

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)

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 25 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

2012-2017 Project Priorities

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

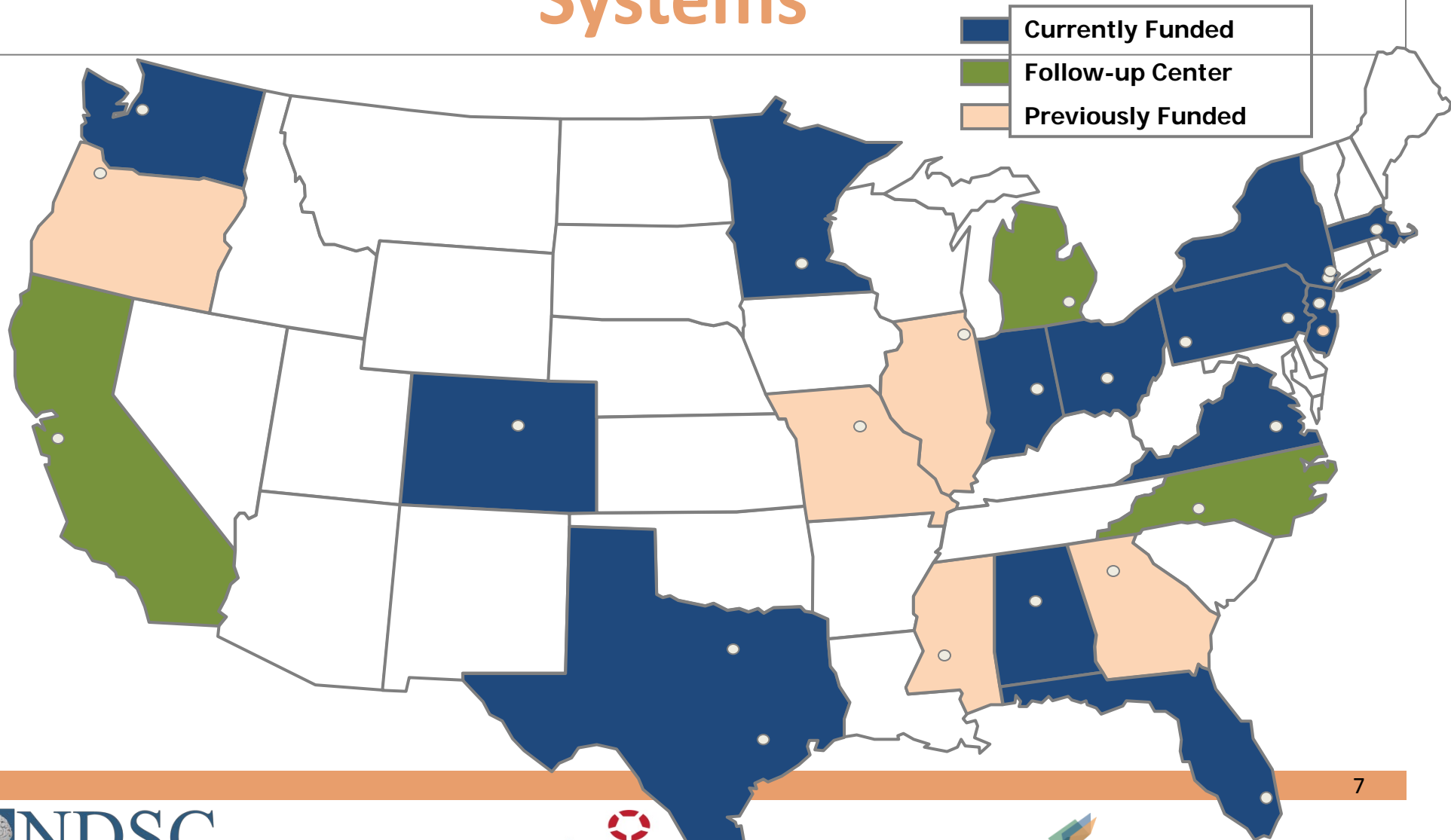
Requirements of TBIMS Centers

- 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



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, John D. Corrigan, PhD

TBIMS Collaborative Studies

- Multicenter Evaluation of Memory Remediation After TBI with Donepezil
 - 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: 2012-17

TBIMS Center	Principal Investigator	State
University of Alabama at Birmingham	Thomas Novack	AL
Craig Hospital	Cindy Harrison-Felix	CO
University of Miami	Doug Johnson-Greene	FL
Indiana University-Rehab Hospital of IN	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	Wayne Gordon	NY
NYU Medical Center-Rusk Institute	Tamara Bushnik	NY
Ohio State University	John Corrigan	OH
University of Pittsburgh	Amy Wagner	PA
Albert Einstein Healthcare-Moss Rehab	Tessa Hart	PA
Institute for Rehab and Research-Baylor	Mark Sherer	TX
Baylor Research Institute	Shahid Shafi/Kyle Womack	TX
Virginia Commonwealth University	Jeffrey Kreutzer	VA
University of Washington	Jeanne Hoffman	WA

TBIMS Follow-up Centers: 2012-17

TBIMS Center	Principal Investigator	State
The Rehabilitation Research Center/Santa Clara Valley Health and Hospital Systems	Linda Isaac	CA
Rehabilitation Institute of Michigan	Robin Hanks	MI
Carolinas Rehabilitation/Carolinas HealthCare System	Tami Guerrier	NC

TBIMS Center-Specific Studies 2012-17

Study Type	n	Topics
Drug Intervention	2	<ul style="list-style-type: none">▪ Sumatriptan for post-traumatic headache▪ Buspirone for post-traumatic irritability/aggression
Other Intervention	12	<ul style="list-style-type: none">▪ Brief intervention for substance misuse▪ Acceptance & Commitment Therapy to decrease distress and improve participation▪ Connecting patients, families, and providers to each other and to TBI resources (remotely)▪ Processing speed training to improve cognition▪ Promoting survivor resilience and adjustment▪ Couples skill-building, supportive & ed. training▪ Home-based virtual reality treatment for balance problems▪ Volunteer activity to improve psychological well being▪ Rewarding activity to promote emotional health▪ Light therapy for post-TBI fatigue▪ Online emotional regulation group treatment▪ Treatment of sleep disordered breathing▪ Evaluation of a tele-health weight management treatment program

TBIMS Center-Specific Studies 2012-17

Study Type	n	Topics
Instrument Development	4	<ul style="list-style-type: none"> Aggression and Irritability Impact Measure Observational pain scale Assessing responsiveness & sensitivity of TBI Quality of Life (TBI-QOL) computerized adaptive testing Measuring self reported pain
Assessment and Prediction of Outcomes	6	<ul style="list-style-type: none"> Neuroimaging to reduce diagnostic error & facilitate communication in persons with DOC Impact of co-morbidities on deterioration 5 years post TBI Dopamine dysfunction Comparative effectiveness research in TBI rehab Imaging dopamine function and impact on outcome Cultural disparities in TBI rehab healthcare

TBIMS Multicenter Research 2012-17 *

Study Type	Study Topics
Intervention	<ul style="list-style-type: none">▪ Effect of light exposure during acute rehabilitation on sleep after traumatic brain injury.
Assessment and Prediction of Outcomes	<ul style="list-style-type: none">▪ Cognitive testing in the TBI Model Systems▪ Development of an extended measure of global function to support clinical trials originating in acute care▪ Internet use and online social participation among individuals with TBI▪ Long-term medical co-morbidities and functional decline following TBI▪ Evaluating the validity and responsiveness of the TBI-QOL Instrument▪ Resilience after TBI▪ Test-retest reliability of TBIMS Form II measures with persons with TBI▪ Statins and outcomes after TBI: an observational study▪ Weight and traumatic brain injury

* 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 – 15,608 cases (as of 3/31/2017)
- Form II – 53,614 follow-ups* - 18% attrition (4%**)
 - Year 1 – 14,946 – 14% attrition (2%**)
 - Year 2 – 13,412 – 15% attrition (4%**)
 - Year 5 – 10,396 – 17% attrition (6%**)
 - Year 10 – 6,142 – 18% attrition (7%**)
 - Year 15 – 2,565 – 16% attrition (9%**)
 - Year 20 – 665 – 15% attrition (0%**)
 - Year 25 – 206 – 13% 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)

Categories of NDB content

- I. PreInjury history
- II. Demographic characteristics of the population
- III. Causes and severity of injury
- IV. Nature of diagnoses
- V. Types of treatment/services
- VI. “Costs” of treatment/services
- VII. Measurement and prediction of outcomes including impairment, disability and participation

I. PreInjury History

- Drug use
- Alcohol use (NHSDA/BRFSS)
- Tobacco use
- Conditions and limitations
- Psychiatric History
- Arrests/felony incarcerations
- Learning/behavior problems
- Military History

II. Demographic Characteristics

- Age
- Gender
- Race
- Ethnicity
- Marital Status
- Residence
- Zip Code
- Living with
- Level of Education
- Employment
- Height
- Weight
- Primary Language
- Country of Birth

III. Causes of Injury

- Date of injury
- ICD-9 external cause of injury codes

III. Severity of Injury

- Glasgow Coma Scale Score
- Duration of unconsciousness
- Duration of Post Traumatic Amnesia

IV. Diagnoses

- Spinal Cord Injury
- Intracranial CT scan findings
- Intracranial hypertension
- Neuropsychological assessment
- ICD-9 diagnosis codes
- Cause of death

V. Treatments

- Surgical procedures
- Rehospitalizations

VI. “Costs” of Treatment

- Length of stay
- Payer source

VII. Measure and Predict Outcome at Follow-up

- Impairment
 - Mortality
 - Lifetime History of TBI
- Disability
 - Disability Rating Scale (DRS)
 - FIM[®] instrument
 - Glasgow Outcome Scale-Extended (GOS-E)
 - Supervision Rating Scale (SRS)

VII. Measure and Predict Outcome at Follow-up (cont.)

- Health/Behavior
 - Height and Weight
 - History of Specific Health Conditions
 - Subjective General Health
 - Drug use
 - Alcohol use (NHSDA/BRFSS)
 - Tobacco use
 - Psychiatric problems
 - TBIQOL - Anxiety
 - TBIQOL - Depression
 - Satisfaction with Life Scale (SWLS)

VII. Measure and Predict Outcome at Follow-up (cont.)

- Participation
 - Participation Assessment (PART)
 - Living with
 - Residence (e.g., private home, SNF, AFC, hospital)
 - Address
 - Marital Status

VII. Measure and Predict Outcome at Follow-up (cont.)

- Participation (cont.)
 - Level of education
 - Employment
 - Drug use
 - Alcohol use (NHSDA/BRFSS)
 - Tobacco use
 - Transportation
 - Arrests

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



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

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

Links to other Model Systems Programs

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

Online TBI Model Systems National Database Syllabus



Syllabus

The citation for the TBIMS National Database is "Traumatic Brain Injury Model Systems National Database Syllabus. Traumatic Brain Injury Model Systems National Data and Statistical Center, 2009. Url: <http://www.tbindsc.org>."

Printed Syllabus

Syllabus

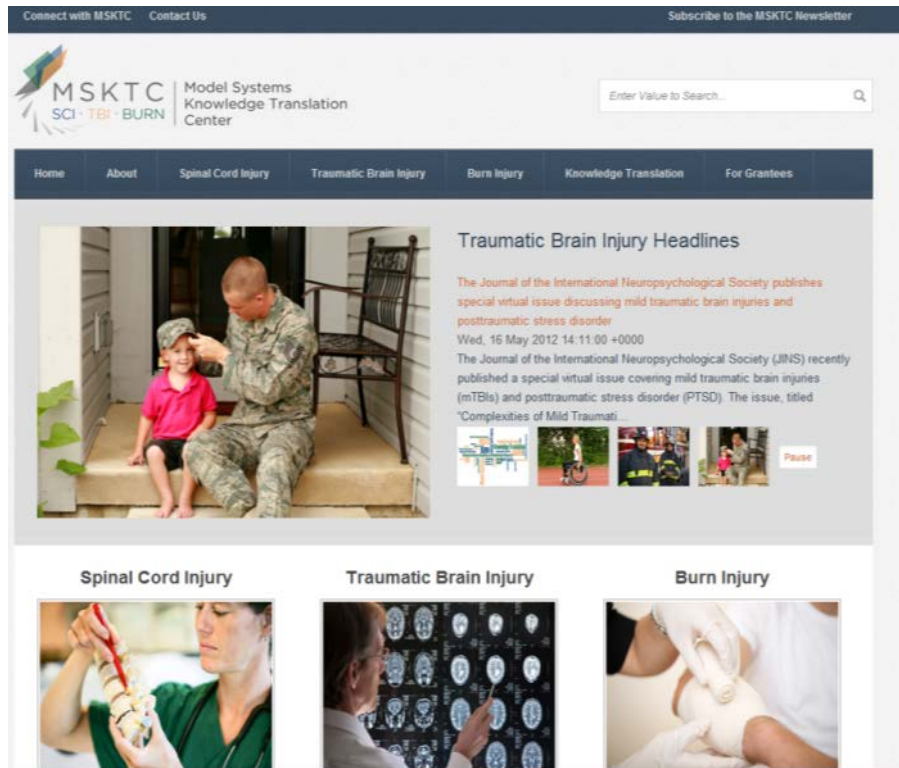
Please select which Form Variables you would like to see. Form I variables are the variables asked about the initial rehabilitation stay. Form II variables are questions asked to an individual at follow-up. Once you select Form I or Form II you have a choice of viewing either the actual fields that the variable group has ("Show Fields"), or you can view the data dictionary page ("Select") for the selected variable group.

Select which form you want to see

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

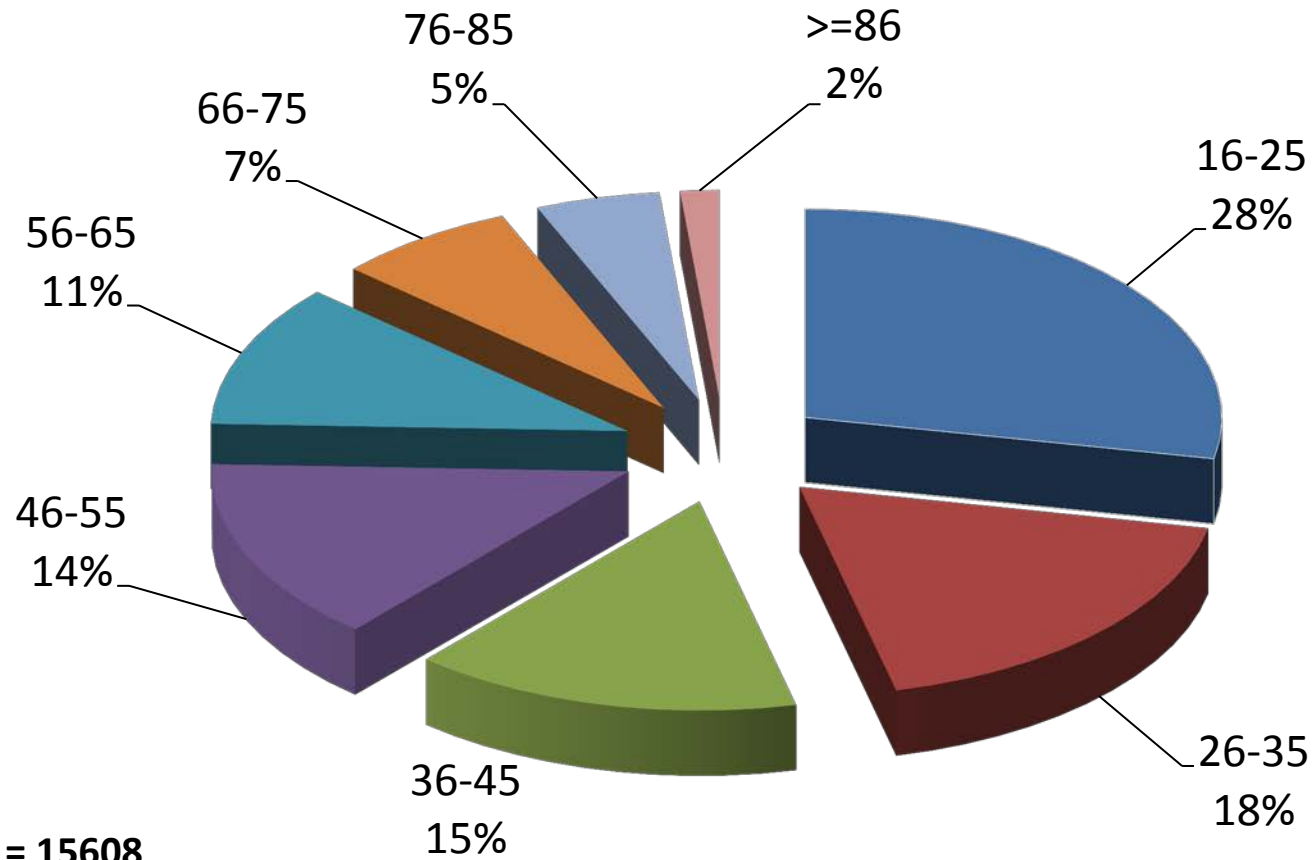
MSKTC Activities 2011-2014 Highlights

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

TBIMS National Database Descriptive Data Summary

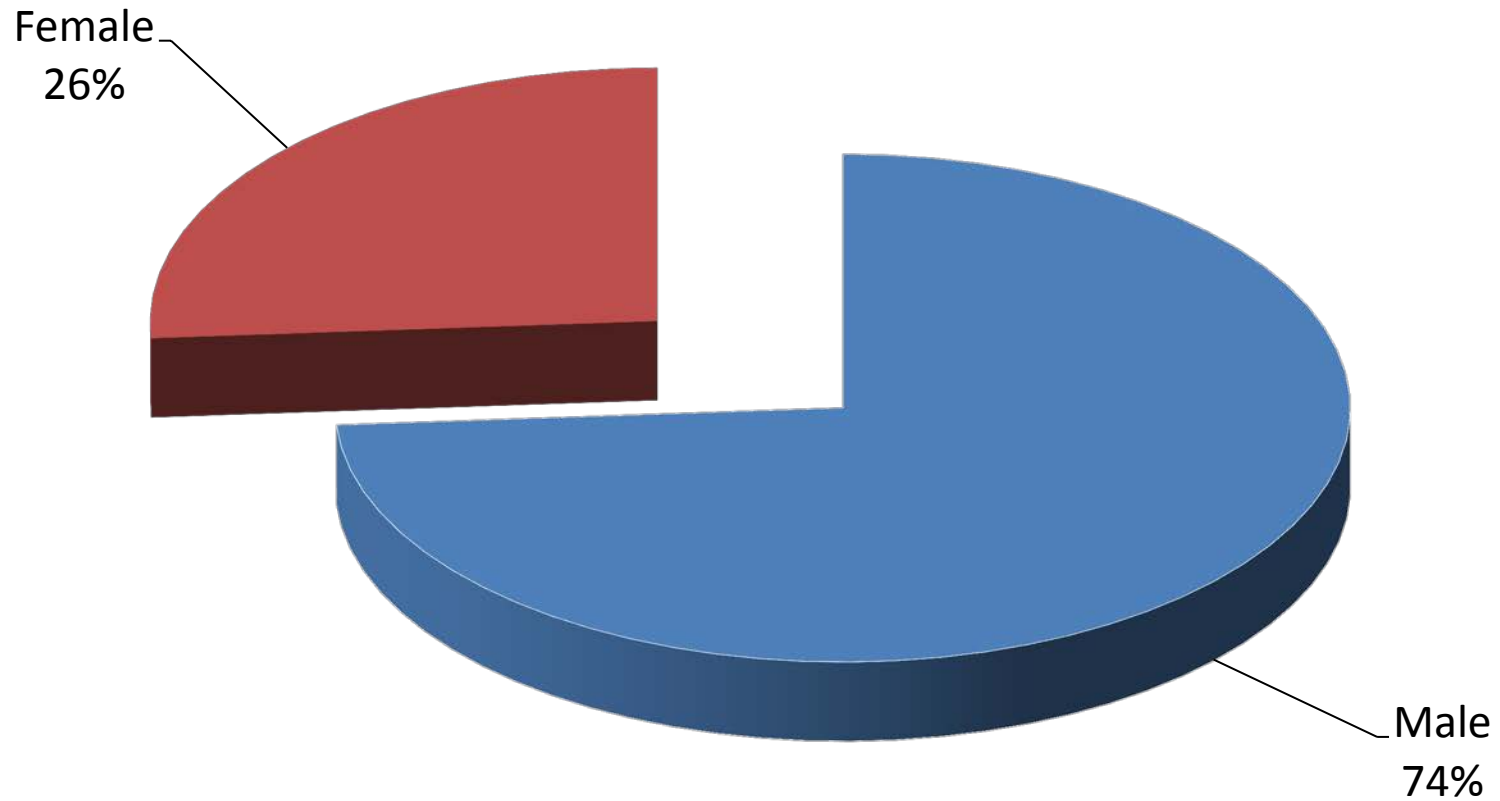
[Includes data from 01/01/1989 – 12/31/2015]

Age



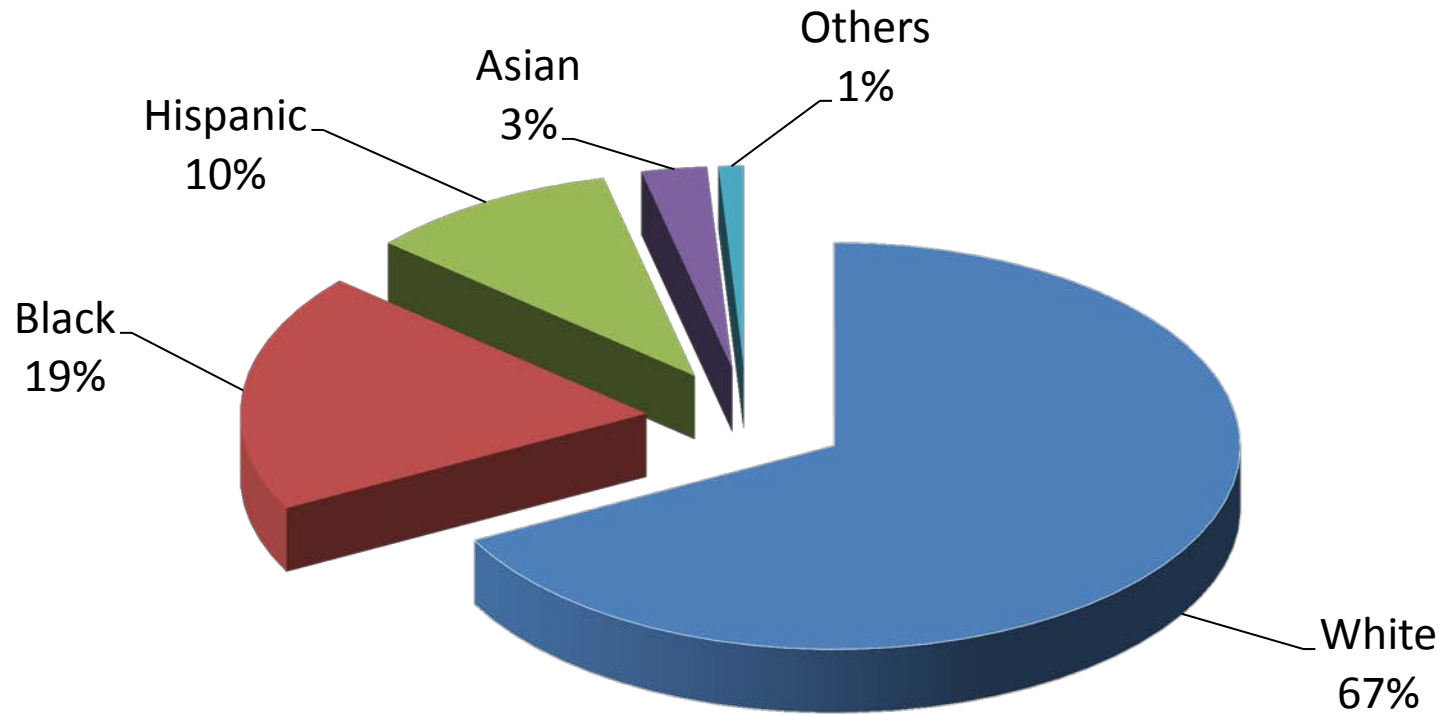
mean = 41.59; n = 15608

Gender



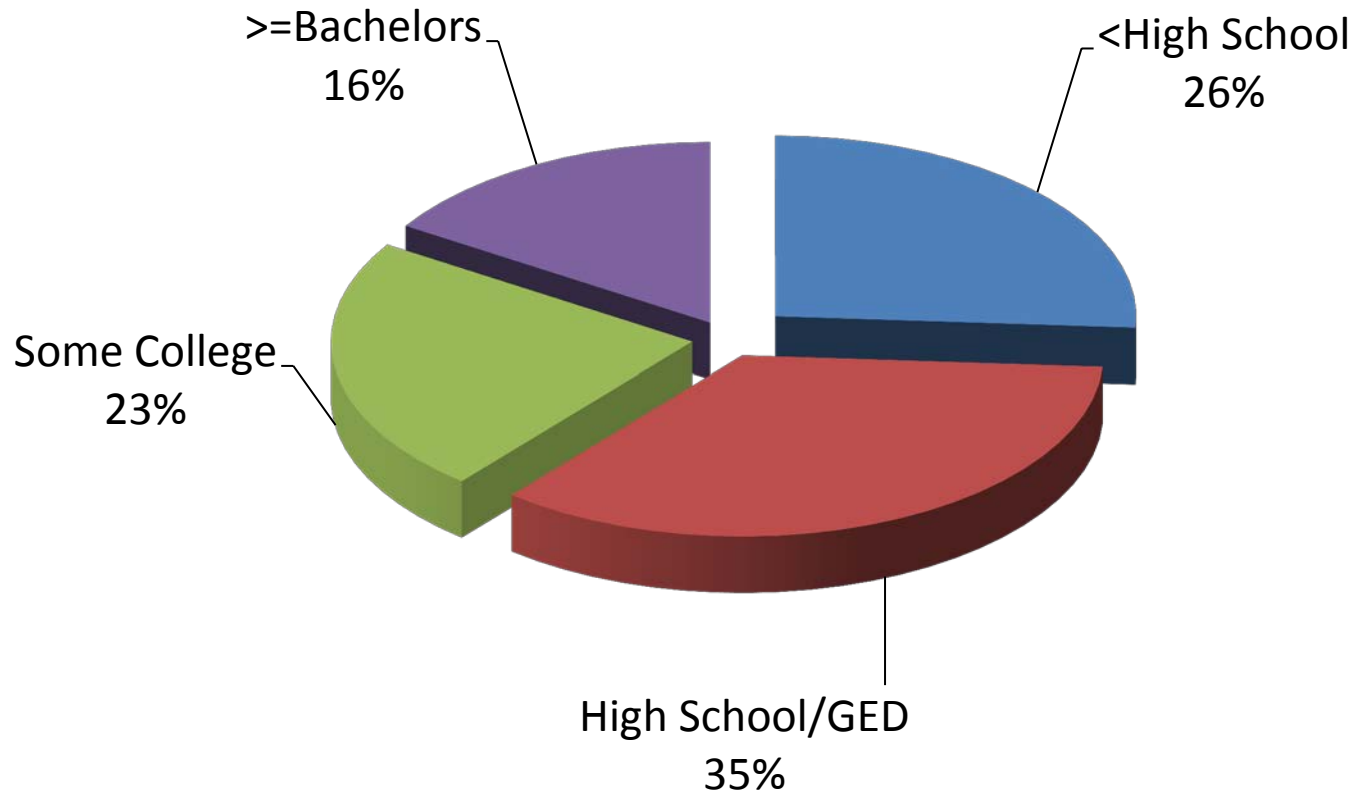
n = 15605

Race



n = 15599

Level of Education At Injury

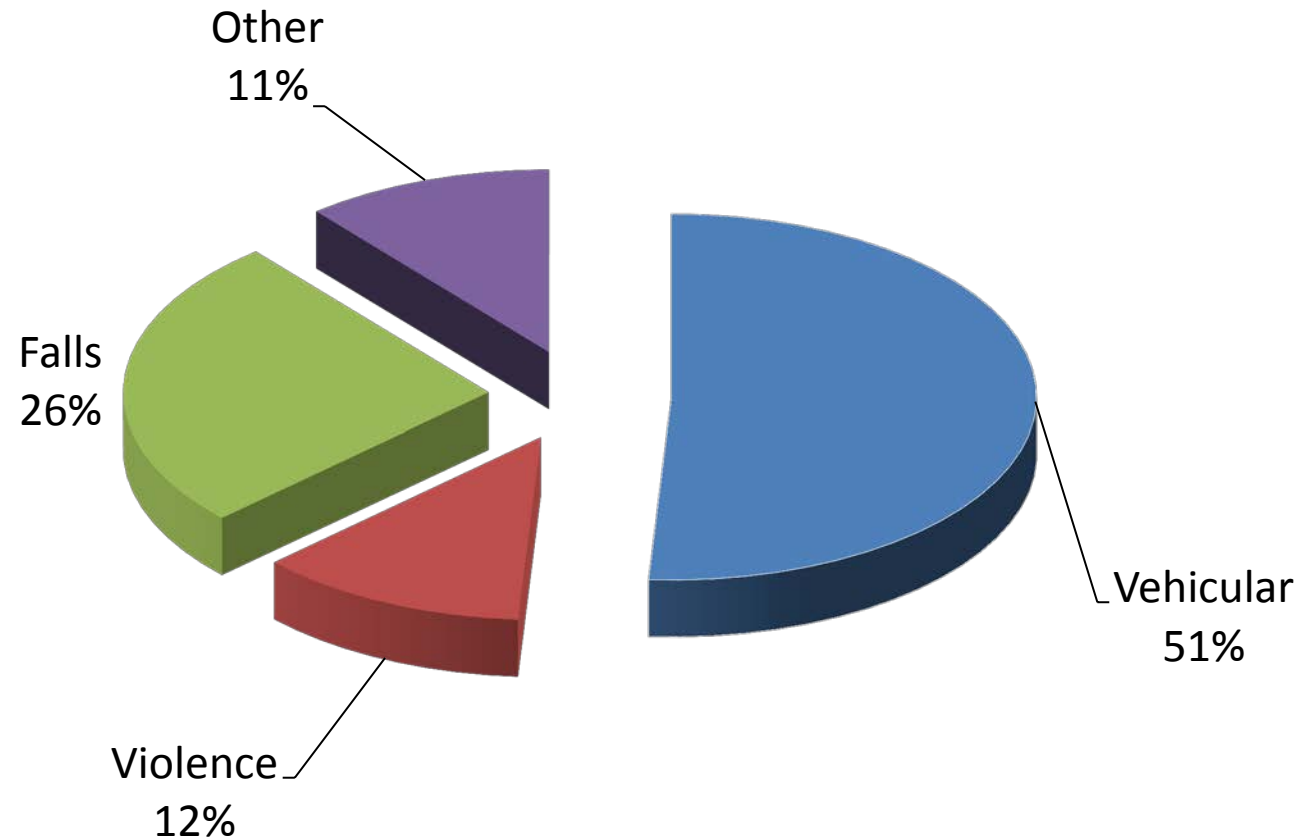


n = 15360

Summary

- Demographic Characteristics of the Population
 - Average age = 41.59
 - Male (74%)
 - Minority population (33%)
 - High school education or less (61%)

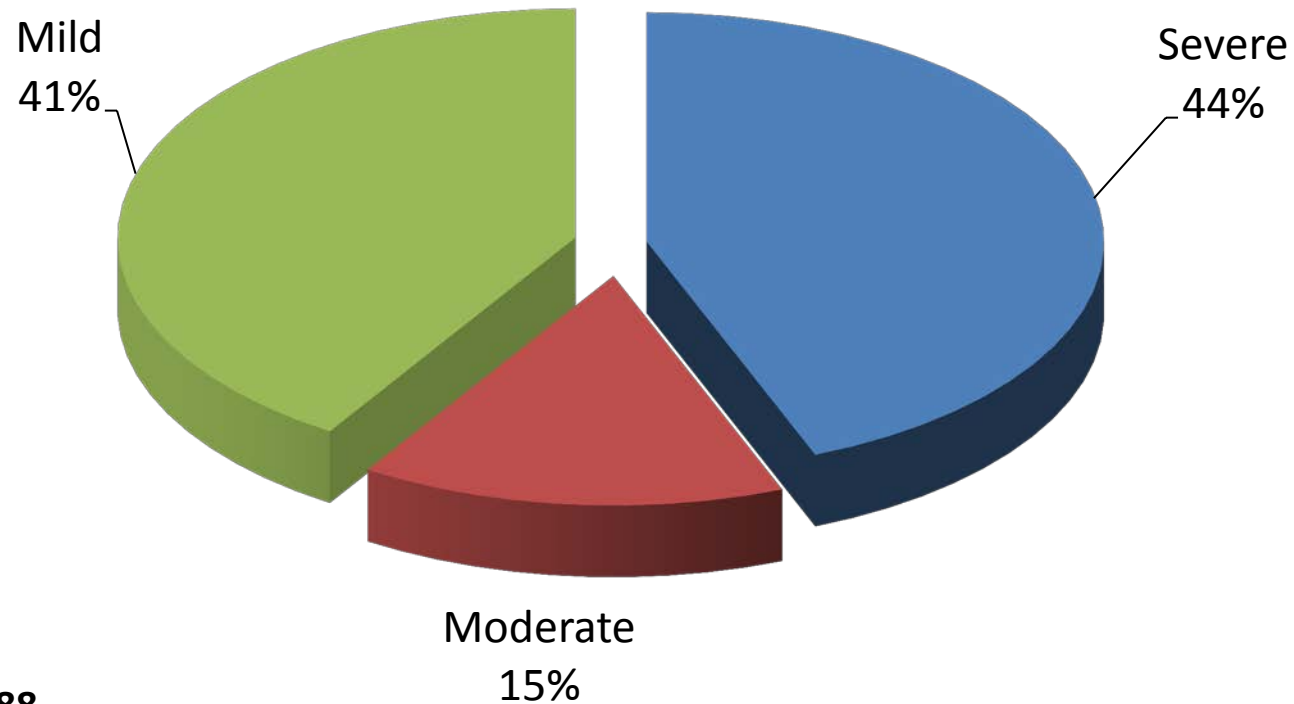
Etiology of Injury



n = 15571

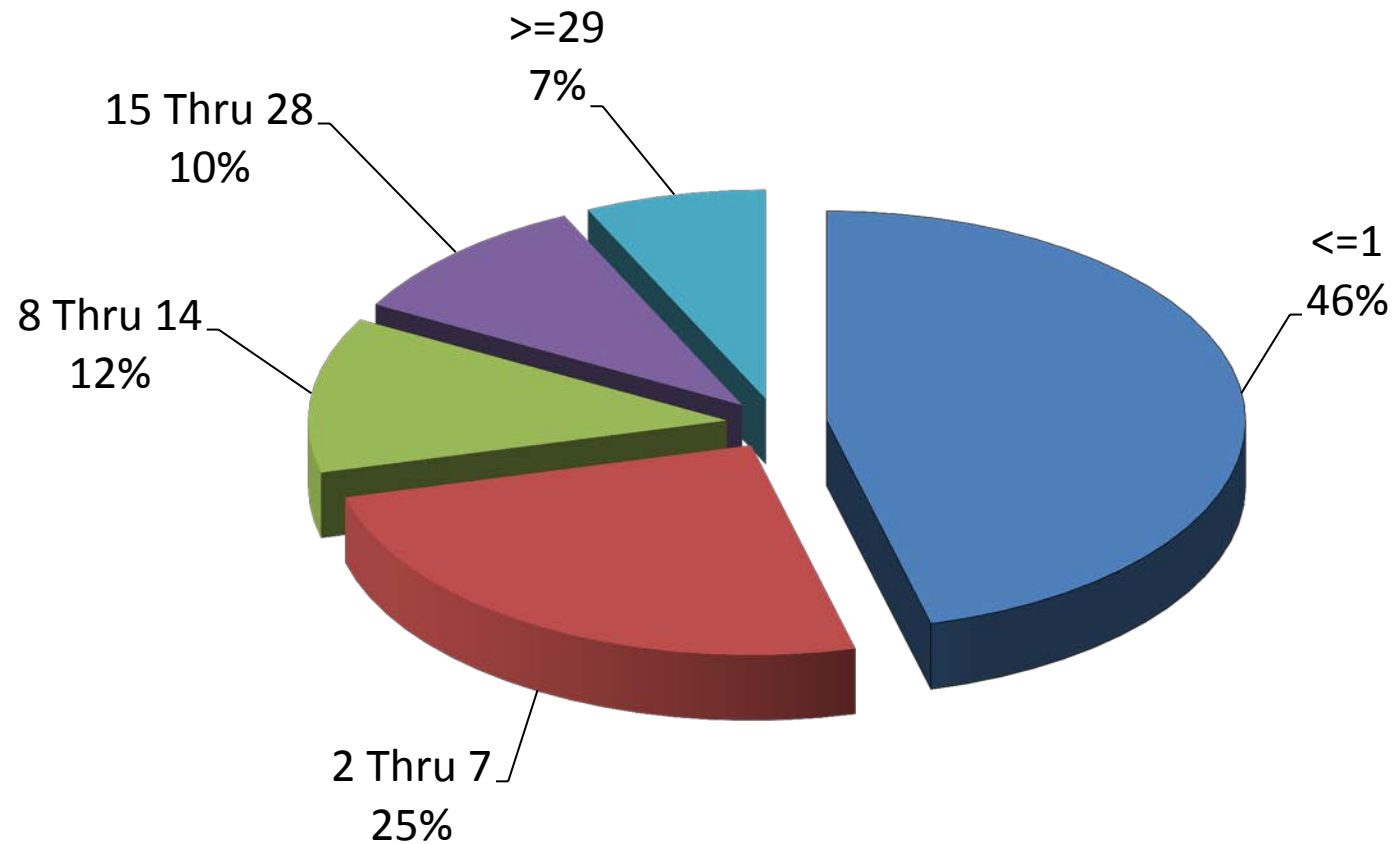
Glasgow Coma Scale Score

At Emergency Department Admission



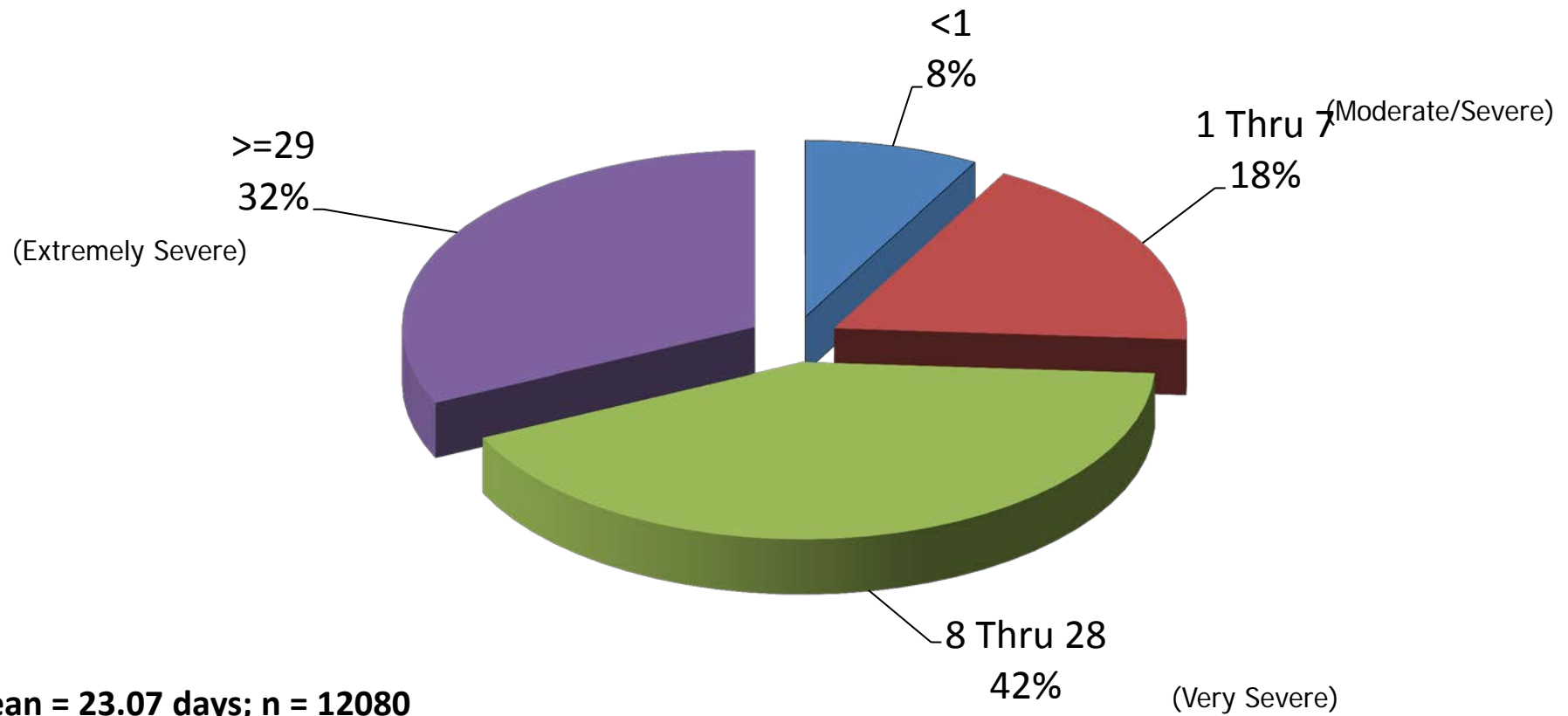
mean = 9.63; n = 12088

Duration of Unconsciousness



mean = 7.87 days; n = 14995

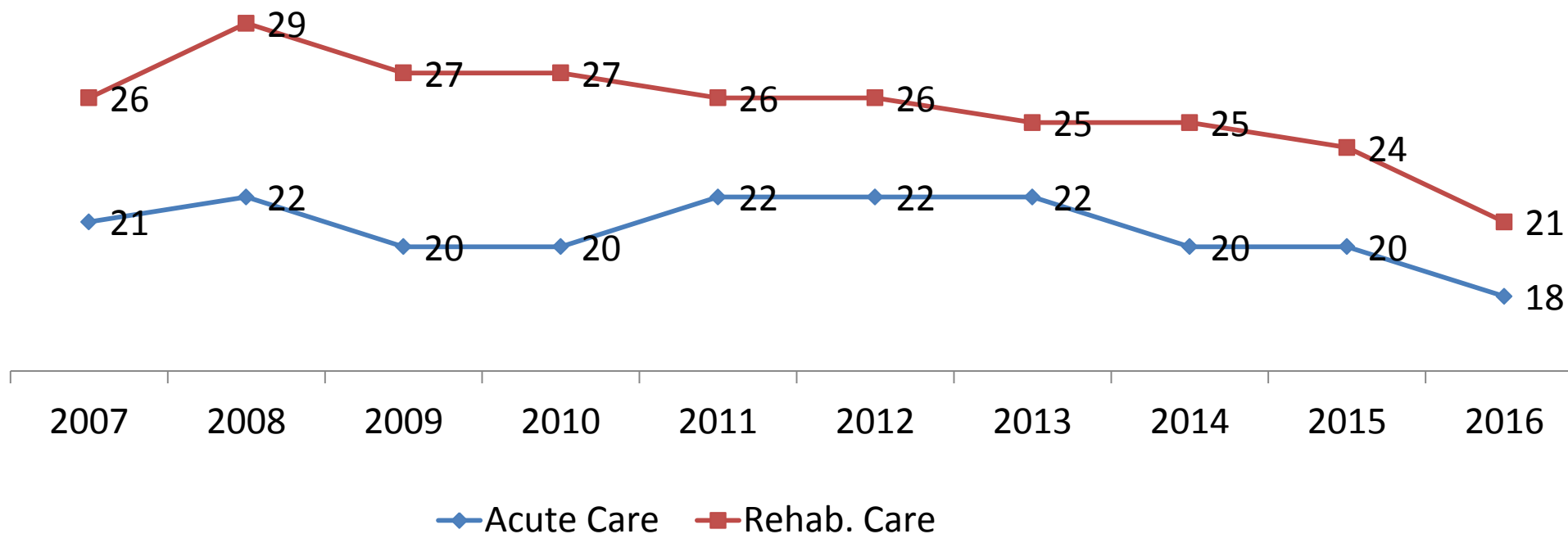
Duration of PTA



Summary

- Causes of Injury
 - Primary cause is vehicular (51%), followed by falls (26%) and violence (12%)
- Severity of Injury
 - Average duration of LOC is 7.87 days
 - Average duration of PTA is 23.07 days

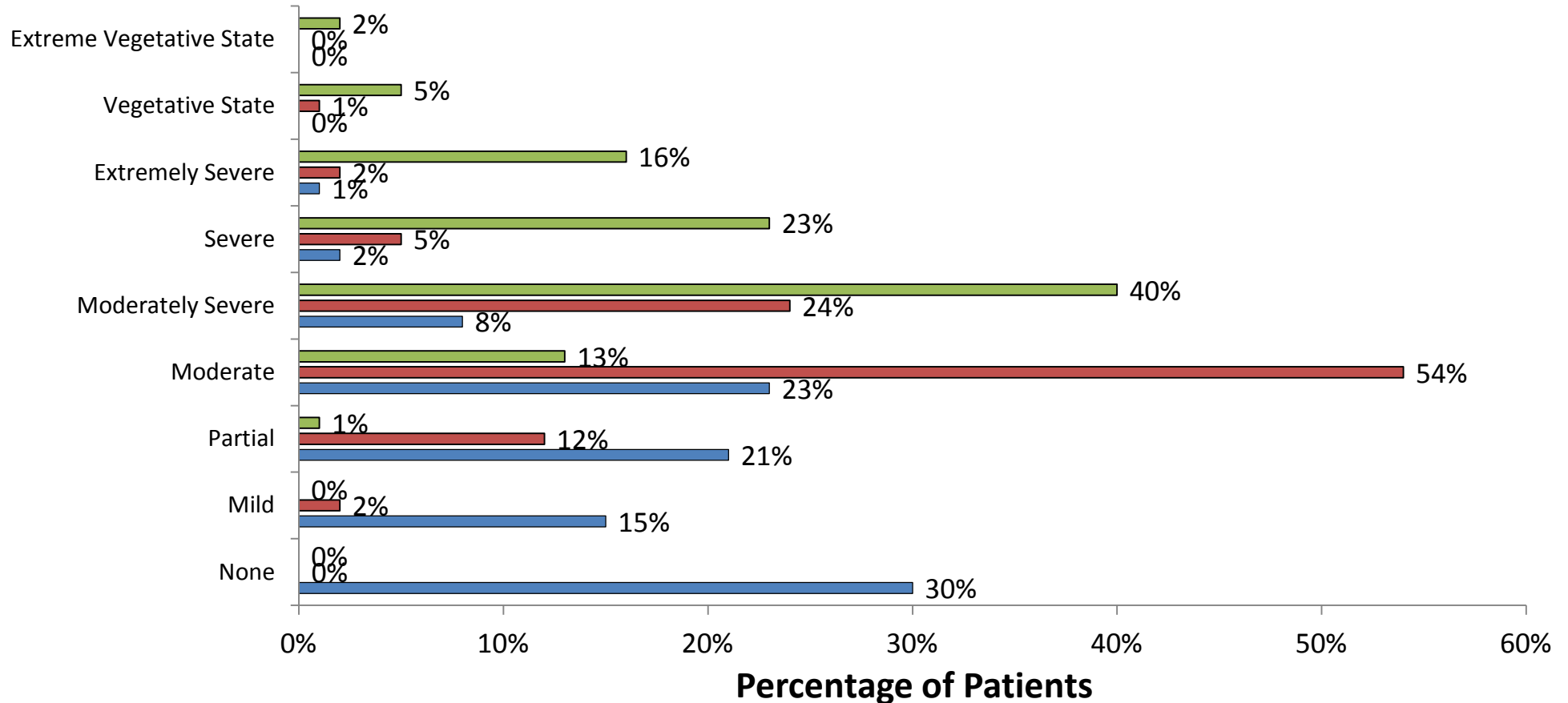
Mean Length of Stay



Summary

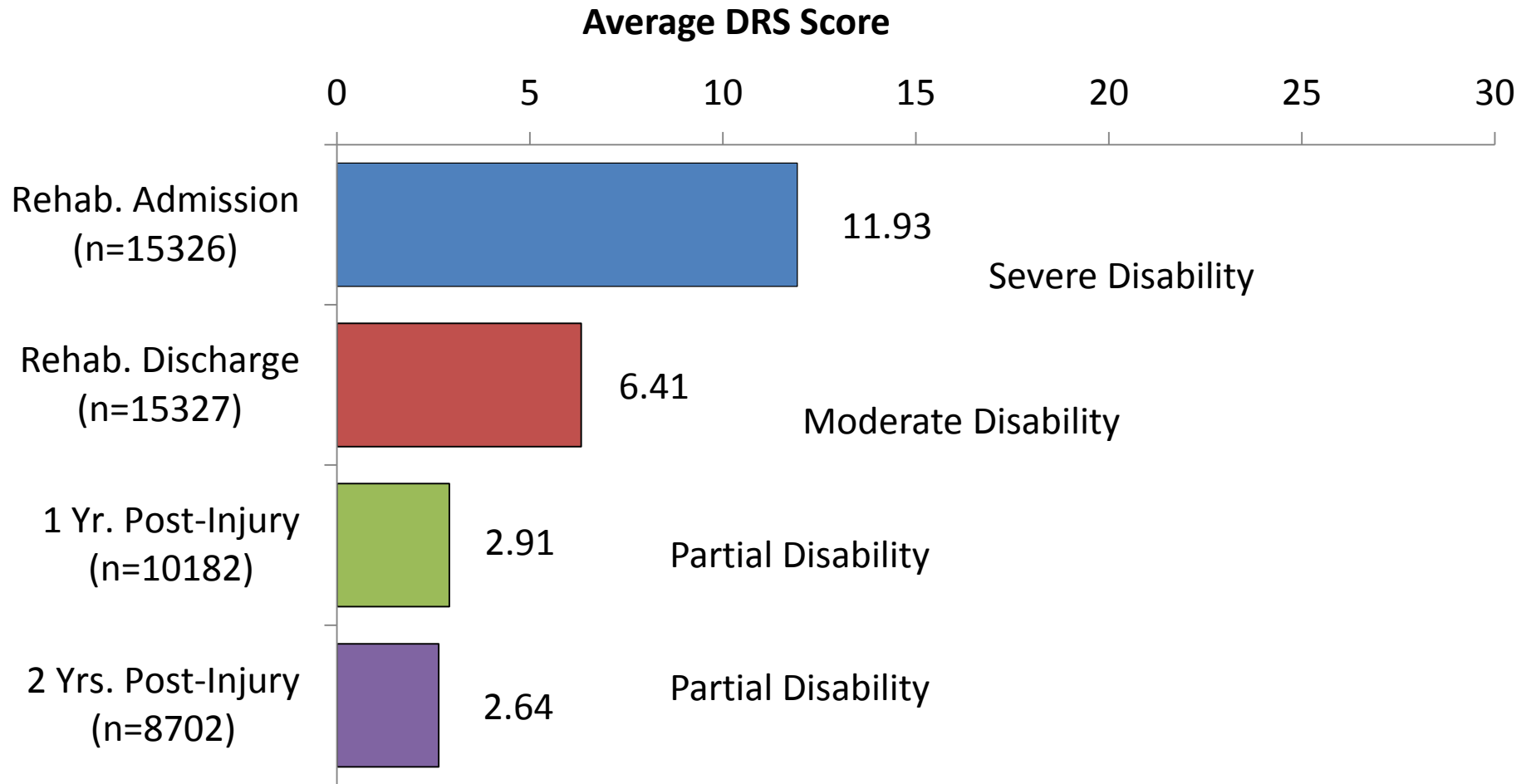
- Costs of Treatment
 - Total LOS has consistently decreased over the last 4 years for both acute and rehab.
 - Total acute LOS in 2016 represents the lowest in the past decade.
 - Total rehab LOS in 2016 represents the lowest in the past decade.
 - 37% have government-sponsored rehabilitation care (M'caid/M'care)

Disability Rating Scale

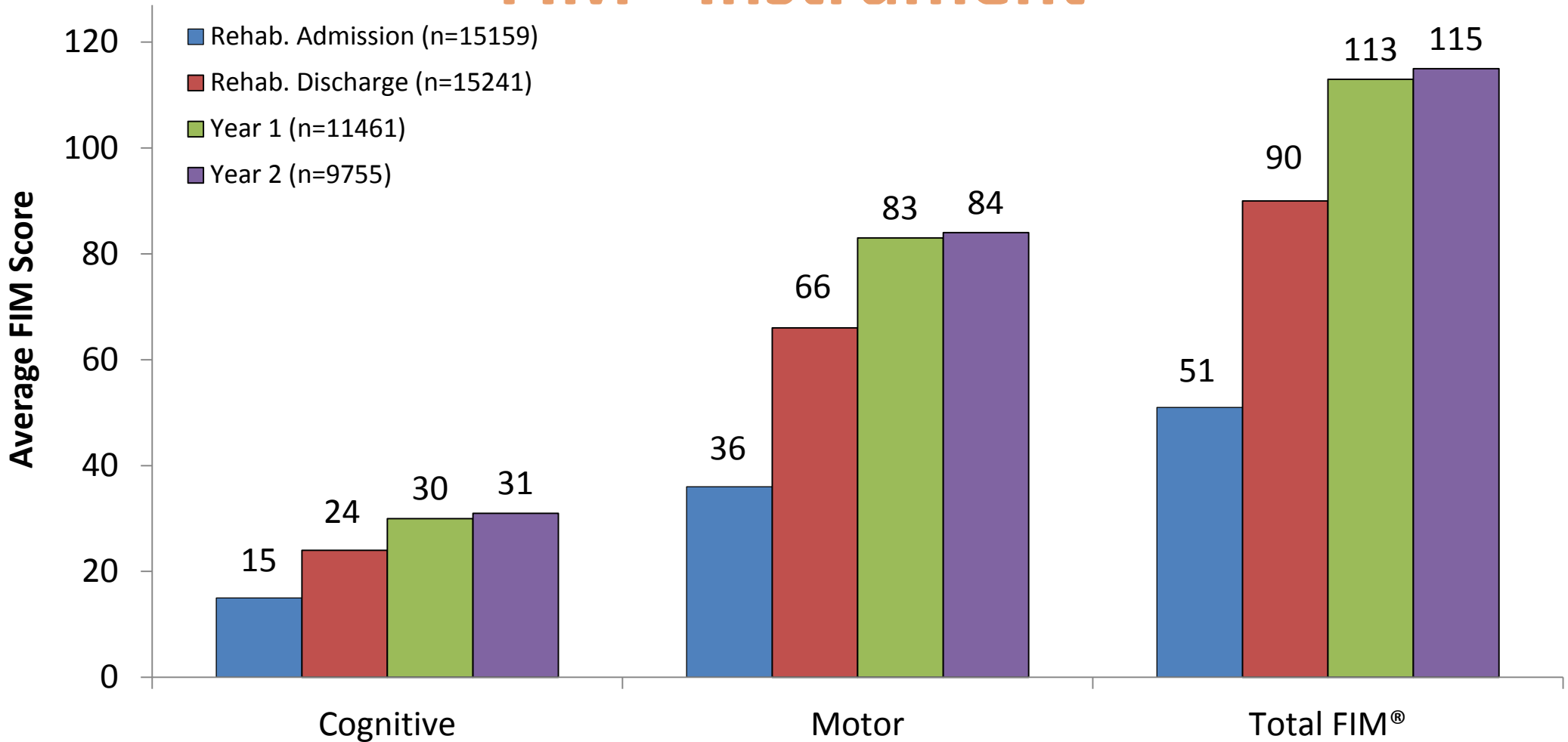


■ Rehab. Admit (n=15326)
 ■ Rehab. DC (n=15327)
 ■ 1 Yr. Post-Injury (n=10182)

Disability Rating Scale



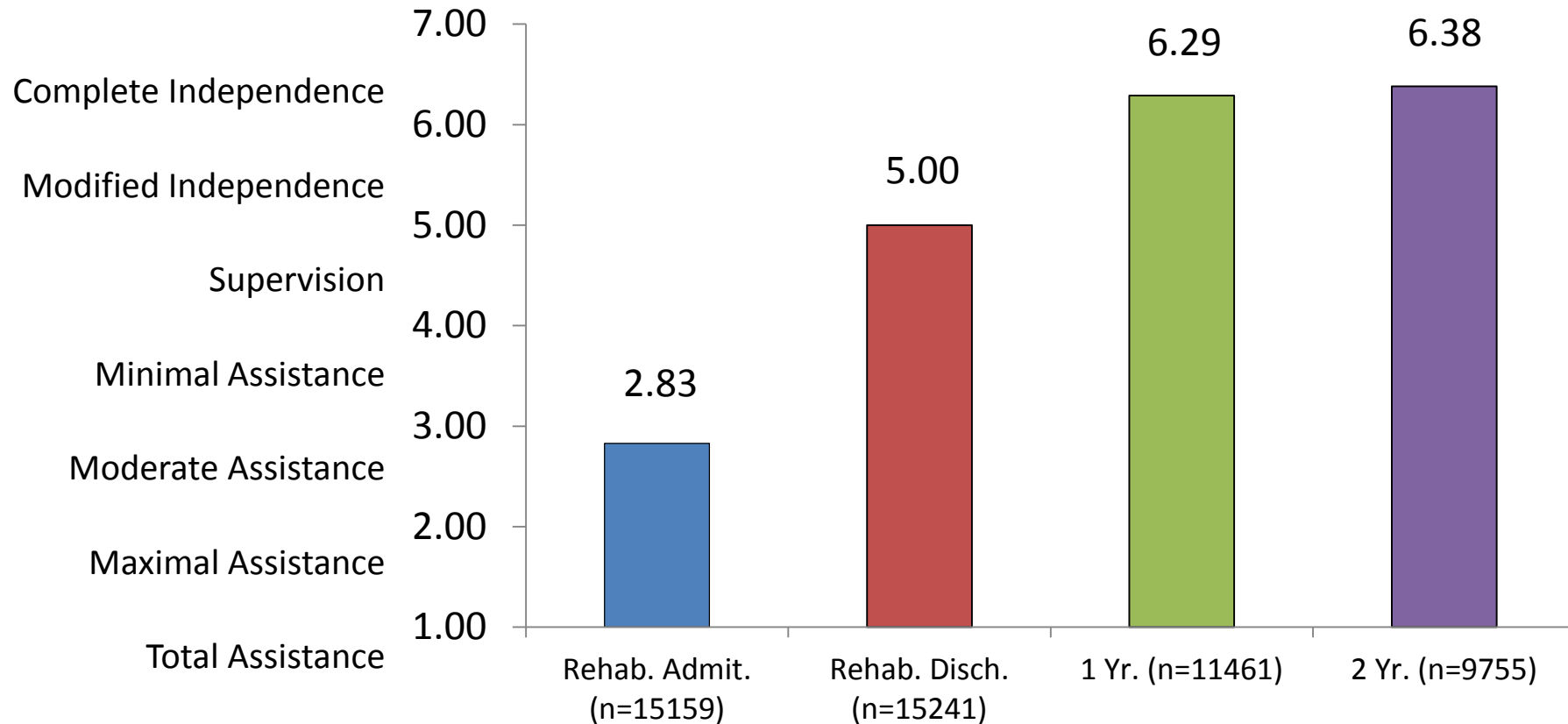
FIM[®] Instrument



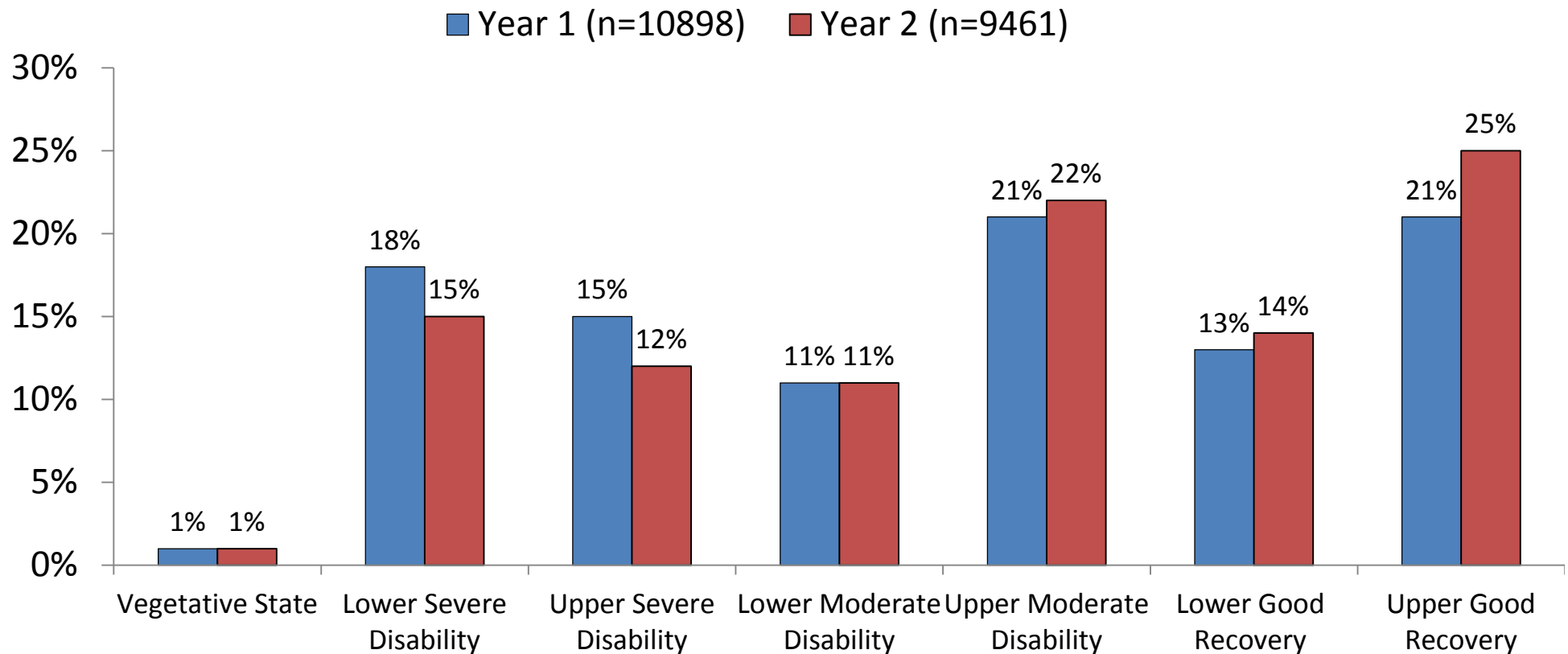
*Note: The value of n is reflective of Total FIM[®] measure

FIM[®] Instrument

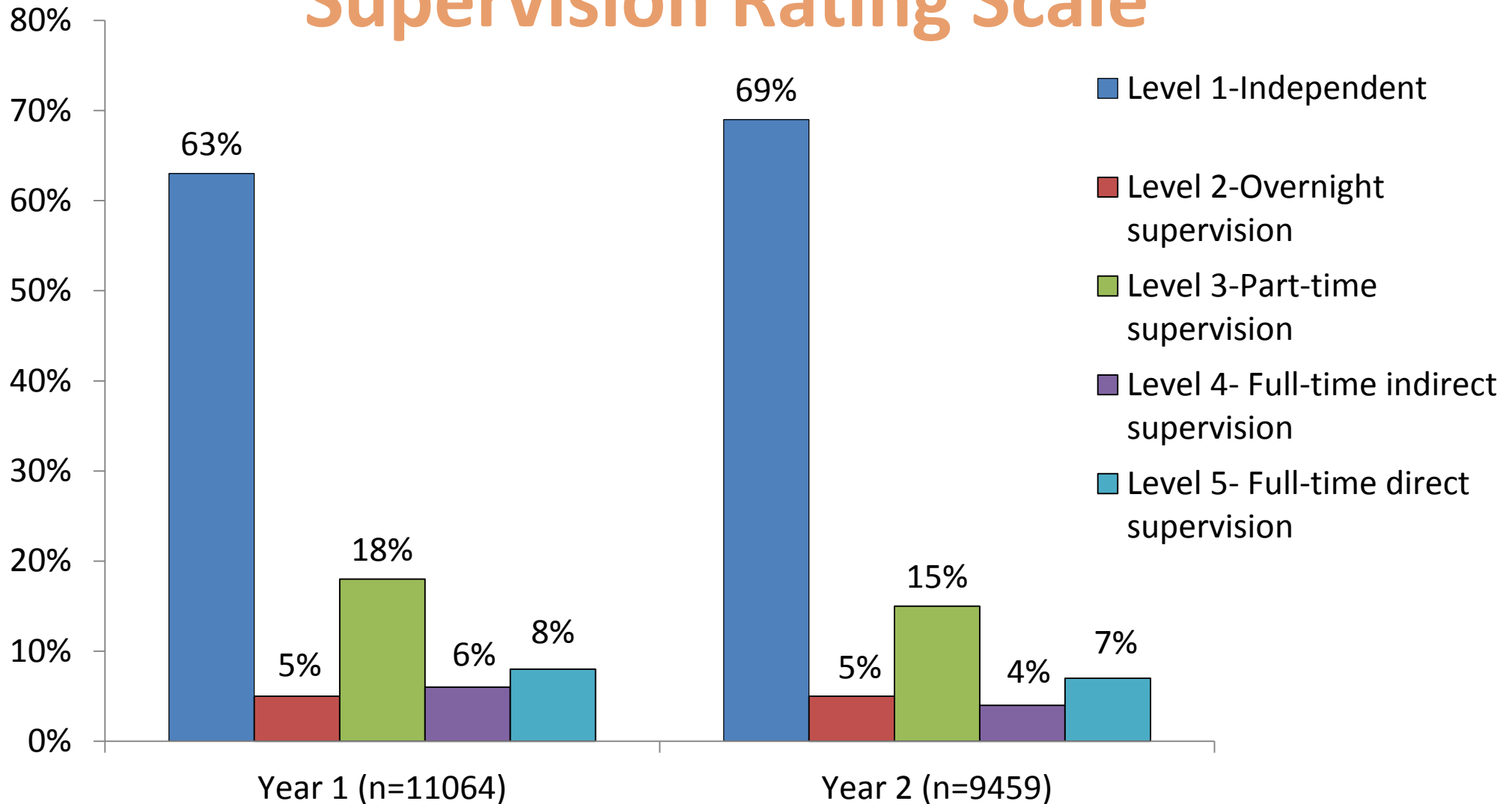
Mean Scores converted to 7-point scale



Glasgow Outcome Scale-Extended



Supervision Rating Scale



Satisfaction With Life Scale

	Year 1	Year 2	Year 5
Number	9113	7905	5820
Mean	21.26	21.57	21.90
SD	8.24	8.39	8.33
Min	5	5	5
Max	35	35	35

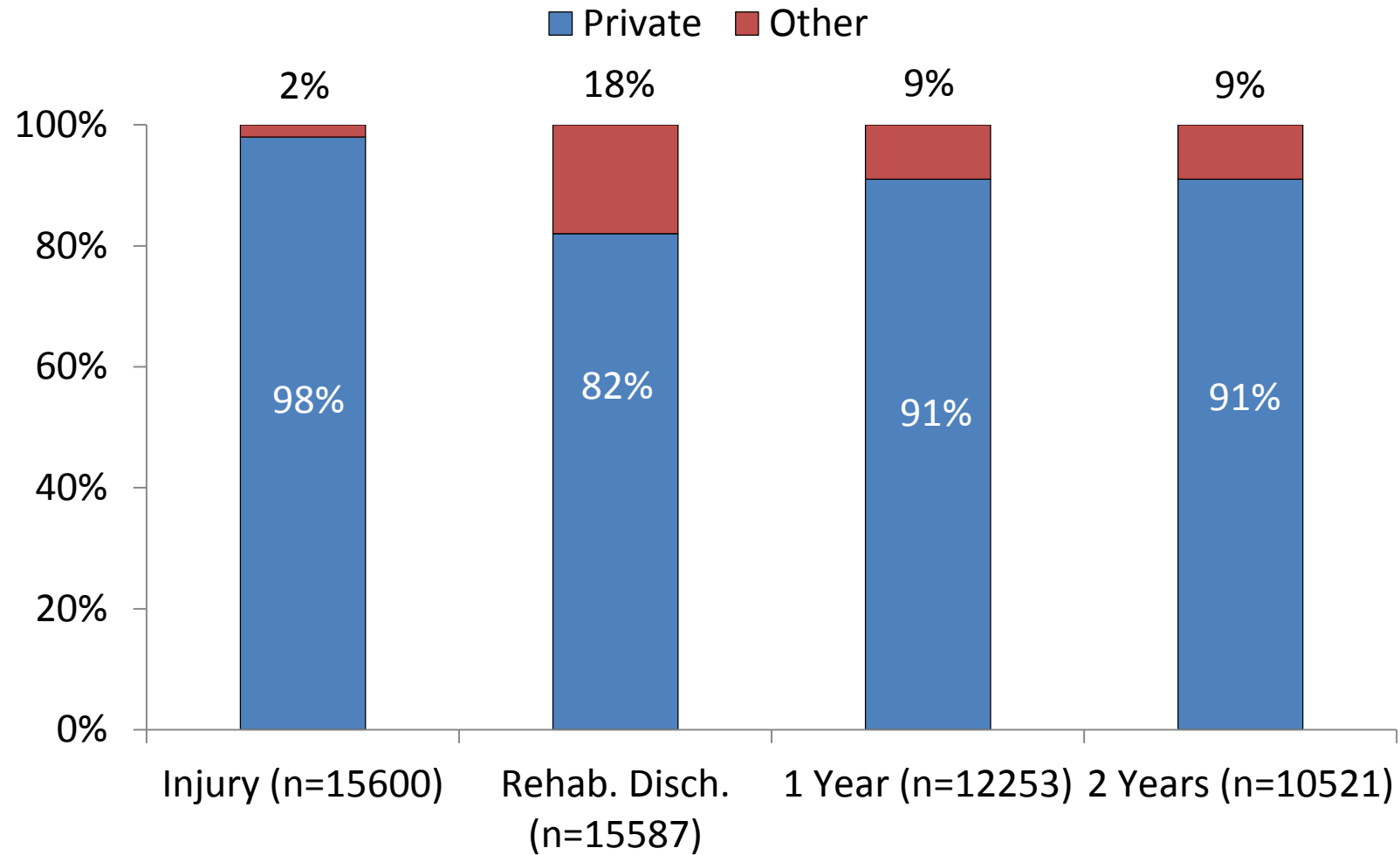
Summary

- 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.

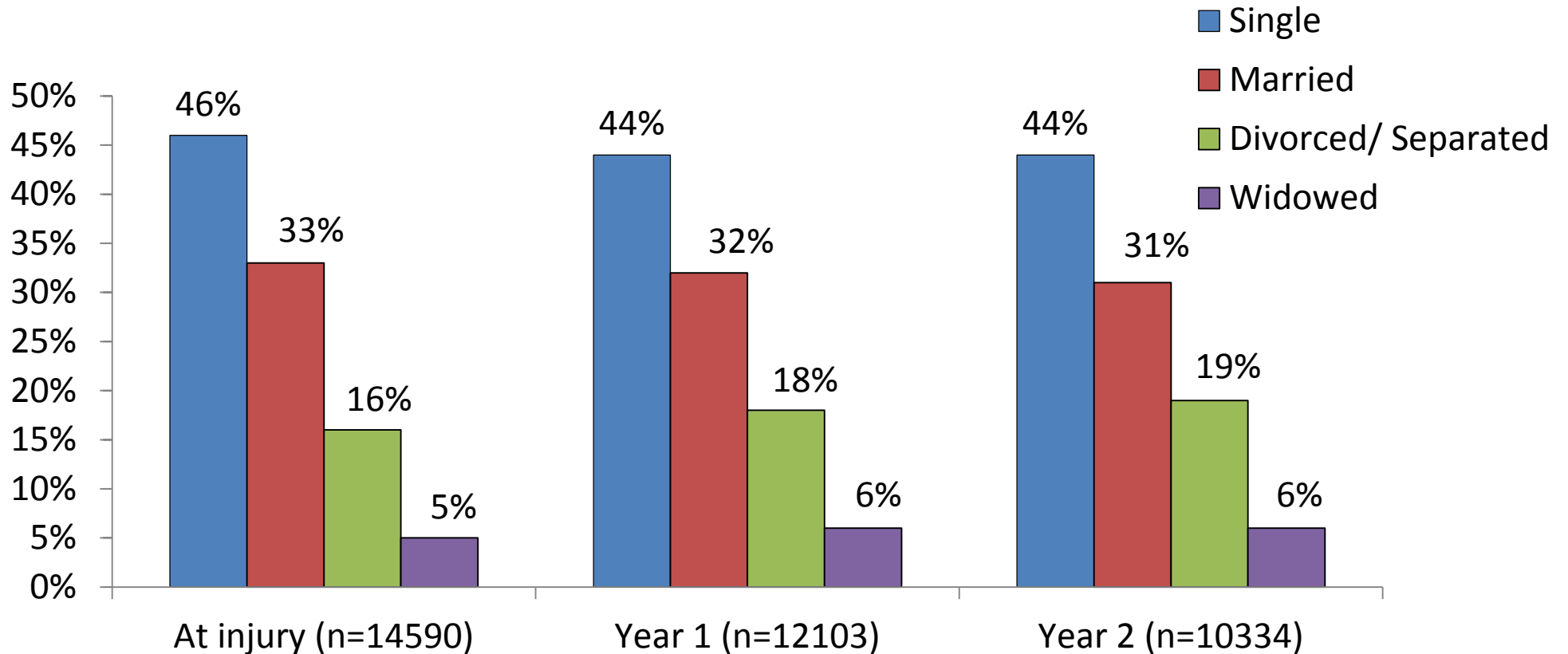
Summary

- 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

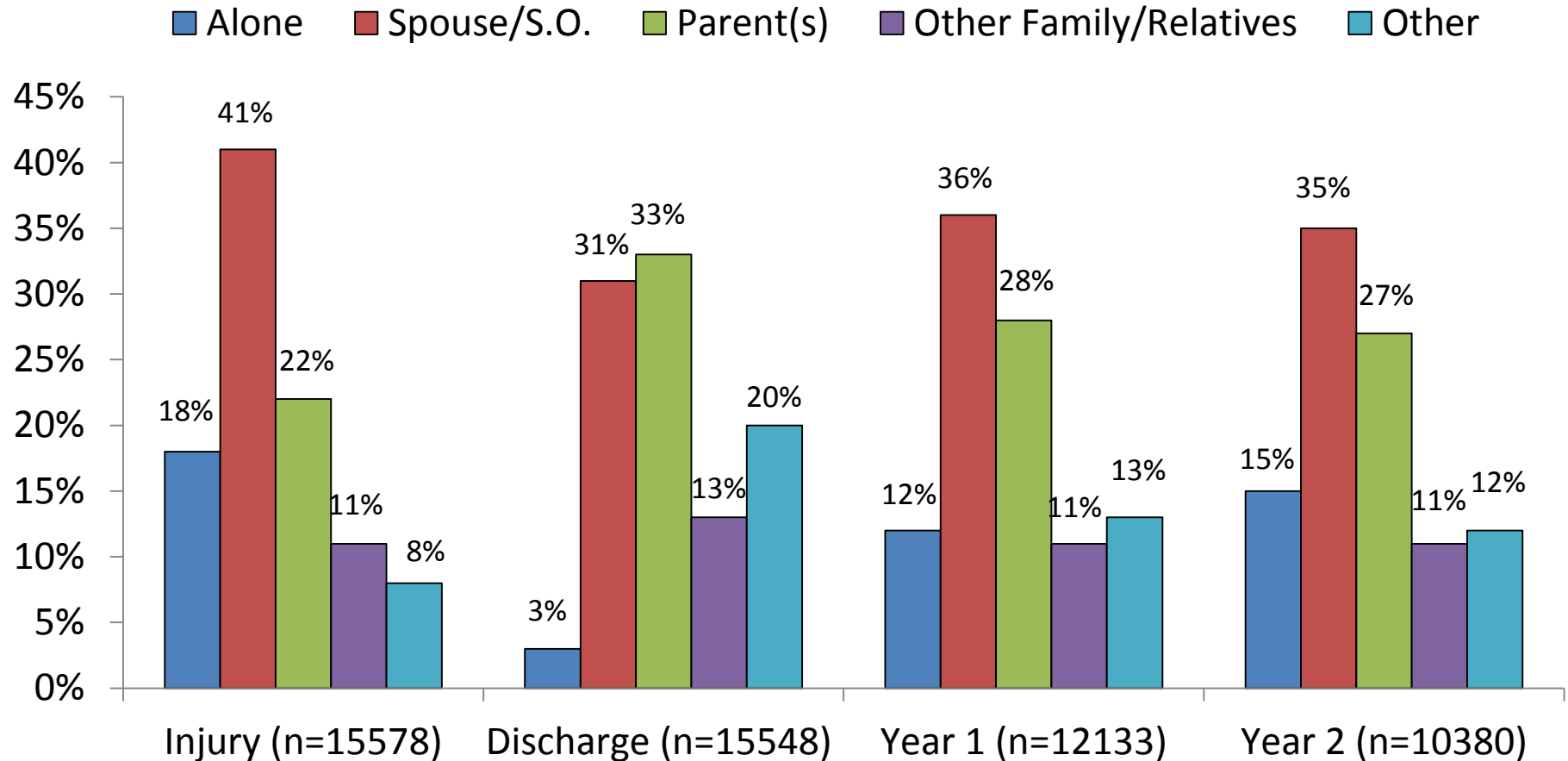
Residence



Marital Status

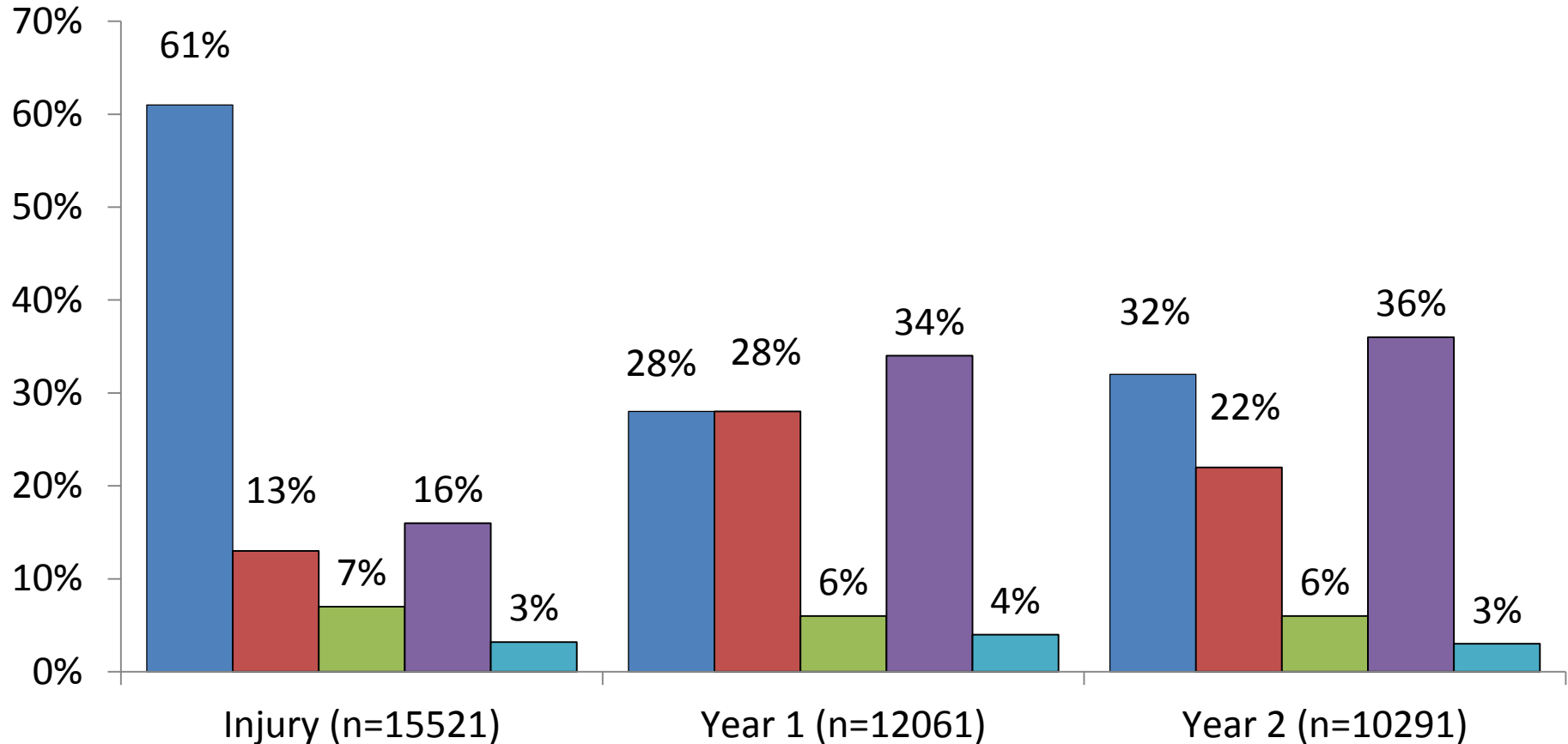


Living Situation



Employment Status

■ Employed ■ Unemployed ■ Student ■ Retired ■ Other



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%)
 - 28% 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 13,500 cases with up to 25 years of follow-up.