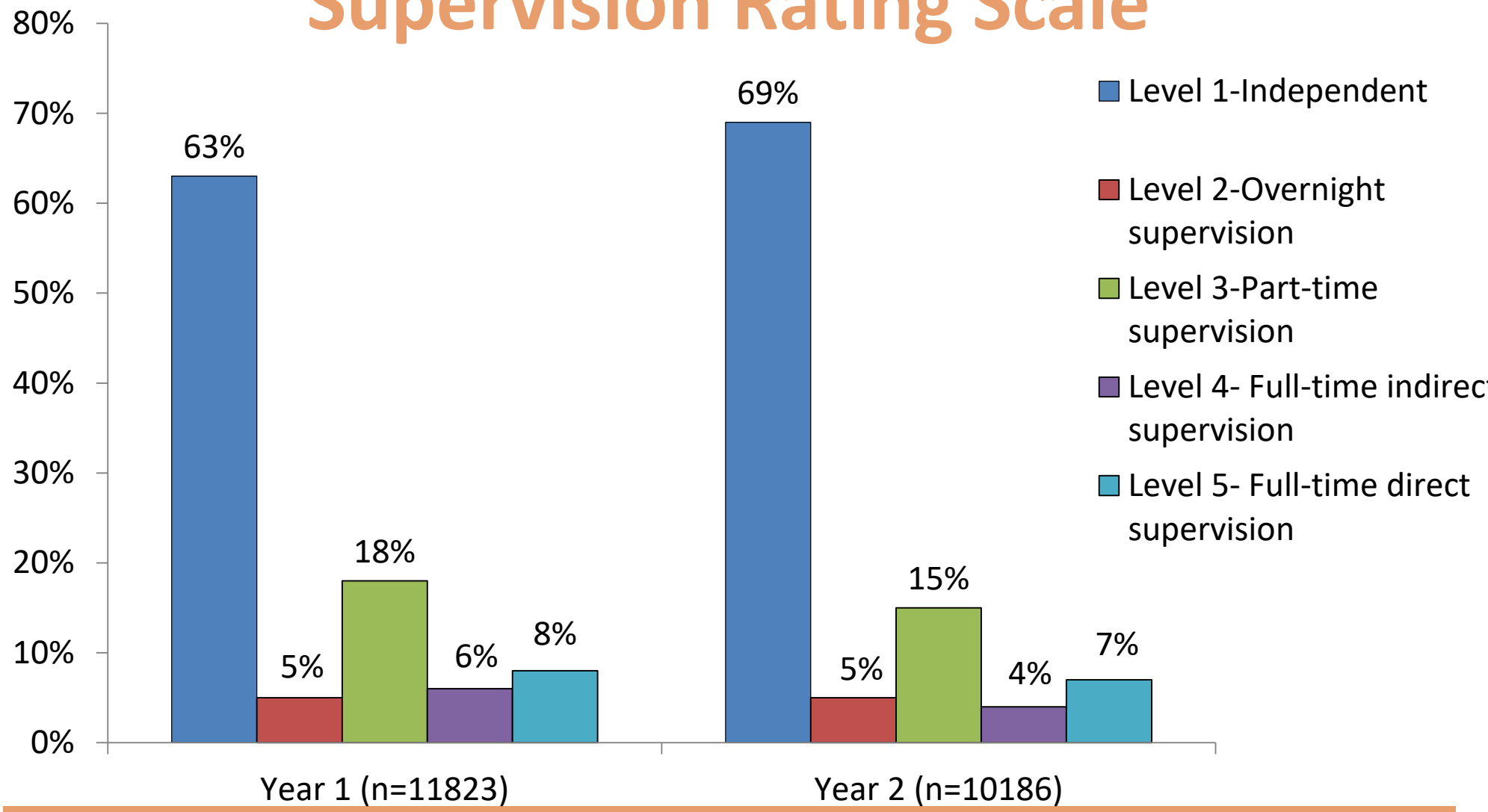
Mean Scores converted to 7-point scale



# Glasgow Outcome Scale-Extended



# Supervision Rating Scale



# Satisfaction With Life Scale

| | Year 1 | Year 2 | Year 5 |
|---|---|---|---|
| Number | 9627 | 8455 | 6222 |
| Mean | 21.26 | 21.57 | 21.90 |
| SD | 8.24 | 8.39 | 8.32 |
| Min | 5 | 5 | 5 |
| Max | 35 | 35 | 35 |

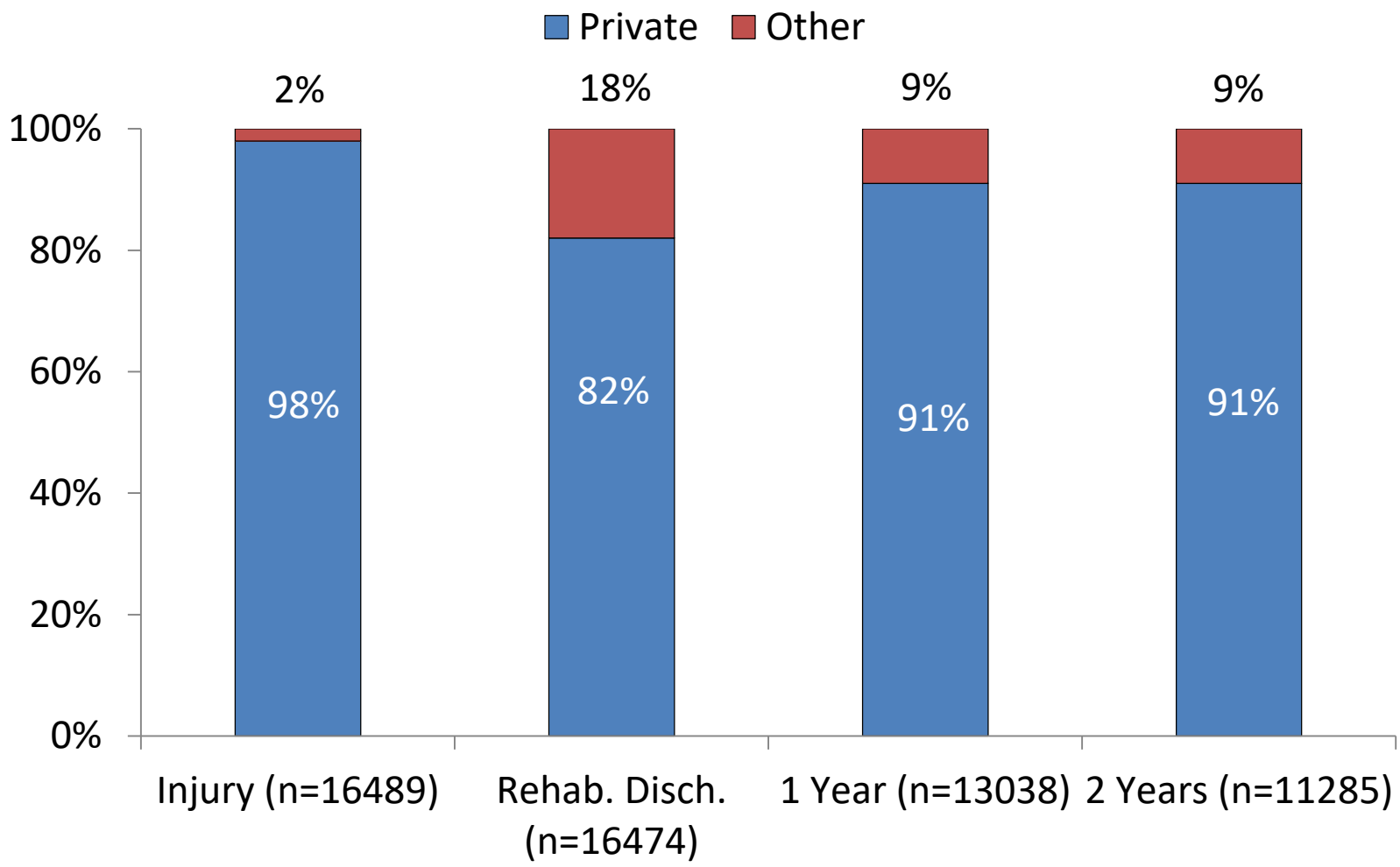
# Summary

- Disability Outcomes
  - DRS indicates improvement in level of disability from SEVERE DISABILITY at rehab. admission to PARTIAL DISABILITY at 1 and 2 yrs. post-injury
  - FIM® Instrument indicates improvement in functional ability from level requiring MODERATE ASSISTANCE at rehab. admission to MODIFIED INDEPENDENCE at 1 and 2 yrs. post-injury
  - SRS indicates that 37% of individuals require some level of supervision at 1 yr. post-injury and 31% at 2 yrs. post-injury.

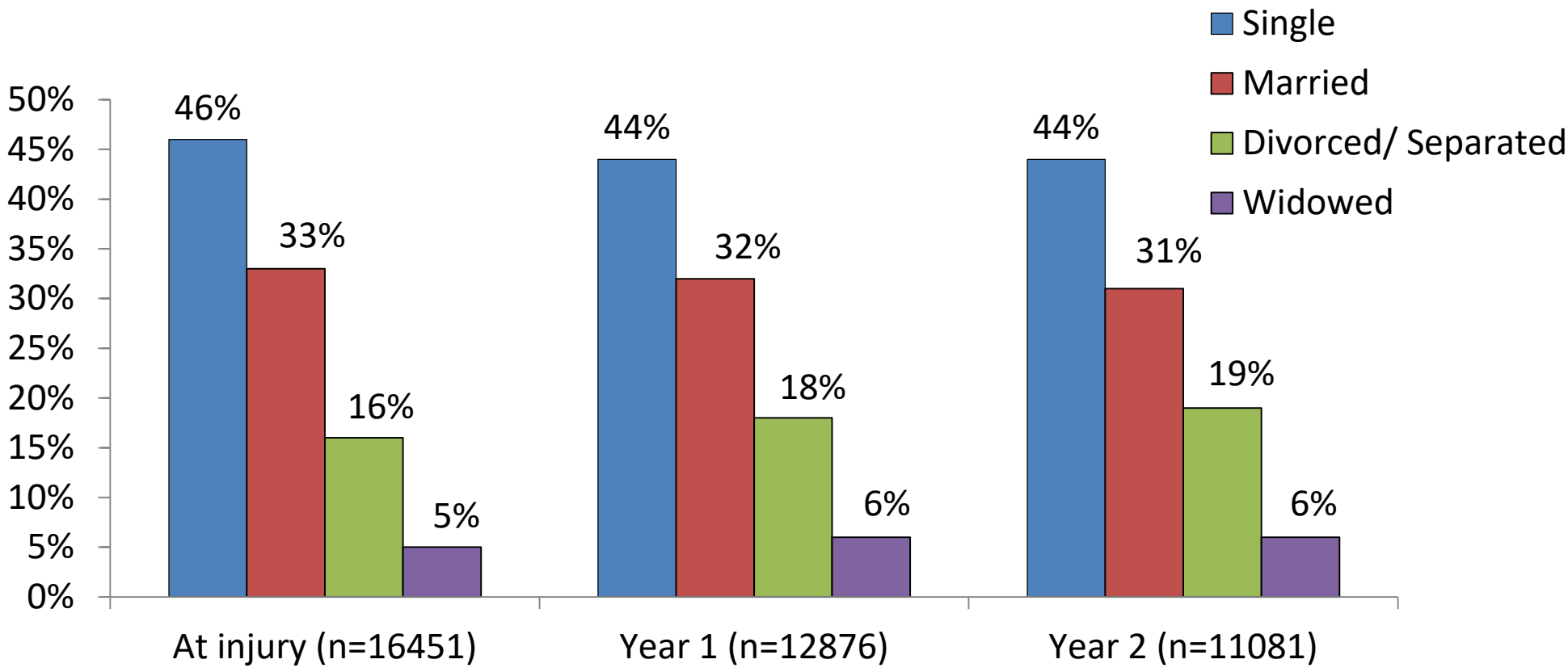
# Summary

- Disability Outcomes (cont.)
  - Most improvement in level of disability and functional ability occurs during inpatient rehabilitation
  - Continued improvement is seen at 1 yr. post-injury
  - Level of disability and functional ability appear to plateau between 1 and 2 yrs. post-injury

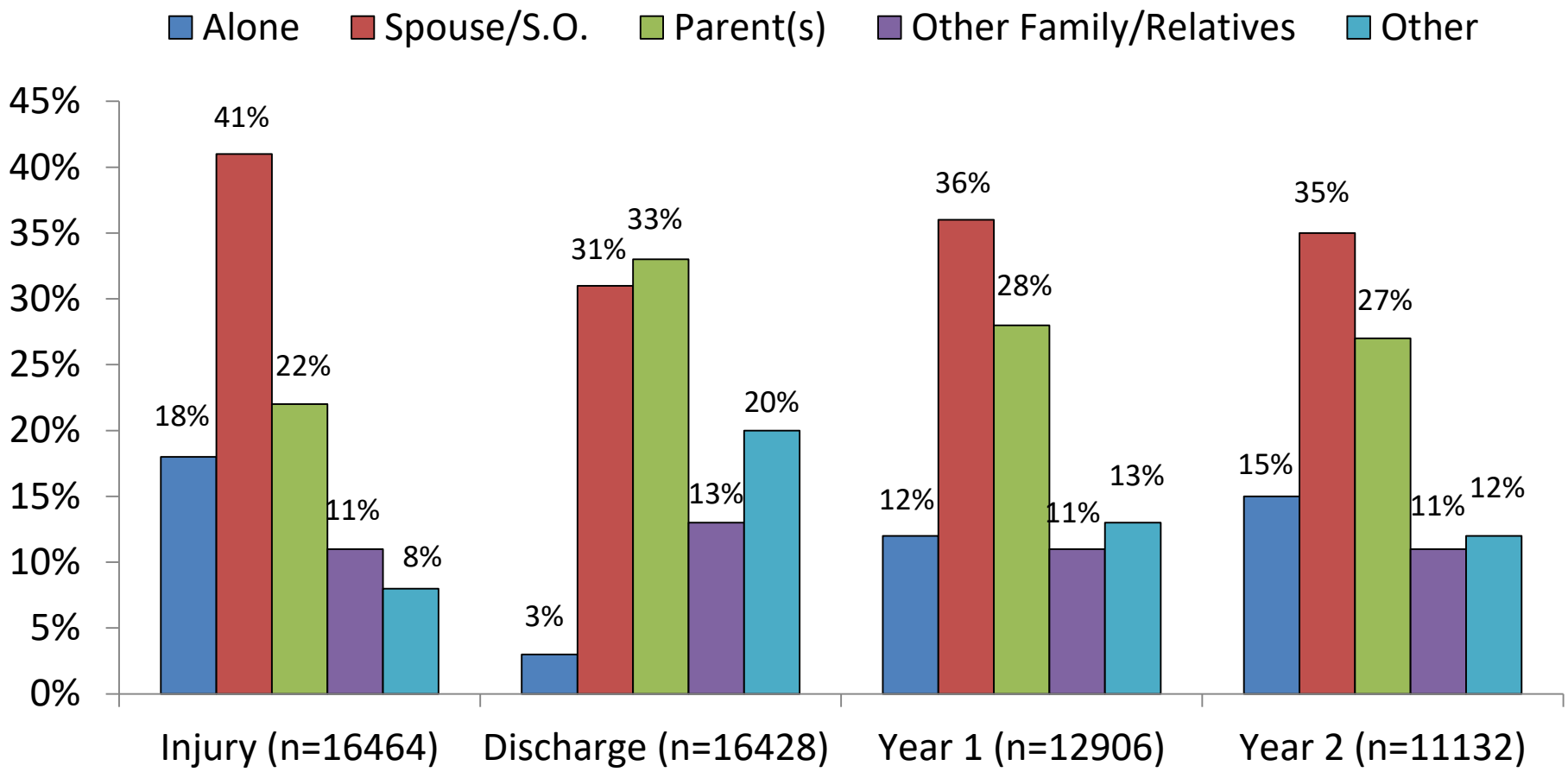
# Residence


Private
Other
2%
18%
9%
9%
100%
80%
60%
40%
20%
0%
98%
82%
91%
91%
Injury (n=16489)
Rehab. Disch. (n=16474)
1 Year (n=13038)
2 Years (n=11285)

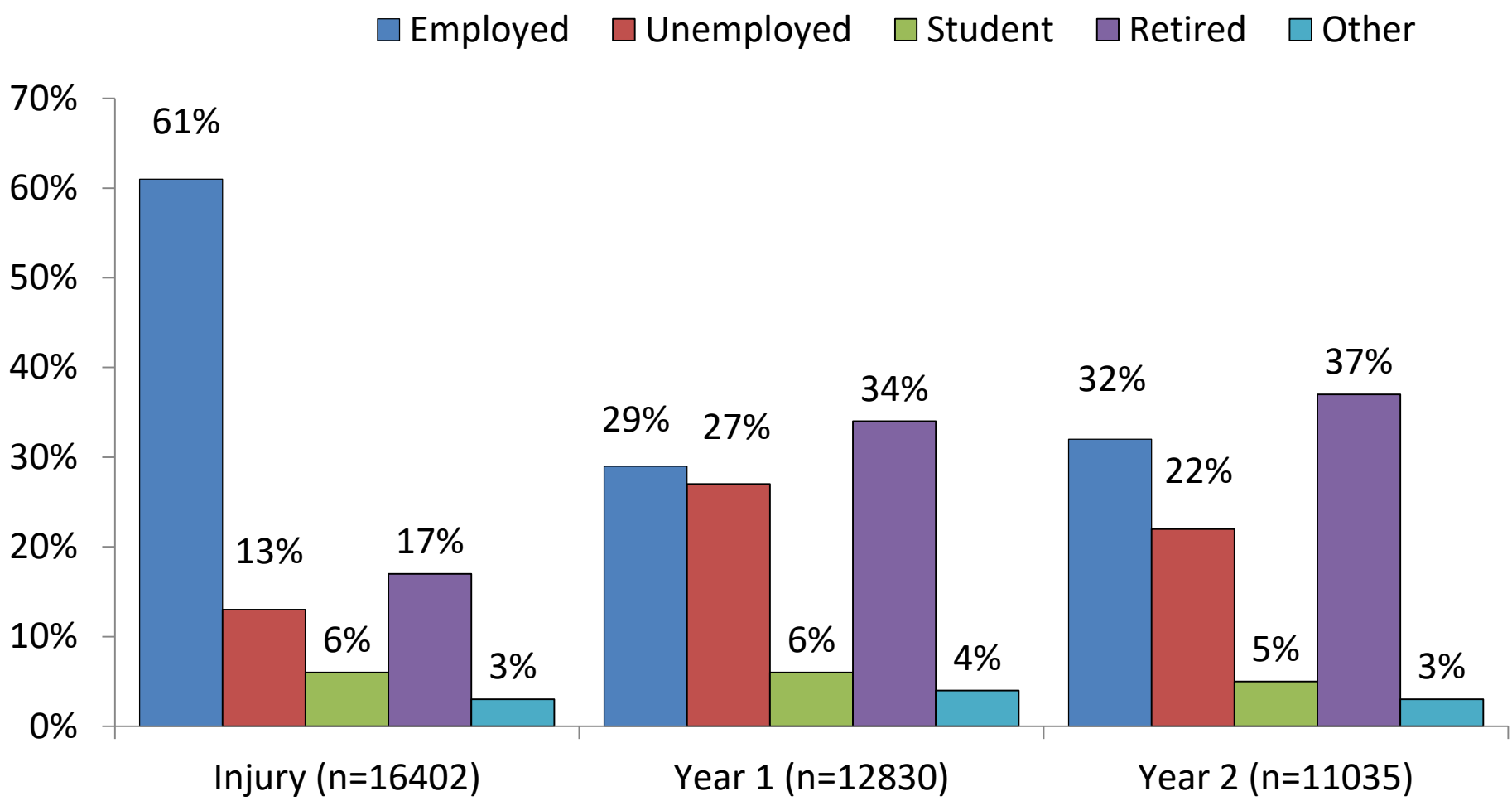
# Marital Status



# Living Situation



# Employment Status



# Summary

- Participation Outcomes
  - Most live in a private residence following rehab. discharge (82%)
  - Few live alone at rehab. discharge (3%), with the highest proportion living with parent(s) (33%), or spouse/SO (31%)
  - 29% are employed at 1 yr. 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 already containing over 16,000 cases with up to 30 years of follow-up.