Traumatic Brain Injury Model Systems Data Report

National Data and Statistical Center

2026-04-15

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Welcome

The Traumatic Brain Injury Model System Centers Program

The Traumatic Brain Injury Model System (TBIMS) Centers program, begun in 1987, currently consists of 16 centers across the US that are competitively funded for 5 years by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The TBIMS Centers are situated in centers of excellence for clinical care and innovative research focused on improving the lives of people with TBI, their families, and close others. The primary focus is on moderate to severe TBI, as patients are recruited from inpatient rehabilitation to participate in research; however, many TBIMS investigators are also interested in mild TBI, or concussion.

The National Database (NDB), managed by the TBIMS National Data and Statistical Center, is at the core of the TBIMS Centers program. More than 20,000 individuals are currently enrolled in the NDB. Each TBIMS center collects and enters into the NDB an identical data set on each individual, which captures:

- Emergency and acute care information such as CT scan findings and depth/ duration of loss or alteration of consciousness;
- Status and progress during inpatient rehabilitation;
- Pre-injury social and demographic data;
- Findings from a battery of measures assessing functional, social, emotional, cognitive, and medical outcomes at 1, 2, 5, 10, 15 years after the TBI and every five years thereafter. The TBIMS is unique in the scope of its longitudinal data on the outcomes of persons with complex mild/ moderate/ severe TBI.

Recent research(Corrigan et al. 2012; Cuthbert et al. 2012) has confirmed that the TBIMS NDB is representative of persons receiving inpatient rehabilitation for TBI in the US.

In addition to the enrollment and data capture for the NDB, NIDILRR funding supports the following types of TBI research within TBIMS Centers:

- Data mining studies, which examine relationships among existing data elements in the NDB;

- Local research projects, which are site-specific studies proposed for each 5-year grant cycle;
- Module research projects, which are time-limited, multi-center studies designed to capitalize on the TBIMS infrastructure to address focused research questions that cannot feasibly be answered by a single center. In each 5-year cycle, centers propose and participate in moduler studies of interest to them. Module projects have produced new knowledge on (e.g.) the natural history and typology of headache after TBI, the prevalence and outcomes of treatments for deep venous thrombosis, and the feasibility and utility of assessing cognitive function via telephone.

The TBIMS centers work in collaboration with the separately-funded Model Systems Knowledge Translation Centerhttps://msktc.org to provide scientific results and information for dissemination to stakeholders, including persons with TBI and their families, researchers, clinicians, and policymakers.

Participating Centers

Currently, there are 16 TBIMS Centers and 4 TBIMS Longitudinal Follow-Up Centers,* sponsored by the NIDILRR.

- Georgia Model Brain Injury Systems, Atlanta GA
- Indiana University/Rehabilitation Hospital of Indiana, Indianapolis IN
- Mayo Clinic Traumatic Brain Injury Model System Center, Rochester MN
- Moss Traumatic Brain Injury Model System, Philadelphia PA
- New York Traumatic Brain Injury Model System, New York NY
- North Texas Traumatic Brain Injury Model System, Dallas TX
- Northern New Jersey Traumatic Brain Injury System, East Hanover NJ
- Rusk Rehabilitation TBI Model System, New York NY
- Southeastern Michigan Traumatic Brain Injury System, Detroit MI
- Spaulding-Harvard Traumatic Brain Injury System, Charlestown MA
- The Ohio Regional TBI Model System, Columbus OH
- The Rocky Mountain Regional Brain Injury System, Englewood CO
- TIRR Memorial Hermann/Baylor College of Medicine/UT Health Collaborative, Houston TX
- University of Alabama at Birmingham Traumatic Brain Injury Care System, Birmingham AL
- University of Washington Traumatic Brain Injury Model System, Seattle WA
- Virginia Traumatic Brain Injury Model System, Richmond VA
- * Carolinas Traumatic Brain Injury Rehabilitation and Research System, Charlotte NC
- * JFK Johnson Rehabilitation Institute Traumatic Brain Injury Model System, Edison NJ
- * Northern California TBI Model System, San Jose CA

- * University of Pittsburgh Medical Center Traumatic Brain Injury Model System, Pittsburgh PA

Components of the Traumatic Brain Injury Model System Centers

As stated in the current Traumatic Brain Injury Model System (TBIMS) Centers Program priority, TBIMS centers must provide “a multidisciplinary system of rehabilitation care specifically designed to meet the needs of individuals with TBI. The system must encompass a continuum of care, including emergency medical services, acute care services, acute medical rehabilitation services, and post-acute services.”

There has historically been substantial variability in the components of care within the TBIMS centers and the manner in which these various components interact. The number of acute care hospitals in any one current TBIMS center varies from 1–12, with trauma center designations of Level 1–Level 4. Although not a stated requirement, all current TBIMS Centers include at least one Level 1 trauma center. Relationships with these hospitals range from formal (written affiliation agreements with trauma departments, emergency departments, or hospital administration) to verbal agreements. Faculty from the acute care facilities may or may not be coinvestigators within the TBIMS Centers program. In some cases, acute care facilities require their own IRB review and approval and in other cases they do not.

Access to medical records from the referring/acute care hospital also varies. In some cases, staff visit the referring hospital and view records onsite to abstract data. Other hospitals send the medical record in paper or digital form, when a signed release of information request is received.

The TBIMS Centers Program priority requires that a minimum of 35 persons be enrolled annually in the TBIMS National Database by each TBIMS Center. Multiple acute care/referring hospitals may be included in systems of care to increase the annual enrollment of that system, or to increase the representativeness of the sample.

In most cases, participants are transferred directly from referring acute care hospitals to inpatient brain injury rehabilitation facilities (IRFs). Some Centers have incorporated long-term acute care hospitals (LTACHs) into their system of care. Among these Centers, the role of the LTACH is variable. In some Centers, the LTACH serves as the primary and sole rehabilitation setting. In all cases, patients remain within the system of care through discharge from the rehabilitation facility. While all Centers must provide multidisciplinary brain injury rehabilitation services, the number of therapy hours provided per day may vary by setting. All TBIMS Centers are required to follow established protocols for the collection of enrollment and follow-up data on all participants.

Table 1: Components of a TBI Model System of Care

Components of a TBI Model System of Care	Components Less Frequently Included
At least one Level 1 trauma center	Level 2 trauma centers
At least one inpatient rehabilitation hospital	Day treatment community integration program
Individual outpatient therapies	Alcohol and substance abuse outpatient therapy
Physician follow-up clinic	Vocational rehabilitation
Neuropsychology follow-up clinic	Skilled nursing facility
	LTACH
	Assistive technology
	Spasticity/dystonia management clinic
	Clubhouse programs

Acknowledgement

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

TBIMS National Database

This chapter serves as a quick reference guide on the policies associated with accessing and using data from the Traumatic Brain Injury Model Systems (TBIMS) National Database for those in the general scientific community who are not affiliated with funded TBIMS data collection sites. Topics covered include the following:

- What is the TBIMS National Database?
- Policies and procedures for obtaining data from the National Database
- Publication policies when using the National Database
- Failure to follow policies and procedures

What Is the TBIMS National Database?

The TBIMS National Database is a prospective, longitudinal database that examines the course of recovery and outcomes following the delivery of coordinated acute neurotrauma and inpatient rehabilitative care to people with TBI. As of September 2024, the National Database contained information on more than 20,000 people with TBI who were admitted for inpatient acute rehabilitation. The people included in the National Database are representative of adults in the United States who experience TBIs that are severe enough to require hospitalization and inpatient rehabilitation. The National Database is the largest longitudinal database about TBI in the world and it includes data on pre-injury, injury, acute care, rehabilitation, and outcomes at 1, 2, and 5 years post-injury and every 5 years thereafter. The National Database contains some data on people who are 30 years postinjury. The National Database has been used to inform research, treatment, and policy to benefit individuals with TBI and their families. For further information, please see the TBIMS National Database Description or visit the Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) website at www.tbindsc.org.

Policies and Procedures for Obtaining Data From the National Database

Requesters can access the data by sending a formal request as described in steps 1–7 below, or they can obtain the public use dataset by going to https://www.tbindsc.org/Re-

searchers.aspx for instructions. This dataset is composed of de-identified data that have been collected up to 2 years prior to the last quarter. To submit a data request, follow the procedures below, which were designed to be simple and to encourage external researchers to use the data while maintaining the integrity of the data and the confidentiality of the database participants.

1. Complete a Data Request and Use Agreement Form, available at https://www.tbindsc.org/Researchers.aspx. Once you complete the form, email it to tbimsdata@craighospital.org at the TBINDSC.
2. The NDSC and the TBIMS Research Committee will review the completed Data Request and Use Agreement Form for the principal investigator's (PI) affiliation, scientific purpose, and scientific overlap with existing approved projects.
3. The NDSC will post the proposal from the data requester and the recommendations from the TBIMS Research Committee to the TBIMS Notification Listserv for further comment by the TBIMS Project Directors. After the proposal has been posted to the TBIMS Notification Listserv for 10 working days, the NIDILRR TBIMS Centers Program Manager will make the final decision regarding the proposal with feedback from the NDSC, the TBIMS Research Committee, and the TBIMS Project Directors.
4. After approval, the PI will work with NDSC staff to detail the proposal so that an appropriate de-identified dataset can be released to the PI.
5. Before releasing the dataset, the Institutional Review Board (IRB) approval number and expiration date must be received from the requesting institution.
6. Before releasing the dataset, the NDSC will delete the ID code of the contributing center, or, if a center-to-center comparison is part of the objective, or if the center identity is used in statistical analysis, NDSC will replace the standard center identity codes with other randomly selected codes. Analysts are not allowed to "unscramble" these codes, and center identity must always be treated as masked in any reports and in publications, unless all centers involved give written prior approval for identification of their center.
7. Use of the data for this request is limited to 2 years. After that time, a new External Use Request and Data Use Agreement Form must be sent to the TBINDSC for re-approval.
8. During analysis, applicants should send annual updates to the NDSC that include the name of the PI, the title of the project, progress on the project, and an updated anticipated completion date

Publication Policies When Using the National Database

1. At no time should a researcher who has been given access to the data attempt to identify individual patients.

2. All manuscripts should accurately describe the methods of data collection for the TBIMS National Database.

3. Any dissemination of the proposed study findings, including manuscripts, posters, presentations, and other products must include the following citation for the TBIMS National Database:

> **Citation**
>
> - 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: 2024 • URL: http://www.tbindsc.org
> - Version: https://osf.io/a4xzb/

4. Any dissemination of the study findings including all manuscripts, posters, presentations, and other products must include the following acknowledgment: "The TBI Model Systems National Database is a multicenter study of the TBI Model Systems Centers Program, and is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), a center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). However, these contents do not necessarily reflect the opinions or views of the TBI Model Systems Centers, NIDILRR, ACL or HHS.

5. The PI will submit manuscripts to the TBINDSC for administrative review at least 4 weeks before submission for publication. The NDSC will forward such manuscripts to the TBIMS Research Committee members for review. Abstracts for meeting presentations also need to be submitted for review.

6. The PI will apprise the NDSC of acceptance or rejection of manuscripts, abstracts, and presentations.

7. The PI will provide the NDSC with the URL and complete citation for any published manuscript, abstract, or presentation that uses TBIMS data, when such information is available.

Standard Operating Procedures

The NIDILRR priority requires the NDSC to develop and revise standard operating procedures (SOPs) that provide guidance for TBIMS Center operations. Formally implemented by the NDSC in 2008, these documents describe the regularly occurring operations of the TBIMS for data collectors, researchers, analysts, data managers, and the NDSC. Having such SOPs increases the likelihood that operations are carried out consistently and systematically across all TBIMS Centers, serves as training documentation for new TBIMS staff, and preserves an historical record of how and why processes have changed during the lifecycle of the project.

To make it easier to search within all SOPs at once, during the 2021-2026 grant cycle the NDSC combined all SOPs into a single indexed PDF. The NDSC also restructured the SOPs to align with the workflow of the NDSC and the TBIMS Centers, organizing them into the following five major chapters which correspond to the elements of the data lifecycle.

Indexed, searchable document that contains all Standard Operating Procedures

If you open the document and show the document outline, you will see that there are 5 major chapters included in the PDF

Data Aquisition

- Identification of Subjects
- Sampling for NDB Enrollment
- Guidelines and Strategies for TBIMS National Database Recruitment & Consenting
- Guidelines for Medical Record Abstraction and Record Requests
- Guidelines for Collection of Follow-Up Data
- Guidelines and Strategies for Maximizing Follow-Up
- Handling Unexpected Events at Follow-up

Data Processing

- Quarterly Submission Process for Data Center
- Quarterly Submission Process for TBIMS Centers
- Editing, Entering, and Submitting Old Data

- Obtaining and Coding Cause of Death in the TBIMS National Database
- Notification of Staff Changes

Data Quality

- Data Quality Guidelines and Principal Investigator Verification of Compliance
- Performance Target Monitoring
- Prevention and Investigation of Possible Falsification of Data
- Resolving Data Collection and Coding Questions
- Methods for Locking and Unlocking Records

Data Sharing

- Access to the TBIMS National Database
- TBIMS Project Director Request for National Database
- Submission of TBIMS Data to FITBIR
- Non-TBIMS Collaborative Relationships
- VA PRCs Collaborative Relationships
- Follow-up Centers Collaborative Relationships
- Access to TBIMS Module Project Datasets

TBIMS Operations

- TBIMS Data Collection Integrity Pledge
- Implementing Changes to the National Database
- TBIMS Committees, Modules and Special Interest Groups, and Election Process for Committee Chairs and Co-Chairs
- Procedure for Creating and Changing SOPs
- Branding and Authorship of Manuscripts and Other Products Using Data from the TBIMS National Database, Archived Module Datasets, and Ongoing TBIMS Module Studies
- Adding Affiliate Hospitals to a TBI Model System

Eligibility

Person are considered eligible if they meet the case definition of TBI.

Definition of TBI

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. Penetrating wounds fitting definition listed above are included.

This definition of TBI excludes several conditions when criteria above are not met: Lacerations or contusions of the face, eye, or scalp, without other criteria listed above; Fractures of skull or facial bones, without criteria listed above; Primary anoxic, inflammatory, toxic, or metabolic encephalopathies which are not complications of head trauma; Brain infarction (ischemic stroke); Intracranial hemorrhage (hemorrhagic stroke) without associated trauma; Airway obstruction (e.g., near - drowning, throat swelling, choking, strangulation, or crush injuries to the chest); Seizure disorders (Grand mal, etc.); Intracranial surgery; Neoplasms

The Inclusion Criteria for the TBIMS NDB are:

1. fitting the above definition;
2. meeting at least one of the following criteria for moderate to severe TBI:
    - PTA > 24 hours
    - Trauma related intracranial neuroimaging abnormalities
    - Loss of consciousness exceeding 30 minutes (unless due to sedation or intoxication)
    - GCS in the emergency department of less than 13 (unless due to intubation, sedation,or intoxication);
3. who are age 16 or older at the time of injury;
4. presenting to the TBIMS's acute care hospital within 72 hours of injury;

5. must receive both acute hospital care and comprehensive rehabilitation in a designated brain injury inpatient rehabilitation program within the TBIMS. Comprehensive rehabilitation must occur in a hospital, rehabilitation unit, rehabilitation hospital, hospital-based skilled nursing facility, skilled nursing facility, or long-term acute care hospital that meets the following criteria:
    - Medical and rehabilitation care are supervised on a regular basis by a physician affiliated with the TBIMS
    - 24-hour nursing care is provided to the patient
    - PT, OT, Speech, Rehabilitation Psychology/Clinical Neuropsychology, and family support/education are provided in an integrated, team approach with the expectation of further gain.
    - Regardless the setting in which it is constituted, a comprehensive rehabilitation program operates in a manner consistent with (a) CARF standards for brain injury inpatient rehabilitation and/or (b) Medicare requirements for inpatient rehabilitation.
    - If a TBIMS's comprehensive rehabilitation program co-exists with programming that does not meet the above criteria, the TBIMS must explicitly define its methodology for establishing the dates of admission and discharge from comprehensive rehabilitation that will be reported to the TBIMS Data and Statistical Center (NDSC). These dates will represent the period of time during which CARF and/or Medicare criteria are met. This period may include interruptions during which the criteria are not met for medical reasons but after which a rehabilitation programming meeting CARF and/or Medicare criteria is resumed.
    - All data required by the National Database are accessible and transferable to the NDSC with appropriate informed consent;
6. who understand and provide informed consent to participate or, if unable, family or legally authorized representative understands and provides informed consent for the patient.

ℹ Screening Data

Screening data on an individual level was introduced in 2020. Up until then cumulative reports were sent to the NDB. Therefore the following enrollment tables represent people admitted to inpatient rehabilitation after **2020-01-01**.
The overall consent rate for the TBIMS Model Systems is 62%. Below are the demographic breakdowns for who is Eligible, Randomized and Consented.

Characteristic	Overall N = 13,184	No N = 6,939	Yes N = 6,245
Sex, n (%)			
Female	3,582 (27)	1,849 (27)	1,733 (28)
Male	9,547 (73)	5,047 (73)	4,500 (72)
Unknown	7 (<0.1)	6 (<0.1)	1 (<0.1)
Missing	48	37	11
Age, n (%)			
< 16	220 (1.7)	219 (3.2)	1 (<0.1)
16 - 25	2,589 (20)	1,497 (22)	1,092 (18)
26 - 35	1,801 (14)	879 (13)	922 (15)
36 - 45	1,475 (11)	733 (11)	742 (12)
46 - 55	1,394 (11)	726 (10)	668 (11)
56 - 65	1,795 (14)	905 (13)	890 (14)
66 - 75	1,817 (14)	937 (14)	880 (14)
76 - 85	1,468 (11)	723 (10)	745 (12)
86 +	594 (4.5)	297 (4.3)	297 (4.8)
Unknown	2 (<0.1)	2 (<0.1)	0 (0)
Missing	29	21	8
Race, n (%)			
Asian/Pacific Islander	624 (4.7)	336 (4.9)	288 (4.6)
Black	1,925 (15)	833 (12)	1,092 (18)
Hispanic Origin	1,312 (10.0)	643 (9.3)	669 (11)
Native American	44 (0.3)	28 (0.4)	16 (0.3)
Other	345 (2.6)	192 (2.8)	153 (2.5)
Unknown	883 (6.7)	498 (7.2)	385 (6.2)
White	8,010 (61)	4,381 (63)	3,629 (58)
Missing	41	28	13

Characteristic	N = 6,939
Reason Not Eligible, n (%)	
Admitted > 72 Hours Post-Injury	609 (8.8)
From Non-TBIMS Acute Hospital	4,838 (70)
Not applicable	42 (0.6)
Other	656 (9.5)
Too Mild A TBI	617 (8.9)
Too Young	173 (2.5)
Missing	4

Characteristic	**Overall** N = 6,199	**No** N = 1,017	**Yes** N = 5,182
Sex, n (%)			
Female	1,719 (28)	273 (27)	1,446 (28)
Male	4,468 (72)	739 (73)	3,729 (72)
Unknown	1 (<0.1)	0 (0)	1 (<0.1)
Missing	11	5	6
Age, n (%)			
< 16	1 (<0.1)	0 (0)	1 (<0.1)
16 - 25	1,079 (17)	188 (19)	891 (17)
26 - 35	913 (15)	159 (16)	754 (15)
36 - 45	739 (12)	134 (13)	605 (12)
46 - 55	664 (11)	109 (11)	555 (11)
56 - 65	889 (14)	130 (13)	759 (15)
66 - 75	875 (14)	136 (13)	739 (14)
76 - 85	734 (12)	114 (11)	620 (12)
86 +	297 (4.8)	46 (4.5)	251 (4.9)
Missing	8	1	7
Race, n (%)			
Asian/Pacific Islander	287 (4.6)	30 (3.0)	257 (5.0)
Black	1,082 (17)	167 (17)	915 (18)
Hispanic Origin	664 (11)	110 (11)	554 (11)
Native American	16 (0.3)	4 (0.4)	12 (0.2)
Other	152 (2.5)	14 (1.4)	138 (2.7)
Unknown	379 (6.1)	83 (8.2)	296 (5.7)
White	3,606 (58)	604 (60)	3,002 (58)
Missing	13	5	8

Eligible Demographics

Reasons why persons are not eligible

Randomized Demographics

The TBIMS uses established criteria to determine eligibility for enrollment and participation in the TBIMS National Database (NDB). Since inception, it has been the expectation that TBIMS centers approach every eligible subject for enrollment in the NDB. However, beginning on January 1, 2020, it is expected that through randomization of eligible cases a center will have a target of 35 cases per year. This procedures that will take place for all centers, providing them with a sampling strategy that maintains the representativeness of their sample of subjects.

Consented Demographics

Characteristic	**Overall** N = 5,200	**Consent Status Pending** N = 171	**No** N = 1,935	**Yes** N = 3,094
Sex, n (%)				
Female	1,451 (28)	34 (20)	546 (28)	871 (28)
Male	3,742 (72)	135 (80)	1,385 (72)	2,222 (72)
Unknown	1 (<0.1)	0 (0)	1 (<0.1)	0 (0)
Missing	6	2	3	1
Age, n (%)				
< 16	1 (<0.1)	0 (0)	0 (0)	1 (<0.1)
16 - 25	893 (17)	16 (9.4)	282 (15)	595 (19)
26 - 35	755 (15)	17 (9.9)	247 (13)	491 (16)
36 - 45	607 (12)	16 (9.4)	229 (12)	362 (12)
46 - 55	557 (11)	27 (16)	181 (9.4)	349 (11)
56 - 65	761 (15)	25 (15)	284 (15)	452 (15)
66 - 75	743 (14)	36 (21)	301 (16)	406 (13)
76 - 85	622 (12)	22 (13)	280 (15)	320 (10)
86 +	254 (4.9)	12 (7.0)	127 (6.6)	115 (3.7)
Missing	7	0	4	3
Race, n (%)				
Asian/Pacific Islander	259 (5.0)	12 (7.1)	135 (7.0)	112 (3.6)
Black	918 (18)	24 (14)	340 (18)	554 (18)
Hispanic Origin	556 (11)	35 (21)	216 (11)	305 (9.9)
Native American	12 (0.2)	0 (0)	5 (0.3)	7 (0.2)
Other	139 (2.7)	10 (5.9)	49 (2.5)	80 (2.6)
Unknown	296 (5.7)	12 (7.1)	118 (6.1)	166 (5.4)
White	3,012 (58)	76 (45)	1,068 (55)	1,868 (60)
Missing	8	2	4	2

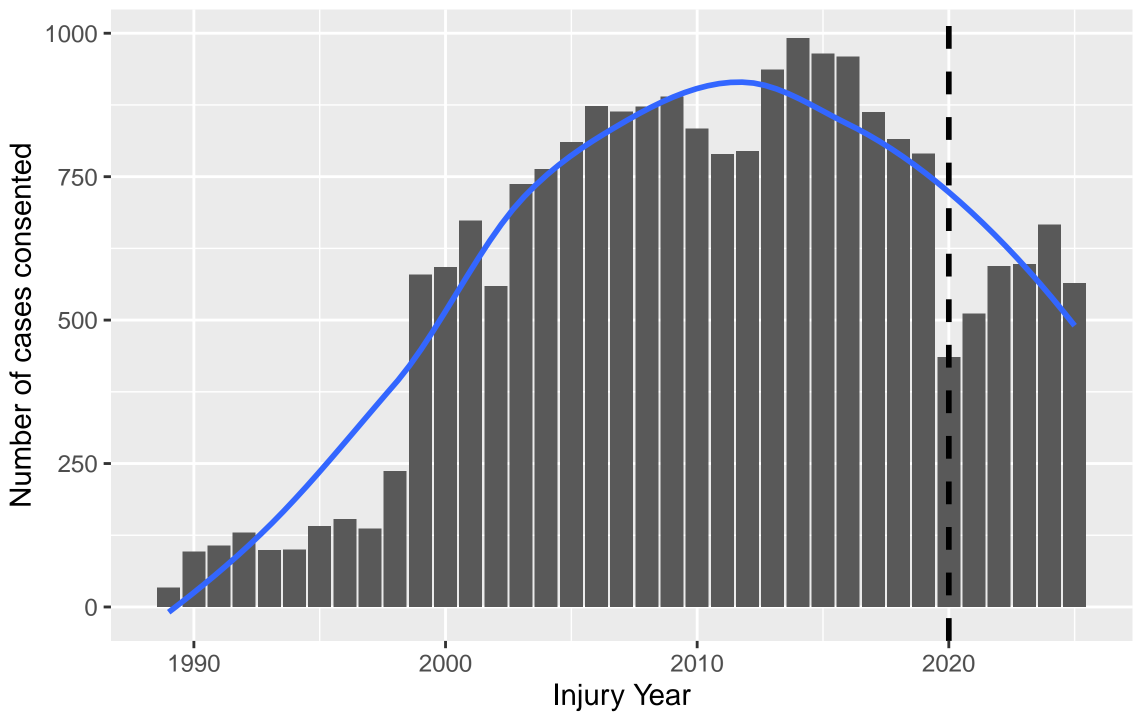
Database Numbers

> **Note**
>
> You are reading the work-in-progress first edition of TBIMS Annual Report. This chapter should be readable but is currently undergoing final polishing.

Number of Subjects

There are `21543` subjects in the data set.

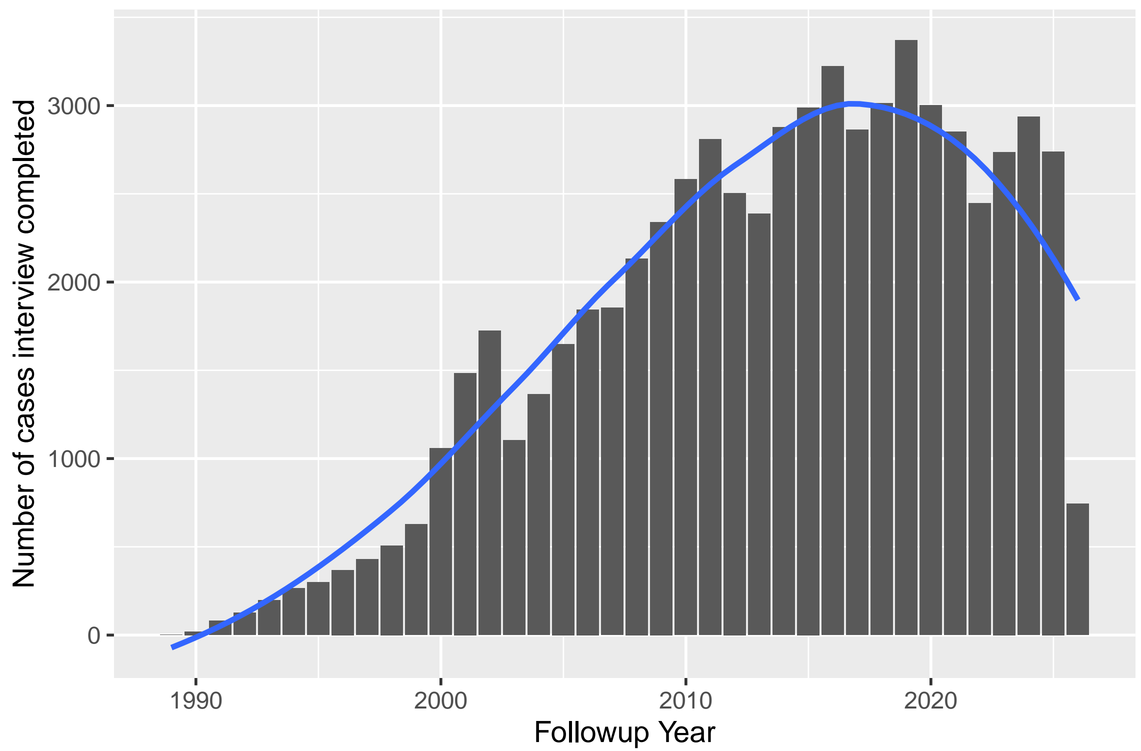
Plot of Enrolled Subjects by Injury Year



Number of Followups

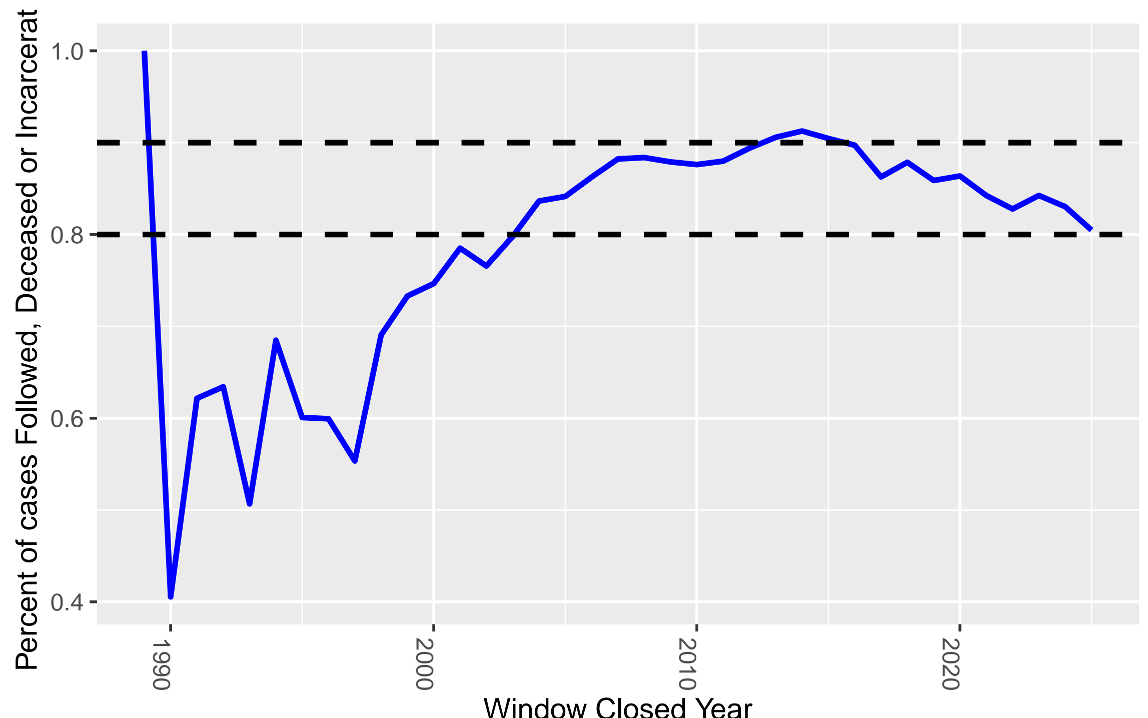
There are 82781 possible followups in the data set. Of those 84% percent were followed successfully *(87% if you include centers who had no funding for followup)*

Plot of Followed Subjects by Year



Characteristic	**Followed** N = 60,859	**Lost** N = 9,665	**Refused** N = 663	**Incarcerated** N = 1,276	**Wit**
Followup period:, n (%)					
Year 1	17,126 (82)	1,868 (8.9)	171 (0.8)	213 (1.0)	
Year 2	15,148 (79)	1,996 (10)	158 (0.8)	294 (1.5)	
Year 5	11,898 (71)	1,961 (12)	116 (0.7)	281 (1.7)	
Year 10	8,063 (66)	1,665 (14)	106 (0.9)	229 (1.9)	
Year 15	4,985 (65)	1,128 (15)	63 (0.8)	154 (2.0)	
Year 20	2,470 (61)	687 (17)	29 (0.7)	73 (1.8)	
Year 25	875 (62)	283 (20)	15 (1.1)	26 (1.8)	
Year 30	255 (66)	70 (18)	5 (1.3)	5 (1.3)	
Year 35	39 (64)	7 (11)	0 (0)	1 (1.6)	

Plot of Percent Followed Subjects by Year



Dotted lines represents the 80% target for year 5 + and the 90% target for year 1 and 2

Below are the status breakdowns for Follow-up Period, Race, Sex, and Age.

Characteristic	**Followed** N = 60,859	**Lost** N = 9,665	**Refused** N = 663	**Incarc**
Race Summary Variable, n (%)				
No to All Race Indicators	156 (84)	10 (5.4)	0 (0)	
White only	39,125 (76)	4,606 (8.9)	436 (0.8)	
Black/African-American only	10,629 (69)	2,313 (15)	84 (0.5)	
Asian only	1,519 (81)	242 (13)	17 (0.9)	
Native Hawaiian or Other Pacific Islander only	86 (85)	11 (11)	0 (0)	
Hispanic Origin only	2,852 (58)	1,309 (27)	49 (1.0)	
American Indian or Alaskan Native only	296 (72)	55 (13)	3 (0.7)	
Multiple Races	5,824 (79)	813 (11)	55 (0.8)	
Other	195 (32)	233 (38)	14 (2.3)	
Missing	177	73	5	

Characteristic	**Followed** N = 60,859	**Lost** N = 9,665	**Refused** N = 663	**Incarcerated** N = 1,276	**Withdrew** N
Sex:, n (%)					
Female	16,357 (76)	2,110 (9.8)	193 (0.9)	94 (0.4)	355 (1.
Male	44,347 (73)	7,502 (12)	467 (0.8)	1,180 (1.9)	845 (1.
Missing	155	53	3	2	1

Characteristic	**Followed** N = 60,859	**Lost** N = 9,665	**Refused** N = 663	**Incarcerated** N = 1,276	**Withdrew** N
Age, n (%)					
< 25 yr	17,076 (75)	2,902 (13)	174 (0.8)	529 (2.3)	258 (1.
25-44 yr	21,590 (74)	3,888 (13)	210 (0.7)	630 (2.2)	368 (1.
45-64 yr	14,898 (74)	2,113 (11)	186 (0.9)	108 (0.5)	327 (1.
65+ yr	7,099 (67)	697 (6.6)	90 (0.9)	7 (<0.1)	242 (2.
Other	196 (64)	65 (21)	3 (1.0)	2 (0.7)	6 (2.0)

Characteristic	**Followed** N = 2,852	**Lost** N = 1,309	**Refused** N =
What is the primary language spoken in your home?, n (%)			
English	1,093 (77)	189 (13)	13 (0.9)
Spanish	1,339 (70)	359 (19)	20 (1.0)
Other Language	29 (66)	12 (27)	0 (0)
Missing	391	749	16

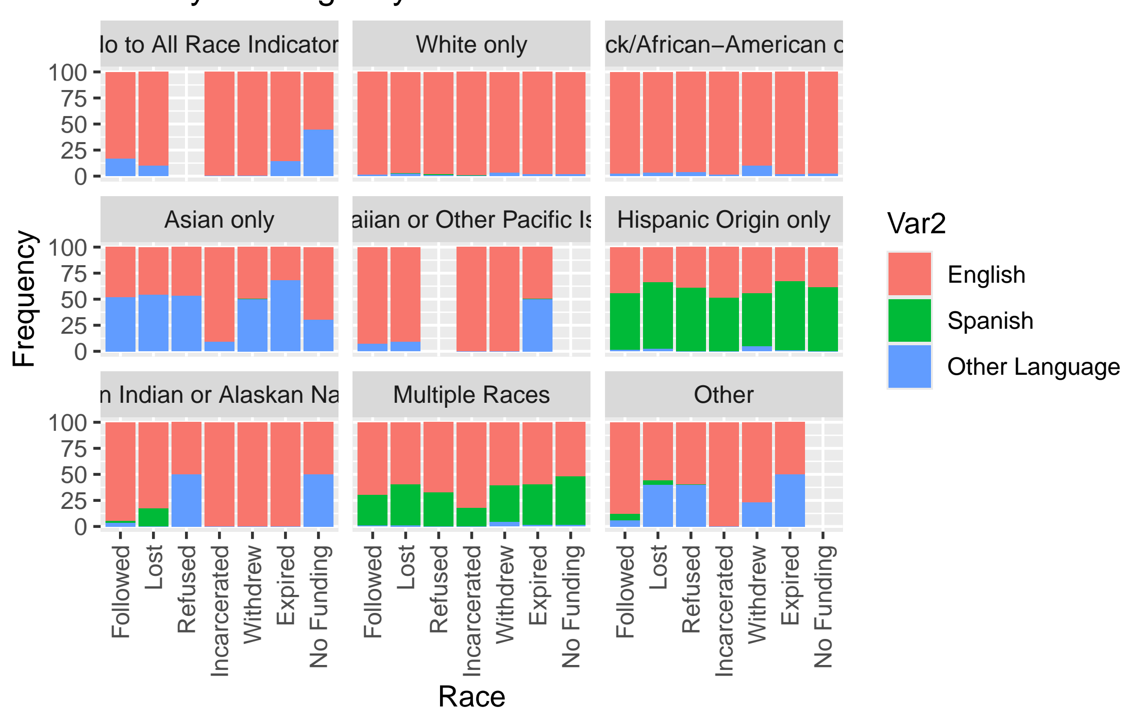
Follow-up Status by Follow-up Period

Followup by Race

Followup by Sex

Followup by Age

Followup Language



Part I

Data Summaries

The TBIMS Centers collect data for 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. The NDSC stores the data in the NDB and makes it available for researchers to conduct research that contributes to evidence-based rehabilitation interventions and clinical and practice guidelines that improve the lives of individuals with TBI.

The objectives for the NDB are to:

- 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

The data is collected via repeated surveys of individuals at regular intervals post-injury. This includes an interview administered at inpatient rehabilitation discharge, called Form 1, which includes <336> variables. It further includes follow-up interviews administered via telephone, in person, or mailout questionnaire, called Form 2, which includes <315> variables. Sources of data include abstraction of medical records, specialized data collection forms, patient interview and testing, and family interview. The patient is the primary source of follow-up information; if the patient cannot be interviewed, follow-up is attempted with a proxy.

The NDSC performs multiple data quality checks to ensure the integrity of the data in the NDB. These include checks at the point of data entry, such as checks for valid codes and correct ranges, logical checks between variables, and consistency checks between variables over time. The data entry system will also identify cases with errors or blanks, notify of follow-ups coming due, warn about overdue follow-ups, calculate missing data rates, and calculate follow-up rates.

The TBIMS NDB has been used in <266> studies from its inception through the end of calendar year <2023>. These studies have focused on the epidemiology of moderate-to-severe TBI, the natural history of TBI outcomes and comorbidities, predictors of TBI outcomes and comorbidities, validation of severity and outcome measurement, and longitudinal change over time.

Data categories include demographic characteristics of the population, causes and severity of injury, pre-injury conditions and limitations, disability, health measurements, mood and behavior measurements, and participation outcomes. The charts and tables presented in the next section comprise a descriptive summary of a subset of the variables in the TBIMS NDB. All variable definitions and histories can be found in the [data dictionary]https://www.tbindsc.org/DataDictionary.aspx.

ℹ Note

The following chapters are devoted to reviewing data elements that are currently captured in the TBIMS. Overall the dataset is reduced to persons who were admitted to inpatient rehabilitation between 1989-10-01 and 2025-12-31 and whose followup window have closed as of 2025-12-31. Furthermore, the data set has been restricted to follow-up years 1,2,5,10 and every 5 years after. There exists 5282 follow-ups that were conduced in the "off" years that are not represented in this dataset.

Date Added

The data set for each measure has been filtered for when the variable was added to the database. For example if a variable was added October 1, 2017 then all cases with a rehab admission date or followup date prior would be filtered out. In the rare instance where there were multiple add dates this report includes data only where the variable was asked.

Tables and graphs

Where appropriate, calculated fields are used for exploration. This will help reveal a "true missingness" of the variable. Each Data element will have a table representing the data as well as a graph visualizing the data. Further, each table will have a missingness column or row depending on the type of variable. There will be a sentence describing the overall missingness of the variable (either by Form 1 or Form 2). If there are harmonized variables between Form 1 and 2. the data will be stacked. Form 1 variables referencing "at the time of injury" will be labeled "INJ" others will be "ADM" or "DIS" representing Admission or Discharge Scores. Form2 Variables will be designated by the followup year.

1 Demographics

1.1 Sex

1.1.0.1 Definition

Current sex of subject

1.1.0.2 Form

[X] Form 1
[ ] Form 2

1.1.0.3 Source

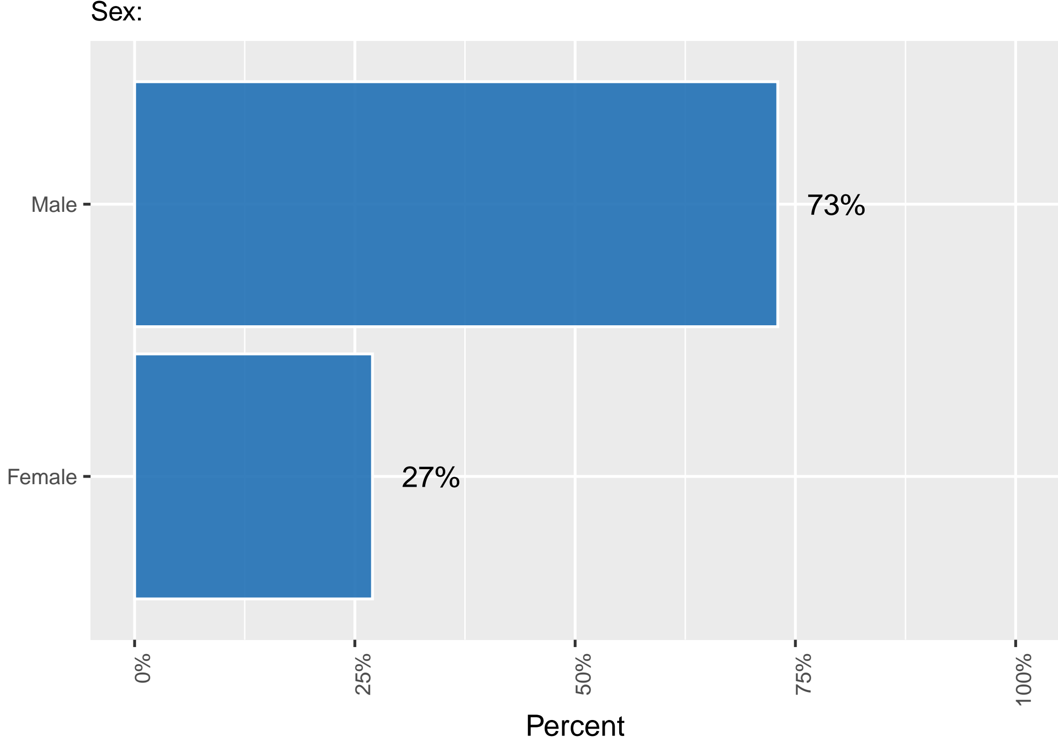
Abstraction (acute or rehab record)

1.1.0.4 Details

If transgender, record current sex.

Sex:

Characteristic	N = 21,526
Sex:, n (%)	
Female	5,717 (27)
Male	15,800 (73)
Missing	9



100% of the abstracted people have valid data

1.2 Race

Caution

Race and Ethnicity are asked at Form 2 and are back filled into a Primary Race Category.

1.2.0.1 Definition

Ethnicity - Self-reported Ethnicity for two categories: "Hispanic, Latino, or Spanish", and "Not Hispanic, Latino, or Spanish". To code this variable, participants are asked "Are you of Hispanic, Latino, or Spanish origin?"

Race - Self-Reported racial identification for each of the following five categories: "White", "Black, African American", "Asian", "American Indian or Alaskan Native", and "Native Hawaiian or other Pacific Islander". To code these variables, participants are asked "What racial group

or groups do you most identify as?". To account for mixed race, all race categories that a participant indicates should be coded.

Form 1 - Follow-up question is asked if more than one race or ethnicity is asked to capture primary race participant identies as - "If you selected more than one race or ethnicity, with which do you identify most strongly?"

1.2.0.2 Form

[X] Form 1
[X] Form 2

1.2.0.3 Source

Form I - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-Out (participant or proxy)

1.2.0.4 Details

Patient's or significant other's statement is preferred to hospital record information.

Record participant's statement regarding his/her race, or record race of father.

In obtaining a statement from the participant regarding his/her race/ethnicity, ambiguity may be resolved by asking which race/ethnicity is more important in his/her daily life.

It is acceptable to collect RACE variables from an SO if individual cannot answer for themselves.

The RACE questions are to be asked only once, NOT at every follow-up.

1.2.0.5 Characteristics

On 1/15/2023, "What is your race?" was removed from Form 1 data collection and replaced with race questions from Form 2 - "Are you of Hispanic, Latino, or Spanish origin?; and "What racial group or groups do you most identify as? (Select all that apply)"; Race as a single variable is mapped to RacePrimary to ensure consistency with prior data collection

New follow-up question - "If you identified with more than one race in the above questions, what is the race you identify with the most?" was added on 4/1/2023 - This was to insure a crosswalk with the Race variable that was asked prior to the Race Ethnicity split.

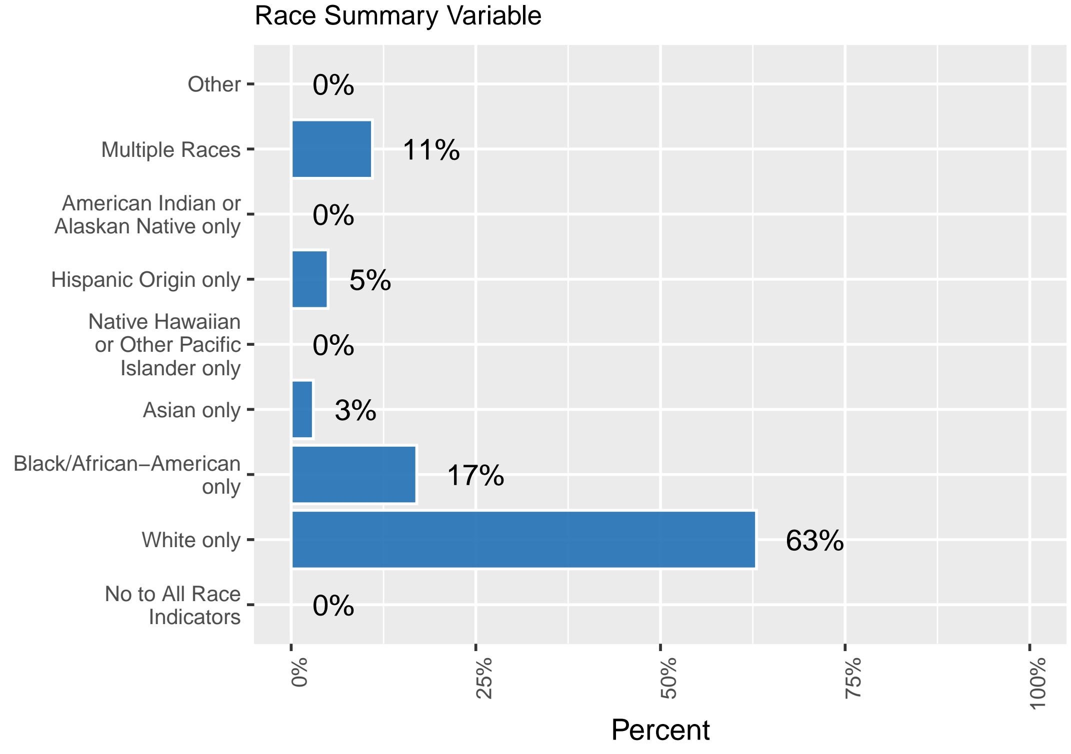
Characteristic	N = 21,526
Race Summary Variable, n (%)	
No to All Race Indicators	49 (0.2)
White only	13,608 (63)
Black/African-American only	3,798 (18)
Asian only	499 (2.3)
Native Hawaiian or Other Pacific Islander only	28 (0.1)
Hispanic Origin only	1,350 (6.3)
American Indian or Alaskan Native only	93 (0.4)
Multiple Races	1,870 (8.7)
Other	170 (0.8)
Missing	61
Are you of Hispanic, Latino, or Spanish origin?, n (%)	
No	14,508 (86)
Yes	2,294 (14)
Missing	4,724

Code “6-Biracial or Multiracial” added to Primary Race Question on 10/1/2023

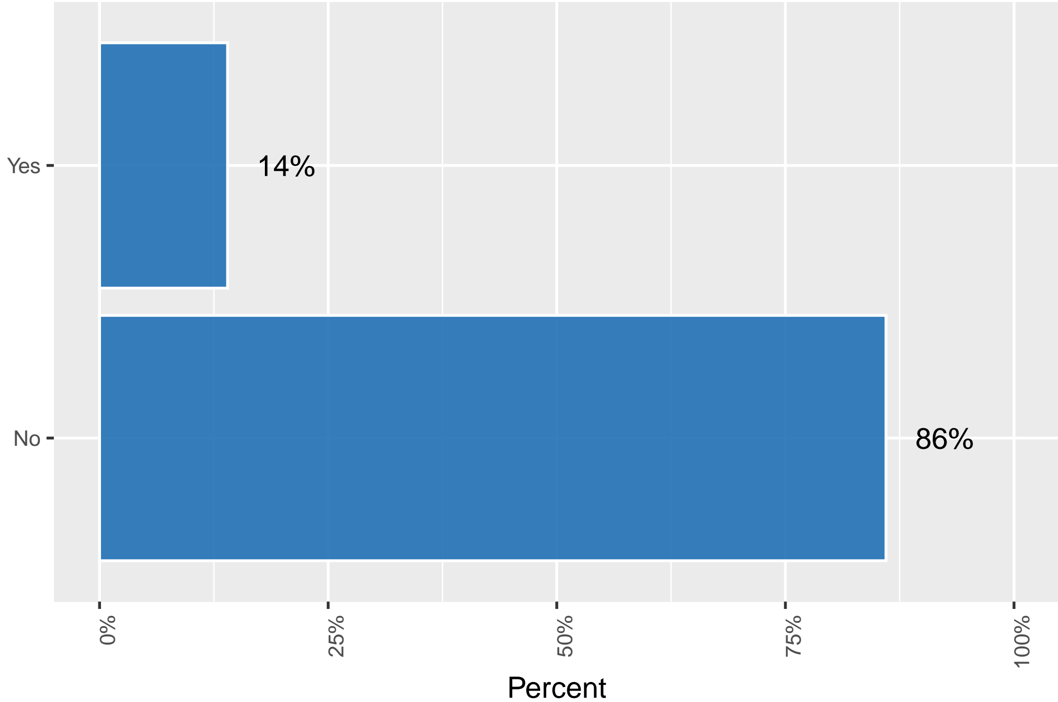
1.2.0.6 Reference

2000 Census, Department of Commerce: See - External Links

Office of Management and Budgets Federal Register
Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity


Race Summary Variable
Other
0%
Multiple Races
11%
American Indian or
Alaskan Native only
0%
Hispanic Origin only
5%
Native Hawaiian
or Other Pacific
Islander only
0%
Asian only
3%
Black/African–American
only
17%
White only
63%
No to All Race
Indicators
0%
0%
25%
50%
75%
100%
Percent

Are you of Hispanic, Latino, or Spanish origin?



1.3 Language

Caution

Language Spoken at home is a Variable that is asked at Form 2 to back fill Form 1 information. Thus the start date has been modified to reflect that data *can* be collected on everyone

1.3.0.1 Definition

Primary Language spoken in the participant's home
To code this variable, participants will be asked;
"Before the injury, what was the primary language spoken in your home?" (Form 1)
"What is the primary language spoken in your home?" (Form 2)

Languages other than English or Spanish will be recorded in a secondary text field.

Individual Race Categories

Characteristic	N = 21,526
White:, n (%)	
No	4,630 (28)
Yes	12,152 (72)
Missing	4,744
Asian:, n (%)	
No	16,108 (96)
Yes	608 (3.6)
Missing	4,810
American Indian, or Alaskan Native:, n (%)	
No	16,183 (97)
Yes	537 (3.2)
Missing	4,806
Native Hawaiian or other Pacific Islander:, n (%)	
No	16,598 (99)
Yes	110 (0.7)
Missing	4,818
Black, African American:, n (%)	
No	13,518 (81)
Yes	3,214 (19)
Missing	4,794

Country of birth; To code this variable, participants will be asked “What is your country of birth?” Countries other than the United States will be recorded in a secondary text field.

Years in US; The number of years that a participant has lived in the United States (if they were not born in the US). To code this variable, participants who report a country of birth other than the United States will be asked “How many years have you been in the United States?”

1.3.0.2 Form

[X] Form 1
[X] Form 2

1.3.0.3 Source

Form I - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-Out (participant or proxy)

1.3.0.4 Details

For participants enrolled prior to addition of this variable, ask the question at the time of the next Form 2 follow-up.

Primary Language

If 2 or more languages are spoken in the home, try to get the participant to choose which language they consider to be the primary language.

Country of Birth

Country of Birth for participants enrolled prior to addition of this variable; ask the question at the time of the next Form 2 follow-up.

If born in Puerto Rico count as born in the US.

Years in US

This question should only be asked of participants whose country of birth is other than the United States. Therefore, it should be asked after the question on country of birth.

Begin by asking the number of years participants have been in the United States. If less than 1 year, then ask number of months. Code 6 months or greater as 1 year. Code less than 6 months as 0 years.

If participants have lived in the United States intermittently, with periods separated by time spent in another country, record the total number of years spent in the United States. Example

- Participant has spent 3-4 months of every year in the US for the last 30 years. To determine the total number of years spent in the US, multiply the 30 years by 3.5 months (mid-point of a "3 - 4" month range). That gives us a total of 105 months in the US. Divide that by 12 months for a total of 8.75 years, and then round up for a total of 9 years spent in the US.

1.3.0.5 Characteristics

Recommendations for using data collected at Form 2 include two options:

1. Only use a given response at the time it was collected when analyzing data from that year. This would limit sample size but would be the most accurate use of the variable reflecting the participant's self-report of length of time in the U.S. at that moment.

2. Use the variable to derive a value representing a common time point across all individuals who immigrated to the U.S. Any calculated variables derived from this would have to be understood as an estimate and reported as such in publications. For example:

    a. Estimated Age of Entry Into the U.S.
        i. Subtracting current age at the time of the response from the reported length of time in the U.S. would be an estimate of age of entry into the U.S. with the understanding that this represents an upper estimate.
        ii. True age of entry may be younger for individuals who have lived for one or more years outside of the U.S. after their initial immigration.

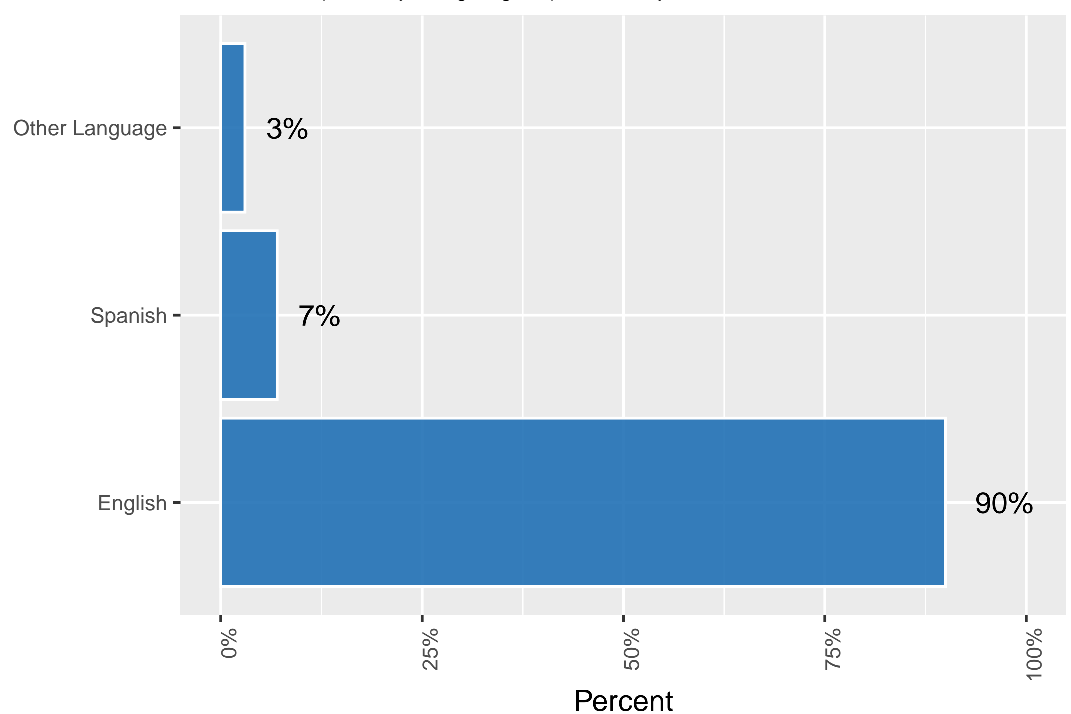
    b. Estimated Years in the U.S. at the Time of Injury.
        i. For those who were asked this question at a follow-up time point, subtracting the years since injury at the time this was asked from the response provided would estimate time in the U.S. at the time of injury.
        ii. This can result in a negative number as in this example:

Someone from abroad visiting U.S. relatives has a TBI. After rehabilitation, they return to their home country. They then immigrate to live in the U.S. for 3 years. At their year 5 follow-up, they state they have been living in the U.S. for 3 years. Subtracting 5 from this value results in -2 years in the U.S. at the time of injury.

In this case, the value can be counted as 0 years in the U.S. at the time of injury.

What is the primary language spoken in your home?

Characteristic	N = 21,526
What is the primary language spoken in your home?, n (%)	
English	15,895 (90)
Spanish	1,240 (7.0)
Other Language	587 (3.3)
Missing	3,804



82% of the abstracted people have valid data

1.4 Age

1.4.0.1 Definition

AGE - This calculated variable determines the precise age, in full years, of the participant by comparing their fixed Date of Birth (Birth) against a flexible Reference Date (Injury Date or Follow-up Date). This logic is designed to be mathematically accurate, ensuring that the age in years reflects whether the participant's birthday had passed as of the specified reference date.

AGEF - Age at Follow-Up

AGENoPHI - Age Calculated for Non-PHI calculates age at injury without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

AGENoPHIF - Age at Follow-Up Calculated for Non-PHI calculates age at follow-up without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

BMI, BMIF - (Body Mass Index at Injury) (kg/m2) is calculated from height in inches and weight in pounds as [weight(lbs)/height(in)^2]*703

BMICat, BMICatF classifies BMI into categories between severely underweight to very severely obese, using the BMI calculated from height and weight

RuralF (Urbanicity) - Urbanization based on zip code of address.

1.4.0.2 Notes

AGEF - Calculates years from Birth to Follow-Up

CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END AS AGE

AGENoPHIF - Calculates years from Birth to Follow-Up
(CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) >= 89 THEN 989 ELSE (CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) END AS AGENP

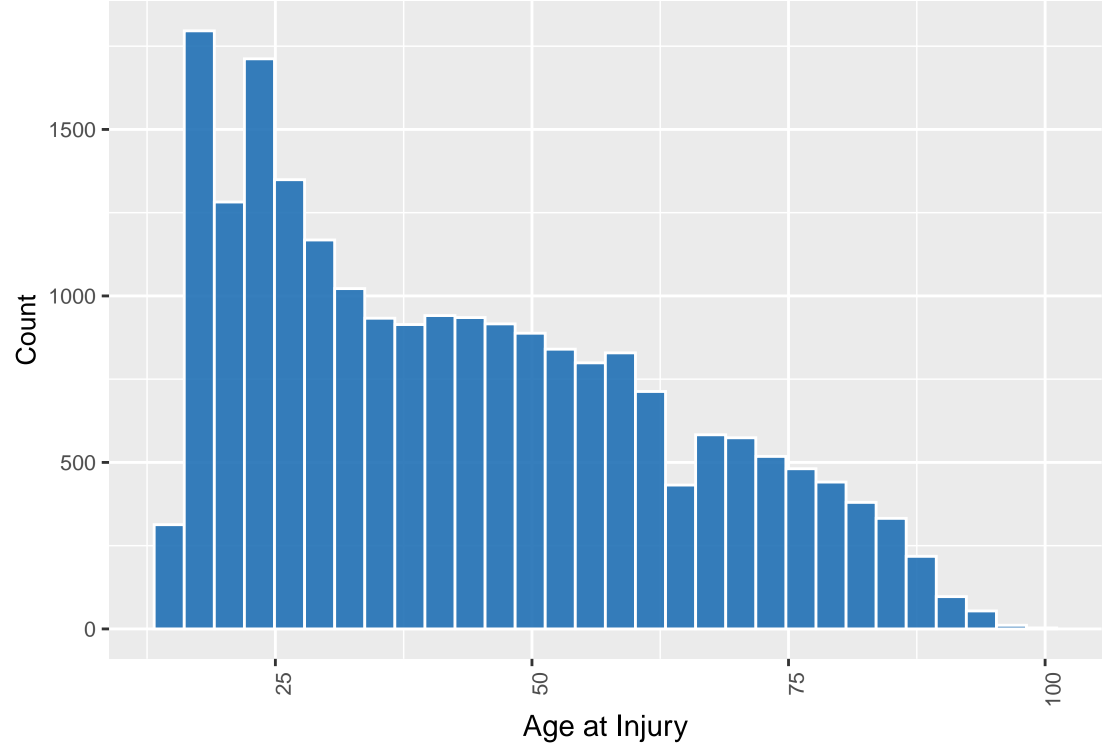
BMI, BMIF - If height or weight is not available or a subject had an arm or leg amputation, then BMI is not calculated.
- Computes BMI = Weight /Square(Height) *703 - 888 or 777 is BMI is not available or subject

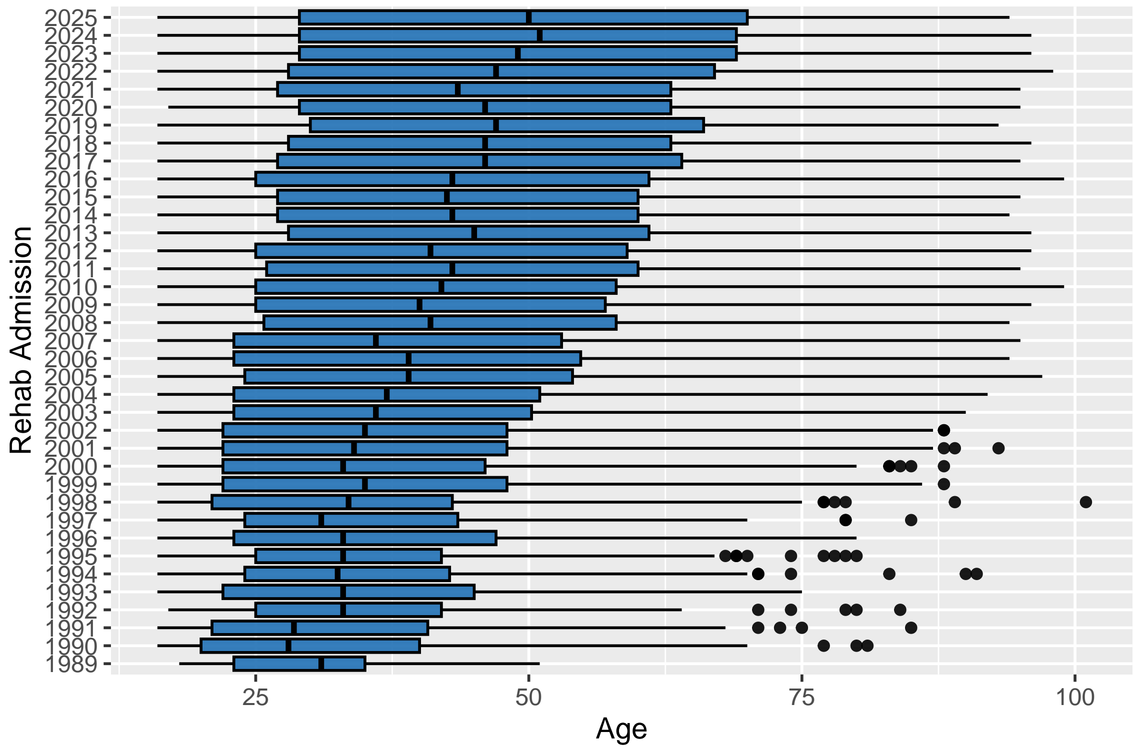
Age at Injury

Characteristic	N = 21,474
Age at Injury	
N Non-missing	21,474
Mean (SD)	43 (20)
Median (Q1, Q3)	40 (25, 59)
Min, Max	16, 101

had an arm or leg amputation
- 999 or NULL is BMI is unknown

RURALF - Urbanicity classifies a person's location as urban, rural, or suburban based on their zip code. The mapping of zip codes to these categories come from a dataset located at http://greatdata.com/rural-urban-data/.





100% of the abstracted people have valid data

1.5 Military Service

Caution

Military Service is a Variable that is asked at Form 2 to back fill Form 1 information. Thus the start date has been modified to reflect that data *can* be collected on everyone

1.5.0.1 Definition

Determine history of military service. These variables are intended to allow for better comparison with DOD/VA data.

The following questions are asked:

Have you ever served in the military?

Characteristic	N = 21,526
Have you ever served in the military?, n (%)	
No	14,032 (88)
Yes	1,845 (12)
Missing	5,649

- Have you ever served in the military?
- If yes, how many years of active duty did you serve?
- If yes, were you ever deployed in a combat zone?

1.5.0.2 Form

[X] Form 1
[X] Form 2

1.5.0.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.5.0.4 Details

Guard or reserve duty should be considered as service in the military, but does not count toward years of active duty.

Include service in foreign military.

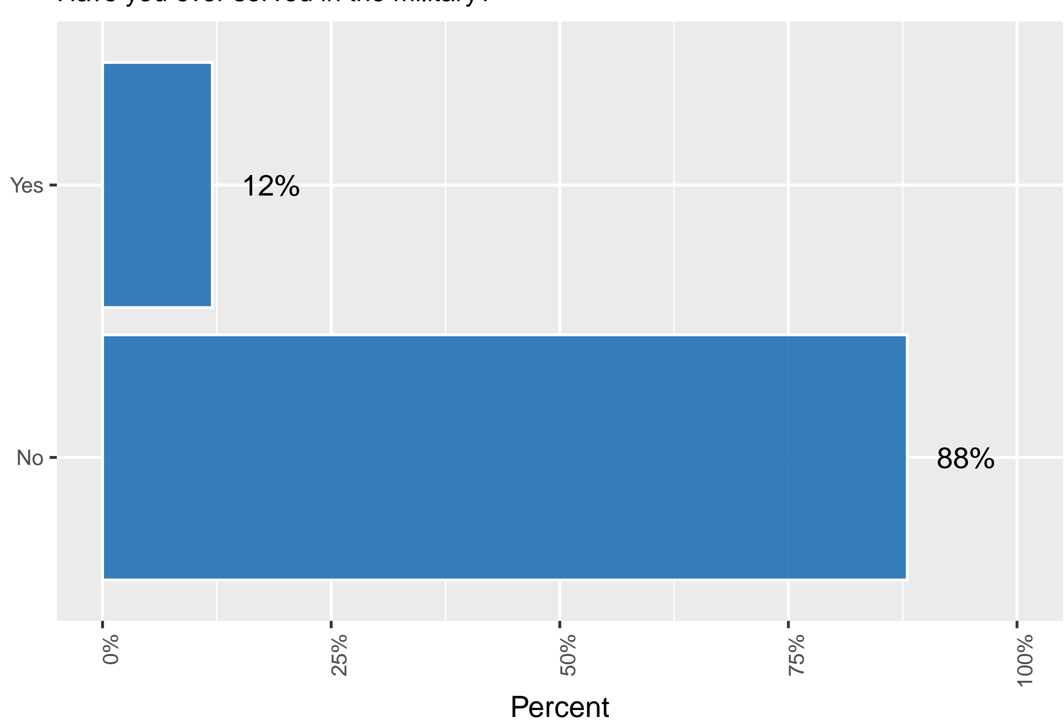
Round up if months of duty are given (e.g., month of active duty = .5 years; 14 months of active duty = 1.5 years)

How many years of active duty have you served in the military?

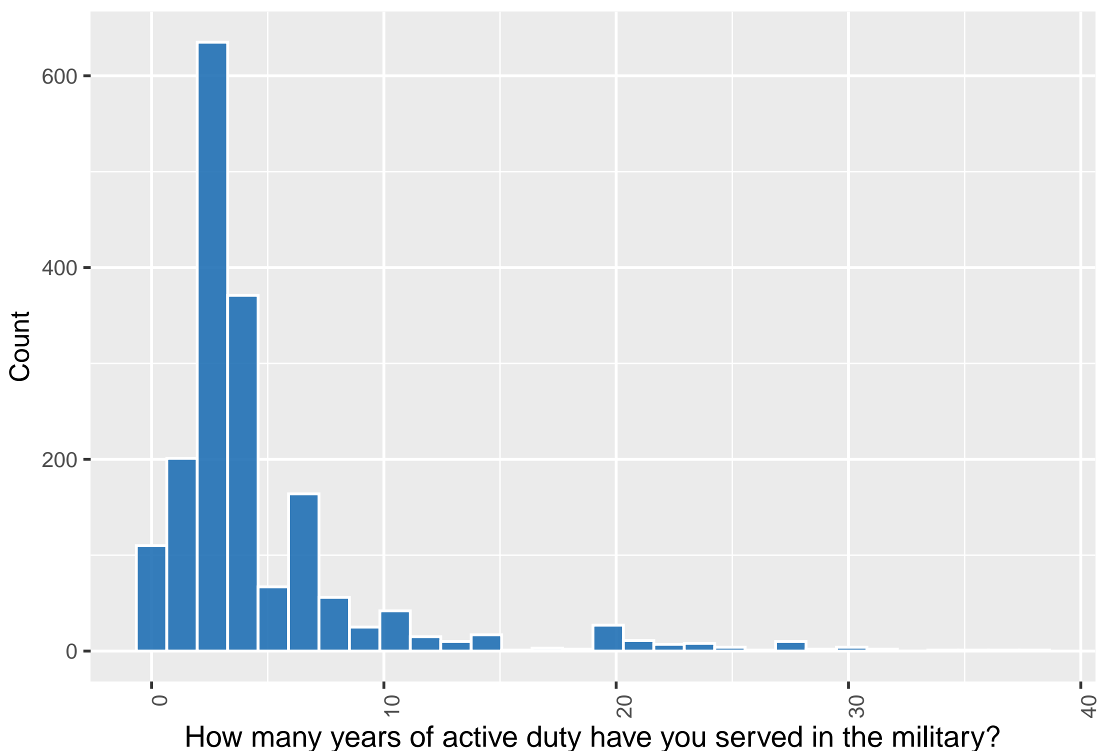
Characteristic	N = 1,845
How many years of active duty have you served in the military?	
N Non-missing	1,799
Mean (SD)	4.6 (5.1)
Median (Q1, Q3)	3.0 (2.0, 5.0)
Min, Max	0.0, 38.0
Unknown	46

1.5.0.5 Reference

DVBIC SIG



74% of the abstracted people have valid data



98% of the abstracted people have valid data

1.5.0.6 Definition

Determine history of military service. These variables are intended to allow for better comparison with DOD/VA data.

The following questions are asked:

- Have you ever served in the military?
- If yes, how many years of active duty did you serve?
- If yes, were you ever deployed in a combat zone?

1.5.0.7 Form

[X] Form 1
[X] Form 2

Were you ever deployed in a combat zone?

Characteristic	N = 1,845
Were you ever deployed in a combat zone?, n (%)	
No	1,229 (68)
Yes	587 (32)
Missing	29

1.5.0.8 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.5.0.9 Details

Guard or reserve duty should be considered as service in the military, but does not count toward years of active duty.

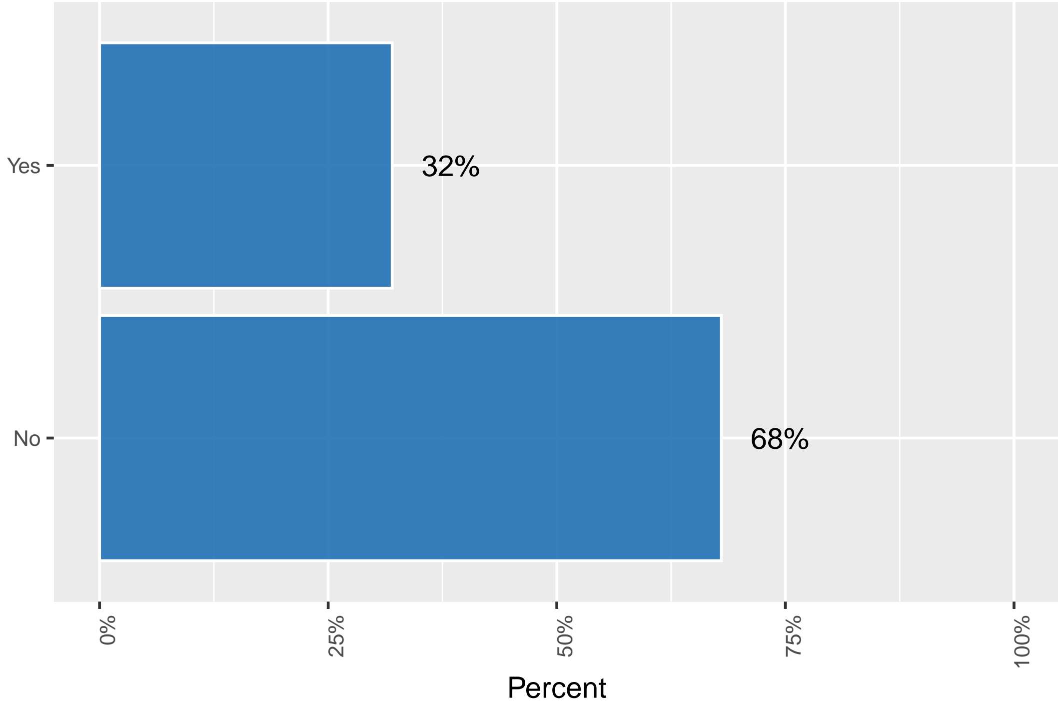
Include service in foreign military.

Round up if months of duty are given (e.g., month of active duty = .5 years; 14 months of active duty = 1.5 years)

1.5.0.10 Reference

DVBIC SIG

Were you ever deployed in a combat zone?



98% of the abstracted people have valid data

1.6 Insurance

1.6.0.1 Definition

Primary (largest) payor source(s) for both acute and rehabilitation hospitalizations

4 - Private Insurance includes Employee Insurance, Privately Purchased Policies such as BCBS, HMO, PPO, TRICARE/TRIWEST, Federal Exchanges, etc.
8 - State or County includes State Crippled Children, Department Of Rehab, etc.
14 - Charity includes Hospital Provided Free Care

1.6.0.2 Form

[X] Form 1
[ ] Form 2

1.6.0.3 Source

Form 1 - Abstraction (acute record, rehab record)

1.6.0.4 Details

Any given payor may have many kinds of policies, so the name of the payor is often not sufficient information for determining type of policy. If the payor source is not clear, contact your hospital's billing department to determine correct payor source.

Code '55. Payor Source Pending' should be used only as a place holder until the actual payment source is known.

Payor sources fitting more than 1 category should be coded only once, and are not to be broken-out between the primary and secondary sources. If present, any type of ''managed care' ' category should be given the highest prioritization. For example, if the payor source is "Auto Insurance with HMO" code '6. HMO.'

Medicaid HMO should be coded '2. Medicaid'.

1.6.0.5 Characteristics

All cases coded as '01 - Medicare' or '02 - Medicaid' prior to 4/2/99 remained in these coding categories. Centers with the ability to perform retrospective re-coding, re-coded these cases to codes 15 through 18 as appropriate.

Several categories were combined / re-defined on 10/1/2011:

01 = Medicare (unable to determine if traditionally or managed care administered) [CHANGED TO 01 = Medicare]
02 = Medicaid (unable to determine if traditionally or managed care administered) [CHANGED TO 02 = Medicaid]
03 = Workers' Compensation [UNCHANGED]
04 = Blue Cross/Shield [COMBINED WITH 05 = Private Insurance (Other); CHANGED TO 04 = Private Insurance, Other (BC/BS, Employee Insurance, Privately Purchased Policies, Etc.)]
05 = Private Insurance (Other) [COMBINED WITH 04 = Blue Cross/Blue Shield; CODE 05 REMOVED]
06 = HMO (Health Maintenance Organization) [UNCHANGED]
07 = Private Pay [CHANGED TO 07 = Self Or Private Pay]
08 = State Crippled Children's [COMBINED WITH 09 = Department of Rehabilitation; CHANGED TO 08 = State or County (State Crippled Children, Department of Rehab, Etc.)]
09 = Department of Rehabilitation [COMBINED WITH 08 = State Crippled Children's;

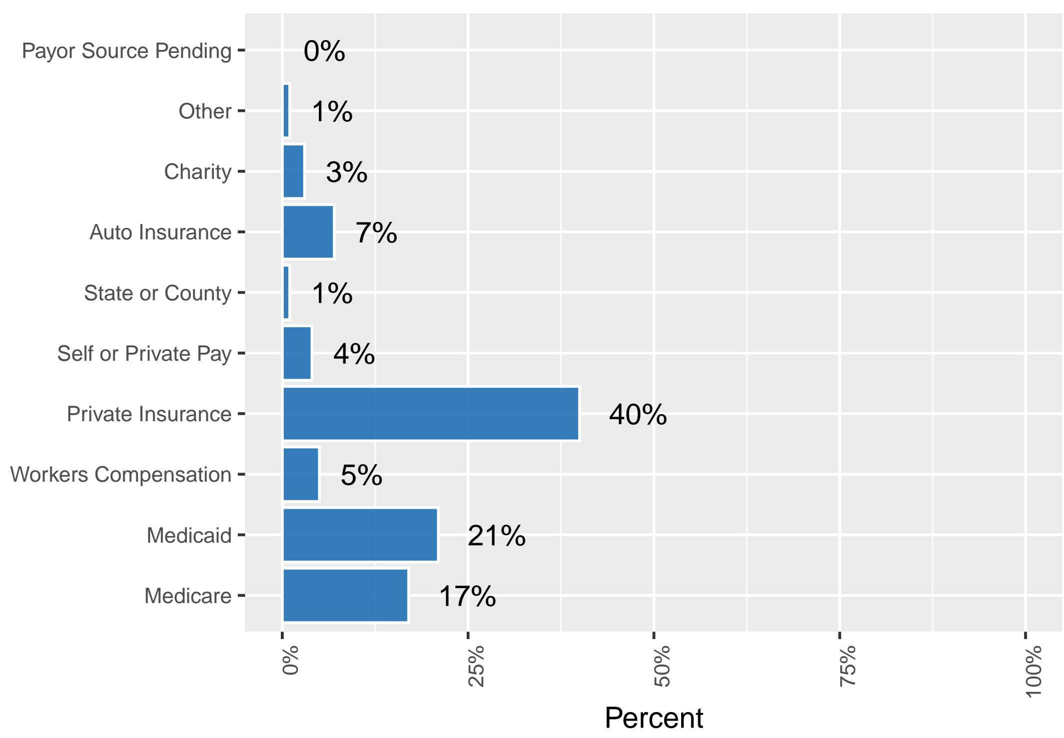
CODE 09 REMOVED]
10 = No Fault Insurance [CHANGED TO 10 = Auto Insurance]
11 = PPO [UNCHANGED]
12 = CHAMPUS [CHANGED TO 12 = TRICARE/TRIWEST (Formerly CHAMPUS)]
14 = Hospital (free bed) [CHANGED TO 14 = Hospital Free Care]
15 = Medicare (traditionally administered) [COMBINED WITH 01 = Medicare (unable to determine if traditionally or managed care administered); CODE 15 REMOVED]
16 = Medicaid (traditionally administered) [COMBINED WITH 02 = Medicaid (unable to determine if traditionally or managed care administered); CODE 16 REMOVED]
17 = Medicare (managed care administered) [COMBINED WITH 01 = Medicare (unable to determine if traditionally or managed care administered); CODE 17 REMOVED]
18 = Medicaid (managed care administered) [COMBINED WITH 02 = Medicaid (unable to determine if traditionally or managed care administered); CODE 18 REMOVED]
19 = DoD (VA database only - not a TBIMS code) [UNCHANGED]
20 = VA (VA database only - not a TBIMS code) [UNCHANGED]
55 = Medicaid Pending [CHANGED TO 55 = Payor Source Pending]
77 = Other [UNCHANGED]
88 = N/A (No care given or no secondary payor) [CHANGED TO 88 = Not Applicable (No Secondary Payor)]
99 = Unknown [UNCHANGED]

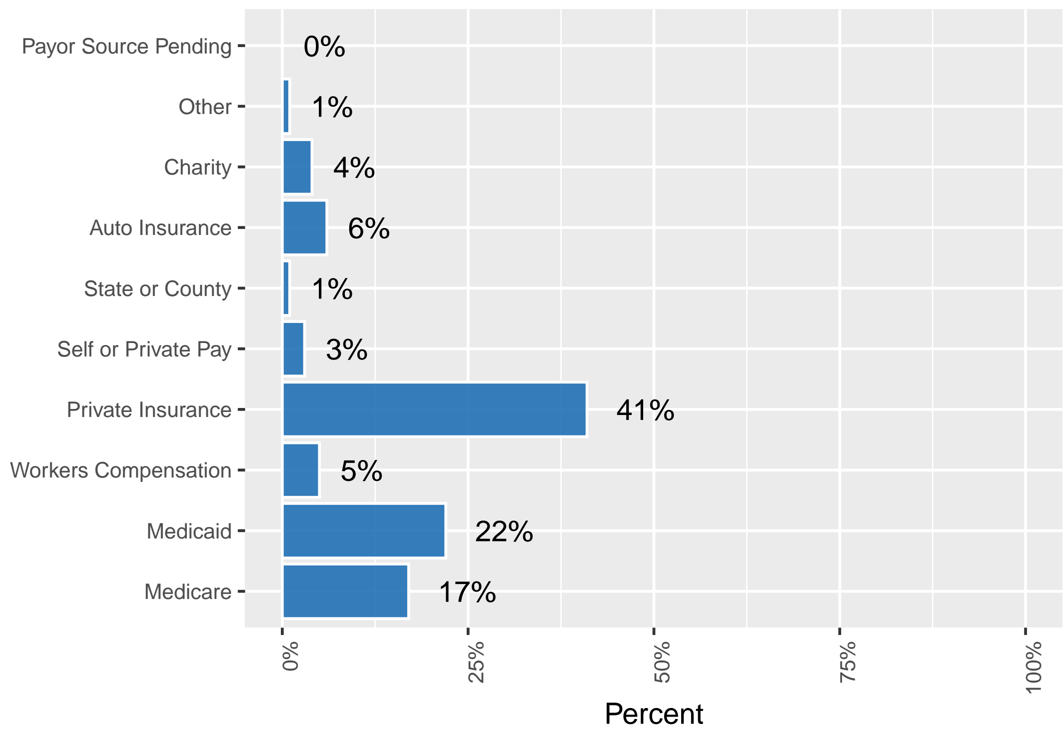
In 2017 More categories were combined - the existing variable was copied to the variable archive and the live variable was recoded by combining all private insurance together (4-private insurance: other; 6-HMO; 11-PPO; and 12-TRICARE/TRIWEST). Also recommended to rename “Hospital Free Care” as “Charity.”

In 2018, copied current variable to Archives and re-coded variable to combine all private insurances together and rename Hospital Free care to “Charity”

Payor

Characteristic	N = 21,526
Primary acute payor:, n (%)	
Medicare	3,605 (17)
Medicaid	4,527 (21)
Workers Compensation	1,012 (4.8)
Private Insurance	8,505 (40)
Self or Private Pay	901 (4.2)
State or County	216 (1.0)
Auto Insurance	1,576 (7.4)
Charity	666 (3.1)
Other	255 (1.2)
Payor Source Pending	5 (<0.1)
Missing	258
Primary rehabilitation payor:, n (%)	
Medicare	3,663 (17)
Medicaid	4,669 (22)
Workers Compensation	1,046 (4.9)
Private Insurance	8,722 (41)
Self or Private Pay	663 (3.1)
State or County	203 (0.9)
Auto Insurance	1,306 (6.1)
Charity	937 (4.4)
Other	233 (1.1)
Payor Source Pending	1 (<0.1)
Missing	83


Payor Source Pending
Other
Charity
Auto Insurance
State or County
Self or Private Pay
Private Insurance
Workers Compensation
Medicaid
Medicare
0%
1%
3%
7%
1%
4%
40%
5%
21%
17%
0%
25%
50%
75%
100%
Percent



100% of the abstracted people have valid data

1.7 Etiology

1.7.0.1 Definition

Includes Cause of Injury, Primary and Secondary ICD External Cause of Injury Codes.

Guidelines for coding ICD External Cause of Injury Codes : See Links

Cause of Injury
1 - Motor Vehicle Does not include auto racing. Auto racing is coded 18
2 - Motorcycle Includes 2-wheeled, motorized vehicle including mopeds, motorized dirt bikes, and motorized scooters
3 - Bicycle Includes tricycles and unicycles
4 - All-Terrain Vehicle (ATV) and All-Terrain Cycle (ATC) Includes both 3-wheeled and 4-wheeled recreational vehicles, dune buggy and go-cart
5 - Other Vehicular: Unclassified Includes tractor, bulldozer, steam roller, train, road grader, forklift, aircraft

10 - Gunshot Wound
11 - Assaults With Blunt Instrument Non-penetrating
12 - Other Violence Includes all other penetrating wounds: stabbing, impalement. Also includes explosions. (Those caused by bomb, grenade, dynamite, gasoline)
13 - Water Sports Includes diving, water skiing, surfing (includes body surfing), swimming, boating, etc.
14 - Field/Track Sports Includes football, baseball, softball, basketball, volleyball, field hockey, lacrosse, soccer, rugby, high jump and pole vault
15 - Gymnastic Activities Includes trampoline, breakdancing and other gym activities
16 - Winter Sports Includes snow skiing, sled, snow tube, toboggan, snowmobile, etc.
17 - Air Sports Includes hang gliding, parachuting, para-sailing, glider kite, etc. (Does not include airplane. Airplane is coded 05)
18 - Other Sports Includes wrestling, horseback riding, rodeo (e.g. bronco/bull riding), skateboard, auto racing, etc.
19 - Fall Includes jumping and being pushed
20 - Hit By Falling/Flying Object Includes ditch cave-in, avalanche, rock slide
21 - Pedestrian
22 - Other Unclassified Includes lightning, kicked by an animal, machinery accidents
999 - Unknown

1.7.0.2 Form

[X] Form 1
[ ] Form 2

1.7.0.3 Source

Abstraction (acute record)

1.7.0.4 Details

Cause of Injury

Cause of Injury is an important variable. Data collector should always know cause of TBI (needed to determine study inclusion), therefore cause and ICD External Cause of Injury codes should never be missing or unknown.

Cause of injury should correspond with the primary ICD External Cause of Injury Code and both codes should correspond with the narrative documented in the medical chart (history and physical) pay special attention to description of injured person (ie passenger, driver, pedal cyclist, etc.)

If the cause is not known, investigate as thoroughly as feasible and make a determination if possible. Also, be alert to information becoming available at a later time and be ready to record and submit it.

If person is found "down", try to determine what happened.

On rare occasions, the cause of injury (Cause of Injury and ICD External Code variables) may be coded as "unknown" if unable to determine the mechanism or circumstances of injury. However, the data collector/admitting physiatrist should still be able to conclude that the primary mode of injury was traumatic in these cases, as this is a requirement for inclusion in the study.

ICD External Cause of Injury Codes

When taking External Cause of Injury Codes from the Medical Record, they should be checked to ensure that they reflect the best / most current information available about the cause of the injury. Data collectors may submit ICD External Cause of Injury Code that differ from those recorded in the Medical Record in cases where they feel the Medical Record ICD External Cause of Injury Code may not reflect the best / most current information available. There should be clear documentation on the data collection form when an ICD External Cause of Injury Code entered into the database does not reflect the ICD External Cause of Injury Code recorded in the Medical Record. In unusual cases where no ICD External Cause of Injury Code relative to the injury that resulted in traumatic brain injury is recorded in the Medical Record, the data collector should use best judgement and the consultation of other personnel, as necessary, to determine the appropriate ICD External Cause of Injury Code from the TBIMS database list.

Code 2 causes of injury if there were 2 causes. If only one cause, the second ICD External Cause of Injury Code should be coded as the place of injury.

Place of injury codes should be used with any primary ICD External Cause of Injury Code to denote the PLACE where the accident or poisoning occurred. This code should always be secondary, never primary.

Late effects of injury codes are to be used to indicate circumstances classifiable as the cause of death or disability from late effects related to an injury. These include conditions reported as such, or occurring as sequelae one year or more after injury purposely inflicted by another person or injuries where intention is undetermined.

The TBIMS inclusion criteria specifies that participants present to the Model System ED with injuries occurring within 72 hours of admission. Therefore, all cases with a late effect external code listed as primary should be reviewed to assure that the injury is truly new and not pre-existing. If the current admission is due to a pre-existing TBI, this case does not fit the TBIMS inclusion criteria and should be excluded from the study.

ICD External Cause of Injury Codes can be assigned by data collector if medical record personnel unavailable.

888 (fall) is a valid External Cause of Injury ICD Code. Don’t use 888 as “not applicable” (88888 = not applicable).
88888 should NEVER be the primary External Cause of Injury ICD Code, but can be the secondary code.

Include the preceding “V”, “W”, “X”, or “Y” for ICD-10 cause of injury codes.

The following ICD External Cause of Injury Code should rarely, if ever, be the primary. These codes should be reviewed and validated prior to data entry: - accidental poisoning by drugs, medicinal substances; - accidental poisoning by other solid and liquid substances, gases, and vapors; - misadventures to patients during surgical and medical care; surgical and medical procedures as the cause of abnormal reaction of patient or later complication, without mention of misadventure at the time of the procedure; - accidents caused by fire and flames; - accidents due to natural and environmental factors; - accidents caused by submersion, suffocation, and foreign bodies; - assault by corrosive or caustic substance (except poisoning) - assault by poisoning - assault by hanging and strangulation - assault by submersion - drowning - assault by hot liquid - injuries undetermined whether accidentally or purposely inflicted

If two vehicles are involved, the cause of injury should be coded according to the vehicle on/in which the patient was riding (e.g. patient cycling on a bicycle and hit by a car, the cause would be the bicycle since that is the vehicle the patient was riding on.)

If two events are involved, the cause of injury should be coded according to the initial event (e.g. patient riding a bicycle fell, lost control and fell into ditch would be coded as a bicycle accident, not a fall.)

If two events are involved, and the participant sustains injuries from both events, the cause of injury should be coded according to the initial event. (e.g. patient hit in the head and fell to ground hitting head again would be coded as assault). If in doubt which event occurred first, ask the TBIMS physician which cause would be primary based on the extent of injury apparently caused by both events.

If person jumps from a moving vehicle, use code 19 in this variable, however, use appropriate vehicular ICD external code (E818.? for ICD-9 or V87.8XXA for ICD-10) ICD External Cause of Injury Code [CSEICD].

If injury occurred in parking lot of a public building, code “Y92.481 - Parking lot as the place of occurrence of the external cause”.

Cause of injury for patients who were “struck by a fist” should be coded as ‘’11 = Assaults with blunt instrument (non-penetrating)’‘. Although an’‘instrument’ ’ was not technically utilized in the assault, this code best describes the etiology of the injury.

Do not include codes regarding drug or alcohol use or intoxication at the time of the injury in the External ICD code fields.

Cause of injury:

Characteristic	N = 21,526
Cause of injury:, n (%)	
Motor Vehicle	7,114 (33)
Motorcycle	2,137 (9.9)
Bicycle	621 (2.9)
All-Terrain Vehicle (ATV) and All-Terrain Cycle (ATC)	337 (1.6)
Other Vehicular: Unclassified	162 (0.8)
Gunshot Wound	833 (3.9)
Assaults With Blunt Instrument	1,268 (5.9)
Other Violence	183 (0.9)
Water Sports	23 (0.1)
Field/Track Sports	22 (0.1)
Gymnastic Activities	2 (<0.1)
Winter Sports	137 (0.6)
Air Sports	8 (<0.1)
Other Sports	185 (0.9)
Fall	6,431 (30)
Hit By Falling/Flying Object	269 (1.3)
Pedestrian	1,667 (7.8)
Other Unclassified	81 (0.4)
Missing	46

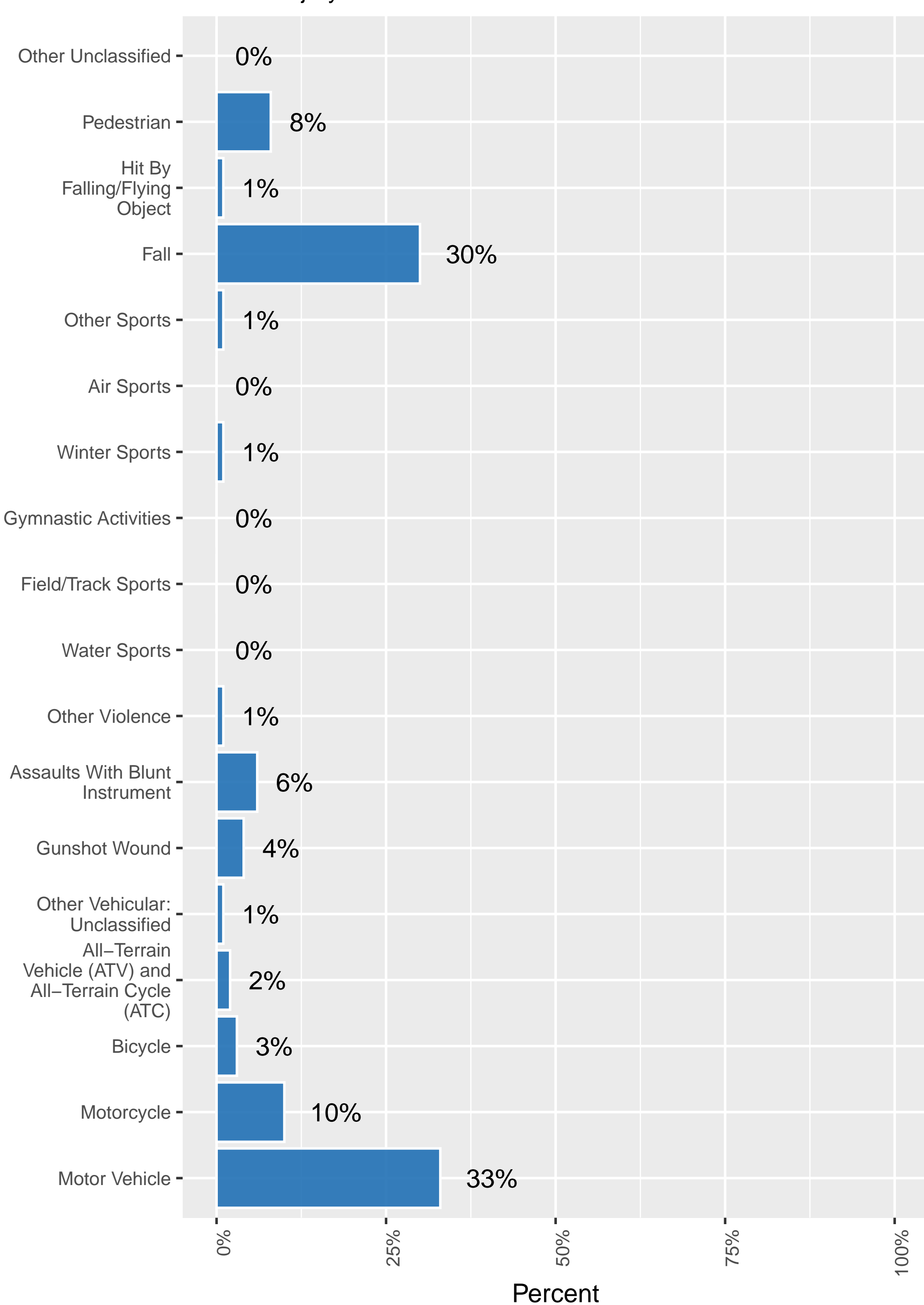
1.7.0.5 Links

ICD-10-CM List of External Cause of Morbidity Codes
ICD-10-CM/PCS Medical Coding Reference
ICD-10-CM Place of occurrence of External Cause

1.7.0.6 Reference

SCVMC (Santa Clara Valley Medical Center

ICD-9-CM 2001: International Classification of Diseases 9th Revision Clinical Modification, AMA Press. Volume 1, 2000, 251-279. ISBN: 1579471501.


Cause of injury:
Other Unclassified
0%
Pedestrian
8%
Hit By Falling/Flying Object
1%
Fall
30%
Other Sports
1%
Air Sports
0%
Winter Sports
1%
Gymnastic Activities
0%
Field/Track Sports
0%
Water Sports
0%
Other Violence
1%
Assaults With Blunt Instrument
6%
Gunshot Wound
4%
Other Vehicular: Unclassified
1%
All–Terrain Vehicle (ATV) and All–Terrain Cycle (ATC)
2%
Bicycle
3%
Motorcycle
10%
Motor Vehicle
33%
0%
25%
50%
75%
100%
Percent

100% of the abstracted people have valid data

1.8 Marital Status

1.8.0.1 Definition

Form 1 - Marital status at time just prior to injury.

Form 2 - Marital status at follow-up evaluation according to the best source of information (person with brain injury unless unavailable or unreliable).

1 - Single (Never Married) A person who has never married
2 - Married A person who is married, whether legally or by common law
3 - Divorced A person who is legally divorced
4 - Separated Includes both legal separation and living apart from a married partner

1.8.0.2 Form

[X] Form 1
[X] Form 2

1.8.0.3 Source

Form 1 Mar - Pre-Injury History (participant or proxy)
Form 2 MarF - Interview, Mail-Out (participant or proxy)

1.8.0.4 Details

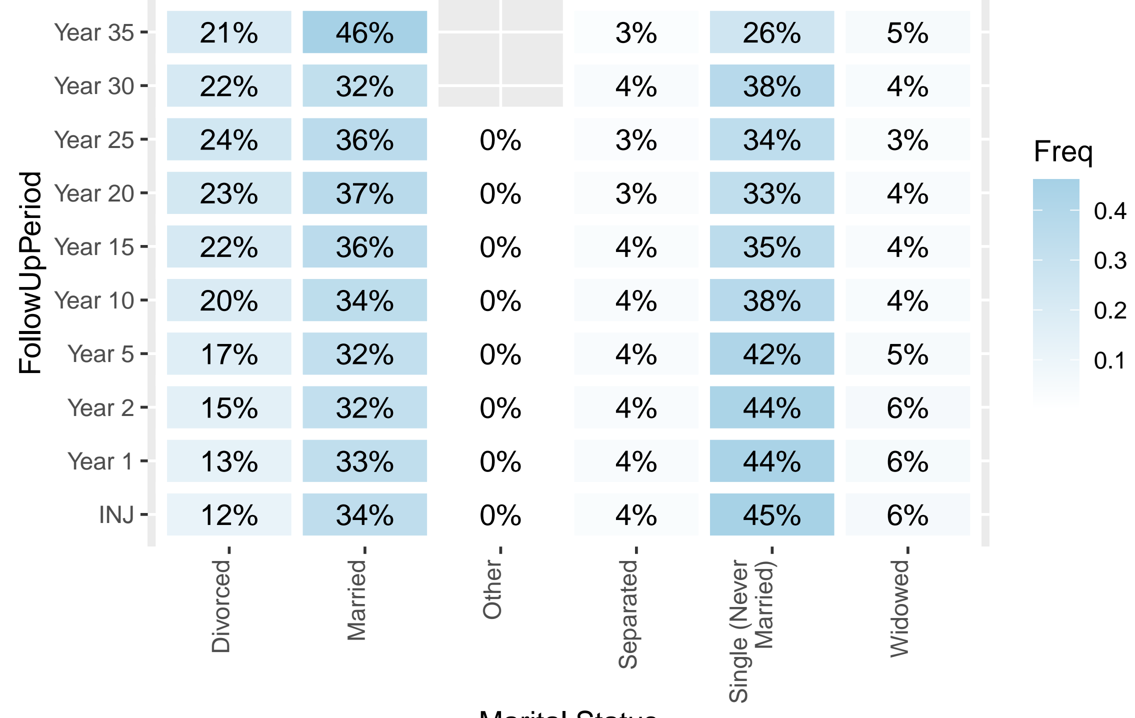
If separated but living together for more than 7 years, code as "2. Married".

Characteristic	Overall N = 82,363	INJ N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Year 10 N = 8,062	Year 1

1.8.0.5 Reference

UAB

Characteristic	Overall N = 82,363	INJ N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Year 10 N = 8,062	Year 1
Mar, n (%)							
Divorced	12,479 (15)	2,514 (12)	2,262 (13)	2,202 (15)	2,021 (17)	1,561 (20)	1,(
Married	27,194 (33)	7,192 (34)	5,589 (33)	4,834 (32)	3,770 (32)	2,754 (34)	1,7
Other	134 (0.2)	39 (0.2)	22 (0.1)	21 (0.1)	19 (0.2)	11 (0.1)	1
Separated	3,037 (3.7)	758 (3.5)	661 (3.9)	566 (3.8)	458 (3.9)	315 (3.9)	17
Single (Never Married)	34,656 (42)	9,745 (45)	7,502 (44)	6,523 (44)	4,928 (42)	3,012 (38)	1,7
Widowed	4,221 (5.2)	1,200 (5.6)	943 (5.6)	842 (5.6)	593 (5.0)	330 (4.1)	18
Missing	642	78	135	156	106	79	



100% of the abstracted people have valid data

99% of the interviewed people have valid data

1.9 Living Situation

1.9.0.1 Definition

Primary person with whom the person with TBI is living with at time of evaluation, according to the best source of information (person with brain injury unless unavailable or unreliable).

LivWhoInj - at time just prior to injury
LivWhoDis - at discharge from Rehabilitation
LivWhoF - Person Living with Currently: Primary

1.9.0.2 Form

[X] Form 1
[X] Form 2

1.9.0.3 Source

Form 1 LiveWhoInj - Pre-Injury History (participant or proxy)
Form 1 LivWhoDis - Abstraction (rehab record)
Form 2 LivWhoF - Interview, Mail-Out (participant or proxy)

1.9.0.4 Details

If living with more than one person, list the person most involved in the patient's life and care.

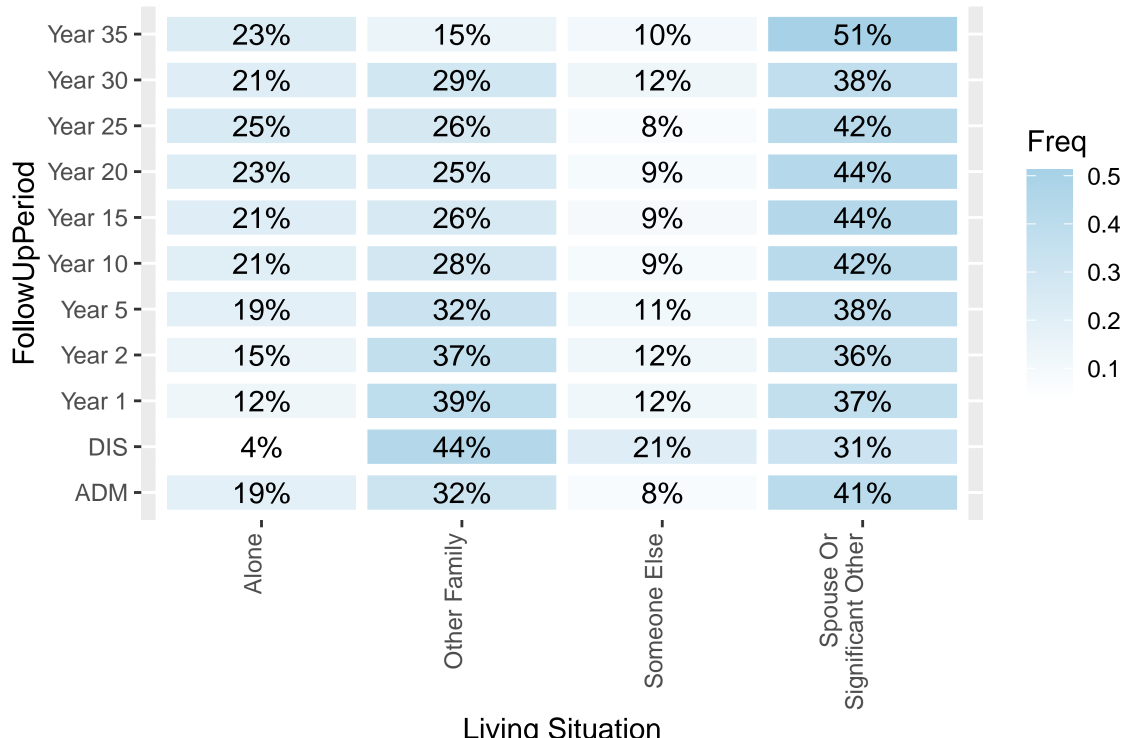
1.9.0.5 Characteristics

On 4/1/2022, the response categories were collapsed from the following coding choices;
1 - Alone; 2 - Spouse; 3 - Parent(s); 4 - Sibling(s); 5 - Child/Children Under 21 Years Of Age; 6 - Other Relative(s) Or Adult Child/Children 21 Years Of Age Or Older; 7 - Roommate(s) Or Friend(s); 8 - Significant Other; 9 - Other Patients; 10 - Other Residents (Group Living Situation); 11 - Personal Care Attendant; 77 - Other (Includes Correctional Facility Inmates); 99 - Unknown

…to the choices below;
1. Alone, 2. With spouse or significant other, 3. Other family, 4. Someone else, 99. Unknown (LivWhoDis has an additional code of 88-Not Applicable: Expired in Rehab.)

Existing cases were recoded as follows;
- Cases coded as '4 - Sibling(s)', '5 - Child/Children Under 21 Years Of Age', or '6 - Other Relative(s) Or Adult Child/Children 21 Years Of Age Or Older' were recoded to '3 - Other Family'.
- Cases coded as '7 - Roommate(s) Or Friend(s)', '9 - Other Patients', '10 - Other Residents (Group Living Situation)', '11 - Personal Care Attendant', '77 - Other (Includes Correctional Facility Inmates)', were recoded to '4. Someone else'.
- Cases coded as '8 - Significant Other' were recoded to '2 Spouse'.

Characteristic	Overall N = 103,889	ADM N = 21,526	DIS N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Y
LivWho, n (%)							
Alone	14,894 (14)	4,032 (19)	770 (3.6)	2,120 (12)	2,261 (15)	2,195 (19)	
Other Family	36,629 (36)	6,834 (32)	9,496 (44)	6,584 (39)	5,501 (37)	3,777 (32)	
Someone Else	12,815 (12)	1,723 (8.0)	4,475 (21)	2,036 (12)	1,779 (12)	1,304 (11)	
Spouse Or Significant Other	38,834 (38)	8,852 (41)	6,702 (31)	6,232 (37)	5,464 (36)	4,518 (38)	
Missing	717	85	83	142	139	101	



100% of the abstracted people have valid data

99% of the interviewed people have valid data

1.10 Residence

1.10.0.1 Definition

Where the person with brain injury is living:
ResInj - residence at the time just prior to injury
ResDis - residence at discharge from Rehabilitation
ResF - residence at the time of follow-up evaluation, according to the best source of information (person with brain injury unless unavailable or unreliable)

Residence Codes
1 - Private Residence Includes house, apartment, mobile home, foster home, condominium, dormitory (school, church, college), military barracks, boarding school, boarding home, rooming house, bunk-house, boys ranch, fraternity/sorority house, commune, migrant farmworkers camp

2 - Nursing Home/Subacute Care Includes medi-center, residential, institutions licensed as hospitals but providing essentially long-term, custodial, chronic disease care, etc.
3 - Adult Home Includes adult foster care, indep. living center, transitional living facility, assisted living, supported living, group home
4 - Correctional Institution Includes prison, jail, penitentiary, correctional center, labor camp, halfway house, etc.
5 - Hotel/Motel Includes YWCA, YMCA, guest ranch, inn
6 - Homeless Includes a shelter for the homeless
9 - Hospital: Other Includes mental hospital, inpatient drug treatment

1.10.0.2 Form

[X] Form 1
[X] Form 2

1.10.0.3 Source

Form 1 ResInj - Pre-Injury History (participant or proxy)
Form 1 ResDis - Abstraction (rehab record)
Form 2 ResF - Interview, Mail-Out (participant or proxy)

1.10.0.4 Details

If there is uncertainty regarding residence, treat it as a self-report variable. If residence is not clear, a reliable respondent (when possible, the person with TBI) should be asked, eg., “Where were you [the person with TBI] living (‘prior to injury’, or at ‘follow-up’)?”. If the response is ambiguous (as may happen, eg., if the person is transient) use probes in order to adequately understand the respondent’s belief regarding residence, then code that. Do not probe to obtain additional objective information about the living situation and then (the data collector) use that information in determining the correct code. When residence is at all ambiguous, treat it as a self-report variable.

Patients discharged to temporary living facilities while still enrolled in outpatient programs should be coded according to the level of supervision or assistance they receive. If the facility is for the use of patients and their families, code these transitional residences as “private residence” rather than an “adult home/transitional living facility”, as supervision or assistance in this setting would be provided by the family member or the attendant residing with the person, rather than by a staff overseeing a group of individuals which is more typical in an “adult home/transitional living facility.”

If participant is still in the hospital at follow-up, data collectors are encouraged to find out reason for hospitalization and if they will be discharged while still in the follow-up window. If participant is expected to still be hospitalized when the window closes, then code as '7-Hospital (Acute Care)'.

Code government or non-profit subsidized SRO (Single Resident Occupancy) housing as "3-Adult Home (Includes adult foster care, independent living center, transitional living facility, assisted living, supported living, group home)". Even though some of these vary from a single private room within a larger building or a full apartment, the space that they occupy could be viewed as a transitional and supported living situation given that it is not a permanent housing solution and/or it is funded by government/subsidy.

Participants living in a boat, RV or other living situation where they "take their home with them" should be coded as "Private Residence".

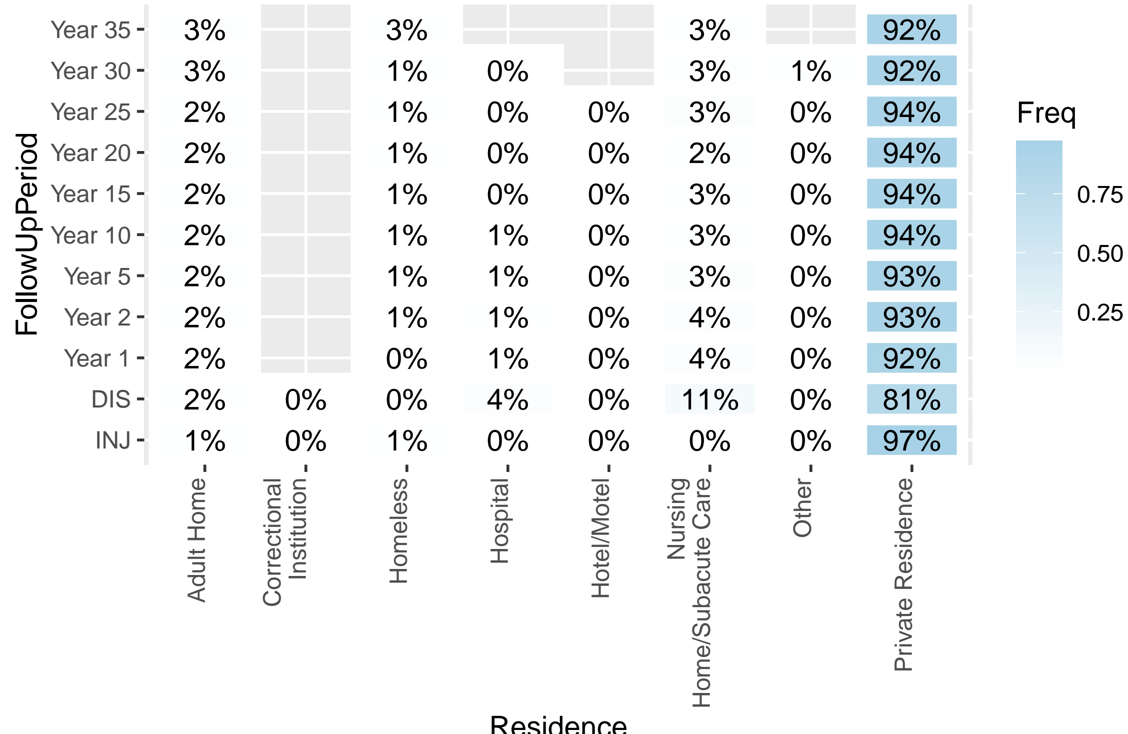
1.10.0.5 Links

List of Online Offender Database

1.10.0.6 Characteristics

Deleted the category "shelter" from code 01 and moved it to 06 as "shelter for the homeless" as of 10/1/2004 meaning that prior to this date, persons in that category are in 01 and after that date they are in 06.

Characteristic	Overall N = 103,889	INJ N = 21,526	DIS N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895
Res, n (%)						
Adult Home	1,827 (1.8)	151 (0.7)	508 (2.4)	283 (1.7)	307 (2.0)	250 (2.1)
Correctional Institution	34 (<0.1)	16 (<0.1)	18 (<0.1)	0 (0)	0 (0)	0 (0)
Homeless	576 (0.6)	206 (1.0)	44 (0.2)	74 (0.4)	80 (0.5)	71 (0.6)
Hospital	1,409 (1.4)	18 (<0.1)	957 (4.5)	199 (1.2)	104 (0.7)	64 (0.5)
Hotel/Motel	209 (0.2)	52 (0.2)	60 (0.3)	27 (0.2)	24 (0.2)	16 (0.1)
Nursing Home/Subacute Care	4,520 (4.4)	21 (<0.1)	2,428 (11)	741 (4.4)	529 (3.5)	361 (3.0)
Other	304 (0.3)	94 (0.4)	65 (0.3)	34 (0.2)	44 (0.3)	31 (0.3)
Private Residence	94,565 (91)	20,899 (97)	17,366 (81)	15,667 (92)	13,968 (93)	11,056 (93)
Missing	445	69	80	89	88	46



100% of the abstracted people have valid data

100% of the interviewed people have valid data

1.10.1 Urbanicity

1.10.1.1 Definition

AGE - This calculated variable determines the precise age, in full years, of the participant by comparing their fixed Date of Birth (Birth) against a flexible Reference Date (Injury Date or Follow-up Date). This logic is designed to be mathematically accurate, ensuring that the age in years reflects whether the participant's birthday had passed as of the specified reference date.

AGEF - Age at Follow-Up

AGENoPHI - Age Calculated for Non-PHI calculates age at injury without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

AGENoPHIF - Age at Follow-Up Calculated for Non-PHI calculates age at follow-up without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

BMI, BMIF - (Body Mass Index at Injury) (kg/m2) is calculated from height in inches and weight in pounds as [weight(lbs)/height(in)^2]*703

BMICat, BMICatF classifies BMI into categories between severely underweight to very severely obese, using the BMI calculated from height and weight

RuralF (Urbanicity) - Urbanization based on zip code of address.

1.10.1.2 Notes

AGEF - Calculates years from Birth to Follow-Up

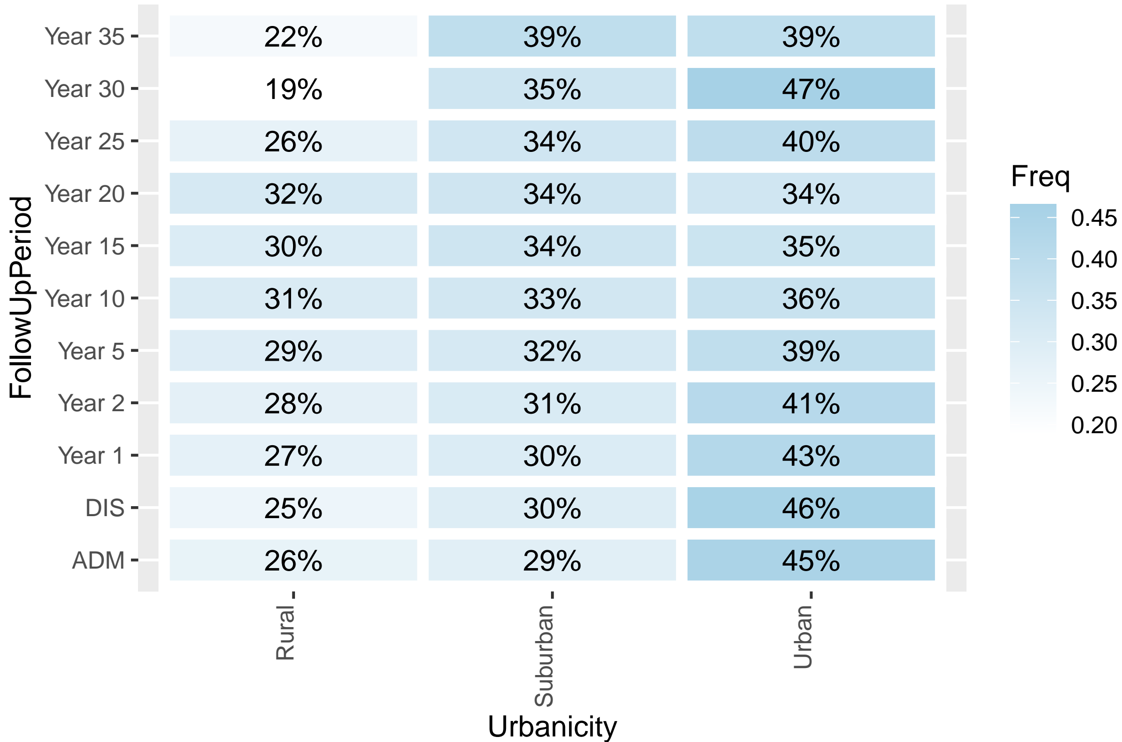
CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END AS AGE

AGENoPHIF - Calculates years from Birth to Follow-Up
(CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) >= 89 THEN 989 ELSE (CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) END AS AGENP

BMI, BMIF - If height or weight is not available or a subject had an arm or leg amputation, then BMI is not calculated.
- Computes BMI = Weight /Square(Height) *703 - 888 or 777 is BMI is not available or subject had an arm or leg amputation
- 999 or NULL is BMI is unknown

RURALF - Urbanicity classifies a person's location as urban, rural, or suburban based on their zip code. The mapping of zip codes to these categories come from a dataset located at http://greatdata.com/rural-urban-data/.

Characteristic	Overall N = 103,889	ADM N = 21,526	DIS N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Year 10 N = 8
Rural, n (%)							
Rural	26,009 (27)	5,000 (26)	4,697 (25)	4,201 (27)	3,892 (28)	3,307 (29)	2,388 (31)
Suburban	29,226 (31)	5,438 (29)	5,668 (30)	4,739 (30)	4,354 (31)	3,600 (32)	2,561 (33)
Urban	39,910 (42)	8,605 (45)	8,711 (46)	6,614 (43)	5,842 (41)	4,345 (39)	2,809 (36)
Missing	8,744	2,483	2,450	1,560	1,056	643	304



88% of the abstracted people have valid data

94% of the interviewed people have valid data

1.11 Education

1.11.0.1 Definition

EduYears - Highest grade of school completed at the time just prior to injury (Form 1)
EduYearsF - Number of years of education successfully completed at the time of follow-up interview (Form 2)

1.11.0.2 Form

[X] Form 1
[X] Form 2

1.11.0.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.11.0.4 Details

The number of years of education coded may not equal the actual number of years spent in school. For example, a person who is held back two years in elementary school and then drops out of school in the 10th grade (for a total of 11 full years) would be coded as having completed 9 years; or, a person may take 6 years to complete a BA (for a total of 18 years), but, as indicated, only 16 years are coded.

GED, trade school, and other types of schooling not listed, are not counted toward years of education

If person is not sure of number of years, code the greater number.

If person takes a few courses in a college setting with no intention of earning a degree, code "Work toward Associate's degree, no diploma".

If participant attended school in a foreign country, data collectors should prompt the participant to pick the most comparable category.

If during a follow-up, a participant or proxy reports a level of education that conflicts with the level of education previously reported (e.g. a lower level completed at follow-up than at Form 1 or a prior follow-up), confirm with the participant or proxy, and re-code the level of education in the database, as well as on any paper documents, to the correct level.

If a participant's intention changes (e.g. participant reports working towards an Associate's Degree at follow-up, but had previously reported working towards a Bachelor's Degree) do not change previous data.

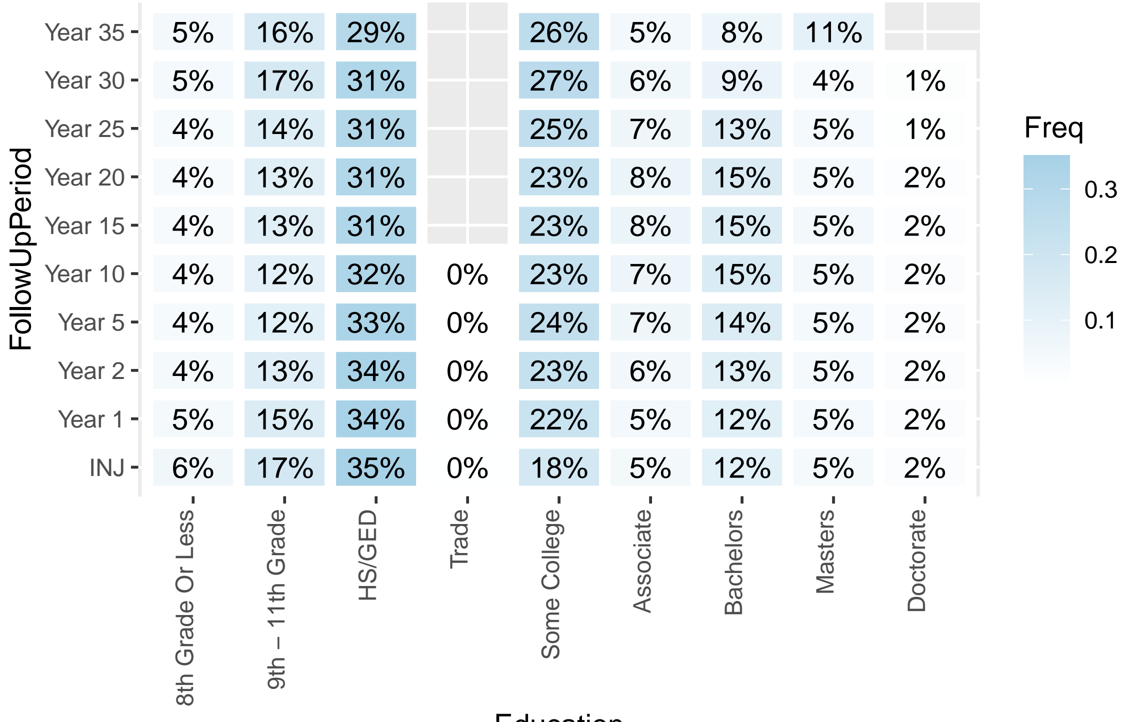
1.11.0.5 Reference

Heaton RK, Miller SW, Taylor MJ, Grant I. Revised Comprehensive Norms for an Expanded Halstead-Reitan Battery: Demographically Adjusted Neuropsychological Norms for African American and Caucasian Adults. Lutz, FL: Psychological Assessment Resources, Inc., 2004, pages 17-18.

1.11.0.6 Characteristics

All data on educational level are available in the calculated variable “EDUCATION” and “EDUCATION2”. This calculated variable merges data from the older variable “Highest grade of school completed”, which EDUYR and EduYearsF replaced on 1/1/01. Prior to 1/15/2010 this variable erroneously included cases with ‘’13=Work toward an Associate’s degree’ ’ and ‘’14=Associate’s degree’ ’ under ‘’5=Some College‘’. Cases with’‘15=Work toward a Bachelor’s degree’ ’ were erroneously included under ‘’6=Associate degree’ ’.

Characteristic	Overall N = 82,363	INJ N = 21,526	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Year 10 N = 8,062	Year 15 N
Education, n (%)							
8th Grade Or Less	3,832 (4.7)	1,290 (6.1)	793 (4.7)	665 (4.5)	479 (4.1)	291 (3.7)	178 (3
9th - 11th Grade	11,364 (14)	3,635 (17)	2,455 (15)	1,899 (13)	1,367 (12)	915 (12)	617 (1
HS/GED	27,223 (34)	7,421 (35)	5,782 (34)	5,034 (34)	3,835 (33)	2,517 (32)	1,531 (
Trade	165 (0.2)	73 (0.3)	45 (0.3)	24 (0.2)	18 (0.2)	5 (<0.1)	0 (0
Some College	17,517 (22)	3,770 (18)	3,637 (22)	3,486 (23)	2,816 (24)	1,822 (23)	1,133 (
Associate	4,897 (6.0)	1,078 (5.1)	909 (5.4)	874 (5.9)	765 (6.5)	594 (7.5)	396 (8
Bachelors	10,475 (13)	2,467 (12)	2,029 (12)	1,875 (13)	1,656 (14)	1,220 (15)	721 (1
Masters	3,932 (4.8)	974 (4.6)	814 (4.8)	724 (4.9)	572 (4.9)	415 (5.2)	258 (5
Doctorate	1,682 (2.1)	451 (2.1)	383 (2.3)	325 (2.2)	239 (2.0)	157 (2.0)	78 (1
Missing	1,276	367	267	238	148	126	72



98% of the abstracted people have valid data

99% of the interviewed people have valid data

1.11.1 Special Education

1.11.1.1 Definition

Pre-injury history of learning and/or behavior problems in school. Was the person with brain injury officially classified as Special Education student prior to his/her injury?

1.11.1.2 Form

[X] Form 1
[ ] Form 2

Special Education

Characteristic	N = 20,578
While in school, were you ever classified as a special education student?, n (%)	
No	18,588 (93)
Yes	1,505 (7.5)
Missing	485

1.11.1.3 Source

Pre-Injury History (participant or proxy)

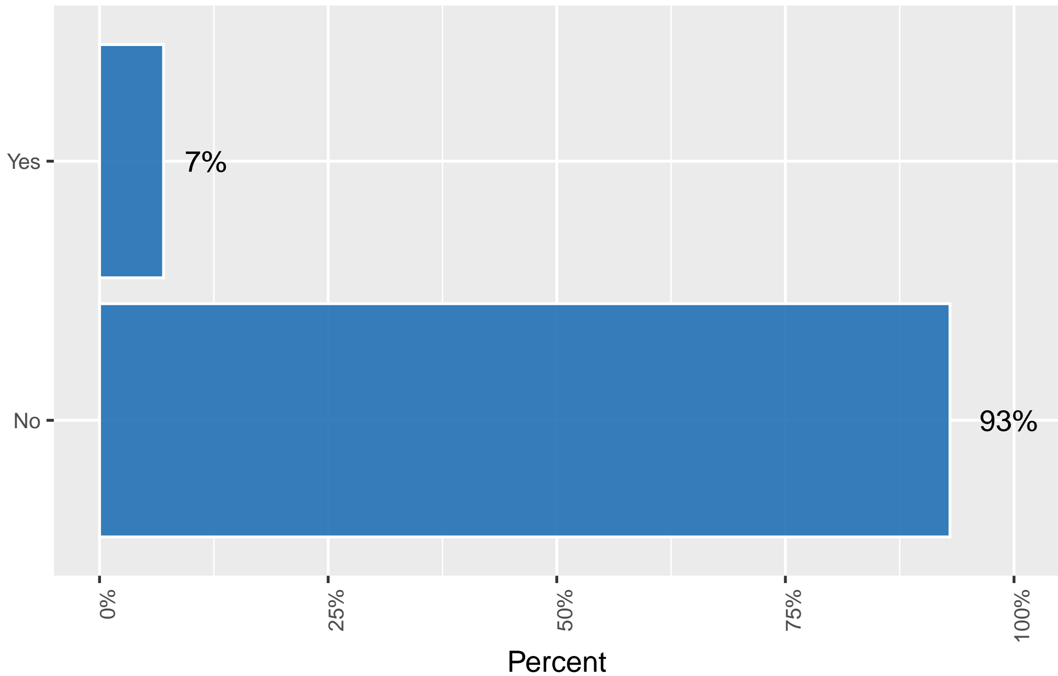
1.11.1.4 Details

Participants who express that they had difficulty with school or were held back a grade or two, but never classified as a special education student should be coded “No”.

Gifted programs do not count as special education.

1.11.1.5 Characteristics

Some cases older than 1/1/97 have data for this variable because Centers were encouraged to collect data retrospectively for older cases.



98% of the abstracted people have valid data

1.12 Employment

1.12.1 Primary Employment Status

1.12.1.1 Definition

Form 1
The purpose of the preinjury employment variables is to record the extent to which participants were engaging in productive work and, also, their personal earning power [Earn] at the time of injury. Whether employment was legal or illegal is not relevant to coding any of the employment variables. (But see NOTE below about collecting information about illegal employment.)

Code employment status in the month prior to injury.

Determine primary employment status using the following prioritization, regardless of the number of hours worked: competitive employment, degree-oriented education, taking

care of house or family, job-directed/on-the-job training, supported employment, sheltered employment, non-directed coursework, volunteer work, retirement (age-related), retirement (disability-related), and no productive activity.

Form 2
Code employment status at the time of the follow-up.

Employment Status Codes

2- Full Time Student Regular class
3 - Part Time Student Regular class
5 - Competitively Employed Minimum wage or greater, legal or illegal employment, *includes on leave with pay - not related to index injury.
8 - Special Employed Sheltered workshop, supportive employment, has job coach
10 - Unemployed: Looking Looking for work in the 4 weeks prior to injury
13 - Unemployed: Not looking Not looking for work in 4 weeks prior to injury for any reason
14 - Hospitalized Without Pay During Most of 4 Weeks Prior to Injury During Most of 4 Weeks Prior to Injury

1.12.1.2 Form

[X] Form 1
[X] Form 2

1.12.1.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.12.1.4 Details

Competitive Employment is employment for which an individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals who are not disabled.

If patient is in the hospital at the time of follow-up, employment status is that status existing at the time of admission to the hospital.

If participant is employed for only part of the month prior to the injury, code employment status as during the majority of the work days during that month.

If participant has been hired but has not yet started work, they should NOT be coded as competitively employed.

Students - Code student as full-time or part-time based on self-report.

- If participant is a student at the time of injury, but has not gone back to school yet at time of follow-up, they are still considered a student.

- If participant is not a student at the time of injury, but is planning on attending school, they should NOT be considered a student.

- If participant is regularly attending GED classes and not working, code Employment Status as “3-Part Time Student”.

Special Employment

- If participant returns to previous job, but is unable to complete all the duties they previously were responsible for without the assistance of others, code as ‘08 - Special Employment (sheltered workshop, supportive employment, has job coach)’.

Retirement

- Code “9 - Retired: Age-related” if respondent indicates that retirement was due to age (use respondent’s definition).
- If participant reports retiring due to fatigue (presumably “Retired: Disability” due to the brain injury) and due to the job not being the kind of work they were trained to do (ie “Retired: Other”), code according to the coding priority. The coding priority lists “Retired: Disability” but does not list “Retired: Other”, so “retired, disability” is the higher priority and is the correct code.
- The term “retired” can be used even if there has never been any competitive employment, so that based on age, one may consider themselves as retired.

Illegal Employment

- Competitive employment includes work that is illegal (e.g., selling drugs) as well as illegally engaging in legal work (e.g., non-citizens doing construction work without proper work authorization documentation).
- Do not ask the respondent if employment at the time of injury was legal or illegal. That distinction is not needed for any of the employment questions. If in the course of the interview you learn that some or all employment was illegal, continue asking the employment questions as long as providing that information does not become uncomfortable for the respondent and would therefore risk jeopardizing the rest of the interview.

Military

- Active Duty soldiers who have not yet returned to work should be coded as “13 - Unemployed: Not Looking”, and the rest of the employment variables as “NA - No competitive employment”.

Other

- Competitive sub-minimum wage employment such as baby-sitting, newspaper delivery, and piecework should be coded "55 - Other."

- If participant works in a foreign country, assume wage is not sub-minimum unless there is information to the contrary.

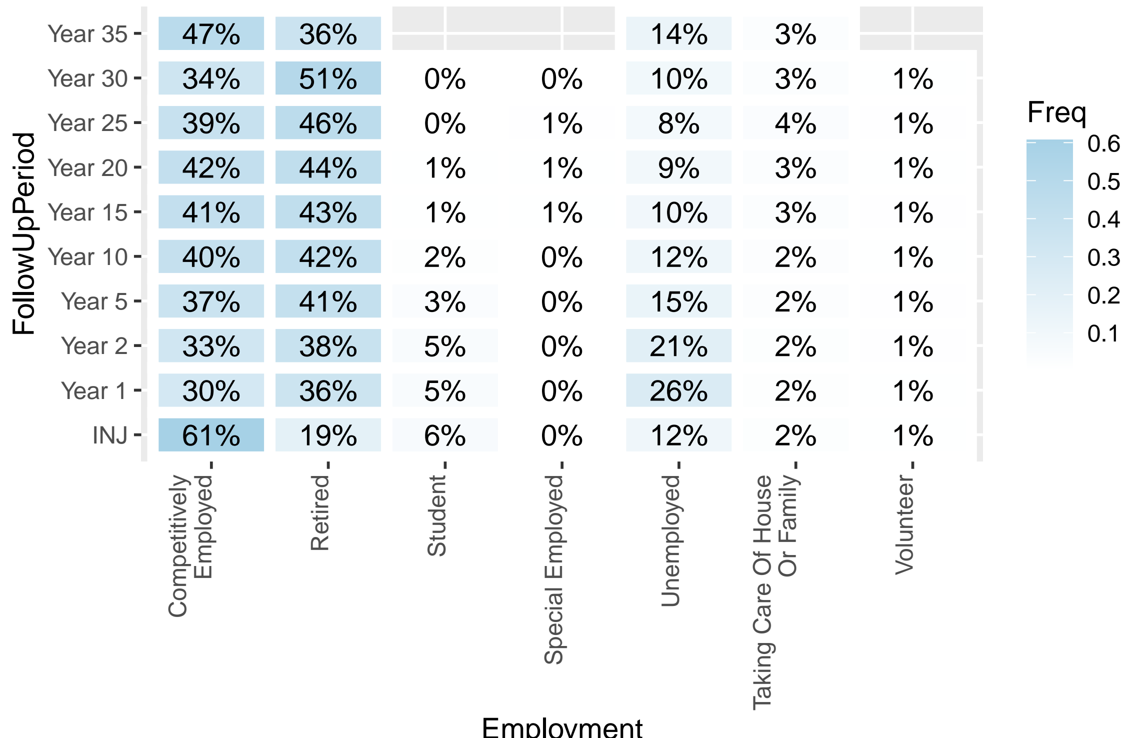
- Worker's compensation and temporary disability should both be coded "55-Other".
- Participants who are working in a "trial job" through workers compensation and not receiving any separate payment should be coded as "55 - Other".

1.12.1.5 Characteristics

Starting 7/1/01, data are entered into a new field that uses the additional coding categories implemented on 7/1/01. The old field has been retained in the database. Data for all cases is available in the calculated variable "EMPLOYMENT", which merges these two fields.

*As of 1/1/06, all cases with "77" were recoded as "55", in order to allow "77" to be used for "refused".

Characteristic	**Overall N = 82,363**	**INJ N = 21,526**	**Year 1 N = 17,114**	**Year 2 N = 15,144**	**Year 5 N = 11,895**	**Year 10 N = 8,06**
Employment, n (%)						
Competitively Employed	33,430 (42)	12,861 (61)	4,884 (30)	4,772 (33)	4,286 (37)	3,165 (40)
Retired	27,160 (34)	4,007 (19)	5,845 (36)	5,523 (38)	4,771 (41)	3,314 (42)
Student	3,493 (4.4)	1,291 (6.1)	869 (5.3)	745 (5.1)	403 (3.5)	125 (1.6)
Special Employed	317 (0.4)	45 (0.2)	67 (0.4)	63 (0.4)	50 (0.4)	34 (0.4)
Unemployed	13,280 (17)	2,469 (12)	4,260 (26)	3,049 (21)	1,717 (15)	967 (12)
Taking Care Of House Or Family	1,738 (2.2)	418 (2.0)	293 (1.8)	299 (2.0)	289 (2.5)	194 (2.5)
Volunteer	666 (0.8)	129 (0.6)	140 (0.9)	150 (1.0)	111 (1.0)	62 (0.8)
Missing	2,279	306	756	543	268	201



99% of the abstracted people have valid data

99% of the interviewed people have valid data

1.12.2 Occupational Status

1.12.2.1 Definition

OCC - The major census occupational category in which the patient's occupation is included for his/her primary occupation in the year prior to injury.

OCCF - The major census occupational category in which the patient's occupation is included for his/her primary occupation in the month prior to follow-up evaluation.

Instructions from Bureau of Census for collecting this information appear to not distinguish legal from illegal employment. The TBIMS Data Committee clarified that illegal employment is to be included (to take effect 1/1/06). See Employment Status for more information and for data collection instructions.

1.12.2.2 Form

[X] Form 1
[X] Form 2

1.12.2.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.12.2.4 Details

Form 2 - Code only if Employment Status is coded "05 - Competitively Employed" or "08 - Special Employed" for either the primary or secondary occupation. Otherwise this variable must be coded "888 - Not Applicable."

Code the patient's primary occupation. For a list of the specific occupations in each coding category, see the "1990 Census of Population Occupational Classification System", pages 9-22 of this document: See External Link. For instructions using this document see External Links.

Classification Principles listed in the Standard Occupational Classification User Guide may be followed to assist in coding occupational categories. Newer Standard Occupational Classifications may also be used to help categorize occupations not included in the list of 1990 Census Occupation Codes. (see External Link - Standard Occupational Classification User Guide)

If an occupation can be found using the newer SOC Classification and Coding Structure, try to identify other occupations in the same Minor Group that are included in the list of 1990 Census Occupation Codes. Select the 1990 classification that includes other occupations in the same SOC Classification and Coding Minor Group. If other occupations in the same Minor Group are not included in the list of 1990 Census Occupation Codes, try to find other occupations in the same Major Group. Note: There is a search function on the left side of the SOC webpage that is extremely helpful for finding occupations under their Major Group.

Example: Interpreter; Major Group = Arts, Design Entertainment, Sports, and Media Occupations; Minor Group = Media and Communication Workers; Other occupations under Media and Communication Workers = Public Relations Specialists and Announcers; 1990 Classification for Public Relations Specialists and Announcers = Professional Specialty Occupations.

Data collectors should clarify duties involved with ambiguous job titles to ensure accurate assignment of occupational category as needed.

Occupation at Admission

Characteristic	N = 12,861
Occupation, n (%)	
Administrative Support Including Clerical	691 (5.4)
Executive, Administrative, And Managerial	1,219 (9.6)
Farming, Forestry, And Fishing	354 (2.8)
Handlers, Equipment Cleaners, Helpers, And Laborers	1,722 (13)
Machine Operators, Assemblers, And Inspectors	722 (5.7)
Military Occupations	36 (0.3)
Precision Production, Craft, And Repair	2,005 (16)
Private Household	73 (0.6)
Professional Specialty	1,615 (13)
Protective Service	276 (2.2)
Sales	1,003 (7.9)
Service, Except Protective And Household	1,684 (13)
Technicians And Related Support	640 (5.0)
Transportation And Material Moving	719 (5.6)
Missing	102

1.12.2.5 Links

1990 Census Occupation Codes
Standard Occupational Classification User Guide

1.12.2.6 Reference

1990 Occupational Classification System, Alphabetical Index of Industries and Occupations, 1990 Census of Population and Housing, Bureau of the Census, U.S. Department of Commerce, pp 9-22. See External Links

Of the people competitivly employed…

99% of the abstracted people have valid data

96% of the interviewed people have valid data

Occupation at Followup

Characteristic	N = 20,569
Occupation, n (%)	
Administrative Support	1,290 (6.5)
Executive, Administrative, And Managerial	2,424 (12)
Farming, Forestry, And Fishing	449 (2.3)
Handlers, Equipment Cleaners, Helpers, And Laborers	2,079 (10)
Machine Operators, Assemblers, And Inspectors	975 (4.9)
Military Occupations	28 (0.1)
Precision Production, Craft, And Repair	2,054 (10)
Private Household	94 (0.5)
Professional Specialty	3,454 (17)
Protective Service	380 (1.9)
Sales	1,865 (9.4)
Service, Except Protective And Household	2,464 (12)
Technicians And Related Support	1,341 (6.8)
Transportation And Material Moving	941 (4.7)
Missing	731

1.13 Substance Use

1.13.1 Smoking Tobacco

1.13.1.1 Definition

Form 1 - At the time of your injury, or just prior to your injury, did you smoke cigarettes every day, some days or not at all?
Form 2 - Do you currently smoke cigarettes everyday, some days or not at all?

1.13.1.2 Form

[X] Form 1
[X] Form 2

1.13.1.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.13.1.4 Details

These measures are to be collected from best source available for the Form I Pre-Injury History Questionnaire/Interview. Do not be influenced by information about smoking habits that may be available from hospital records, etc.

If unable to get patient's response, get information from family. If unable to get family's response, then use medical chart.

Base the data recorded for these questions on self-response.

For cigarettes, do not include: electronic cigarettes (e-cigarettes, NJOY, Bluetip), herbal cigarettes, cigars, cigarillos, little cigars, pipes, bidis, kreteks, water pipes (hookahs), or marijuana.

1.13.1.5 Reference

Cigarette Smoking
BRFSS 7.2 - national and state norms

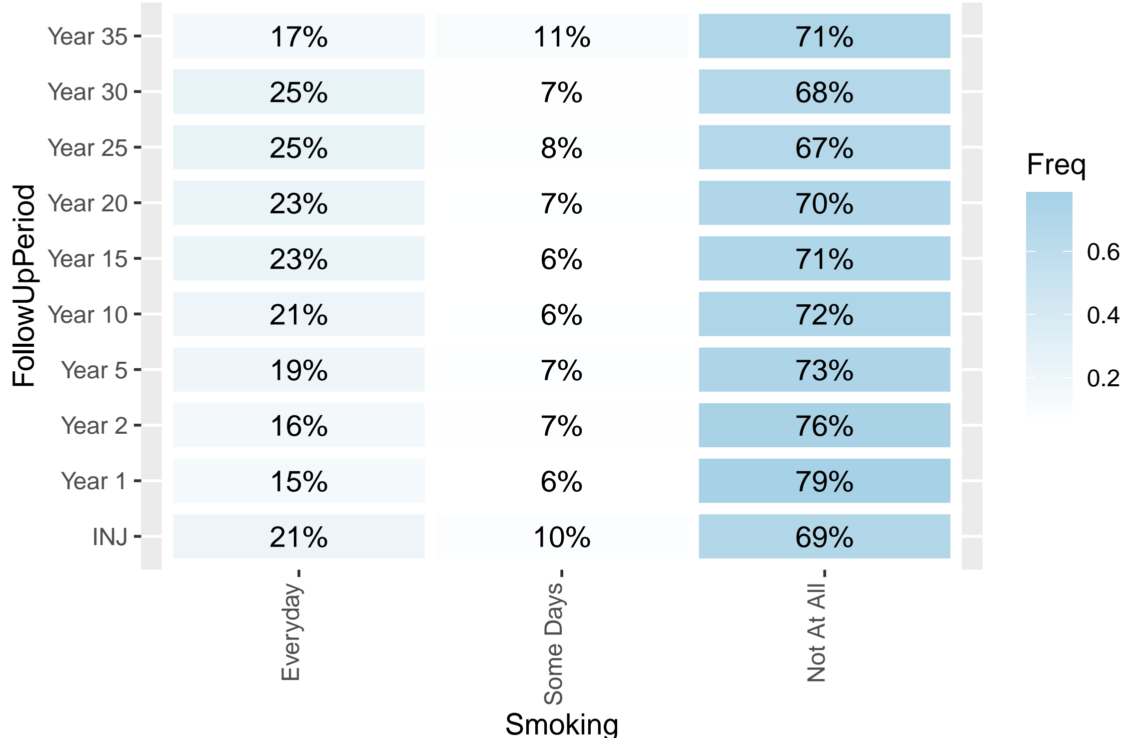
1.13.1.6 Characteristics

On 4/1/2013 codes were changed, and existing cases were re-coded in the database.

Codes at implementation:
1 - Everyday
2 - Some Days
3 - Not At All

Codes on/after 4/1/2013:
1 - Not At All
2 - Some Days
3 - Everyday

Characteristic	Overall N = 46,832	INJ N = 9,872	Year 1 N = 8,269	Year 2 N = 7,664	Year 5 N = 7,108	Year 10 N = 6,029	Year 15 N = 4,468
Smoking, n (%)							
Everyday	8,797 (19)	2,037 (21)	1,227 (15)	1,205 (16)	1,334 (19)	1,229 (21)	990 (23)
Some Days	3,339 (7.4)	946 (9.7)	479 (6.0)	533 (7.2)	509 (7.4)	376 (6.5)	267 (6.2)
Not At All	33,212 (73)	6,760 (69)	6,268 (79)	5,621 (76)	5,017 (73)	4,217 (72)	3,079 (71)
Missing	1,484	129	295	305	248	207	132



99% of the abstracted people have valid data

96% of the interviewed people have valid data

1.13.2 Alcohol Drinking Category

1.13.2.1 Definition

Form 1 - Drinking habits during the month prior to the injury

Form 2 - Drinking habits during the month prior to the follow-up

A "drink" is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. See External Links.

1.13.2.2 Form

[X] Form 1
[X] Form 2

1.13.2.3 Source

Form 1 - Pre-Injury History (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

1.13.2.4 Details

For ALCAnyDrink:
- If coded "0. No" ALCWeek through ALC4Drinks will be autofilled with "888. Not Applicable."
- If coded "77. Refused", ALCWeek through ALC4Drinks will be autofilled with '777. Refused."
- If coded "66. Variable Did Not Exist", ALCWeek through ALC4Drinks will be autofilled with "666 = Variable Did Not Exist."
- If coded "99. Unknown", ALCWeek through ALC4Drinks will be autofilled with "999 = Unknown"

Base the data recorded for these questions on self-response. Do not be influenced by information about drinking habits that may be available from hospital records, etc.

If cannot get patient's response, get family, if not family then medical chart.

Use the higher score if a range (in # of drinks) is given.

If participant states they only drink once or twice a month, code "Drinks per Week" as "1".

Probe for size of drink, and adjust scoring according to answer received.

A "drink" is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. See External Links.

1.13.2.5 Links

Standard Drink Chart
Substance use - Probelmatic Substance Use Identified in the TBIMS National Dataset

1.13.2.6 Reference

Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System User's Guide. Atlanta: U.S. Department of Health and Human Services, 1998. National Household Survey on Drug Abuse. Substance Abuse and Mental Health Services Administration, Office of Applied Studies.

1.13.2.7 Characteristics

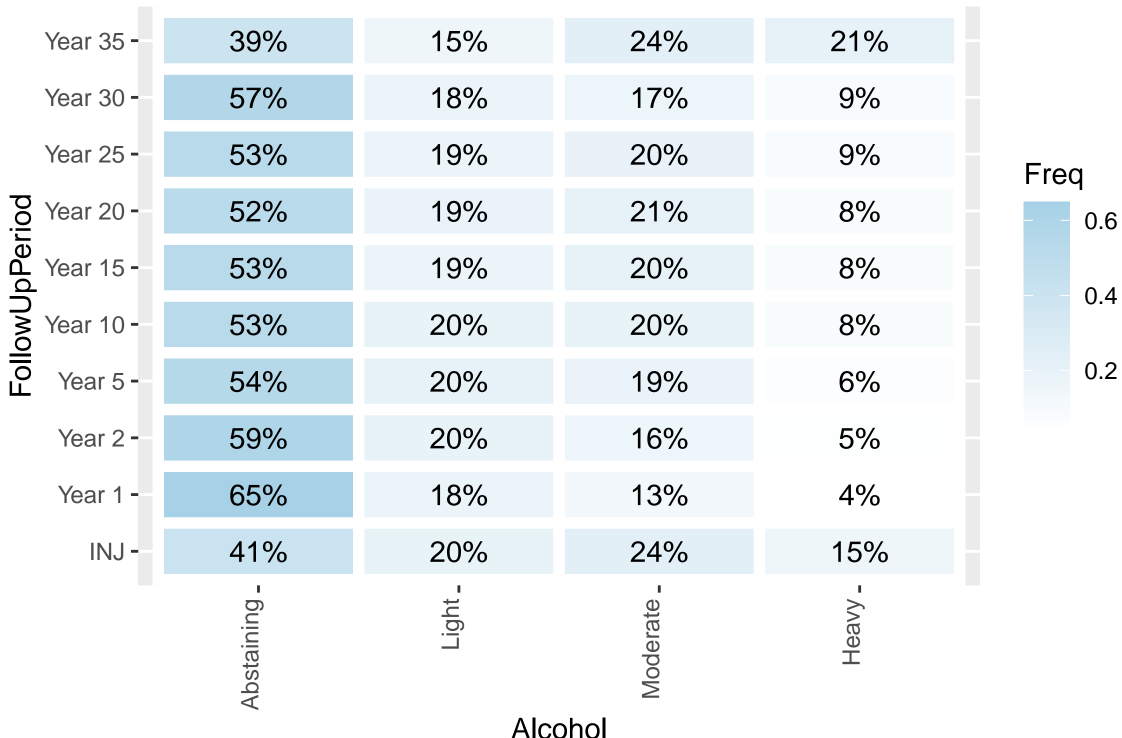
A report on substance use that is based on TBIMS data can be found on COMBI: See Links.

QFVI was added to the Form I database as one of the premorbid history questions on 1/1/97. The QFVI was dropped from both Form I and Form II on 10/1/99 and replaced with alcohol questions from NHSDA and BRFSS module 13. The QFVI data are available in a separate database.
Some cases older than 1/1/97 have data for this variable because Centers were encouraged to collect these data retrospectively for older cases.

STARTING 4/1/04 (version 9.5), THE “7” AND “9” CODES WERE REVERSED IN ORDER TO BE CONSISTENT WITH OTHER VARIABLES (7/77=refused, 9/99=unknown/don’t know/not sure). WHEN WORKING WITH DATA COLLECTION FORMS 9.4 AND EARLIER KEEP IN MIND THAT 7’s ON THE FORM SHOULD APPEAR AS 9’s IN THE DATABASE AND VICE VERSA. TAKE THIS INTO ACCOUNT WHEN DATA ON 9.4 OR EARLIER FORMS ARE BEING CORRECTED, OR COMPARED TO DATA IN THE DATABASE.

In 2003, three Model Systems had difficulty collecting part 1 of this item (the same three Model Systems that had difficulty collecting V192a1:Premorbid Drug Use). (10% or more missing data). Between six and eight Model Systems had difficulty collecting the 3 parts of this item.

Characteristic	Overall N = 79,300	INJ N = 19,935	Year 1 N = 16,432	Year 2 N = 14,634	Year 5 N = 11,630	Year 10 N = 8,047	Year 15 N = 4
Alcohol, n (%)							
Abstaining	40,441 (54)	7,665 (41)	10,144 (65)	8,249 (59)	6,054 (54)	4,037 (53)	2,518 (53
Light	14,679 (20)	3,643 (20)	2,890 (18)	2,786 (20)	2,282 (20)	1,541 (20)	894 (19)
Moderate	14,134 (19)	4,529 (24)	2,042 (13)	2,232 (16)	2,137 (19)	1,514 (20)	976 (20)
Heavy	5,968 (7.9)	2,763 (15)	572 (3.7)	687 (4.9)	698 (6.2)	587 (7.6)	376 (7.9)
Missing	4,078	1,335	784	680	459	368	220



93% of the abstracted people have valid data

95% of the interviewed people have valid data

1.14 BMI CAT

1.14.0.1 Definition

Height
Form 1 - Height at baseline (in inches) as documented in either the acute hospital medical record or rehabilitation record.
Form 2 - “How tall are you without shoes?”

Weight
Form 1 - Weight (in pounds) at acute hospitalization as documented in the acute hospital medical record.
Form 2 - “How much do you weigh without shoes?”

1.14.0.2 Form

[X] Form 1
[X] Form 2

1.14.0.3 Source

Form 1 Height - Abstraction (acute or rehab record) Form 2 HeightF - Interview, Mail-out (participant or proxy) Form 1 Weight - Abstraction (acute record) Form 2 WeightF - Interview, Mail-Out (participant or proxy)

1.14.0.4 Details

Height at baseline can be collected from either the acute hospital medical record or rehabilitation record.

Weight should reflect the first measurement taken during acute hospitalization using a scale or bed scale. If unable to determine if recorded weights were measured using a scale or bed scale, use the first recorded weight in the acute hospital medical record. EMS or paramedic reports should not be used to collect weight.

Round up if half inches or pounds are reported.

If the participant notes any arm or leg amputation(s) when asked about height and weight, code 888 - Not Applicable (Any Arm Or Leg Amputation). The Data Collector does NOT need to probe for amputations when asking the height and weight questions.

If there is a height discrepancy between Form 1 and any height reported during follow-up, height should be verified at the next follow-up, and the discrepancy should be corrected on the Form 1 or Form 2 (database and paper file).

1.14.0.5 Reference

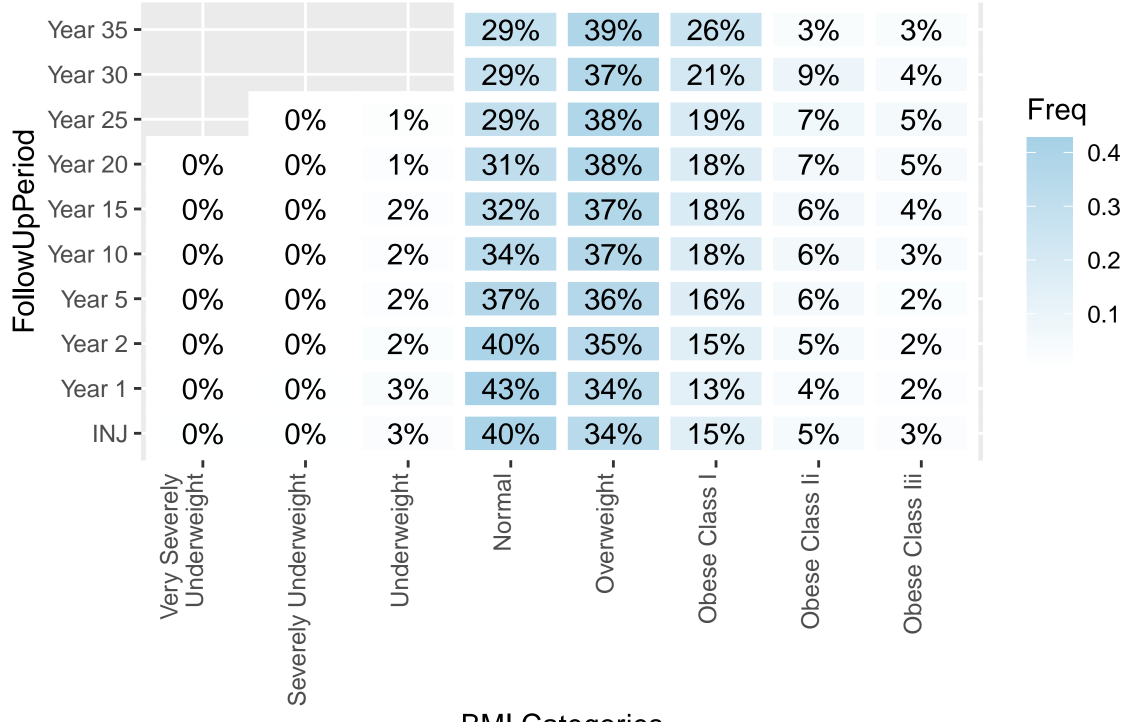
CDC :BMI obesity rate by state; M #53, #54

CDC Survey: The State of Aging and Health in America report assesses the health status and health behaviors of U.S. adults aged 65 years and older and makes recommendations to improve the mental and physical health of all Americans in their later years. The report includes national- and state-based report cards that examine 15 key indicators of older adult health. Data is available for 2003-2004 and 2006-2007.

NHIS National Health Interview Survey (NHIS)

The National Health Interview Survey (NHIS) has monitored the health of the nation since 1957. NHIS data on a broad range of health topics are collected through personal household interviews. For over 50 years, the U.S. Census Bureau has been the data collection agent for the National Health Interview Survey. Survey results have been instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.

Characteristic	Overall N = 46,832	INJ N = 9,872	Year 1 N = 8,269	Year 2 N = 7,664	Year 5 N = 7,108	Year 10 N = 6,029	Year 15
BMICat, n (%)							
Very Severely Underweight	76 (0.2)	31 (0.3)	13 (0.2)	16 (0.2)	4 (<0.1)	3 (<0.1)	6
Severely Underweight	106 (0.2)	30 (0.3)	23 (0.3)	17 (0.2)	14 (0.2)	10 (0.2)	1
Underweight	998 (2.2)	265 (2.7)	227 (2.9)	163 (2.3)	141 (2.1)	92 (1.6)	6
Normal	16,771 (38)	3,894 (40)	3,312 (43)	2,866 (40)	2,465 (37)	1,918 (34)	1,3
Overweight	15,786 (36)	3,314 (34)	2,672 (34)	2,508 (35)	2,429 (36)	2,098 (37)	1,5
Obese Class I	7,061 (16)	1,466 (15)	1,044 (13)	1,075 (15)	1,097 (16)	1,018 (18)	77
Obese Class Ii	2,343 (5.3)	474 (4.9)	307 (4.0)	353 (4.9)	372 (5.6)	349 (6.1)	27
Obese Class Iii	1,219 (2.7)	244 (2.5)	150 (1.9)	161 (2.2)	156 (2.3)	190 (3.3)	16
Missing	2,472	154	521	505	430	351	



98% of the abstracted people have valid data

94% of the interviewed people have valid data

1.15 BMI

1.15.0.1 Definition

AGE - This calculated variable determines the precise age, in full years, of the participant by comparing their fixed Date of Birth (Birth) against a flexible Reference Date (Injury Date or Follow-up Date). This logic is designed to be mathematically accurate, ensuring that the age in years reflects whether the participant's birthday had passed as of the specified reference date.

AGEF - Age at Follow-Up

AGENoPHI - Age Calculated for Non-PHI calculates age at injury without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

BMI

Characteristic	**INJ** N = 9,872	**Year 1** N = 8,269	**Year 2** N = 7,664	**Year 5** N = 7,108	**Year 10** N = 6,029
BMI at Injury					
N Non-missing	9,717	7,747	7,159	6,678	5,678
Mean (SD)	26.6 (5.6)	26.2 (5.4)	26.6 (5.5)	27.0 (5.5)	27.6 (5.6)
Median (Q1, Q3)	25.8 (22.8, 29.5)	25.4 (22.5, 29.0)	25.8 (22.9, 29.5)	26.4 (23.1, 30.0)	26.6 (23.6, 30.6)
Min, Max	9.2, 73.0	11.8, 76.8	12.6, 86.6	11.8, 71.1	14.3, 59.7
Missing	155	522	505	430	351

AGENoPHIF - Age at Follow-Up Calculated for Non-PHI calculates age at follow-up without Protected Health Information by grouping people greater than or equal to the age of 89 so they can't be identified.

BMI, BMIF - (Body Mass Index at Injury) (kg/m2) is calculated from height in inches and weight in pounds as [weight(lbs)/height(in)^2]*703

BMICat, BMICatF classifies BMI into categories between severely underweight to very severely obese, using the BMI calculated from height and weight

RuralF (Urbanicity) - Urbanization based on zip code of address.

1.15.0.2 Notes

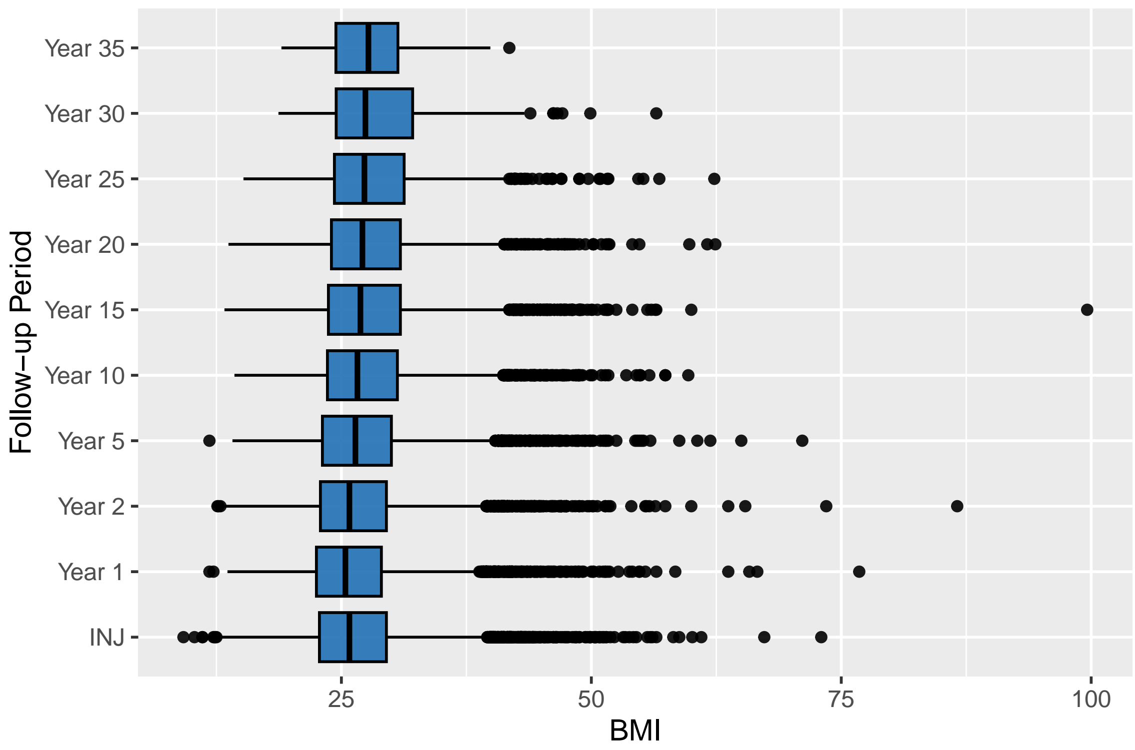
AGEF - Calculates years from Birth to Follow-Up

CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END AS AGE

AGENoPHIF - Calculates years from Birth to Follow-Up
(CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) >= 89 THEN 989 ELSE (CASE WHEN DATEADD(year, DATEDIFF(year, Birth, Injury), Birth) > Injury THEN DATEDIFF(year, Birth, Injury) - 1 ELSE DATEDIFF(year, Birth, Injury) END) END AS AGENP

BMI, BMIF - If height or weight is not available or a subject had an arm or leg amputation, then BMI is not calculated.
- Computes BMI = Weight /Square(Height) *703 - 888 or 777 is BMI is not available or subject had an arm or leg amputation
- 999 or NULL is BMI is unknown

RURALF - Urbanicity classifies a person's location as urban, rural, or suburban based on their zip code. The mapping of zip codes to these categories come from a dataset located at http://greatdata.com/rural-urban-data/.


Year 35
Year 30
Year 25
Year 20
Year 15
Year 10
Year 5
Year 2
Year 1
INJ
Follow−up Period
25
50
75
100
BMI

2 Severity

2.1 Post Traumatic Amnesia (PTA)

2.1.0.1 Definition

Date of emergence from Post-traumatic Amnesia (PTA).

Where possible, PTA emergence should be measured (tracked) prospectively by direct testing. With prospective tracking, emergence from PTA is defined as:

1) two consecutive GOAT scores of 76 or greater with no more than 2 full calendar days between assessments (Assessment 1 = Friday, Assessment 2 = Monday, two full days = Saturday, Sunday)

2) two consecutive scores of 11 or greater on the Revised GOAT with no more than 2 full calendar days between assessments (Assessment 1 = Friday, Assessment 2 = Monday, two full days = Saturday, Sunday)

3) two consecutive scores of 25 or greater on the Orientation-Log with no more than 2 full calendar days between assessments (Assessment 1 = Friday, Assessment 2 = Monday, two full days = Saturday, Sunday)

4) two consecutive scores of 8 or greater on the Non-Verbal version of the Orientation-Log with no more than 2 full calendar days between assessments (Assessment 1 = Friday, Assessment 2 = Monday, two full days = Saturday, Sunday), or

5) in the judgment of a qualified clinician (i.e., speech-language pathologist, physician, neuropsychologist), the person has cleared PTA but administration of an orientation test is not possible due to language functioning.

The day of clearance of PTA is the first day the person gets the first of 2 consecutive scores of 76 or greater on the GOAT, the first of 2 consecutive scores of 11 or greater on the Revised GOAT, the first of 2 consecutive scores of 25 or greater on the Orientation-Log, or the first of 2 consecutive scores of 8 or greater on the Non-Verbal version of the Orientation-Log.

If within a 7-day period, there are multiple scores exceeding the PTA cut-off, but the first two are separated by more than two full calendar days (e.g. Assessment 1 = Friday, Assessment 2 = Tuesday; this would be 3 full calendar days apart), then it is acceptable to use the midpoint between the first and second dates the PTA assessment was administered.

It is the choice of the Project Director as to whether to use the GOAT, Revised GOAT (Bode, Heinemann, & Semik, 2000 – see SOURCES) or the Orientation-Log (Jackson, Novack, & Dowler, 1998; Novack, Dowler, Bush, Glen, & Schneider, 2000 – see SOURCES) to establish the duration of PTA. Alternating use of the scales in an individual patient is not acceptable, however. Preferably, copies of the test protocols documenting PTA tracking should be kept in the research record. If the PTA data is elsewhere (e.g., in the rehabilitation chart), the location should be noted in the research record.

The Non-Verbal version of the Orientation-Log is the preferred assessment of orientation for persons with traumatically induced expressive language disorder with significant difficulty generating comprehensible verbal output. Common causes for this problem include expressive aphasia and severe dysarthria accompanied by an inability to write responses. Non-verbal responses are scored according to the following criteria: 1 = correct upon multiple choice / 0 = incorrect or no response. This scoring adjustment is intended to be used only for non-verbal individuals with significant difficulty generating comprehensible verbal or written output. Careful clinical judgment will be required in each case to determine that the person's expressive problems are clearly due to neurological disorder, and the person is unable to respond in writing.

Determining Date of PTA Emergence During Acute Care

For those patients who are already oriented at rehabilitation admission (as defined by the first two GOAT scores after rehabilitation admission >75), prospective tracking of the date of emergence from PTA is not possible, because the date falls within the acute care stay. In these cases, PTA emergence can be determined via chart review of the acute care records only. (NOTE: Rehabilitation hospital charts may NOT be used for this purpose). The following procedure can be used to determine the length of PTA based on acute care hospital records. This procedure should be followed only for those patients who are oriented at rehabilitation admission.

1. Obtain all available physician, nursing and therapy notes from the acute hospitalization. In most hospital medical records, physician, nursing and therapy notes are filed in different sections. You may have to specifically request therapy and nursing notes, if you routinely only receive the physician progress notes.
2. Review all notes to determine the first DATE on which all notes referencing orientation indicate that the patient is fully oriented, oriented X 3 (or 4), or GCS Verbal Score = 5 (oriented). This is Orientation Day 1.
3. Review notes from the next calendar day to determine if all relevant notes again indicate that the patient is fully oriented.

4. If yes, the second day is Orientation Day 2, and Orientation Day 1 is the resolution date of PTA. If there are missing notes or no comments about orientation on the second day, keep looking for the second day that the notes consistently document full orientation. As long as Orientation Day 2 is no more than 2 full calendar days from Orientation Day 1, and if no notes from intervening days indicate less than full orientation, record Orientation Day 1 as the resolution date of PTA.
5. If any note from calendar days intervening between Orientation Days 1 and 2 indicate less than full orientation, use Day 2 as the new starting point (i.e., new Day 1) and repeat procedure from Step 3 above.
6. If there is no Orientation Day 2 (i.e., if the patient is never fully oriented on more than one day; or if more than 2 full calendar days elapse after Orientation Day 1 with no further notation about orientation), code date of PTA resolution as unknown. An exception would be if on the day before or the day of transfer to rehabilitation, the patient is specifically noted not to be oriented. If the patient then produces GOATs >75 on the first two examinations after rehabilitation admission, code the date of PTA resolution in the usual manner.

2.1.0.2 Form

[X] Form 1
[ ] Form 2

2.1.0.3 Source

Form 1 - Abstraction (acute record only) or measured by direct O-Log or GOAT testing (rehab record)

2.1.0.4 Details

Administer the test every 1 to 3 calendar days until patient emerges from PTA.

There is no code for “unknown” for method of PTA determination because this should never be unknowable. Please contact the TBINDC if you are in a situation in which this variable is truly unknown (and unknowable).

Code date of admission to ER if person was never in PTA.

If PTA lasts less than 24 hours, code day 2 as the date of emergence from PTA, since this would be the first day that they were fully oriented.

If participant was not out of PTA at Rehab discharge score is coded as “888. Person Still in PTA at time of Rehab Discharge”.
If a person was never in PTA the days = 0.

For cases who do not emerge from PTA by rehab discharge, code the method used to decide if the patient is still in PTA.

The same instrument must be used for all scores to capture the date emerged from PTA during rehabilitation. GOAT and O-Log scores may not be mixed and matched.

Record review can not be used to determine Date Emerged from PTA during rehab. If PTA was not tracked with GOAT or O-Log during rehab and patient did not emerge during the acute stay, Date Emerged from PTA should be coded as “09/09/9999 (Unknown)”, and Method of Determination should be coded as “88. (N/A PTA Not Tracked)”.

Patients who don’t have any documented GOAT or O-Log scores possibly due to other cognitive deficits (e.g. “confused due to dementia’ ‘) and formal testing may not have been possible should be’‘09/09/999 - Unknown’ ’ rather than ‘’08/08/8888 - Never Emerged.’ ’ The method of PTA determination should be coded as ‘88. PTA has not been tracked.’. Record review cannot be used to determine emergence from PTA during rehab.

If an acute record states “patient is A&O x3 with choices”, and the patient has aphasia or some other expressive language disorder, then testing with choices would be appropriate to asses orientation and would count as being oriented.

Computer calculates duration of post-traumatic amnesia by subtracting the date of injury from this date.

Duration of PTA is calculated only for those cases which emerge from PTA prior to discharge from inpatient rehabilitation.

Duration of PTA is not to be calculated from date of emergence from coma [FLLW], per decision of the neuropsychology databusters group.

Two consecutive GCS Verbal scores of “5-Oriented” may be used to determine length of PTA when there is no other source of documentation using acute chart review.

For cases who never had PTA, code “Method of PTA Determination” as “1-Acute Chart Review”.

2.1.0.5 Links

PTA - Introduction to O-Log (COMBI)
PTA - O-Log frequently asked questions (COMBI)
PTA - O-Log Syllabus (COMBI)
PTA - O-Log Rating Form (COMBI
PTA - O-Log Properties (COMBI)

PTA - O-Log References (COMBI)
PTA - Bode RK, Heinemann, AW, Semik P. for v144a
PTA - Jackson WT, Novack TA, Dowler RN for v144a
PTA - Novack TA, Dowler RN, Bush BA, Glen T, Schneider JJ. for v144a
PTA - Levin, HS, O'Donnell, VM, & Grossman, RG for v144a

2.1.0.6 Reference

GOAT: Levin, HS, O'Donnell, VM, & Grossman, RG. (1979). The Galveston Orientation and Amnesia Test: A practical scale to assess cognition after head injury. Journal of Nervous and Mental Diseases, 167, 675-684. See External Links

Revised GOAT: Bode RK, Heinemann AW, Semik P. Measurement properties of the Galveston Orientation and Amnesia Test (GOAT) and improvement patterns during inpatient rehabilitation. J Head Trauma Rehabil. 2000 Feb;15(1):637-55. See External Links

Orientation-Log (and Non-Verbal version of the Orientation-Log): Jackson WT, Novack TA, Dowler RN. Effective serial measurement of cognitive orientation in rehabilitation: the Orientation Log. Arch Phys Med Rehabil. 1998 Jun;79(6):718-20. Link to PubMed: See External Links

Novack, TA, Dowler, RN, Bush, BA, Glen, T, Schneider, JJ. Validity of the Orientation Log, Relative to the Galveston Orientation and Amnesia Test. J Head Trauma Rehabil, 2000, 15(3), 957-961. See External Links

2.1.0.7 Characteristics

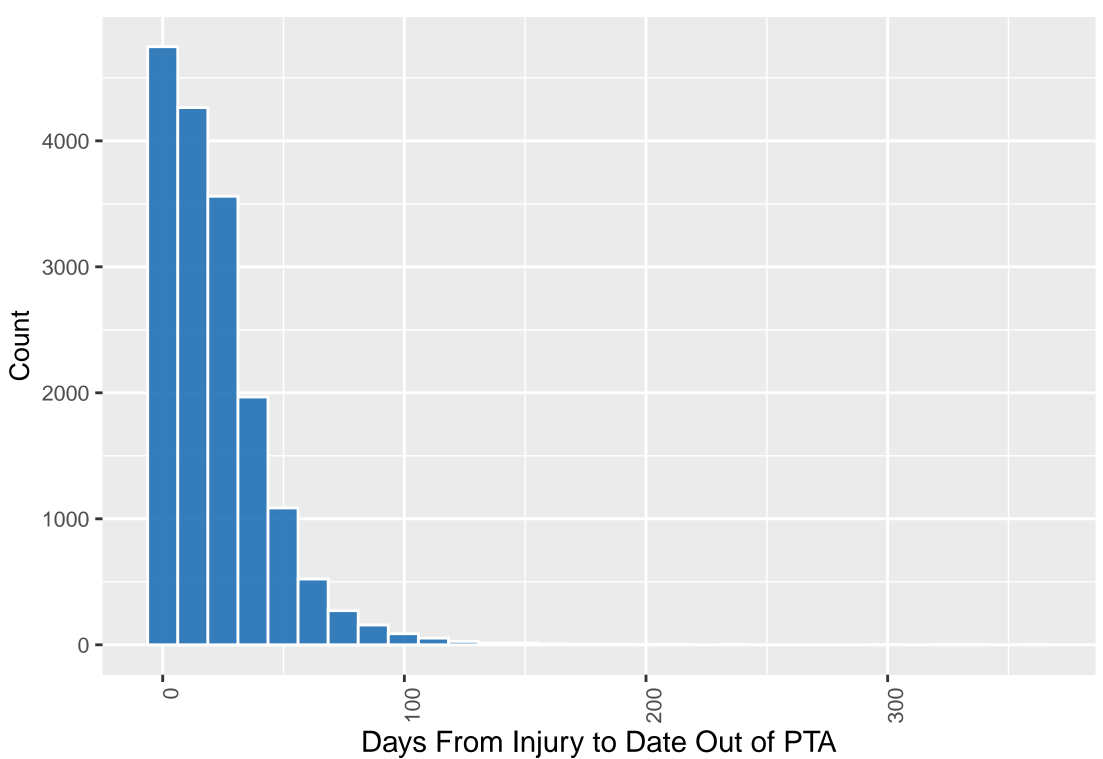
A few participants have a very long time in PTA. These have been checked and found to be correct.

A modified GOAT can be used to assist with this decision. The examiner presents three alternatives, in written form and orally, including the correct choice for each question. The patient is to indicate a choice in some manner, such as nodding or pointing. This procedure can be used for all questions except numbers 4 and 5. The three response alternatives for each question should be arranged vertically in large print on an index card. Error points are assigned and subtracted from 80 (the maximum score with items 4 and 5 removed). A score of 61 or higher is reflective of orientation. PTA is considered resolved when a score of 61 or greater is achieved on two consecutive occasions with no more than 2 full calendar days between assessments (Assessment 1 = Friday, Assessment 2 = Monday, two full days = Saturday, Sunday). Scores from the modified GOAT are for determination of PTA duration only.

Days From Injury to Date Out of PTA

Characteristic	N = 21,526
Days From Injury to Date Out of PTA	
N Non-missing	16,789
Mean (SD)	22 (22)
Median (Q1, Q3)	17 (5, 32)
Min, Max	0, 361
Unknown	4,737

> **Note**
>
> There are 3880 in PTA at the time of discharge.



78% of the abstracted people have valid data

2.2 Time to Follow Commands (TFC)

2.2.0.1 Definition

Date that the individual with brain injury is able to follow simple motor commands. The individual has the ability to follow simple motor commands if:

1) follows simple motor commands accurately at least two out of two times within a 24-hour period, or

2) GCS motor component = 6 (follows simple motor commands), two out of two times within a 24-hour period.

The purpose of this variable is to establish the duration of unconsciousness.

2.2.0.2 Form

[X] Form 1
[ ] Form 2

2.2.0.3 Source

Form 1 - Abstraction (acute or rehab record)

2.2.0.4 Details

A patient with severe motor or sensory impairment (i.e. spinal cord injury, locked in syndrome) must demonstrate some ability to follow eye commands such as close your eyes, look to the right or left, blink eyes.

If patient is able to follow commands, then following surgery he/she can not follow commands for a period of time, use the first date the patient was able to follow commands.

If the two assessments of ability to follow simple motor commands within a 24-hour period fall across two dates, use the second date.

If patient was always able to follow simple motor commands, code date of admission to emergency room.

Notes such as ''following commands at times'' or ''follows some commands'' may be used, as long as the ability to follow commands is documented 2 times consecutively.

Days From Injury to Follow Commands

Characteristic	N = 21,526
Days From Injury to Follow Commands	
N Non-missing	20,708
Mean (SD)	8 (14)
Median (Q1, Q3)	2 (1, 9)
Min, Max	0, 290
Unknown	818

Notes of "inconsistently following commands" should be counted as following.

Other scenarios that indicate following commands include "ability to answer questions appropriately" or "2 consecutive GSC total scores of 15".

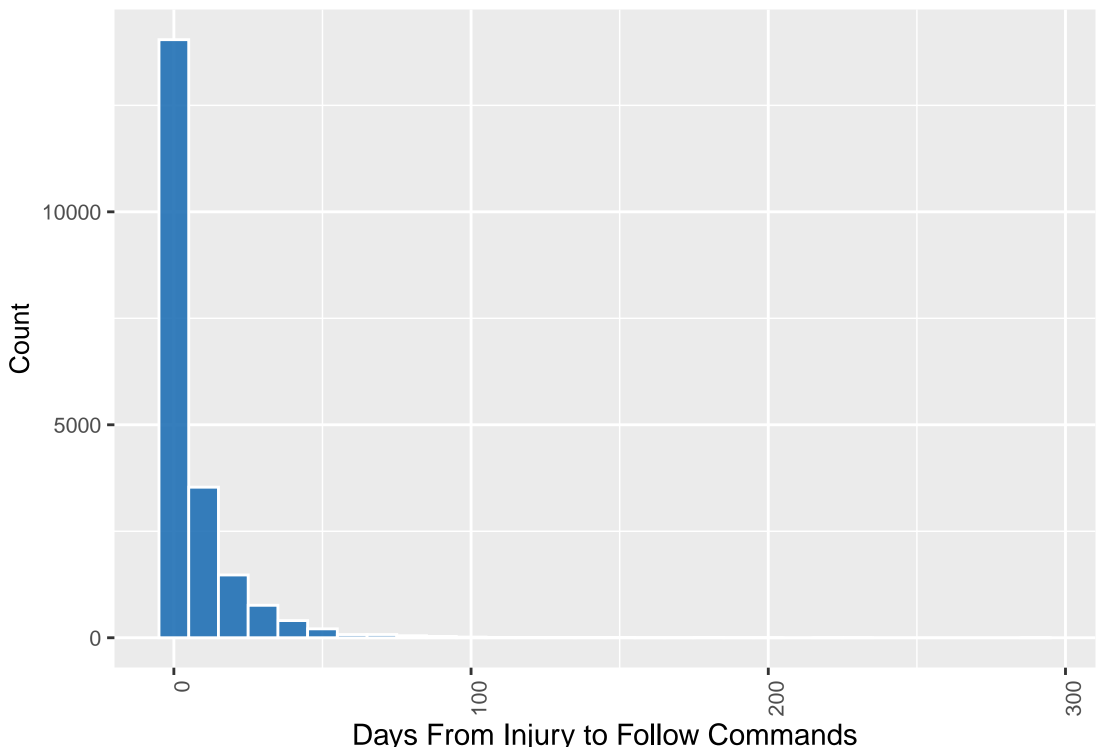
Scenarios that indicate NOT following commands include "localizing", "flexing", "withdraws from pain" or "posturing".

In unusual cases where two or more motor scores of 6 occur within a very short time frame of each other but have motor scores preceding and following that are below 6, data collectors should consult with their Project Director or Medical Director.

If patient was always able to follow simple motor commands, code date of admission to emergency room.

Note

There are 372 who were never able to follow simple motor commands.



96% of the abstracted people have valid data

2.3 Glasgow Coma Scale (GCS)

2.3.0.1 Definition

Glasgow Coma Scale scores on admission to emergency department.

2.3.0.2 Form

[X] Form 1
[ ] Form 2

2.3.0.3 Source

Form 1 - Abstraction (acute record)

2.3.0.4 Details

If patient was admitted to a model systems acute facility within the first 24 hours of injury, use model systems ER data. However, if the patient was not admitted to a model systems acute facility within the first 24 hours of injury, use the first ER to obtain GCS data regardless of whether it was a model systems ER or not.

If only 1 GCS is recorded, use that score for an assessment.

If the patient is chemically paralyzed with neuromuscular blocking agents or barbiturates, or is sedated with anesthetics, code the GCS as 'Chemically Paralyzed or Sedated' even if GCS scores are present in the record. The paralysis or sedation must be induced by medical personnel, and not by the patient.

If however, a GCS score of 15 is present in the record, and there is evidence that the patient was given sedatives, do not code as sedated, and use the Verbal score and Total score provided in the record.

Applicable medications commonly used in emergency care for sedation include…

- Neuromuscular blocking agents: atracurium (TRACRIUM), pancuronium (PAVULON), rocuronium (ZEMURON), succinylcholine (ANECTINE, QUELICIN), vecuronium (NORCURON) and ketamine (KETALAR).
- Barbiturates: pentobarbital (NEMBUTAL), and sodium thiopental (SODIUM PENTOTHAL or THIOPENTAL).
- Anesthetics: fentanyl (ABSTRAL, ACTIQ, DUROGESIC, FENTORA, IONSYS, LAZANDA, ONSOLIS, SUBLIMAZE, SUBSYS), lorazepam (ATIVAN), midazolam (VERSED), and propofol (DIPRIVAN).

If chemical paralysis or sedation at time of arrival is unclear, data collectors should seek the advice of their project director or physician at their hospital.

If patient is intubated at the time of assessment, record the verbal score as 8 and the total score as 88. For the purposes of analysis, these cases will not be included unless specified for recoding during analysis.

If patient is intubated and in chemically-induced coma or paralysis, code 8 for verbal response and 7's for eye opening, motor response and 77 for total GCS.

If patient is only nasally intubated, the patient can provide a verbal GCS score (do not code as intubated).
If patient is only bagged, the patient can provide a verbal GCS score (do not code as intubated). Medical records may show this as "BVM" (bag-valve-mask ventilated).

If patient is intubated using RSI (rapid sequence intubation), code as intubated and sedated.

Characteristic	N = 21,526
GCS, n (%)	
3	2,870 (13)
4	429 (2.0)
5	462 (2.2)
6	1,093 (5.1)
7	1,161 (5.5)
8	786 (3.7)
9	577 (2.7)
10	641 (3.0)
11	669 (3.1)
12	571 (2.7)
13	1,052 (4.9)
14	2,364 (11)
15	3,811 (18)
77	4,740 (22)
88	61 (0.3)
Unknown	239

2.3.0.5 Links

GCS - PubMed:Teasdale et al(1976)

2.3.0.6 Reference

Teasdale G, Jennett B (1976) Assessment and Prognosis of Coma After Head Injury, Acta Neurochir 34, 45-55.

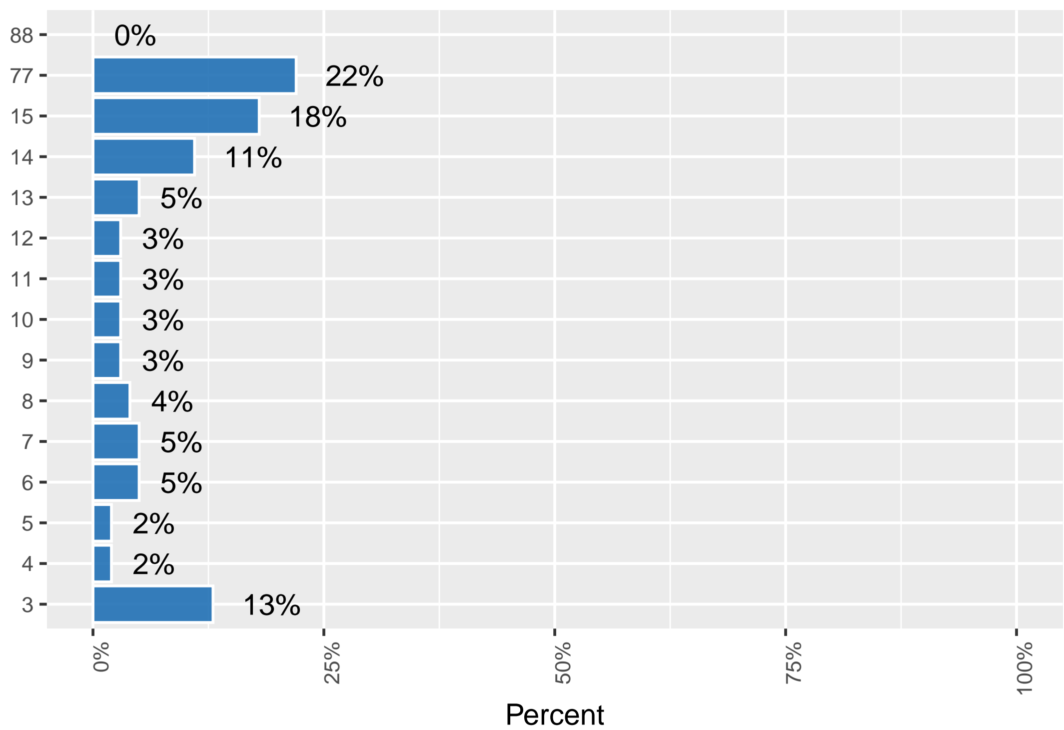
2.3.0.7 Characteristics

In the days that 3 GCSs were collected (highest, lowest, admit), there was the option of using 1 GCS for the other 2 GCSs if they were missing. A cursory check suggests that this was not done consistently.

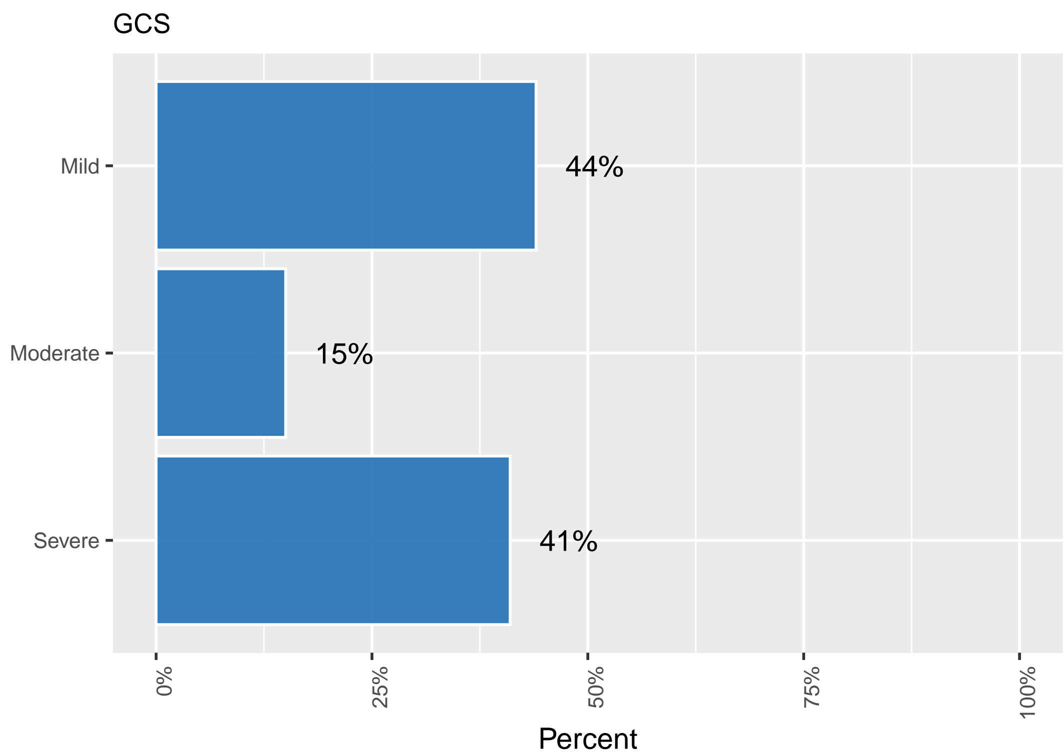
> **Note**
>
> 77 - Patient Chemically Paralyzed or in Chemically-Induced Coma for Treatment Purposes: Sedated; 88 - Intubated

GCS

Characteristic	N = 21,526
GCS Category, n (%)	
Severe	6,801 (41)
Moderate	2,458 (15)
Mild	7,227 (44)
Missing	5,040



99% of the abstracted people have valid data



2.4 Spinal Cord Injury

2.4.0.1 Definition

Any injury to neural elements within the spinal canal.

2.4.0.2 Form

[X] Form 1
[ ] Form 2

2.4.0.3 Source

Abstraction (acute record)

Spinal cord Injury

Characteristic	N = 21,526
Spinal cord injury:, n (%)	
No	20,298 (95)
Yes	1,173 (5.5)
Missing	55

2.4.0.4 Details

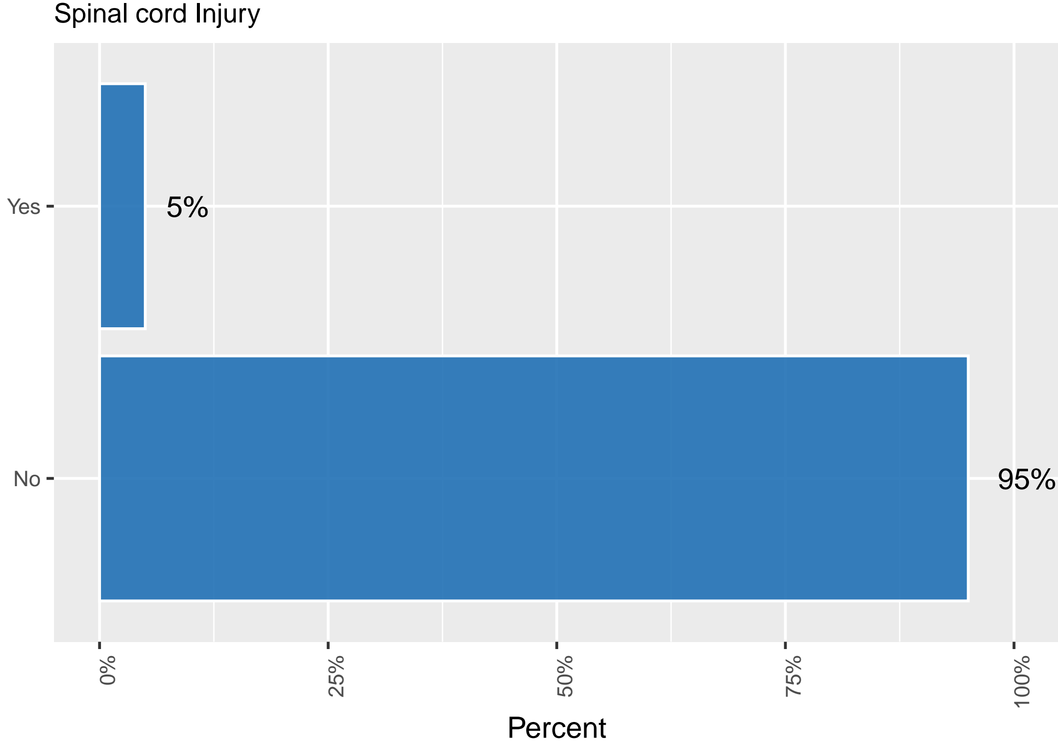
Includes complete and incomplete injuries.

Includes conus medullaris and cauda equina syndromes, but does not include brachial or lumbar plexus injuries occurring outside the spinal canal.

Only spinal cord injuries occurring at the same time as the brain injury should be reported.

2.4.0.5 Reference

ASIA



100% of the abstracted people have valid data

2.5 CT

Caution

There is a known issue for the CT Status variable where the response is unknown yet there is evidence of data stored in the CT form. We are working through a process to get this better alligned and will be fixed in susbequent runs of the report

2.5.0.1 Definition

CT diagnoses based on a combination of reports taken from radio-graphic CT scan results within 7 days of injury.

"CT Data" form: See SOP 0. Current Forms

Code CTStatus as 99-unknown if CT scans/reports done, but unavailable

2.5.0.2 Form

[X] Form 1
[ ] Form 2

2.5.0.3 Source

To be coded by a CT certified individual from all CT reports of the head and/or neck dated within 7 days of injury.

2.5.0.4 Details

A properly trained person at the facility who has been certified following TBIMS procedures may code this variable.

Do not use MRI findings to code this variable.

If CT reports are not available from a system acute hospital, CT reports from non-system hospitals may be used if available.

CTA (CT angiography) reports should not be included.

Findings, including old infarcts and midline shift, should be coded as 'present' regardless of cause.

2.5.0.5 Characteristics

All CT variables were removed from data collection on 6/30/2025.

2.5.0.6 Training

Testing and certification of collectors of this variable is required. It is available from the National Data and Statistical Center.

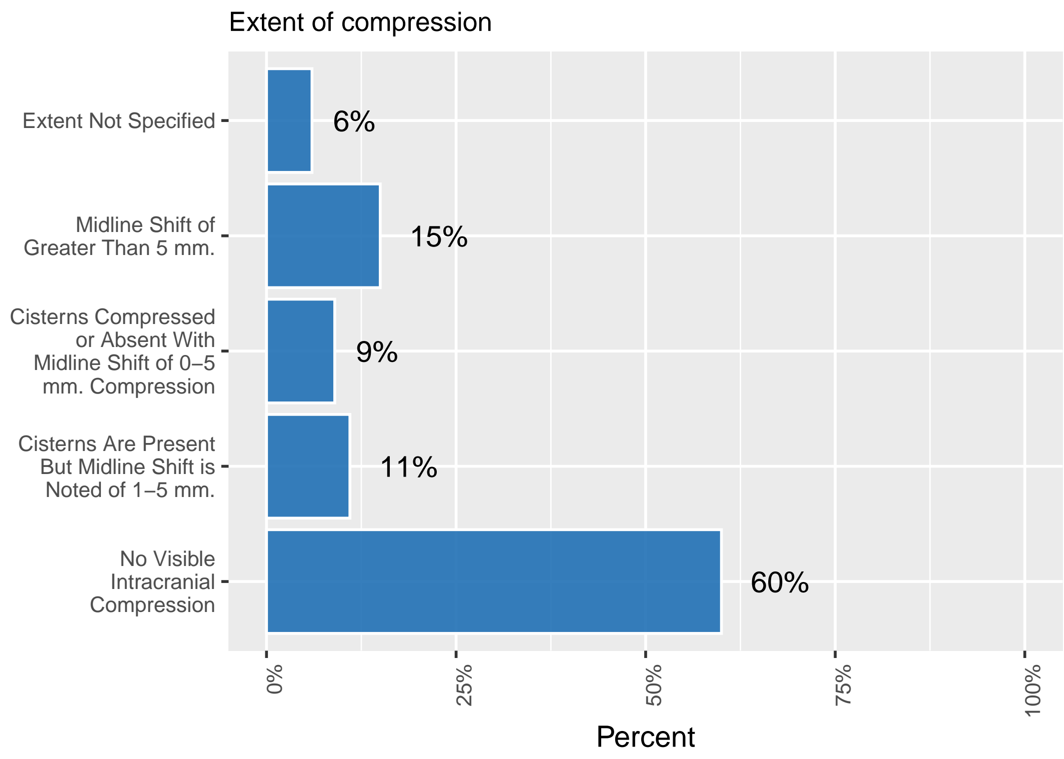
A score of 80% or greater is required for certification.

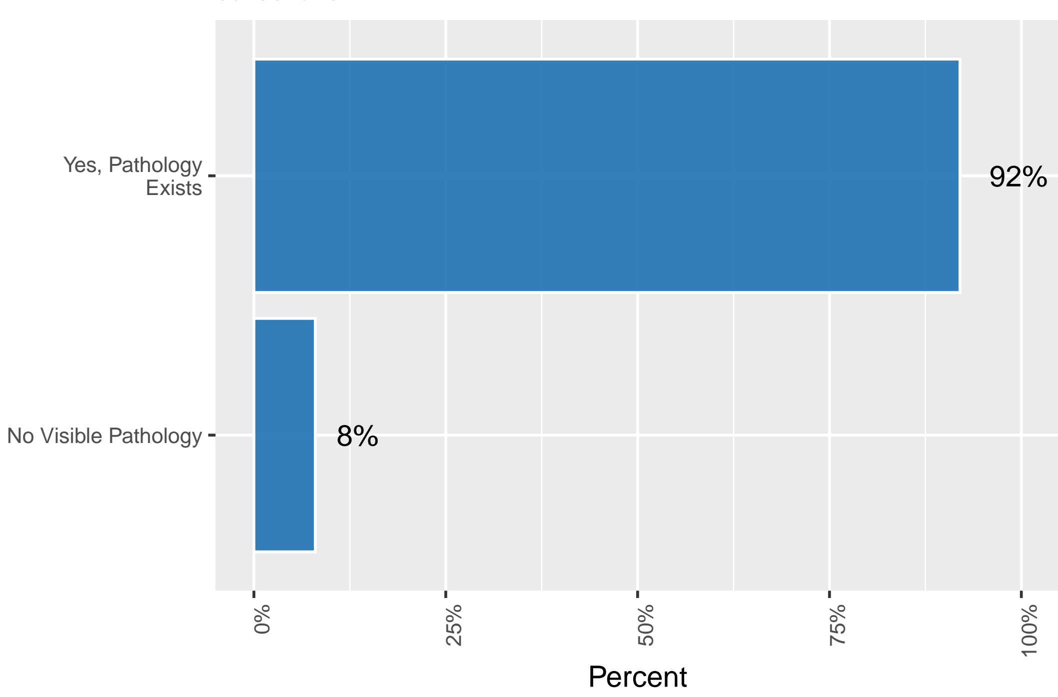
CT Not Done CT Done 142 20134

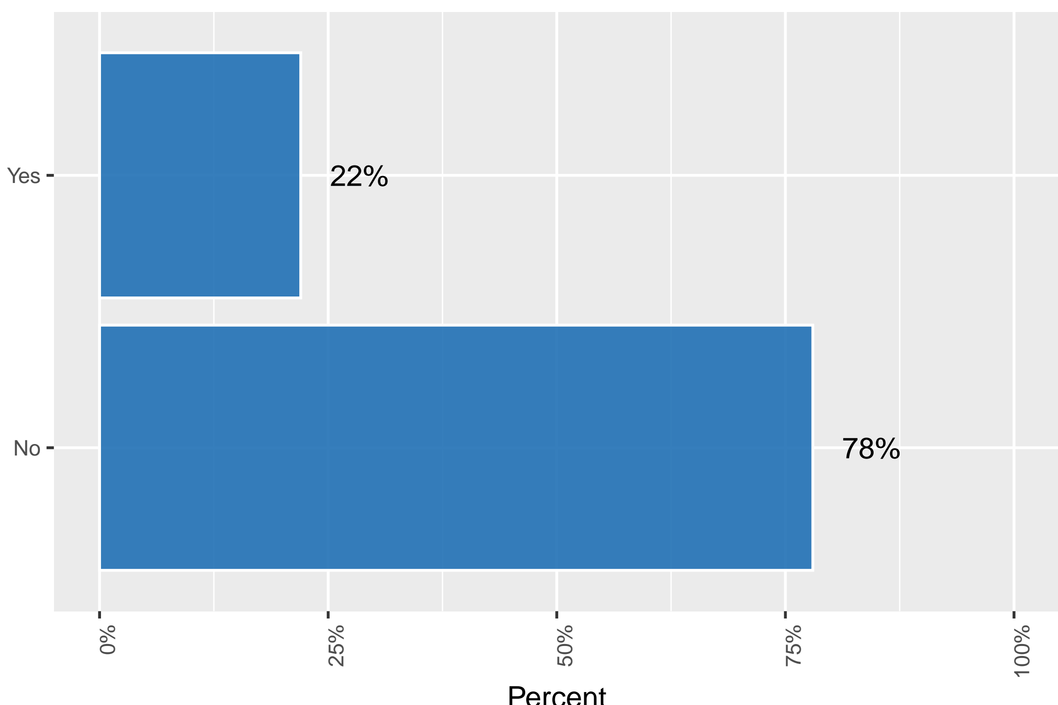
	CT status			
	CT Not Done	CT Done	Unknown	Total
1. Intracranial hemorrhage and/or contusions, extra-axial collections, n				
No Visible Pathology	0	1,613	0	1,613
Yes, Pathology Exists	0	18,475	1	18,476
Unknown	142	46	1,249	1,437
Total, n	142	20,134	1,250	21,526

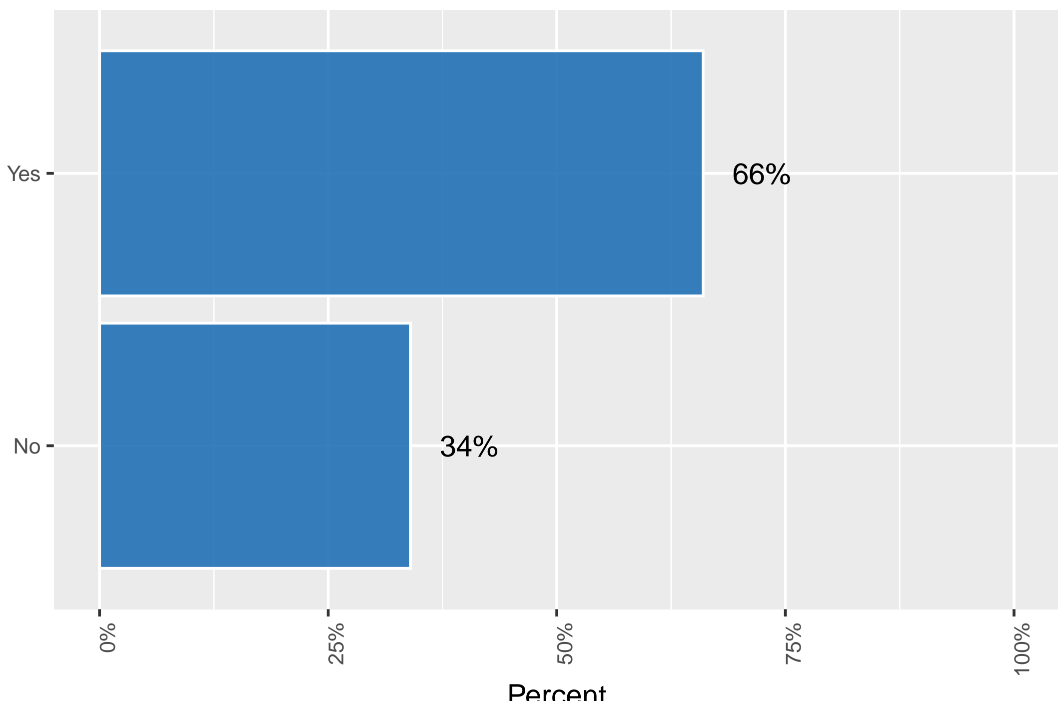
CT

Characteristic	N = 21,526
CT status, n (%)	
CT Not Done	142 (0.7)
CT Done	20,134 (99)
Missing	1,250
Extent of compression, n (%)	
No Visible Intracranial Compression	11,988 (60)
Cisterns Are Present But Midline Shift is Noted of 1-5 mm.	2,116 (11)
Cisterns Compressed or Absent With Midline Shift of 0-5 mm. Compression	1,818 (9.1)
Midline Shift of Greater Than 5 mm.	2,941 (15)
Extent Not Specified	1,128 (5.6)
Missing	1,535
1. Intracranial hemorrhage and/or contusions, extra-axial collections, n (%)	
No Visible Pathology	1,613 (8.0)
Yes, Pathology Exists	18,476 (92)
Missing	1,437
2. Punctate/petechial hemorrhages, n (%)	
No	15,753 (78)
Yes	4,329 (22)
Missing	1,444
3. Subarachnoid hemorrhage, n (%)	
No	6,880 (34)
Yes	13,204 (66)
Missing	1,442
4. Intraventricular hemorrhage, n (%)	
No	14,851 (74)
Yes	5,235 (26)
Missing	1,440

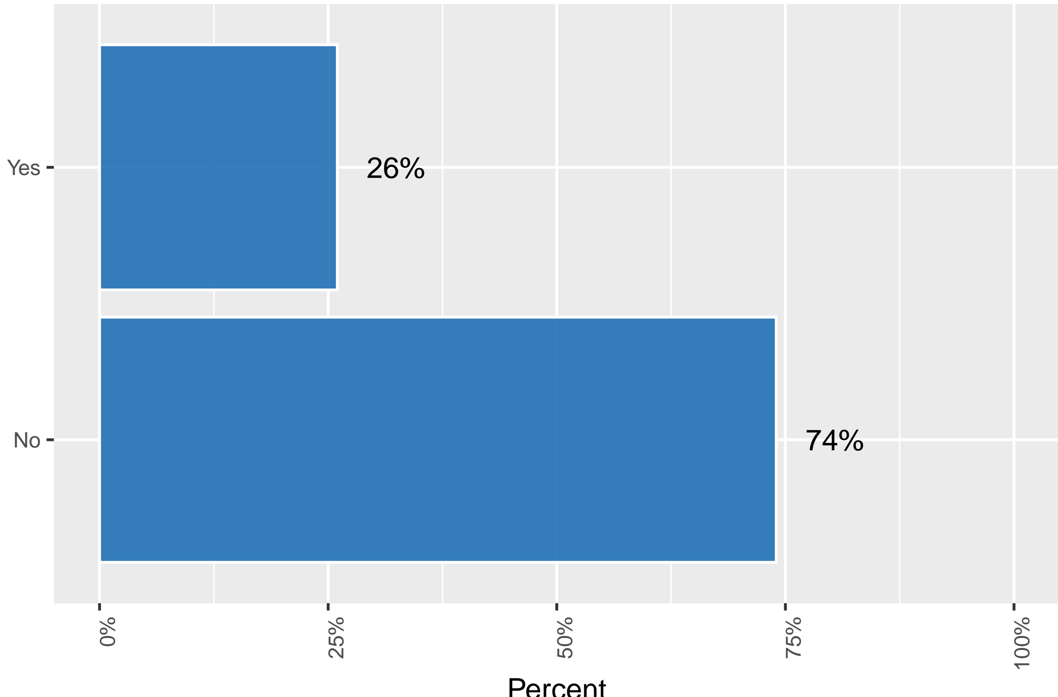

Extent of compression
Extent Not Specified
6%
Midline Shift of Greater Than 5 mm.
15%
Cisterns Compressed or Absent With Midline Shift of 0–5 mm. Compression
9%
Cisterns Are Present But Midline Shift is Noted of 1–5 mm.
11%
No Visible Intracranial Compression
60%
0%
25%
50%
75%
100%
Percent


1. Intracranial hemorrhage and/or contusions, extra−axial collections
Yes, Pathology Exists
No Visible Pathology
92%
8%
0%
25%
50%
75%
100%
Percent


2. Punctate/petechial hemorrhages
Yes
No
22%
78%
0%
25%
50%
75%
100%
Percent


3. Subarachnoid hemorrhage
Yes
No
66%
34%
0%
25%
50%
75%
100%
Percent

4. Intraventricular hemorrhage



94% of the abstracted people have valid data

2.6 Craniotomy

2.6.0.1 Definition

Craniotomy and/or craniectomy performed (separate procedures).
- Craniotomy means “cranium opened, something removed, cranium closed.”
- Craniectomy means “cranium opened and left open.”

2.6.0.2 Form

[X] Form 1
[ ] Form 2

Craniotomy

Characteristic	N = 21,526
Craniotomy/Craniectomy:, n (%)	
Neither Craniotomy Nor Craniectomy	13,157 (74)
Craniotomy	2,409 (13)
Craniectomy	1,771 (9.9)
Both: Separate Procedures	545 (3.0)
Missing	3,644

2.6.0.3 Source

Abstraction (acute record)

2.6.0.4 Details

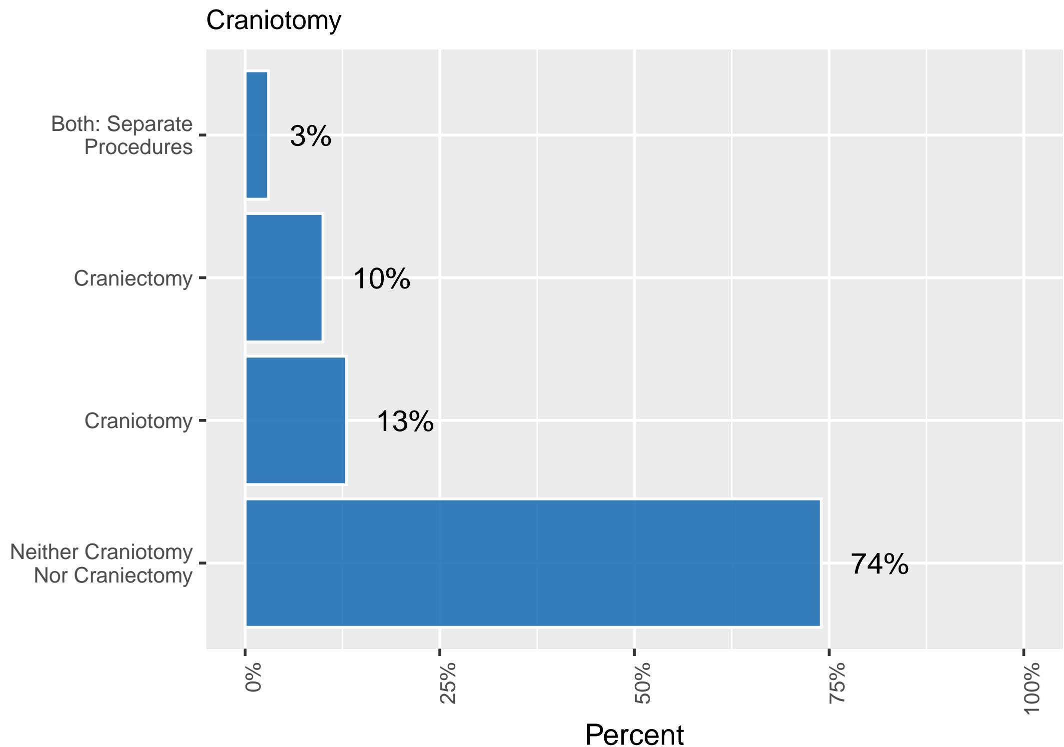
Craniectomy is coded yes when bone flap is removed and not replaced during initial surgery.

The guidelines below should be followed when considering burr holes:

When a burr hole is drilled, the patient is left with a 1 cm diameter hole. Removing a small disc of bone is not equivalent to removing the cranium or any part of the cranium. A burr hole to put in an ICP monitor is neither a craniotomy nor craniectomy, simply placement of a monitor.

Situations where a chronic subdural is drained or washed out through a burr hole should be counted as a craniotomy. It is the removal of the chronic subdural that is the key part, because the goal is to remove something (the liquefied old blood).

An EVD (External Ventricular Drain) should not be counted as a craniotomy.



83% of the abstracted people have valid data

3 Neuropysch

3.1 BTACT

3.1.0.1 Definition

Brief Test of Adult Cognition by Telephone (BTACT)

The BTACT is a brief (15-20 minute) and reliable telephone-administered test that includes six subtests assessing important areas of cognition. The subtests were selected for inclusion in the BTACT based on their ability to assess a wide range of cognitive abilities (see below) and for their sensitivity to normal age-related changes. Other important features of the subtests include well-established psychometric properties, ease of administration via telephone by lay interviewers, and brief administration time. Two psychometrically equivalent alternate forms are available, and the BTACT is available in English and Spanish. Previous research has demonstrated that in-person and telephone administration of BTACT subtests yield equivalent results (Lachman et al., 2011). The subtests in the BTACT include: Rey Auditory Verbal Learning Test, Digits Backward, Number Series, Animal Fluency, Backward Counting.

Descriptions of subtests included in the Brief Test of Adult Cognition by Telephone BTACT:

- **EPISODIC VERBAL MEMORY (Word List Recall)** - Immediate Recall of 15-item word list (RAVLT; 1 trial only) SCORE = Total correct in 60 sec (Optional: repetitions, intrusions, Recall efficiency (total time/#words)) and Delayed Recall of word list (at end of assessment) Score = Total correct (Optional: repetitions, intrusions, Forgetting (Immediate-delayed recall)).
- **WORKING MEMORY** (Digits Backward [WAIS-III]) Score = Longest accurately recalled string.
- **EXECUTIVE** (Category Animal Fluency) Score = Number correct in 60 seconds, (Optional: repetitions, intrusions).
- **REASONING** (Number Series) Score = Number correct (5 trials of increasing difficulty).
- **REACTION TIME** (Backward Counting) Score = Last number reached minus number of errors (reversals, skips, incorrect numbers).

3.1.0.2 Form

[X] Form 1
[X] Form 2

3.1.0.3 Source

BTACT testing to be administered to participant only

3.1.0.4 Details

See BTACT SOP link below for full administration guidelines.

Form 1

- If BTACT window closes prior to patient consenting to the TBIMS, clinical judgement should be used to code whether or not BTACT could have been completed at that time (e.g., consult with treating neuropsychologist or other rehab team members). If determined patient would not have been able to complete the BTACT due to cognitive impairment, code as “Not Attempted due to cognitive impairment.” Do not attempt to abstract information from the medical record to make this determination.
- If a proxy consents to the TBIMS for the participant, all attempts should still be made to complete the BTACT with the participant, even if the participant is not out of PTA.

3.1.0.5 Links

MIDUS Refresher means and SD for cognitive test
BTACT SOP

3.1.0.6 Reference

The Brief Test of Adult Cognition by Telephone (BTACT; Tun & Lachman, 2006)

3.1.0.7 Characteristics

Researchers should evaluate the appropriate “window” for each specific study, and exclude BTACT data collected outside of their preferred window.

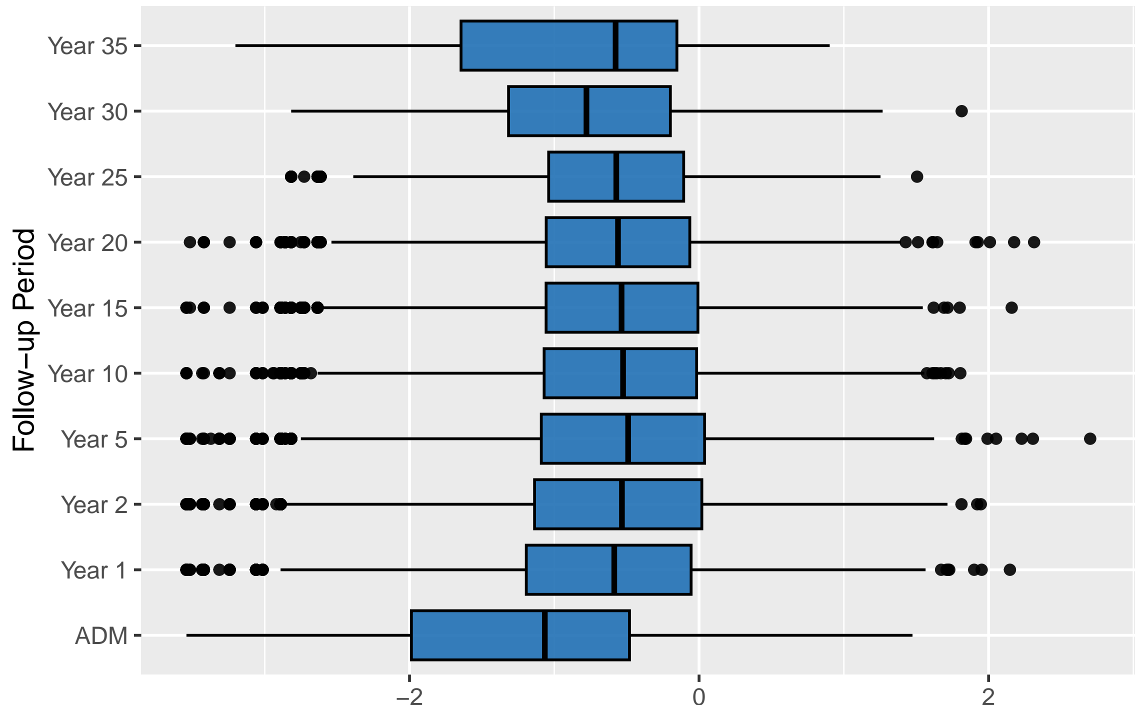
BTACT Total score standardized by age, sex and education

Characteristic	**ADM** N = 5,196	**Year 1** N = 4,415	**Year 2** N =
BTACT Total score standardized by age, sex and education			
N Non-missing	2,472	2,777	2,67
Mean (SD)	-1.23 (1.03)	-0.71 (0.98)	-0.64 (0
Median (Q1, Q3)	-1.07 (-1.99, -0.48)	-0.59 (-1.19, -0.05)	-0.53 (-1.1
Min, Max	-3.54, 1.47	-3.54, 2.15	-3.54, 1
Missing	2,724	1,638	1,53

3.1.0.8 Training

Please refer to the BTACT Training videos under the Training Manual (found under both Form 1 and Form 2 training modules).

3.1.1 BTACT Total Score



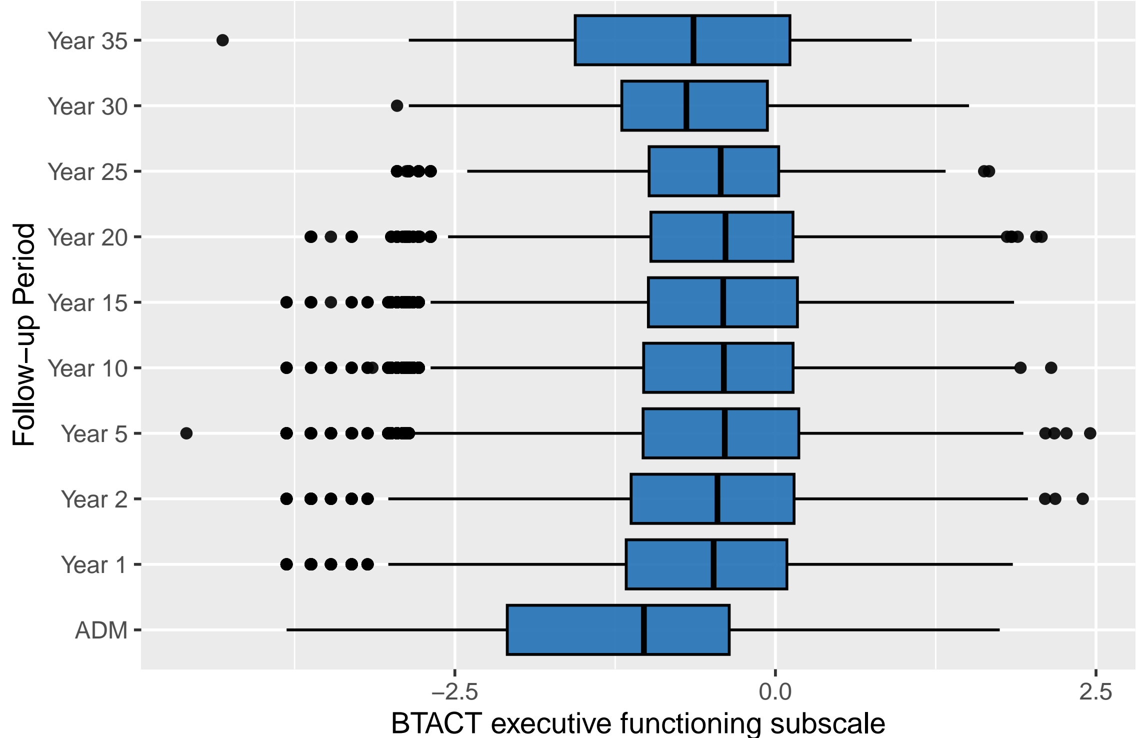
BTACT executive functioning subscale

Characteristic	**ADM** N = 5,196	**Year 1** N = 4,415	**Year 2** N = 4,213	**Year 5** N = 4
BTACT executive functioning subscale				
N Non-missing	2,507	2,819	2,715	2,801
Mean (SD)	-1.20 (1.15)	-0.64 (1.06)	-0.59 (1.07)	-0.53 (1.0
Median (Q1, Q3)	-1.03 (-2.09, -0.36)	-0.48 (-1.16, 0.09)	-0.45 (-1.13, 0.15)	-0.40 (-1.03,
Min, Max	-3.81, 1.75	-3.81, 1.85	-3.81, 2.40	-4.59, 2.4
Missing	2,689	1,596	1,498	1,402

48% of the abstracted people have valid data

64% of the interviewed people have valid data

3.1.2 BTACT Executive Functioning Subscale



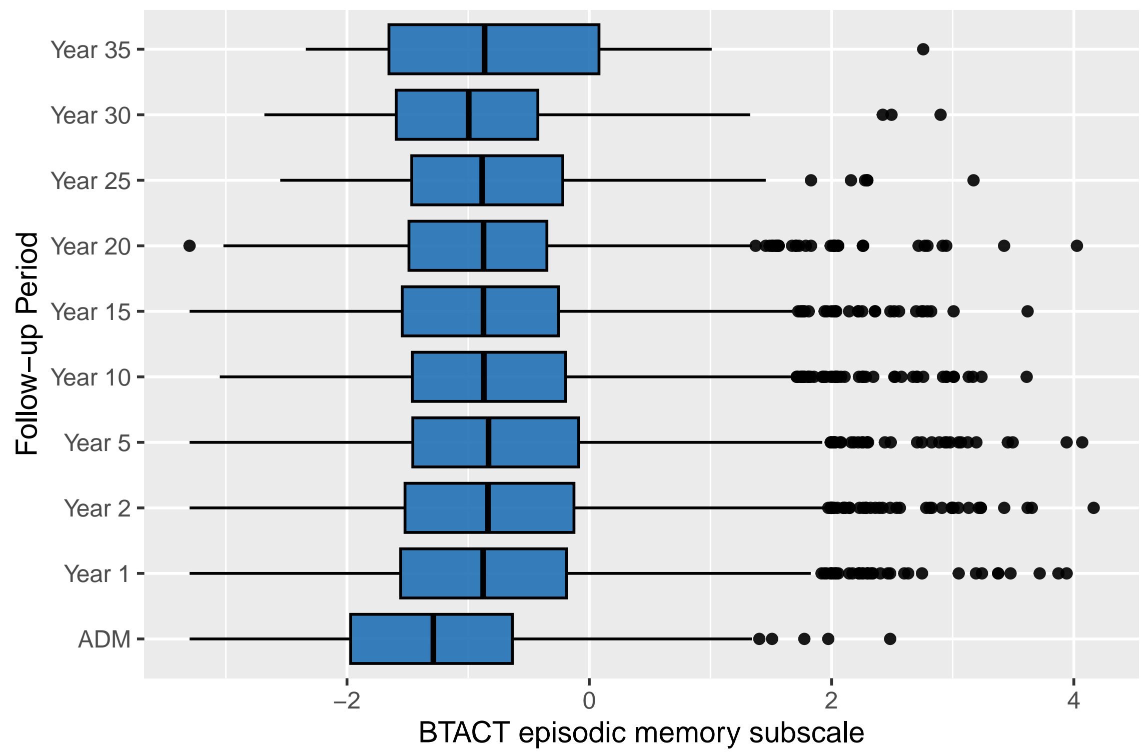
48% of the abstracted people have valid data

65% of the interviewed people have valid data

BTACT episodic memory subscale

Characteristic	**ADM** N = 5,196	**Year 1** N = 4,415	**Year 2** N = 4,213	**Year 5** N = 4,2
BTACT episodic memory subscale				
N Non-missing	2,551	2,903	2,790	2,868
Mean (SD)	-1.29 (0.94)	-0.83 (1.06)	-0.76 (1.09)	-0.74 (1.06)
Median (Q1, Q3)	-1.29 (-1.97, -0.64)	-0.88 (-1.56, -0.18)	-0.84 (-1.52, -0.13)	-0.83 (-1.46, -0.
Min, Max	-3.30, 2.48	-3.30, 3.94	-3.30, 4.16	-3.30, 4.07
Missing	2,645	1,512	1,423	1,335

3.1.3 BTACT Episodic Memory Subscale



49% of the abstracted people have valid data

66% of the interviewed people have valid data

3.1.4 BTACT Test Completion Scores

character(0)

BTACT Test Completion Code at Admission

Characteristic	N = 5,196
BTACTTCC, n (%)	
Test Administered In Full- Results Valid	1,932 (39)
Test Attempted But Not Completed (Due To Cognitive/Neurological Reasons)	65 (1.3)
Test Not Attempted (Due To The Severity Of Cognitive/Neurological Deficits)	504 (10)
Test Not Attempted (Form 1: Not Admitted In Window/Form 2: Collected Out Of Window)	298 (6.0)
Test Not Attempted (Not Consented Within Window)	1,216 (25)
Test Attempted But Not Completed (Due To Non-Neurological Physical Reasons)	9 (0.2)
Test Not Attempted (Due To Non-Neurologic/ Physical Reasons)	89 (1.8)
Test Attempted But Not Completed (Non-English Speaking Patient)	3 (<0.1)
Test Not Attempted (Non-English Speaking Patient)	96 (1.9)
Test Attempted But Not Completed (Refusal To Continue)	60 (1.2)
Test Not Attempted (Refusal)	352 (7.1)
Test Attempted But Not Completed (Logistical Reasons, Other Reasons –Site-Specific)	0 (0)
Test Not Attempted (Logistical Reasons, Other Reasons –Site-Specific)	278 (5.6)
Suspect That A Participant Is Writing Down Answers	1 (<0.1)
Other	29 (0.6)
Missing	264

BTACT Test Completion Code at Followup

Characteristic	N = 22,700
BTACTTCC, n (%)	
Test Administered In Full- Results Valid	13,043 (73)
Test Attempted But Not Completed (Due To Cognitive/Neurological Reasons)	218 (1.2)
Test Not Attempted (Due To The Severity Of Cognitive/Neurological Deficits)	950 (5.3)
Test Not Attempted (Form 1: Not Admitted In Window/Form 2: Collected Out Of Window)	20 (0.1)
Test Not Attempted (Not Consented Within Window)	0 (0)
Test Attempted But Not Completed (Due To Non-Neurological Physical Reasons)	62 (0.3)
Test Not Attempted (Due To Non-Neurologic/ Physical Reasons)	315 (1.8)
Test Attempted But Not Completed (Non-English Speaking Patient)	14 (<0.1)
Test Not Attempted (Non-English Speaking Patient)	237 (1.3)
Test Attempted But Not Completed (Refusal To Continue)	330 (1.8)
Test Not Attempted (Refusal)	1,593 (8.9)
Test Attempted But Not Completed (Logistical Reasons, Other Reasons –Site-Specific)	0 (0)
Test Not Attempted (Logistical Reasons, Other Reasons –Site-Specific)	814 (4.5)
Suspect That A Participant Is Writing Down Answers	16 (<0.1)
Other	283 (1.6)
Missing	4,805

96% of the abstracted people have valid data

79% of the interviewed people have valid data

4 Pre-Injury Conditions/Limitations

Caution

There is a know issue for thr Mental Health question in that there are several records for which people have data in a variable that should have been skipped. This will be fixed in future iterations of this report

4.1 Conditions

4.1.0.1 Definition

The purpose of this variable is to help determine the pre-injury functional level of the Model System participants. This variable was taken from the wording of the Long Form of the 2000 Census, which asks about current function. To meet our needs, this question was revised to ask specifically about the patient's specific function prior to the TBI regarding:

- Blindness or a severe vision impairment
- Deafness or a severe hearing impairment
- A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying.

4.1.0.2 Form

[X] Form 1
[ ] Form 2

4.1.0.3 Source

Pre-Injury History (participant or proxy)

Characteristic
A condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reac
No
Yes
Missing
Blindness or a severe vision impairment:, n (%)
No
Yes
Missing
Deafness or a severe hearing impairment:, n (%)
No
Yes
Missing

4.1.0.4 Details

Pre-Injury long-lasting conditions are based on self-report. If participant views as 'long-lasting' then code as such.

Alcoholism can be considered a preinjury condition if it interferes with the person's functioning.

Having glasses/hearing aid does not constitute a severe impairment. If glasses/hearing aid cannot correct the severe vision/hearing impairment, however, then code 'yes'.

4.1.0.5 Characteristics

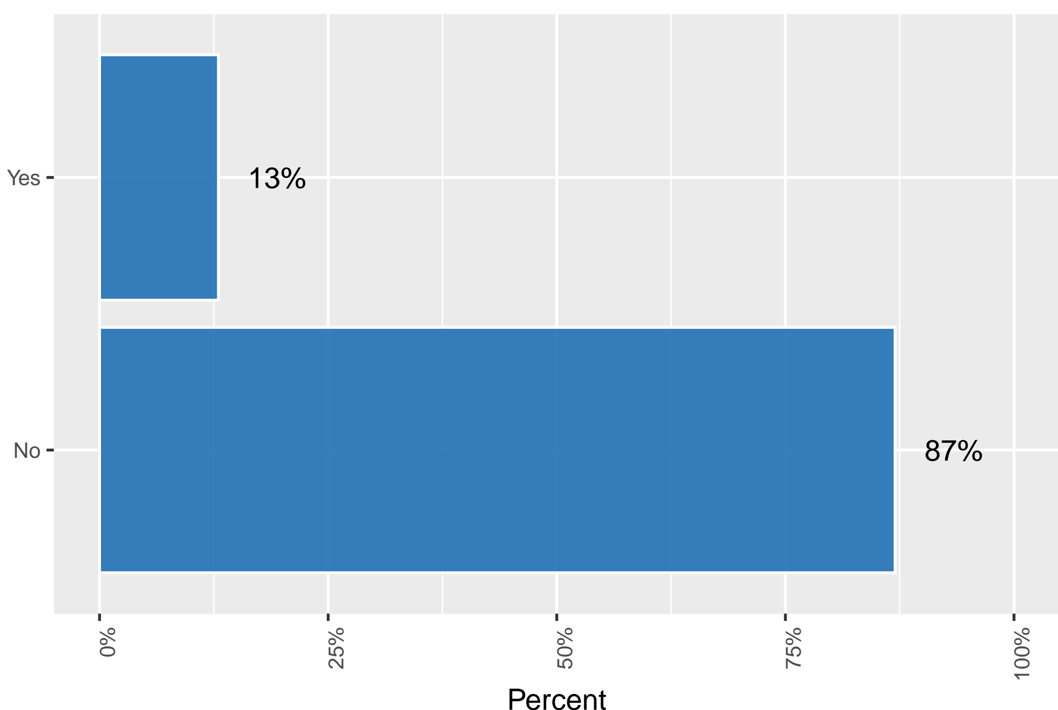
Previously, participants were asked about any preinjury "Blindness, deafness, or a severe vision or hearing impairment" until the questions were split into 2 questions on 7/1/2020 - "Blindness or a severe vision impairment" and "Deafness, or a severe hearing impairment".

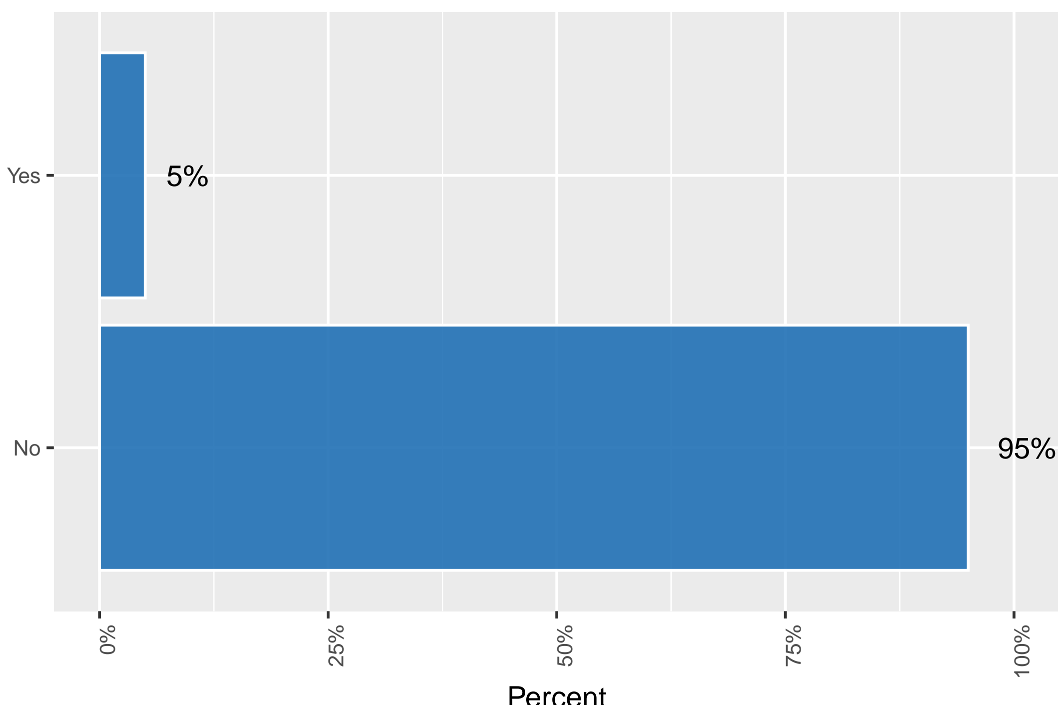
4.1.0.6 Reference

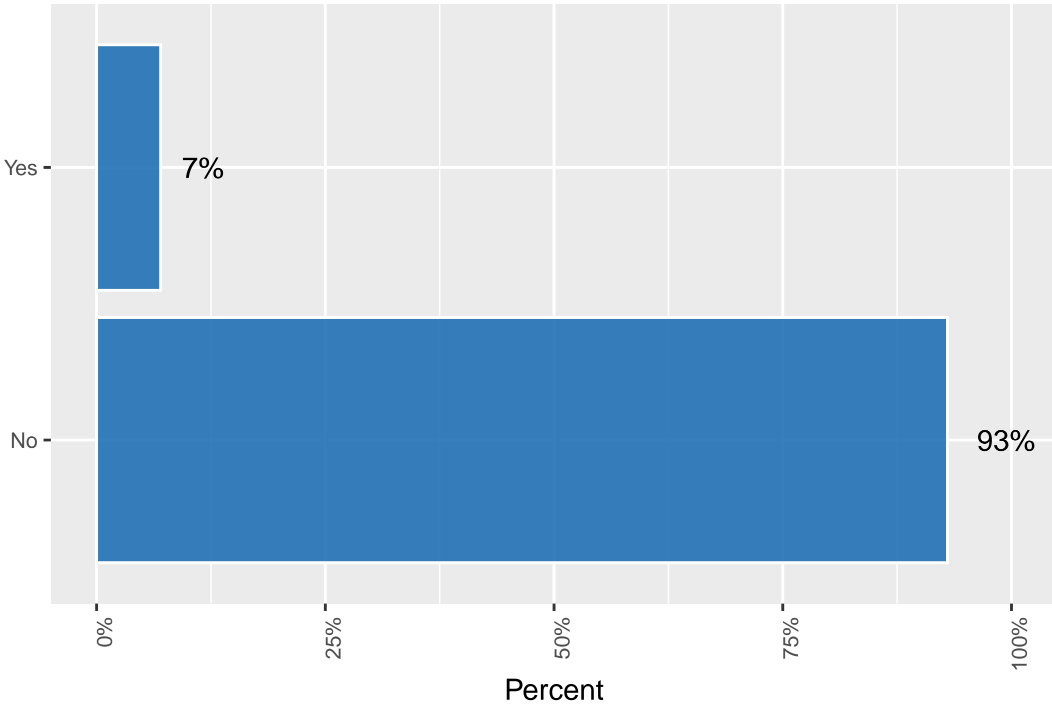
Questions were taken from the long form of the 2000 census and modified to ask about premorbid function instead of current level of function. (Developed by a group headed by Flora Hammond).

Variable was successfully pilot tested in first quarter 2005.

99% of the abstracted people have valid data


Condition that limited activities
Yes
No
13%
87%
0%
25%
50%
75%
100%
Percent


Blindness or a severe vision impairment:
Yes
5%
No
95%
0%
25%
50%
75%
100%
Percent



4.2 Limitations

4.2.0.1 Definition

The purpose of this variable is to help determine the preinjury functional level of the Model System participants. This variable was taken from the wording of the Long Form of the 2000 Census, which asks about current function. To meet our needs, this question was revised to ask specifically about the patient's difficulty in doing the following activities due to a physical, mental, or emotional condition that has been present for at least 6 months:

- Learning, remembering, or concentrating
- Dressing, bathing, or getting around inside the home
- Going outside the home alone to shop or visit a doctor's office
- Working at a job or business

4.2.0.2 Form

[X] Form 1
[ ] Form 2

4.2.0.3 Source

Pre-Injury History (participant or proxy)

4.2.0.4 Details

Include effects due to alcoholism.

If respondent asks for clarification of what is meant by "mental and emotional conditions", the following explanation is acceptable: "Mental conditions affect a person's ability to think or their intelligence. Examples include learning disabilities, dementia, or intellectual disability. Emotional conditions refer to psychological or psychiatric problems."

If the participant was not working at the time of injury (e.g. unemployed, retired), code Pre-Injury Limitation -Working at a Job or Business" [PrelimWork] on the basis of estimated difficulty had he/she been working. Probe to determine if, at the time of injury, they had physical, mental, or emotional problems that–if they had been working–would have caused them difficulty and which they had had for the past 6 months. If problems has been present for at least 6 months, then code "Yes". Otherwise code "No".

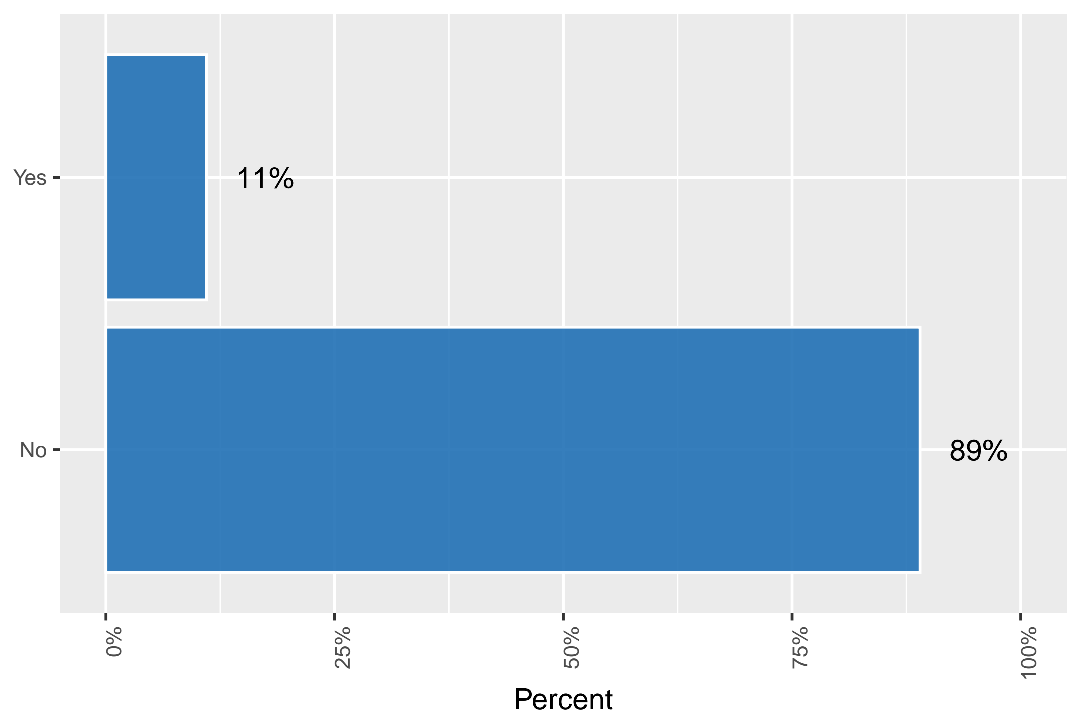
4.2.0.5 Reference

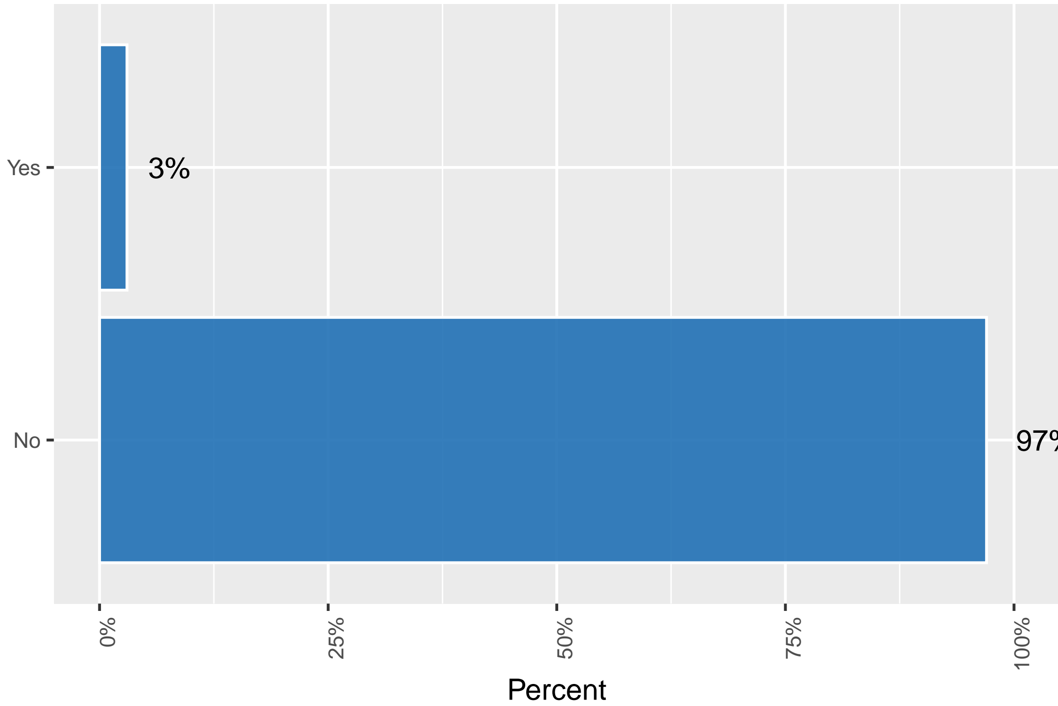
Questions were taken from the long form of the 2000 census and modified to ask about premorbid function instead of current level of function. (Developed by a group headed by Flora Hammond.)

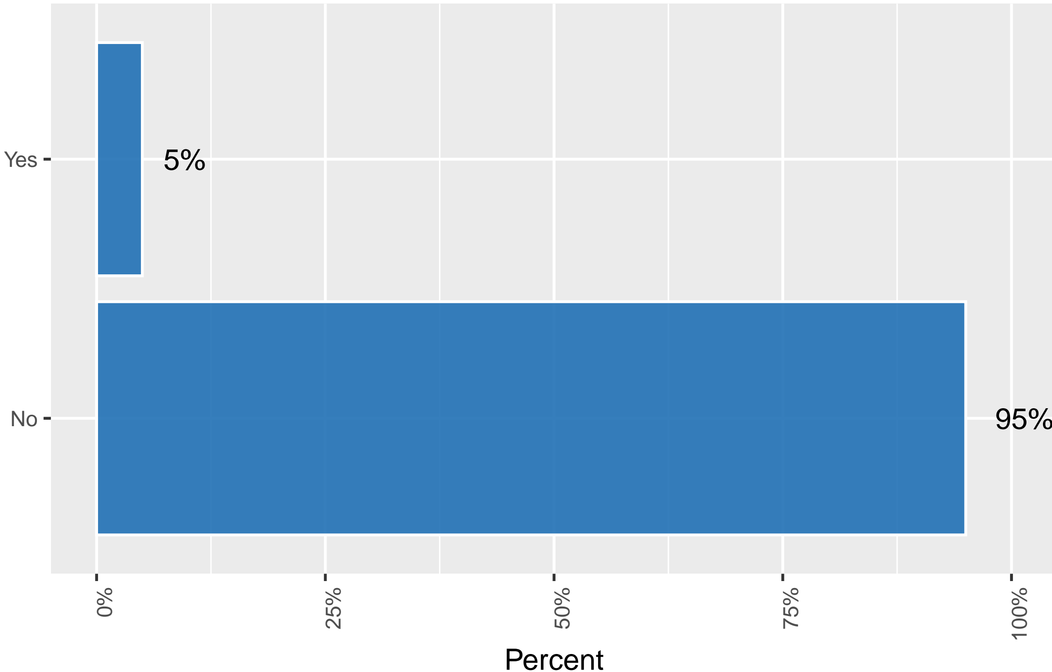
Variable was successfully pilot tested in first quarter 2005.

99% of the abstracted people have valid data

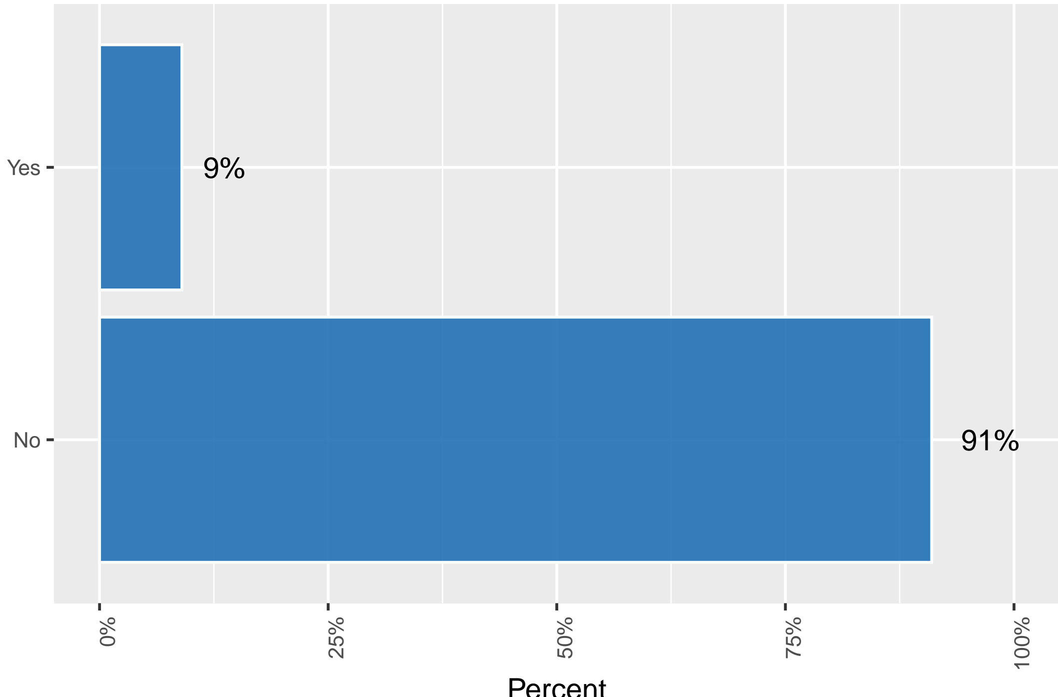
Characteristic	N = 16,084
Learning, remembering, or concentrating:, n (%)	
No	14,103 (89)
Yes	1,778 (11)
Missing	203
Dressing, bathing, or getting around inside the home:, n (%)	
No	15,383 (97)
Yes	510 (3.2)
Missing	191
Going outside the home alone to shop or visit a doctor's office:, n (%)	
No	15,039 (95)
Yes	850 (5.3)
Missing	195
Working at a job or business:, n (%)	
No	14,463 (91)
Yes	1,385 (8.7)
Missing	236




Dressing, bathing, or getting around inside the home:
Yes
No
3%
97%
0%
25%
50%
75%
100%
Percent


Going outside the home alone to shop or visit a doctor's office:
Yes
5%
No
95%
0%
25%
50%
75%
100%
Percent

Working at a job or business:



4.3 Mental Health Tx

4.3.0.1 Definition

Asks “Have you ever received treatment for any mental health problems? (Examples include depression, anxiety, schizophrenia, and alcohol/drug abuse).”

If yes, this question is followed by up by asking “Did you receive treatment for any mental health problems in the year before the injury?”

4.3.0.2 Form

[X] Form 1
[ ] Form 2

Characteristic
Have you ever received treatment for any mental health problems? (Examples include depression, anxiety, schiz
No
Yes
Missing
If yes, did you receive treatment for any mental health problems in the year before injury?, n (%)
No
Yes
Missing

4.3.0.3 Source

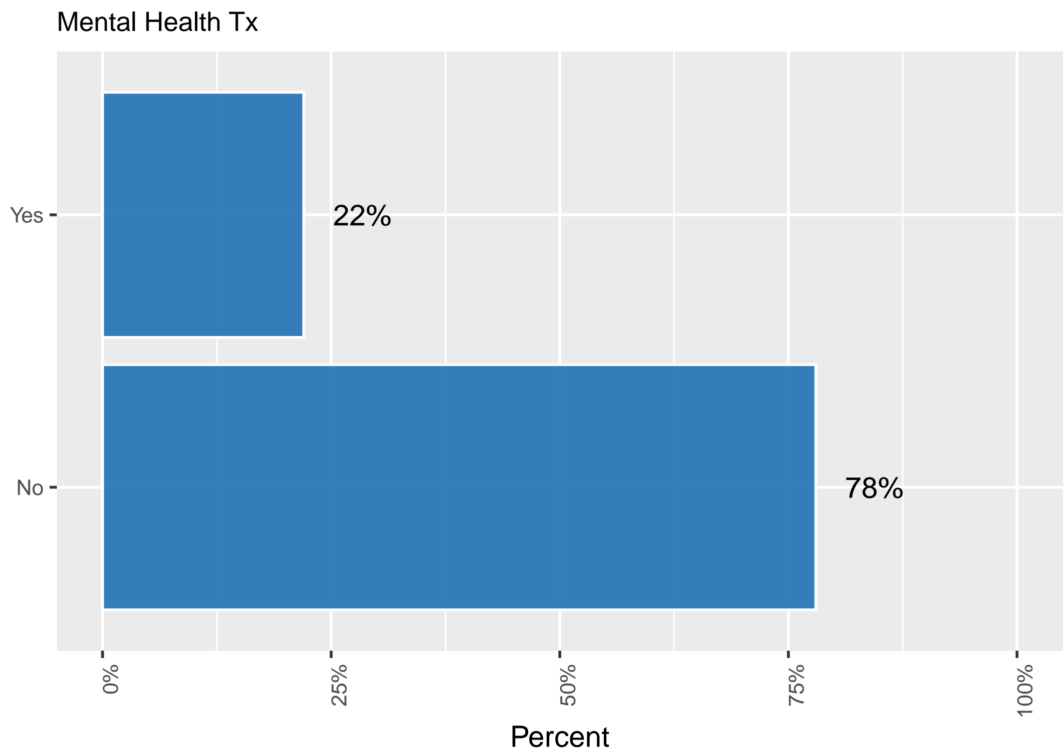
Form 1 Pre-Injury History (participant or proxy)

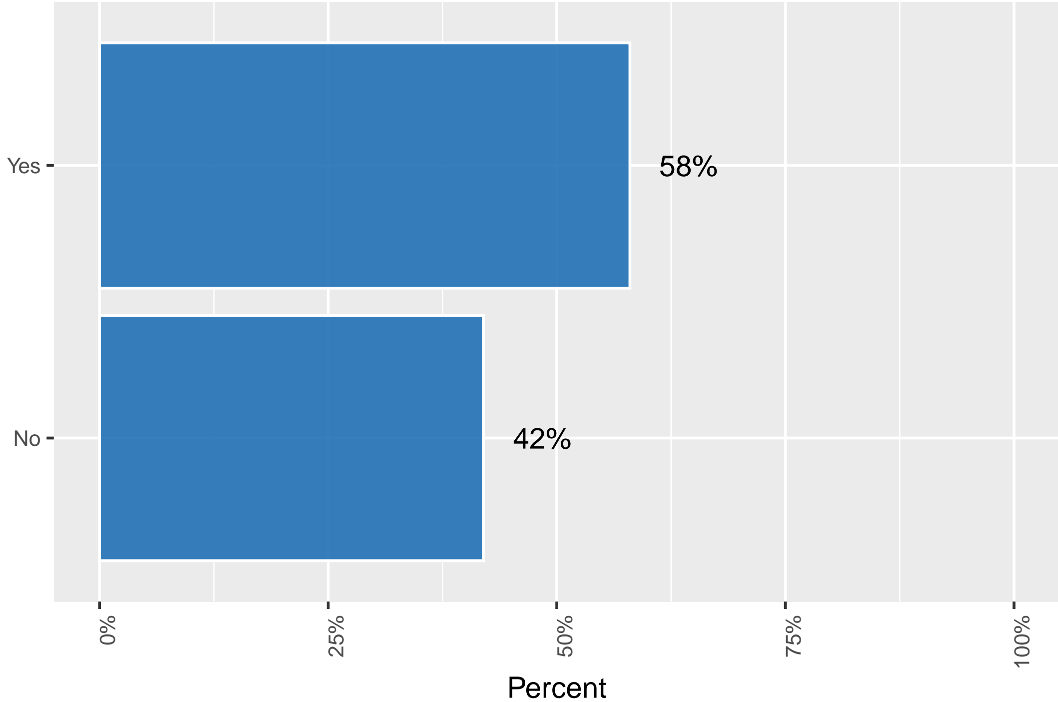
4.3.0.4 Details

Taking a prescribed medication (e.g. antidepressants) should be considered 'treatment' for the underlying condition.

Treatment for ADD/ADHD should NOT be included as treatment for mental health problems.

97% of the abstracted people have valid data


Mental Health Tx
Yes
No
22%
78%
0%
25%
50%
75%
100%
Percent



4.4 Psychiatric Hospital

4.4.0.1 Definition

Determine if the person with brain injury had any psychiatric hospitalizations prior to his/her injury by asking;

- “Have you ever been hospitalized for a psychiatric problem?”

This question is followed by asking whether it happened in the year before injury;

- “Were you hospitalized for a psychiatric problem in the year before the injury?”

4.4.0.2 Form

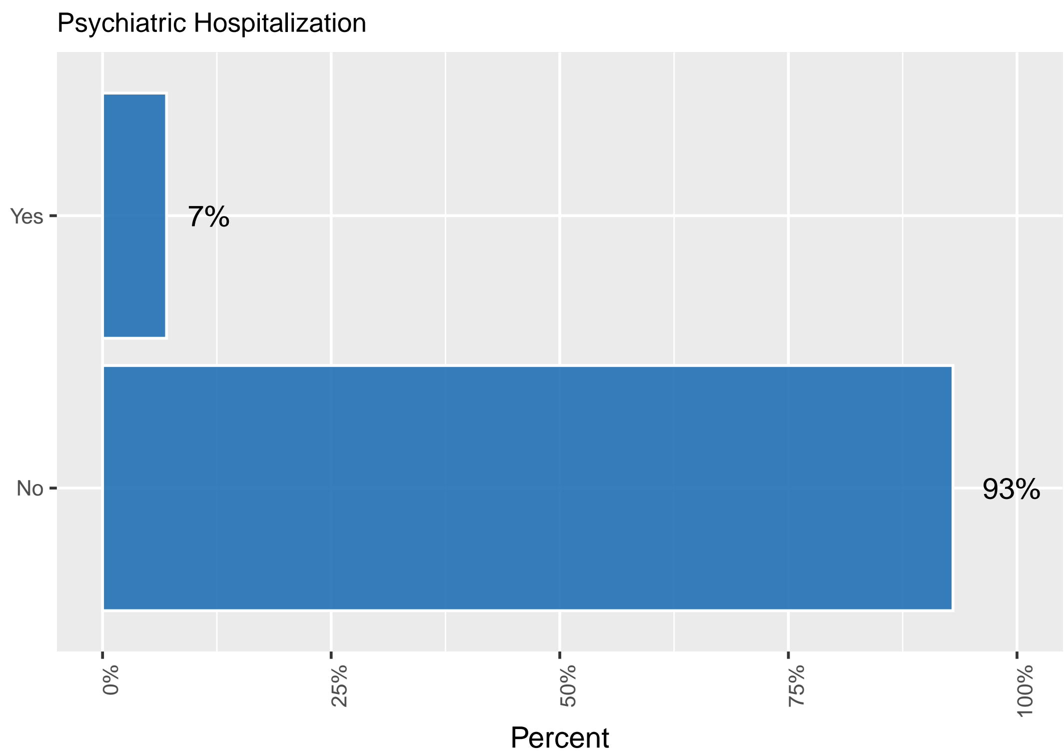
[X] Form 1
[ ] Form 2

Characteristic	N = 13,027
Have you ever been hospitalized for a psychiatric problem?, n (%)	
No	11,919 (93)
Yes	920 (7.2)
Missing	188
If yes, were you hospitalized for a psychiatric problem in the year before the injury?, n (%)	
No	627 (68)
Yes	301 (32)
Missing	12,099

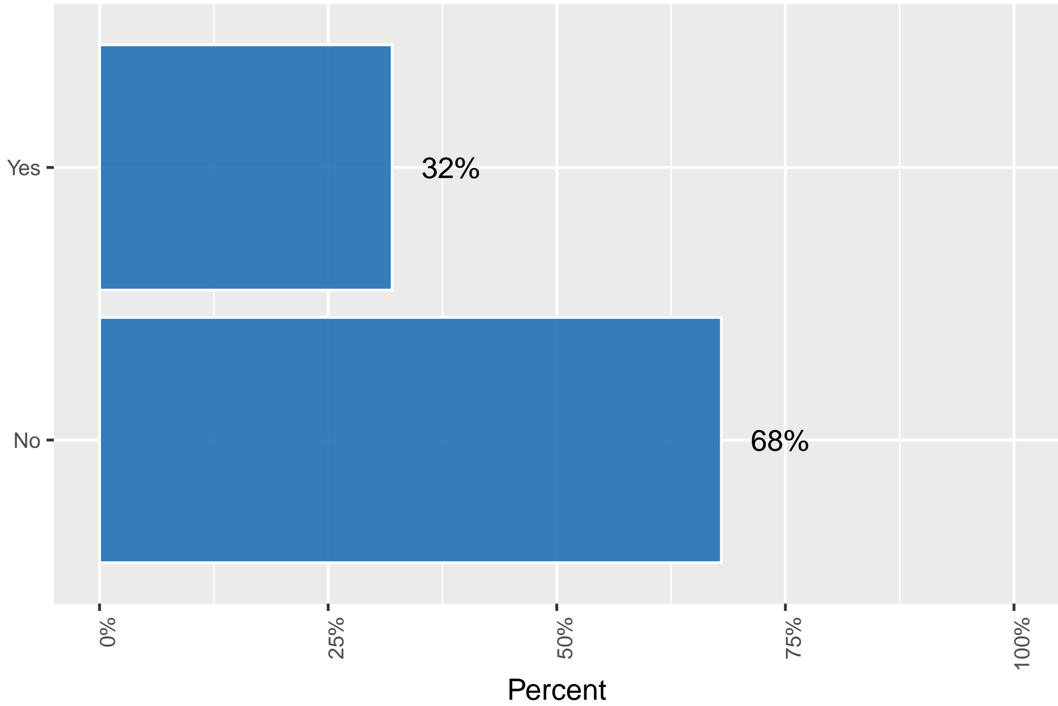
4.4.0.3 Source

Form 1 Pre-Injury History (participant or proxy)

99% of the abstracted people have valid data



Psychiatric Hospitalization year before injury



4.5 Suicide

4.5.0.1 Definition

Determine if the person with brain injury has attempted suicide in the past year.

Form 1
Asks "Have you ever attempted suicide?"

If yes, this question is followed up by asking "Did you ever attempt suicide in the year before the injury?"

Form 2
Asks "In the past year, have you attempted suicide?"

4.5.0.2 Form

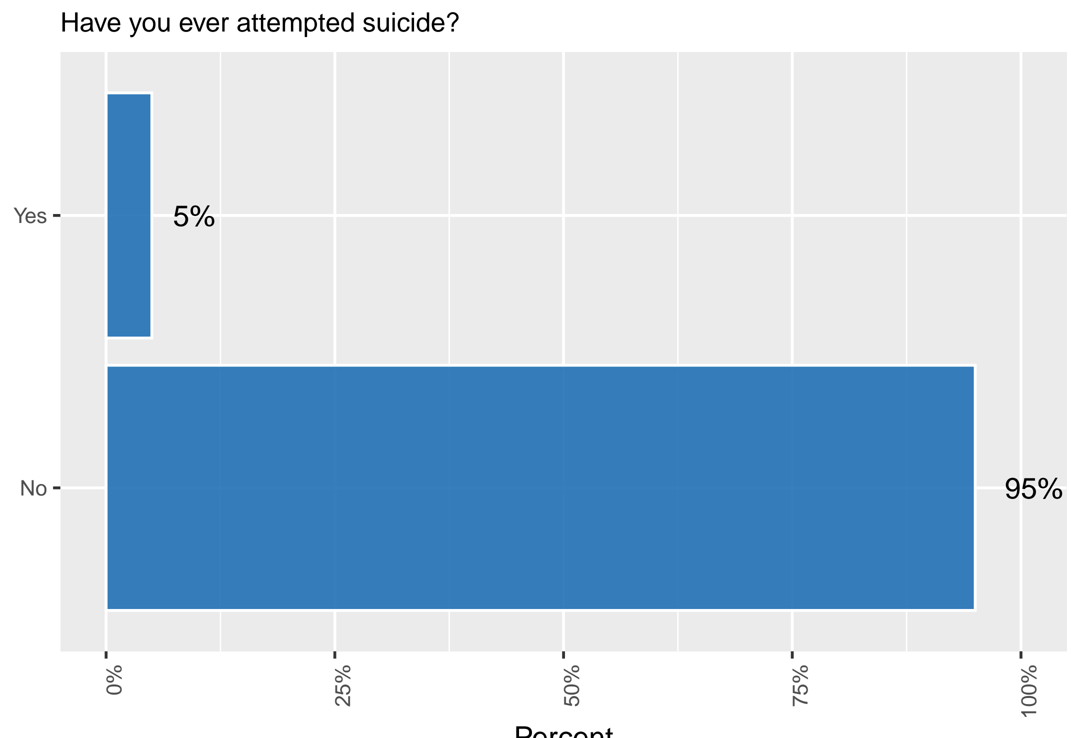
[X] Form 1
[X] Form 2

Characteristic	N = 14,106
Have you ever attempted suicide?, n (%)	
No	13,092 (95)
Yes	732 (5.3)
Missing	282
If yes, did you attempt suicide in the year before the injury?, n (%)	
No	532 (71)
Yes	221 (29)
Missing	13,353

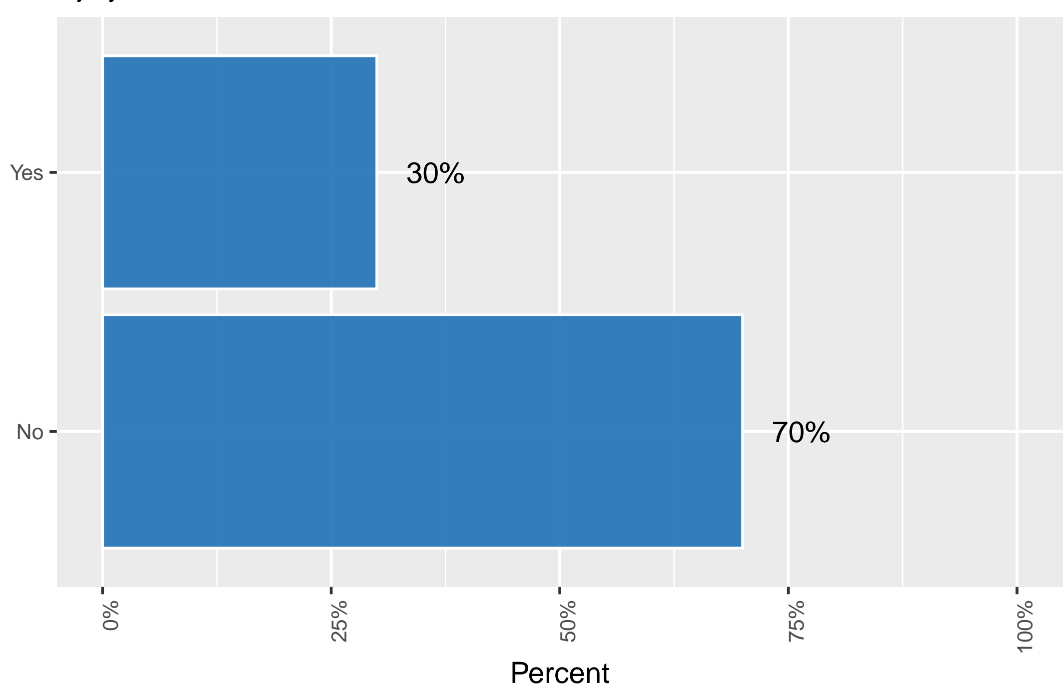
4.5.0.3 Source

Form 1 Pre-Injury History (participant or proxy)
Form 2 Interview, Mail-Out (participant or proxy)

98% of the abstracted people have valid data

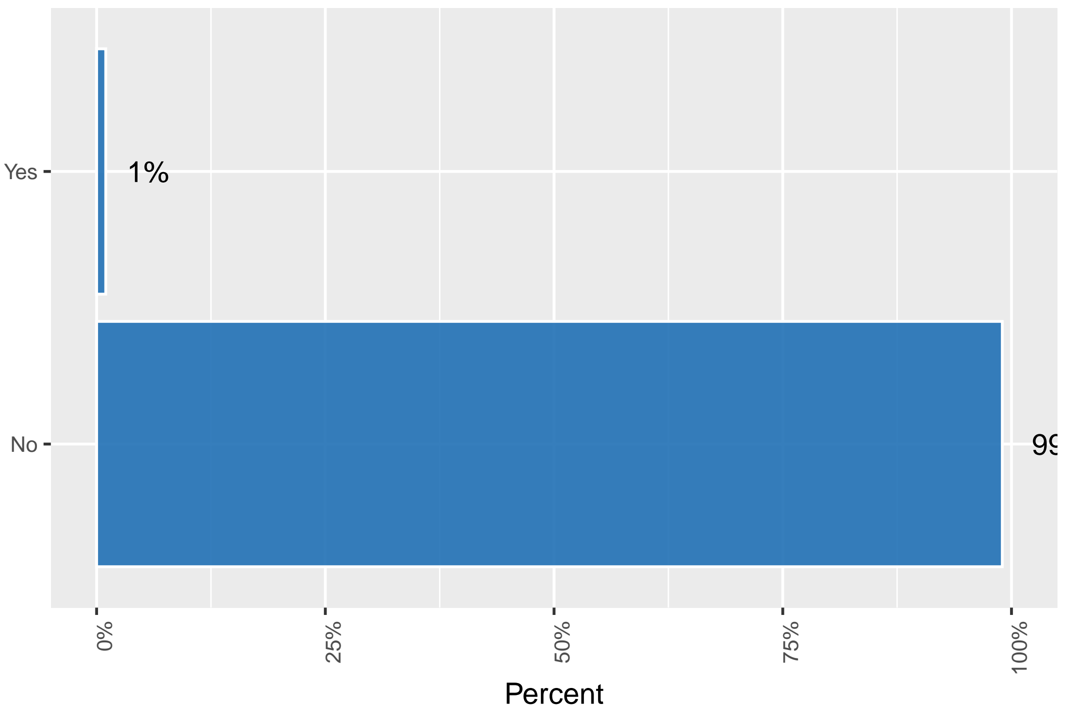


Characteristic	N = 49,263
In the past year, have you attempted suicide?, n (%)	
No	46,641 (99)
Yes	644 (1.4)
Missing	1,978



4.5.1 Suicide at Follow-up

96% of the interviewed people have valid data


In the past year, have you attempted suicide?
Yes
1%
No
99
0%
25%
50%
75%
100%
Percent

5 Disability

5.1 FIM

Caution

FIM Motor was replaced by the Continuity Assessment Record and Evaluation on 7/1/2020. Therfore FIM Motor and Total Score data will not be represented after that date for Admission and Discharge. However it is still collected at Follow-up

5.1.0.1 Definition

The FIM instrument is a measure of disability. It is intended to measure what the person with the disability actually does, not what he or she ought to be able to do, or might be able to do if certain circumstances were different. It is to be completed based on assessment over 3 calendar days for each assessment period.

FIM instrument data are to be collected according to the current (10/01/2012) IRF-PAI coding instructions (see External Links, supplemented by any further instructions in your syllabus). Information about the FIM instrument can be found in the IRF-PAI manual in section III, pages 39-95. If it is not possible for your Center to follow the correct manual, notify the TBINDC.

At Form 1, only Cognitive FIM items are collected.

The rating scale below should be used for each item. The syllabus provides additional detail on the ratings specific to the items.

Ratings should be based on the poorest performance during the 72-hour assessment period.

Rating Scale
7 - Complete Independence (Timely, safely)
6 - Modified Independence (Extra time, device)
5 - Supervision (performs 100%, but needs supervision)
4 - Minimal Assist (>= 75%)
3 - Moderate Assist (50 - 74%)

2 - Maximal Assist (25 - 49%)
1 - Total Assist (< 25%)

5.1.0.2 Form

[X] Form 1
[X] Form 2

5.1.0.3 Source

Form 1 - Abstract from FIM form (rehab record)
Form 2 - Interview (participant or proxy)

5.1.0.4 Details

All FIM items have an “assessment time period”. The assessment time period for all FIM items (except Bladder and Bowel Frequency of Accidents) is 3 days.

Scoring reflects the patient’s poorest (most dependent) functioning during the assessment time period. The evaluation is therefore not a snapshot of the patient’s performance at the time of evaluation, but a summary of performance over the entire assessment time period.

All FIM items must be scored. Record what patient actually does. If FIM assessment cannot be completed within the window of 3 calendar days, it should still reflect the patients’ status within that time period. If this is not possible and the assessments are done out of the window of 3 calendar days, code as “Unknown”. Every effort should be made to obtain the FIM assessments; however, if any items are not assessed, code “Unknown.” Do not leave blanks.

According to the UDS Procedures for Scoring the FIM instrument, “if the subject would be put at risk for injury if tested or does not perform the activity, enter 1.” Use this same rule for the TBI Model Systems FIM instrument data collection.

For Eating, Grooming, Bathing, Dressing Upper and Lower Body, Toileting and Transfers, if activity is not performed, assign code “1. Total Assist” (do not use the “0” code at follow-up).

The “Unknown” code is specific to the Model Systems and is to be used when the activity was not assessed within the window due to site specific reasons (e.g. therapists were unable to track patient down to assess FIM item.) At discharge, if an item is not assessed because the patient does not perform the activity, (e.g., patient is unable to perform activity due to an illness or other reasons, or it is unsafe for them to perform the activity) it should be coded as

a “1-Total Assistance”. If the patient was being evaluated at admission with either of these reasons, the score would be a “0”.

If patient has an intermittent acute care stay during inpatient rehabilitation, use the FIM scores from the first rehabilitation admission and the last definitive discharge. In addition, if a patient has an intermittent stay which is longer than 30 days, it is then considered a system discharge and the discharge date from rehabilitation is the system discharge date and the FIM scores should correspond to that date.

The patient’s score on measures of function should not reflect arbitrary limitations or circumstances imposed by the facility. For example, a patient who can routinely ambulate more than 150 feet throughout the day with supervision (score of 5 for FIM Locomotion: Walking/Wheelchair item), but who is observed to ambulate only 20 feet at night to use the toilet because that is the distance from his/her bed, should receive a Walk score of 5 rather than a lower score (IRF-PAI Training Manual 1/16/02, page III-4).

FIM scores may be abstracted from the medical record as long as the notes are specific (e.g. “patient feeding themselves independently”; “patient is unable to ambulate”; “patient needs the assistance of two people for all transfers”).

If a patient expires while in the rehabilitation facility, record a score of Level 1 for all discharge FIM items.

Total admission FIM is calculated using the admission walking score if participant is walking at discharge or the admission wheelchair score if the person is in a wheelchair at discharge.

At follow-up, FIM may be asked of anyone who would know the details of the participant’s functioning in these areas.

5.1.0.5 Links

FIM Manual - IRF-PAI instructions for FIM data collection
Introduction (COMBI)
Summary of the differences between the 4/2004 instructions and the 1/2002 instructions
FIM Decision Rule
FIM Cognitive Rating Form
Fone FIM for TBIMS * *Fone FIM to be used only as a supplement to assist as needed in determining FIM scoring - not as word-for-word administration.*

5.1.0.6 Reference

Uniform Data System for Medical Rehabilitation 232 Parker Hall SUNY South Campus 3435 Main Street Buffalo, New York 14214 3007 (716) 829 2076; FAX (716) 829 2080

The IRF-PAI instructions for the FIM instrument are disseminated through the website of The Centers for Medicare and Medicaid Services. For information about the CMMS, go to: http://www.cms.hhs.gov/researchers/projects/APR/2003/facts.pdf.

©1997 Uniform Data System for Medical Rehabilitation (UDSMR), a division of UB Foundation Activities, Inc. FIM is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. This version of the FIM instrument has been modified with permission from UDSMR for use by the Traumatic Brain Injury Model Systems.

5.1.0.7 Characteristics

12 additional FAM items were collected from 10/01/1989 to 4/01/1998 when the collection of the FAM items became optional. FAM items were removed 7/01/1999.

On 4/1/02 new fields were created to accept data collected with the new (1/1/02) IRF-PAI instructions. The old fields are still in the database. At present there are no calculated variables that merge old data and with new data. Calculated variables based on either old or new scoring are available.

On 10/1/2019, centers began collecting the CARE Item Set at Form 1, and the collection of FIM Motor variables at Form 1 was no longer required. FIM Cognitive variables continue to be collected.

On 7/1/2020, the collection of FIM Motor variables at Form 1 was discontinued.

On 1/15/2025, a new coding rule was implemented: “If all FIM Cognitive items = 7 and FIM Stairs = 7, then remaining FIM items can be skipped and coded as 7.”. FIM Cognitive questions are now asked first, followed by FIM Stairs and the remaining FIM Motor items in the standard FIM order.

5.1.0.8 Training

Testing and certification of data collectors of this variable is required. Check with your center for their requirements for FIM certification.

ITHealthTrack training and certification materials (DVDs) are available at each local TBIMS center and also on the website under the Training & Certification tab (click on the “Certification” dropdown, then “Certification File Manager”, then “FIM Certification Materials”. Please contact CB Eagye at “PEagye@craighospital.org” for additional training and certification details.

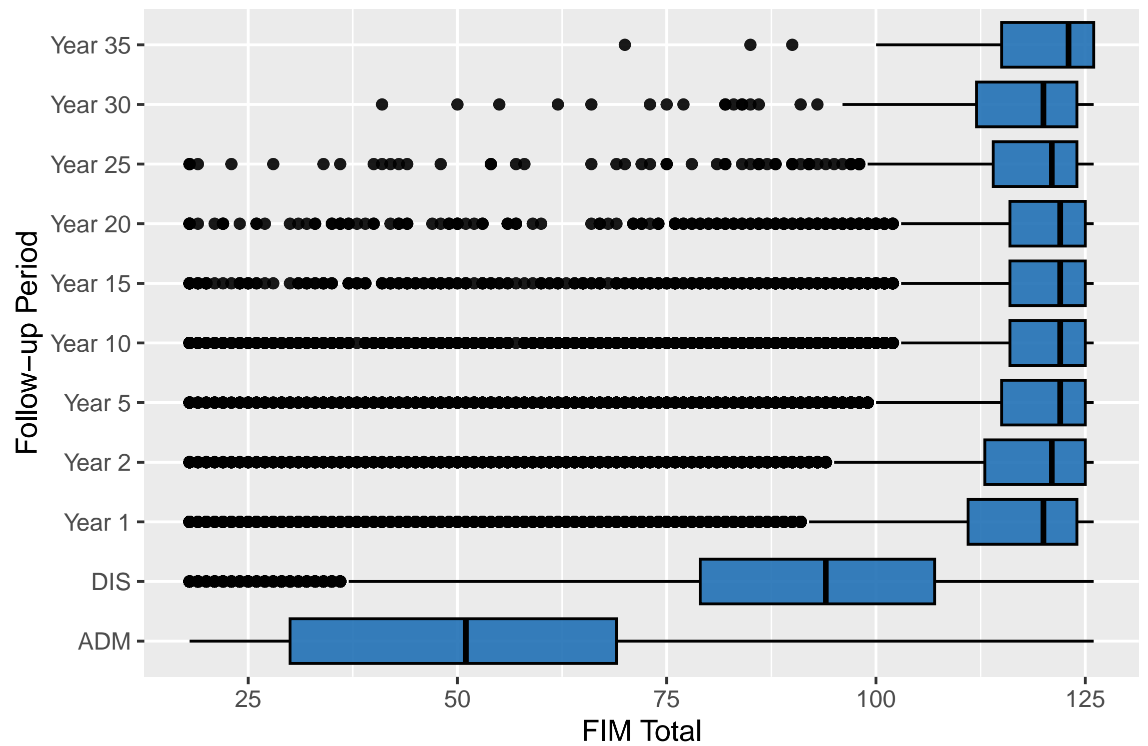
A score of 80% or greater is required for FIM certification.

See external links for ITHealthTrack Exam Instructions and Exam Form.

FIM Total

Characteristic	**ADM** N = 18,309	**DIS** N = 18,309	**Year 1** N = 17,114	**Year 2** N = 15,144	**Year 5** N = 11,895
FIMTOT					
N Non-missing	17,431	17,530	16,085	14,168	11,158
Mean (SD)	51 (23)	90 (23)	113 (20)	114 (19)	115 (18)
Median (Q1, Q3)	51 (30, 69)	94 (79, 107)	120 (111, 124)	121 (113, 125)	122 (115, 125)
Min, Max	18, 126	18, 126	18, 126	18, 126	18, 126
Missing	878	779	1,029	976	737

5.1.1 FIM Total



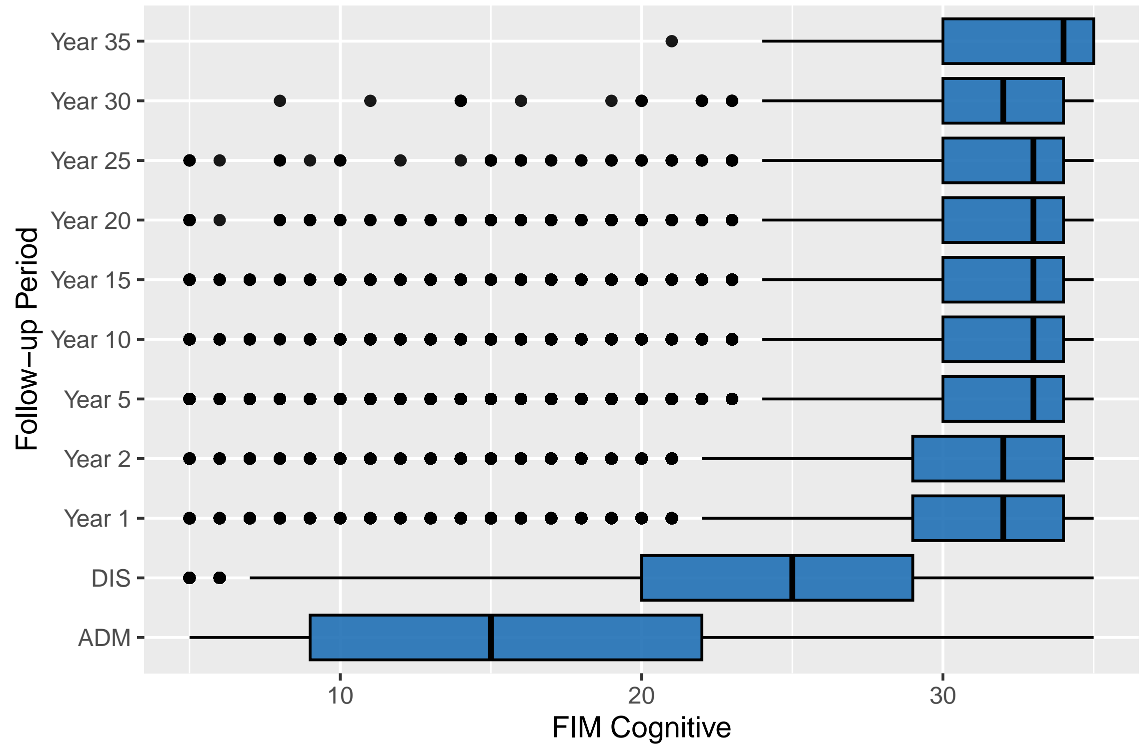
95% of the abstracted people have valid data

93% of the interviewed people have valid data

FIM Cognitive

Characteristic	**ADM** N = 21,526	**DIS** N = 21,526	**Year 1** N = 17,114	**Year 2** N = 15,144	**Year 5** N = 11,895
FIMCOG					
N Non-missing	21,025	20,952	16,253	14,288	11,244
Mean (SD)	16 (8)	24 (7)	30 (6)	31 (5)	31 (5)
Median (Q1, Q3)	15 (9, 22)	25 (20, 29)	32 (29, 34)	32 (29, 34)	33 (30, 34)
Min, Max	5, 35	5, 35	5, 35	5, 35	5, 35
Missing	501	574	861	856	651

5.1.2 FIM Cognitive



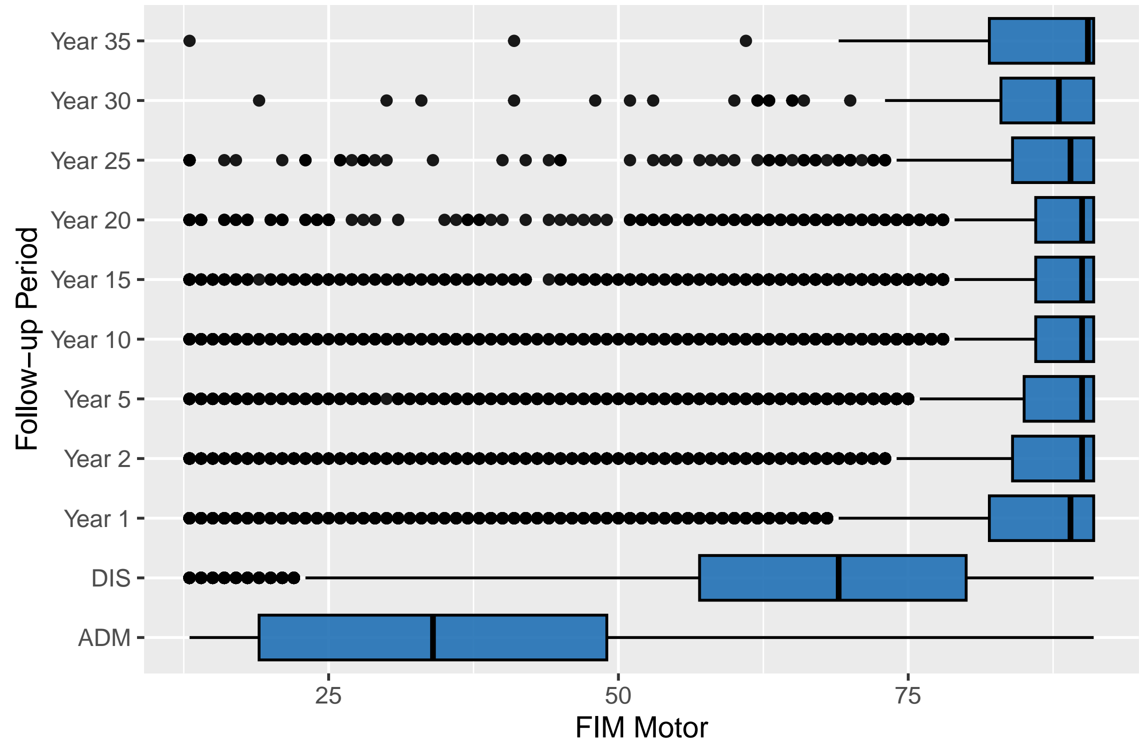
98% of the abstracted people have valid data

94% of the interviewed people have valid data

FIM Motor

Characteristic	**ADM** N = 18,309	**DIS** N = 18,309	**Year 1** N = 17,114	**Year 2** N = 15,144	**Year 5** N = 11,895
FIMMOT					
N Non-missing	17,454	17,574	16,144	14,212	11,193
Mean (SD)	36 (18)	66 (19)	82 (16)	83 (15)	84 (14)
Median (Q1, Q3)	34 (19, 49)	69 (57, 80)	89 (82, 91)	90 (84, 91)	90 (85, 91)
Min, Max	13, 91	13, 91	13, 91	13, 91	13, 91
Missing	855	735	970	932	702

5.1.3 FIM Motor



95% of the abstracted people have valid data

94% of the interviewed people have valid data

5.2 DRS

5.2.0.1 Definition

DRSa refers to Disability Rating Scale at admission (collected at Form 1)

DRSd refers to Disability Rating Scale at discharge (collected at Form 1)

Disability Rating Scale ratings are to be completed within 3 calendar days for each assessment period. Indicate ratings for all items. Information about the DRS is available from COMBI. See External Links

The DRS at Form 2 (DRS PI) is a standardized questionnaire, and questions should be asked the same way every time with no words changed. If the participant is having trouble understanding the question, restate the question as phrased. If additional clarification is needed, then data collectors can rephrase the question or offer clarification.

5.2.0.2 Form

[X] Form 1
[X] Form 2

5.2.0.3 Source

Form 1 - To be completed by clinician or other individual who is trained and certified to code the DRS.
Form 2 - Interview (participant or proxy)

5.2.0.4 Details

Form 1

If DRS assessments cannot be completed within the 3 calendar day window, they should still reflect the patients' status within that time period. If this is not possible and the assessments are done out of the 3 calendar day window, code "Unknown".
Every effort should be made to obtain the DRS assessments, however, if any items can not be assessed, use code "Unknown". Do not leave blanks.

If a patient has an intermittent acute care stay during inpatient rehabilitation, use the DRS scores from the first rehabilitation admission and the last definitive discharge. In addition, if a patient has an intermittent stay which is longer than 30 days, it is then considered a system

discharge and the discharge date from rehabilitation is the system discharge date and the DRS scores should correspond to that date.

Form 2

The DRS for Form II is a standardized questionnaire, and questions should be asked the same way every time with no words changed.

If the answers to specific questions are obvious from answers given prior to the DRS questions, they may be confirmed and skipped.

If the participant is having trouble understanding the question, restate the question as phrased. If additional clarification is needed, then data collectors can rephrase the question or offer clarification.

If in doubt on how to code a response to a DRS item, give the participant the benefit of the doubt. For example, if a participant states that they can give you the correct date and time, but is uncomfortable saying yes because it sometimes takes them up to 30 seconds, give them the credit for being able to do this.

5.2.0.5 Links

Item Definitions (COMBI)
Properties (COMBI)
FAQ (COMBI)
DRS Training (COMBI)
DRS References (COMBI)
DRS Rating Form (COMBI)
DRS Introduction (COMBI)
PubMed:Rappaport M, et al (1987)

5.2.0.6 Reference

Rappaport M, Hall KM, Hopkins K, Belleza T, Cope N. (1982). Disability Rating Scale for severe head trauma patients: Coma to community. Arch Phys Med & Rehabil, 63:118-123. rev 8/87. For an abstract of this article, see External Links

Malec JF, Hammond FM, Giacino JT, Whyte J, Wright J. (2012) A Structured Interview to Improve the Reliability and Psychometric Integrity of the Disability Rating Scale. Arch Phys Med & Rehabil,Epub 2012 Sep;93(9):1603-8.

5.2.0.7 Characteristics

For follow-up, interviewers were originally rating the individual DRS items using the original DRS scoring form. The DRS structured interview was implemented on 10/01/2012.

The DRS-PI provides a structured interview for administration of the Disability Rating Scale (DRS) over the telephone. Except for cases with very severe limitations (eg, minimally conscious), the scoring algorithm for the DRS-PI results in a score that is comparable to the original DRS. However, there are differences between the original DRS and the DRS-PI for cases with very severe limitations. The Motor item of the DRS was not included in the DRS-PI because almost all cases interviewed in the development of the DRS-PI obtained a zero response on this item. In addition, the scoring of the Communication item was altered so that no score above 2 can be obtained. Scoring of the Communication item was altered in this way because very few scores above 2 were obtained in the development sample and collapsing all categories above 2 resulted in better fit of the Communication item with the Rasch model on which the DRS-PI was based. The Eye Opening item of the original DRS was not included in the DRS-PI interview and automatically scored as zero because eye opening should be present in all TBI cases who survive several months or more.

The Expanded DRS-PI adds additional items the DRS-PI and results in a score with a less skewed distribution than either the DRS-PI or the original DRS.

Original DRS. In order to obtain a score similar to the original DRS using the DRS-PI structured interview, an attempt can be made to administer the Motor item over the telephone. This item is only included in the Caregiver version since the Motor score will be zero if the person with TBI is able to respond to the interview questions. The Communication is the same as for the DRS-PI/ Expanded DRS-PI but is scored differently. Scoring algorithms for the DRS-PI, Expanded DRS-PI and Original DRS are at the end of this document.

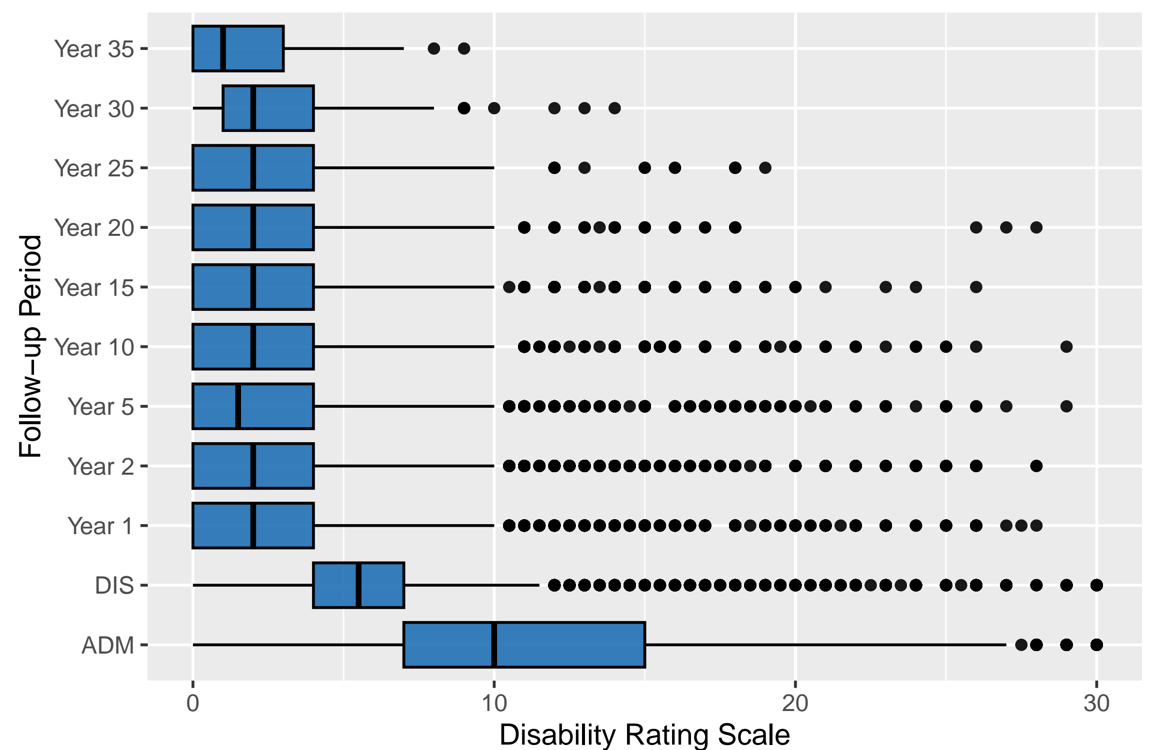
The development of the DRS-PI and Expanded DRS-PI is described in: Malec JF, Hammond FM, Giacino JT, Whyte J, Wright J. A structured interview to improve the reliability and psychometric integrity of the Disability Rating Scale. Arch Phys Med Rehabil 2012;93:1603-8.

5.2.0.8 Training

Testing and certification of data collectors of this variable is required. It is available from the COMBI website. See external links for training and testing materials.

Disability Rating Scale

Characteristic	**ADM** N = 21,526	**DIS** N = 21,526	**Year 1** N = 17,114	**Year 2** N = 15,144
Disability Rating Scale On Admission				
N Non-missing	21,151	21,187	15,892	13,984
Mean (SD)	11.4 (5.5)	6.3 (3.9)	3.0 (3.5)	2.7 (3.4)
Median (Q1, Q3)	10.0 (7.0, 15.0)	5.5 (4.0, 7.0)	2.0 (0.0, 4.0)	2.0 (0.0, 4.0)
Min, Max	0.0, 30.0	0.0, 30.0	0.0, 28.0	0.0, 28.0
Missing	375	339	1,222	1,160



98% of the abstracted people have valid data

91% of the interviewed people have valid data

5.3 CARE

5.3.0.1 Definition

The Continuity Assessment Record and Evaluation (CARE) Item Set was developed as part of the larger Post-Acute Care Payment Reform Demonstration (PAC-PRD), authorized by the Deficit Reduction Act of 2005. It was developed as a standardized set of items for measuring medical, functional, cognitive, and social support factors in the acute hospital, long-term care hospital (LTCH), inpatient rehabilitation facility (IRF), skilled nursing facility (SNF), and home health agency (HHA) settings to provide a way to compare the health status of Medicare beneficiaries across provider types.

Section GG Functional Abilities and Goals (Self-Care and Mobility Activities) includes admission and discharge self-care and mobility performance data elements. Qualified clinicians code each data element, which are activities, using a 6-level rating scale to reflect the patient's/resident's functional abilities based on the type and amount of assistance provided by a helper. If the patient/resident did not perform the activity and a helper did not perform the activity for the patient/resident during the assessment period, one of four "activity not attempted codes" is used.

The 6-Point Scale and Activity Not Attempted Codes

Coding:
Safety and Quality of Performance - If helper assistance is required because patient's/resident's performance is unsafe or of poor quality, score according to amount of assistance provided.
Activities may be completed with or without assistive devices.
01 - Dependent - Helper does ALL of the effort. Patient/resident does none of the effort to complete the activity.
Or, the assistance of 2 or more helpers is required for the patient/resident to complete the activity.
02 - Substantial/maximal assistance - Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
03 - Partial/moderate assistance - Helper does LESS THAN HALF the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
04 - Supervision or touching assistance - Helper provides verbal cues and/or touching/steadying and/or contact guard assistance as patient/resident completes activity. Assistance may be provided throughout the activity or intermittently.
05 - Setup or clean-up assistance - Helper sets up or cleans up; patient/resident completes activity. Helper assists only prior to or following the activity.
06 - Independent – Patient/resident safely completes the activity by him/herself with no assistance from a helper.

If activity was not attempted, code reason:
77 - Patient/resident refused
81 - Not applicable - Not attempted and the patient/resident did not perform this activity prior to the current illness, exacerbation, or injury.
82 - Not attempted due to environmental limitations (e.g., lack of equipment, weather constraints)
83 - Not attempted due to medical condition or safety concerns
84 - Did Not Meet Criteria for Administration (To be used if participant leaves AMA, returns to ICU and does not return to rehab, or is only on rehab unit for 24 hours or less).
99 - Unknown No information, form not completed

5.3.0.2 Form

[X] Form 1
[ ] Form 2

5.3.0.3 Source

Abstracted from CARE tool data submitted to ERehab, UDS or CMS

5.3.0.4 Details

Each core item for functional mobility is scored on a six-level rating scale measuring the need for assistance- dependent, substantial assistance, partial assistance, supervision or touching assistance, set-up or cleanup assistance, or independent.

Code "84 - Did not meet criteria for administration" to be used if participant leaves AMA, returns to ICU and does not return to rehab, or is only on rehab 24 hours.

5.3.0.5 Links

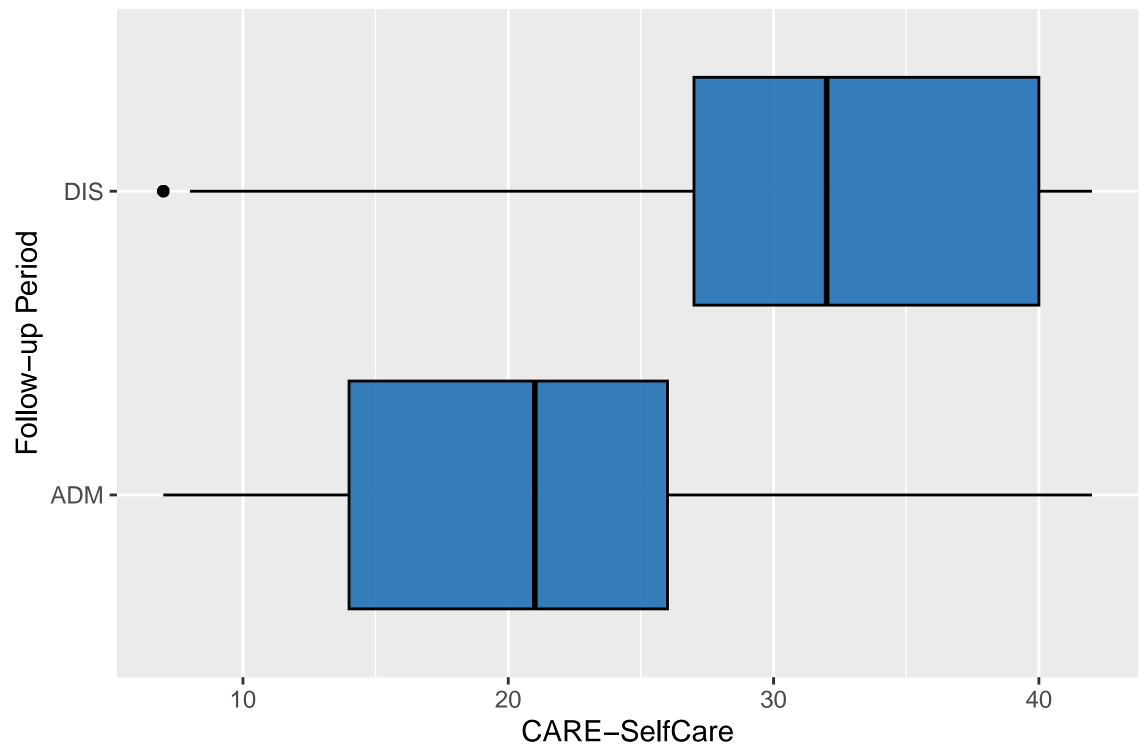
Final IRF-PAI Version 3.0 - Effective October 1 2019 (FY2020) (PDF)
IRF-PAI Manual Chapter 2 - Section GG v3.0-508C

CARE-SelfCare

Characteristic	**ADM** N = 3,217	**DIS** N = 3,217
N Non-missing	3,025	3,078
Mean (SD)	20 (8)	32 (9)
Median (Q1, Q3)	21 (14, 26)	32 (27, 40)
Min, Max	7, 42	7, 42
Missing	192	139

5.3.0.6 Characteristics

CARE Tool was added on 10/01/2019.



94% of the abstracted people have valid data

5.4 Glasgow Outcome Scale Extended

5.4.0.1 Definition

For information about the GOS-E (Glasgow Outcome Scale-Extended), see External Links.

5.4.0.2 Form

[ ] Form 1
[X] Form 2

5.4.0.3 Source

Interview (participant or proxy)

5.4.0.4 Details

Background of Instrument
The Glasgow Outcome Scale (GOS) was originally developed by Jennett and Bond as an examiner-rated measure of outcome. It has most typically been used to assess outcome in neurosurgery studies and has been widely used for clinical drug trials in acute TBI. The original GOS did not have a structured interview to accompany it. Raters, who may have been neurosurgeons, research nurses, or neuropsychologists, would give a GOS outcome rating based on all available information, including interviews with patients and their families, evaluation and examination of the patient, and any factual evidence they were able to obtain. Wilson et al. developed a structured interview to improve reliability of ratings on the GOS, as well as to extend the rating categories so that they would better characterize patients at different levels.

Instructions for Rating
The interview can be administered to either the patient or a family member or other informant. However, the GOS-E is not meant to be a self-perception instrument. Raters should rate each item based on the most accurate information they have, regardless of source. The following guidelines should help with the rating.

- Although you are administering the interview to one person, you can obtain clarification from other sources if you feel that a particular item or items is inaccurate. For example, if the person with injury is the only person available to interview, you would administer the interview to him/her. However, if that person has limited insight into difficulties, and you know from another source that some of the answers are inaccurate, you can rate

those particular items based on the most accurate information you have. For example, if someone who is in your post-acute program at the time of follow-up tells you they can travel without assistance, while their therapist says that they are medically restricted from driving and are currently receiving transportation training, you should assign the GOS-E score based on the information from the source that you feel to be most accurate. This does not mean that you are required to interview multiple sources. It just means that if you happen to have information from multiple sources, you can combine that information to increase the accuracy of your rating.

- Many GOS-E questions overlap with other questions that you may have already asked as part of local or national database projects. It is not necessary to ask the question again for the GOS-E. If you already know the answer to a question, you can fill it in and move on to the next question. (Dr. Dikmen confirmed this with the authors of the GOS-E when we first began using it.)
- Collect and record all subscale scores *unless* instructed to skip some of them by the skip instructions on the Form 2.
- The intention of the GOS-E is to measure the person's ABILITY to do things, whether or not they actually do them, so scoring should be based on what a person is able to do.

All raters should familiarize themselves with the original GOS-E article by Wilson and colleagues. Pay particular attention to the section on Assigning an Outcome Category (p. 576). This includes guidelines on how to account for pre-injury functioning.

Instructions for coding Unknown items

Every effort should be made to obtain the GOS-E assessment, however, if it can not be assessed, use code "99. Unknown." Do not leave blanks.

There should not be many "unknown" answers from a respondent. If there are, then the respondent is probably not sufficiently informed about the person with TBI to be the basis for scoring the GOS-E. If there ARE many "unknown" responses and no better source of information is available, then the overall rating for the GOS-E should be "unknown". Data collectors should use their judgment as to whether there are too many "unknown" responses to allow the GOS-E to accurately indicate the person's level. Confer with your Model System's data manager if uncertain.

For a GOS-E item that the respondent does not provide enough information to score other than "unknown", the data collector should attempt to infer the score from alternative sources, such as the respondent's answers to numerically higher GOS-E items, other items in the Form 2, and probes asked of the respondent and other persons informed about the person with TBI.

Additional Tips

Code deficits due to age as 'Effects of Illness or Injury to Another Part of the Body'.

GOS-E is a "best source" variable. Not necessary to ask the two "supplemental" questions about seizures and source of disability (not present on data collection form).

The employment section can be based on education instead of employment if the participant was not working prior to injury. Evaluate whether the participant was attending school without difficulty (extra time, assistance, tutors, etc.). If the participant has returned to school part-time because she can not return to a full schedule due to the injury, then yes, code 5b as 1-Reduced work capacity. If you don't have enough information to rate their schooling ability, you can skip the employment section and code as 88's, and move onto the next GOS-E section.

If the person was unemployed and not seeking work before the injury, then they should be rated on the answers given to questions 6 and 7. For example, if the person is long-term unemployed or retired, then they should be rated on social and leisure activities and personal relationships. See external link, Wilson et al.- Frequently Asked Questions (p. 576).

The hierarchical nature of the GOS-E items causes lower items in the scale to not contribute to the overall score if the person is able to perform the task described by a higher item.

DATA ENTRY: Enter into the database all subscale scores that do not autofill. For each case that you enter, check to be sure that the auto-filled total score in the database is the same as the total score that has been recorded on the Form 2. Notify your Data Manager of any discrepancies.

DATA MANAGERS: If errors in calculating the total score turn up on the Form 2, provide your data collector(s) with more training in scoring the GOS-E and in calculating the total score. Contact the TBIMS NDSC if you have questions.

5.4.0.5 Links

PubMed: JT Wilson, et. al. (1998) GOSE-Manual Frequently Asked Questions for GOS-E (COMBI) Properties of the GOS-E instrument (COMBI) GOS-E References (COMBI)

5.4.0.6 Reference

JT Wilson, L Pettigrew, G Teasdale. Structured Interviews for the Glasgow Outcome Scale and the Extended Glasgow Outcome Scale: Guidelines for their use. Journal of Neurotrauma, Vol. 15 No. 8, 1998. For an abstract of this article, see External Links.

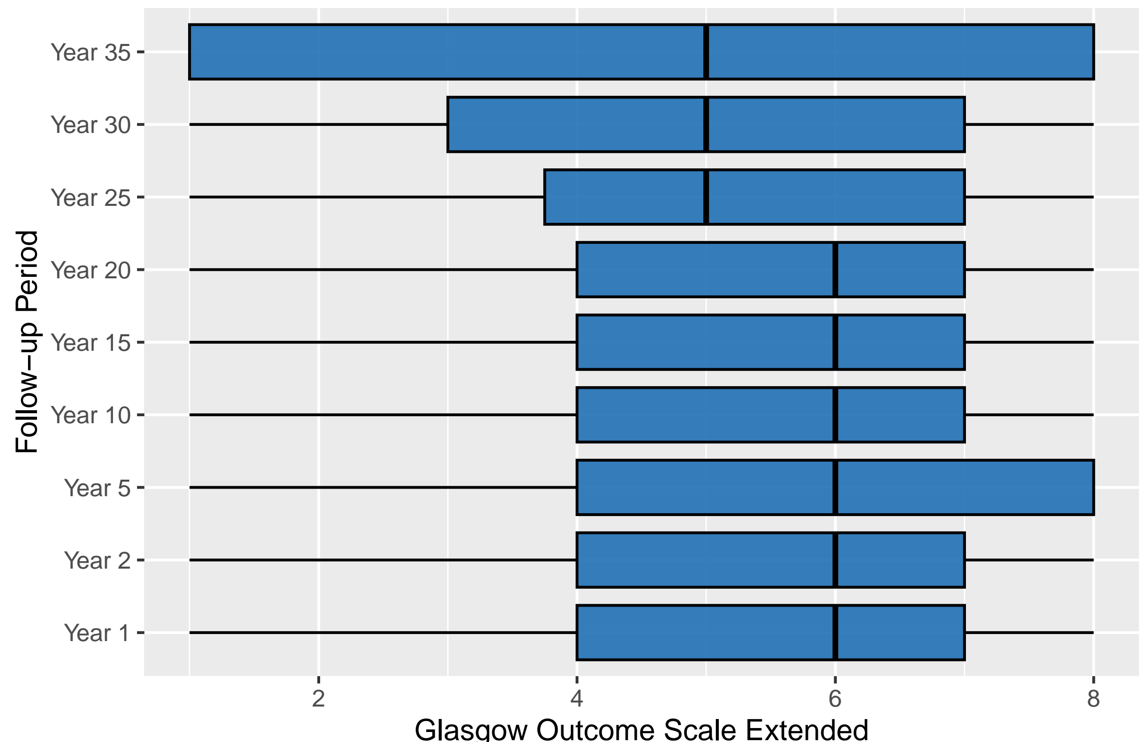
For additional references, see External Links.

5.4.0.7 Characteristics

On 7/1/00 a field for data with the new scoring was created. The old field (data prior to 7/1/00) is also in the database. GOS-E data can be collapsed onto the GOS scale if analyses require.

Glasgow Outcome Scale Extended

Characteristic	**Year 1** N = 17,317	**Year 2** N = 15,235	**Year 5** N = 12,742	**Year 10** N = 9,231	**Year**
GOS-E Incl. Expired, n (%)					
1	725 (4.5)	498 (3.5)	1,030 (8.6)	1,169 (13)	
2	85 (0.5)	59 (0.4)	46 (0.4)	27 (0.3)	
3	2,916 (18)	2,216 (15)	1,466 (12)	879 (10)	5
4	2,212 (14)	1,688 (12)	1,058 (8.8)	687 (7.9)	
5	1,698 (10)	1,637 (11)	1,501 (12)	1,194 (14)	
6	3,182 (20)	2,899 (20)	2,405 (20)	1,625 (19)	
7	2,071 (13)	1,930 (13)	1,506 (13)	1,040 (12)	
8	3,334 (21)	3,435 (24)	3,022 (25)	2,100 (24)	1
Missing	1,094	873	708	510	



94% of the interviewed people have valid data

6 Health

6.1 General Health

6.1.0.1 Definition

- In general, would you say your health is: excellent, very good, good, fair, poor?

6.1.0.2 Form

[ ] Form 1
[X] Form 2

6.1.0.3 Source

Interview, Mail-out (participant only)

6.1.0.4 Details

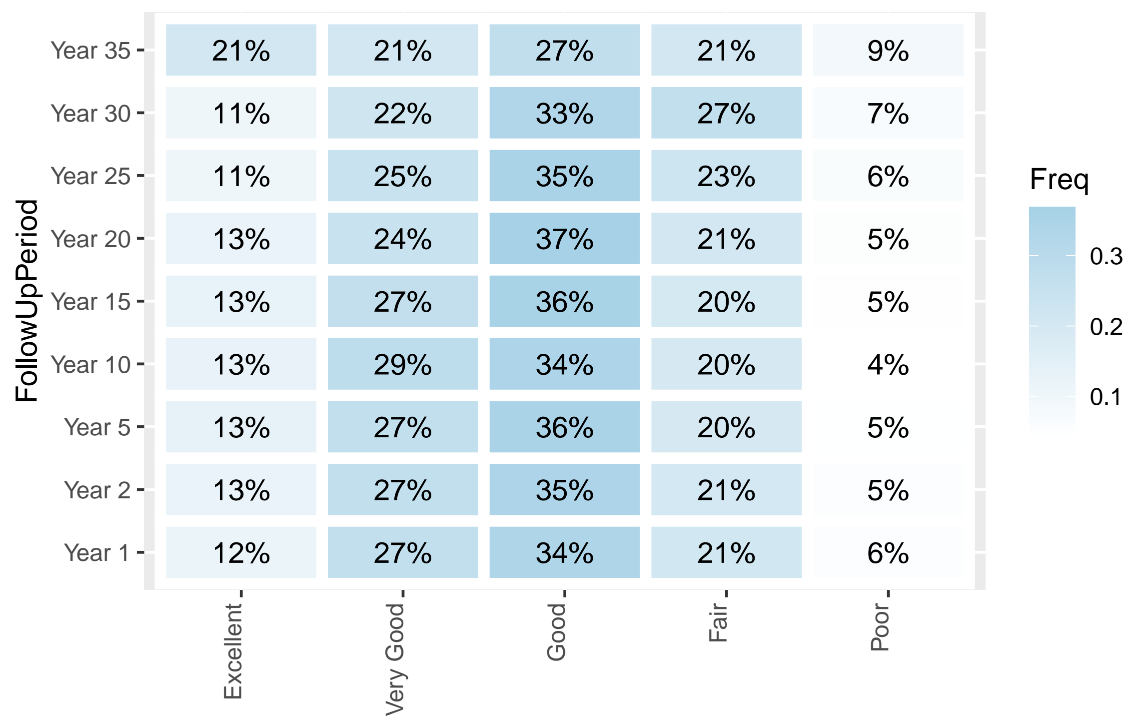
This question is a self-reported measure collected during the Form II interview for all participants.

This question should NOT be administered to a significant other, or any other proxy. If the individual is unable to provide data, use code “88. Not Applicable: No data from person with TBI.”

6.1.0.5 Reference

Question 1: Medicare Survey Question #1; NHANES question
Question 2: Medicare Survey Question #11; CDC question with state comparative data for over 65; NHANES question

Characteristic	Overall N = 36,960	Year 1 N = 8,269	Year 2 N = 7,664	Year 5 N = 7,108	Year 10 N = 6,029	Year 15 N = 4,468	Year 20 N =
GenHlthF, n (%)							
Excellent	3,735 (13)	765 (12)	743 (13)	759 (13)	647 (13)	474 (13)	238 (13
Very Good	7,923 (27)	1,693 (27)	1,584 (27)	1,526 (27)	1,428 (29)	994 (27)	462 (24
Good	10,290 (35)	2,131 (34)	2,042 (35)	2,021 (36)	1,706 (34)	1,352 (36)	699 (37
Fair	6,030 (20)	1,338 (21)	1,225 (21)	1,119 (20)	976 (20)	740 (20)	399 (21
Poor	1,476 (5.0)	361 (5.7)	312 (5.3)	257 (4.5)	209 (4.2)	173 (4.6)	98 (5.2
Missing	7,506	1,981	1,758	1,426	1,063	735	357



80% of the interviewed people have valid data

6.2 Health Conditions

6.2.0.1 Definition

Types of conditions diagnosed, along with if the onset was before, after or about the same time as the TBI.
All definitions provided below are from Mayo Clinic (http://www.mayoclinic.org) except chronic pain. If a participant asks for a definition of the disease, it is acceptable to tell them the following:

Hypertension/High Blood Pressure: High blood pressure is a common condition in which the long-term force of the blood against your artery walls is high enough that it may eventually cause health problems, such as heart disease. Determined by a high reading with a blood pressure cuff.

Congestive Heart Failure: Congestive heart failure occurs when your heart muscle doesn't pump blood as well as it should. Do not include heart murmurs, irregular heartbeats, chest pain, or heart attacks

Myocardial Infarction/Heart Attack: A heart attack occurs when the flow of blood to the heart is blocked, most often by a build-up of fat, cholesterol and other substances, which form a plaque in the arteries that feed the heart (coronary arteries). The interrupted blood flow can damage or destroy part of the heart muscle. (http://www.mayoclinic.org/diseases-conditions/heart-attack/basics/definition/con-20019520)

Stroke: A stroke occurs when the blood supply to part of your brain is interrupted or severely reduced, depriving brain tissue of oxygen and nutrients. This can occur if a brain's blood vessel gets blocks, or if it bursts.

High blood cholesterol: Determined by a lab blood test

Diabetes, high blood sugar, or sugar in the urine: Disease in which too little or no insulin is produced by the pancreas (Type 1) or insulin is produced but cannot be used normally by the body (Type 2) Do NOT include Diabetes Insipidus, Pre-Diabetes or Gestational Diabetes.

Liver Disease, such as Hepatitis: Hepatitis A, B, and C: Hepatitis A, B, and C are infections caused by viruses that attacks the liver. Toxic hepatitis is an inflammation of your liver in reaction to certain substances to which you're exposed. Toxic hepatitis can be caused by alcohol, chemicals, drugs or nutritional supplements. Cirrhosis: a late stage of scarring (fibrosis) of the liver caused by many forms of liver diseases and conditions, such as hepatitis and chronic alcohol abuse. Liver disease includes: viral hepatitis (including hepatitis A, hepatitis B; and hepatitis C); autoimmune liver disease (including primary biliary cirrhosis; autoimmune hepatitis, sclerosing cholangitis); genetic liver diseases (including alpha-1-antitrysin deficiency, hemochromotosis, and Wilson's disease); drug- or medication-induced liver disease; alcoholic liver disease; non-alcoholic fatty liver disease; fatty liver disease; liver cancer; liver cyst;

liver abscess; liver fibrosis; and liver cirrhosis. Do not include gallbladder disease; gallstones; or cholecystitis

Rheumatoid Arthritis: Rheumatoid arthritis is a chronic inflammatory disorder that typically affects the small joints in your hands and feet. Unlike the wear-and-tear damage of osteoarthritis, rheumatoid arthritis affects the lining of your joints, causing a painful swelling that can eventually result in bone erosion and joint deformity

Osteoarthritis: The most common form of arthritis; it involves the wearing away of the cartilage that caps the bones in your joints.

Dementia, like Alzheimer's: Dementia describes a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with your daily life. It isn't a specific disease, but several different diseases may cause dementia, including Lewy Body and frontotemporal dementia. Though dementia generally involves memory loss, memory loss has different causes. Having memory loss alone doesn't mean you have dementia

Parkinson's Disease: Parkinson's disease is a progressive nervous system disorder that affects movement. Symptoms start gradually, sometimes starting with a barely noticeable tremor in just one hand. Tremors are common, but the disorder also commonly causes stiffness or slowing of movement.

Panic Attacks: a sudden episode of intense fear that triggers severe physical reactions when there is no real danger or apparent cause. Panic attacks can be very frightening. When panic attacks occur, you might think you're losing control, having a heart attack or even dying. This problem interferes with daily activities and cause significant distress

PTSD: a mental health condition that's triggered by a terrifying event — either experiencing it or witnessing it. Symptoms may include flashbacks, nightmares and severe anxiety, as well as uncontrollable thoughts about the event. This problem interferes with daily activities and cause significant distress

6.2.0.2 Form

[X] Form 1
[X] Form 2

6.2.0.3 Source

Form 1 - Pre-Injury Interview (participant or proxy)
Form 2 - Interview, Mail-out (participant or proxy)

6.2.0.4 Details

This measure can be collected from best source available during the Form 2 interview for all participants. Conditions with positive responses will remain positive and should not be asked again on subsequent follow-ups.

For conditions that are present, the follow-up question should be asked:
- 'Was that before, after or about the same time as your TBI (insert number of years since TBI)?'

First administration: For participants being administered the NHANES for the first time since study enrollment ask "has a doctor or other health professional ever told you that you had…" for each medical condition.

Follow-up administration: For participants who were previously administered the NHANES, if a condition was positively endorsed at a previous data collection time-point, do not ask that item again. Otherwise ask "has a doctor or other health professional ever told you that you had…"

Before, after or about the same time as TBI: A 6 month window on either side of the injury date would be considered to be 'about the same time' as TBI.

Do not accept self-diagnosis or a diagnosis that does not come from a doctor or other health professional. "Doctor" is meant to include health care providers who diagnose medical conditions.

The following are acceptable: - Medical Doctors (MD) in all medical specialties including Psychiatrists - Doctors of Osteopathic Medicine (DO) - Physician Assistants (PA) -Nurse Practitioners (NP) - Psychologists, Neuropsychologists (Ph.D. or Psy.D) - Podiatrists (DPM)

Not acceptable (these providers treat but do not diagnose) - Speech Pathologists (SLP) - Registered Nurses (RN) - Physical Therapists (PT) - Social Workers (LSW, LICSW) - Occupational Therapists (OT) - Naturopathic Doctors (ND) - Counselors (LMHC, LMFT, CRC) - Chiropractors (DC)

6.2.0.5 Reference

Variables were sourced through the following existing surveys. For items 1-8: * Medicare survey questions #20, 22-26, 32, 33 * Medicare Health Outcomes Survey (MHOS)
* Medicare Survey: SAMPLING METHODOLOGY

2009 Cohort 12 Baseline Sampling
CMS identified beneficiaries who were eligible for sampling as follows: * MAOs with fewer than 500 members were not required to report HOS. * For MAOs with 500 to 1,200 members, all eligible members were included in the sample. * For MAOs with more than 1,200 members

and less than 3,000 members, a simple random sample of 1,200 members was selected for the baseline survey. * For MAOs with 3,000 or more members, members who responded to the 2008 Cohort 11 Baseline survey were excluded from the 2009 Cohort 12 Baseline sample. * Members were defined as eligible if they did not have End Stage Renal Disease (ESRD). The six months enrollment requirement was waived beginning in 2009.

For a more detailed discussion on sampling, data collection and submission please refer to the HEDIS 2009 Volume 6 manual1 and the Medicare HOS website at www.hosonline.org. National Committee for Quality Assurance. HEDIS® 2009, Volume 6: Specifications for the Medicare Health Outcomes Survey. Washington, DC: NCQA Publication, 2009. Not sure how to access the comparative data; there is an application to use the data, to use the full survey or parts of the survey.

National Health and Nutrition Examination Survey (NHANES)
The NHANES interview includes demographic, socioeconomic, dietary, and health-related questions. The examination component consists of medical, dental, and physiological measurements, as well as laboratory tests administered by highly trained medical personnel. Findings from this survey will be used to determine the prevalence of major diseases and risk factors for diseases. Information will be used to assess nutritional status and its association with health promotion and disease prevention. NHANES findings are also the basis for national standards for such measurements as height, weight, and blood pressure. Data from this survey will be used in epidemiological studies and health sciences research, which help develop sound public health policy, direct and design health programs and services, and expand the health knowledge for the Nation. Datasource/Methods: Personal interviews, physical exams, lab tests, nutritional assessment, DNA repository Targeted sample size: 5,000 people/year, all ages. Oversample 60+, blacks & Hispanics Data: Data is available for 1999-2008; the most recent data set available is 2007-2008

National Health Interview Survey (NHIS)
The National Health Interview Survey (NHIS) has monitored the health of the nation since 1957. NHIS data on a broad range of health topics are collected through personal household interviews. For over 50 years, the U.S. Census Bureau has been the data collection agent for the National Health Interview Survey. Survey results have been instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.

6.2.0.6 Characteristics

The following Health Condition items were collected from 10/01/2012 to 10/01/2017. See Health Conditions - Archive for more information.

- Cancer
- COPD
- Diabetes

- Heart Attack
- Heart Conditions
- Heart Failure
- High Blood Pressure
- Liver Disease
- Stroke

On 4/1/2022, collection of age diagnosed, along with the following NHANES items were removed from Data Collection.
- OtherHeartConditions - Heart arrhythmias
- Emphysema - Emphysema or asthma or COPD
- Pneumonia
- SleepDisorder - Sleep disorder like sleep apnea - Cataracts
- ChronicPain
- Alcoholism
- DrugAddiction
- Depression
- Anxiety
- BipolarDisorder - Bipolar disorder or manic-depression - ADDADHD - Attention deficit disorder (ADD) / Attention deficit hyperactivity disorder (ADHD)
- OCD - Obsessive-compulsive disorder

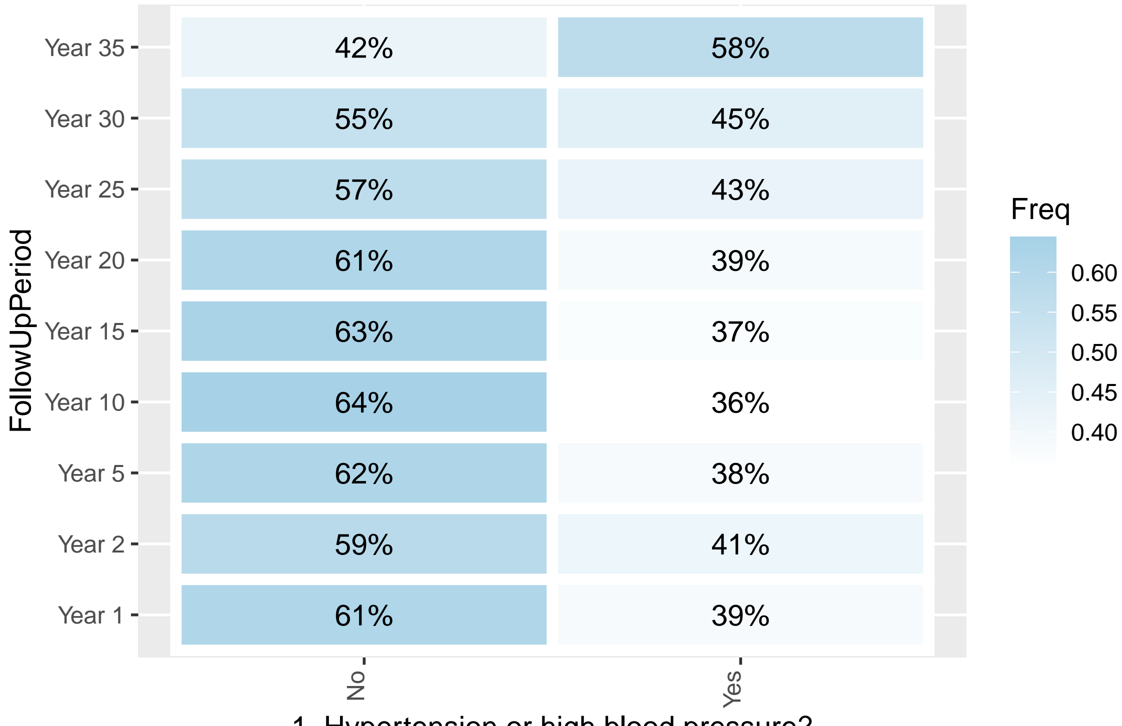
On 10/1/2024, collection of current Form 2 NHANES items were added to Form 1 collection.

6.2.1 Hypertension

6.2.1.1 Definition

Hypertension or high blood pressure - Abnormally high blood pressure. - High blood pressure is a common condition in which the long-term force of the blood against your artery walls is high enough that it may eventually cause health problems, such as heart disease. Determined by a high reading with a blood pressure cuff.

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Year 20
HypertensionF, n (%)	8,379 (39)	1,618 (39)	1,656 (41)	1,558 (38)	1,280 (36)	1,128 (37)	72
Missing	1,019	218	216	154	159	136	



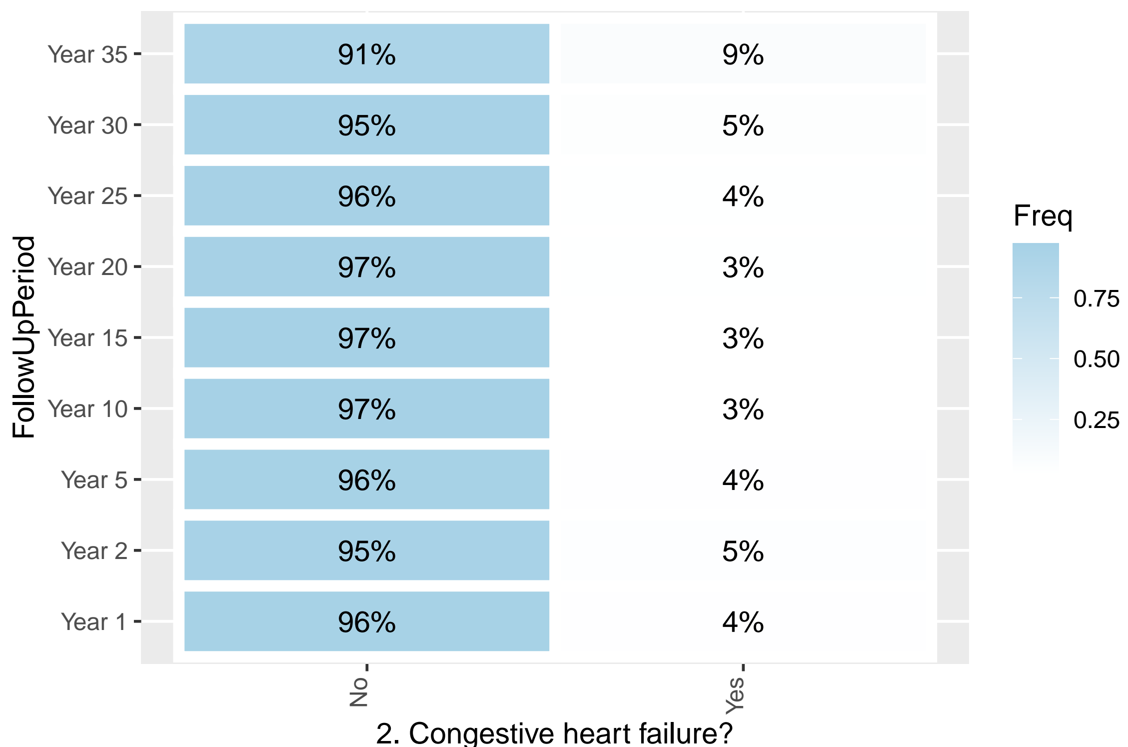
96% of the interviewed people have valid data

6.2.2 Congestive Heart Failure

6.2.2.1 Definition

Congestive heart failure - Disease where the heart is too weak to pump blood throughout the body as well as it should. INTERVIEWER: Do not count heart murmurs, irregular heart beats, chest pain, or heart attacks.

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,1**
CongestiveHeartFailureF, n (%)	818 (3.8)	170 (4.1)	187 (4.7)	161 (4.0)	111 (3.1)	86 (2.8)
Missing	1,152	229	254	187	187	143



95% of the interviewed people have valid data

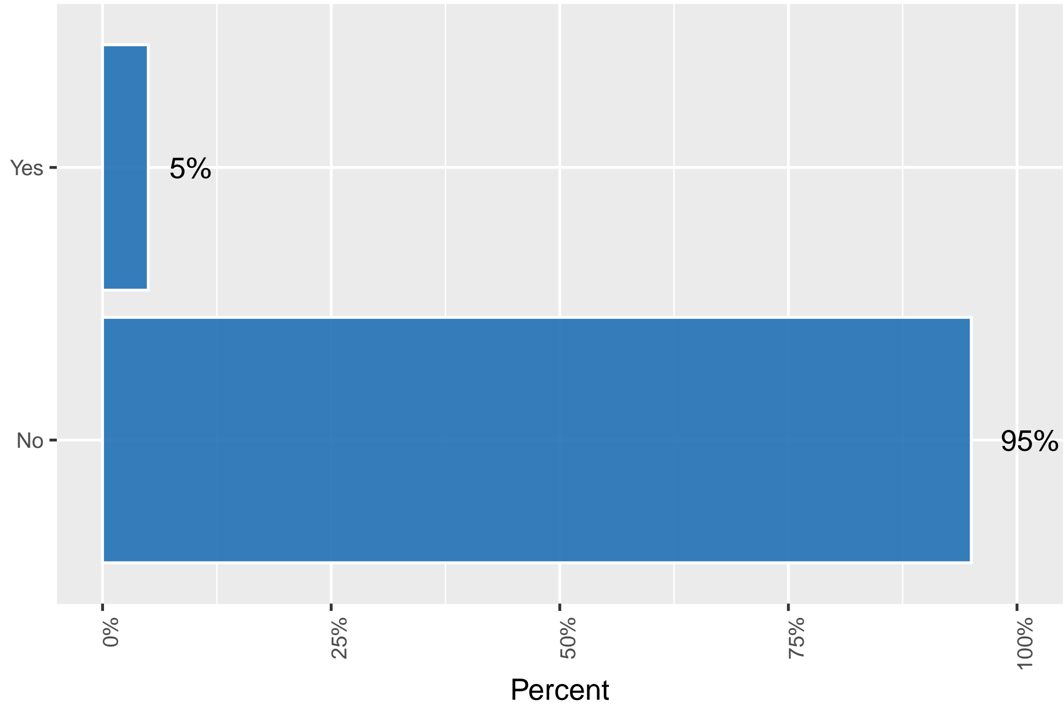
6.2.3 Heart Attack

6.2.3.1 Definition

Myocardial infarction or heart attack - Occurs when flow of blood to the heart is blocked causing damage to a part of the heart muscle.

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Year 20
HeartAttackF, n (%)	979 (4.5)	181 (4.3)	199 (5.0)	187 (4.7)	148 (4.2)	112 (3.7)	94 (
Missing	1,151	232	257	186	190	141	7

3. A myocardial infarction or heart attack?



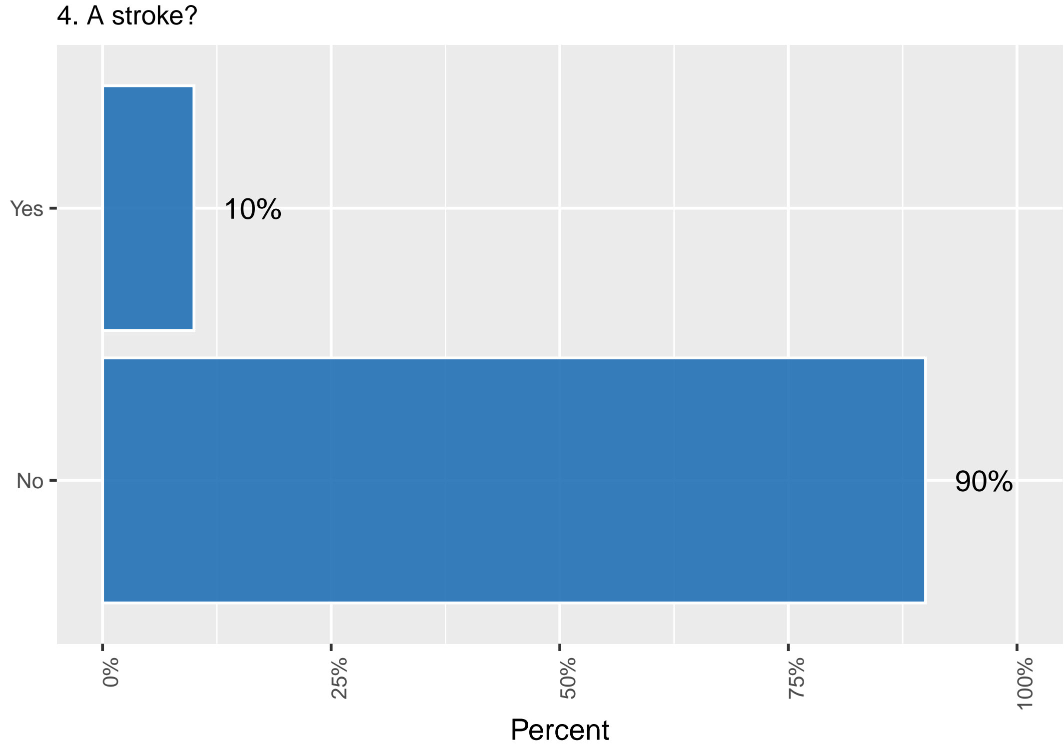
95% of the interviewed people have valid data

6.2.4 Stroke

6.2.4.1 Definition

Stroke - Happens when the blood flow to the brain is interrupted due to narrowing of the blood vessels, clots, or bleeding.

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,172**	**Year 20 N = 1,**
StrokeF, n (%)	2,165 (10)	472 (11)	512 (13)	432 (11)	295 (8.3)	225 (7.4)	142 (7.6)
Missing	1,153	232	256	185	186	145	80



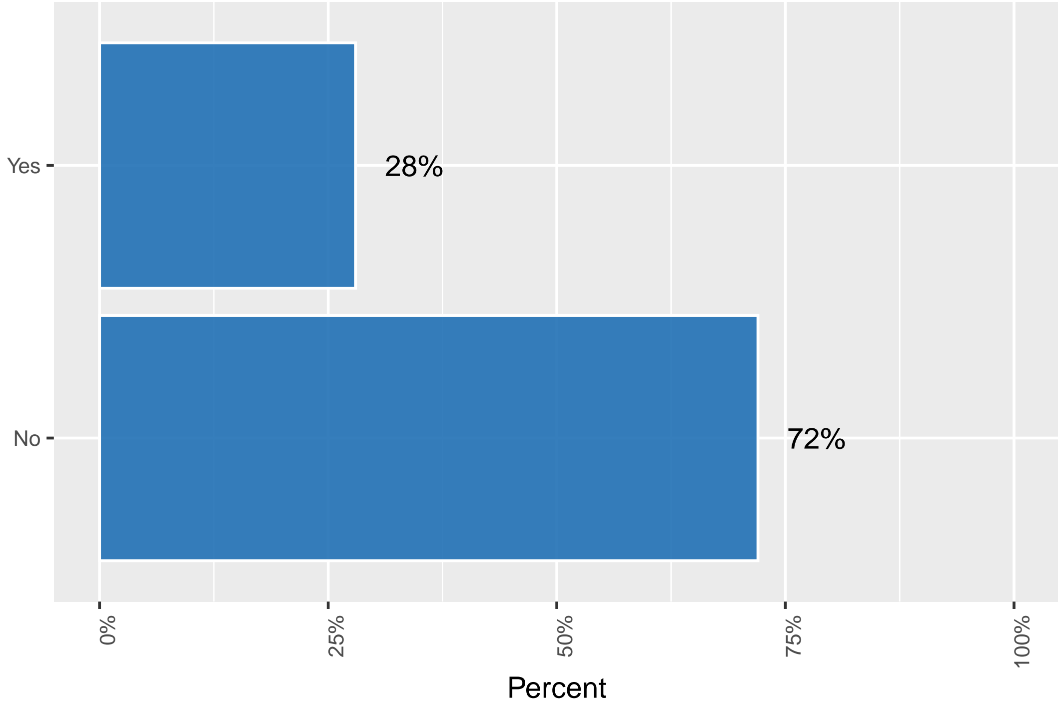
95% of the interviewed people have valid data

6.2.5 High Blood Cholesterol

6.2.5.1 Definition

High blood cholesterol - A compound of the sterol type found in most body tissues. Cholesterol and its derivatives are important constituents of cell membranes and precursors of other steroid compounds, but a high proportion in the blood of low-density lipoprotein (which transports cholesterol to the tissues) is associated with an increased risk of coronary heart disease. - Determined by a lab blood test

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,17**
HighBloodCholesterolF, n (%)	5,932 (28)	980 (24)	1,095 (28)	1,061 (26)	955 (27)	924 (31)
Missing	1,235	261	273	194	191	156



95% of the interviewed people have valid data

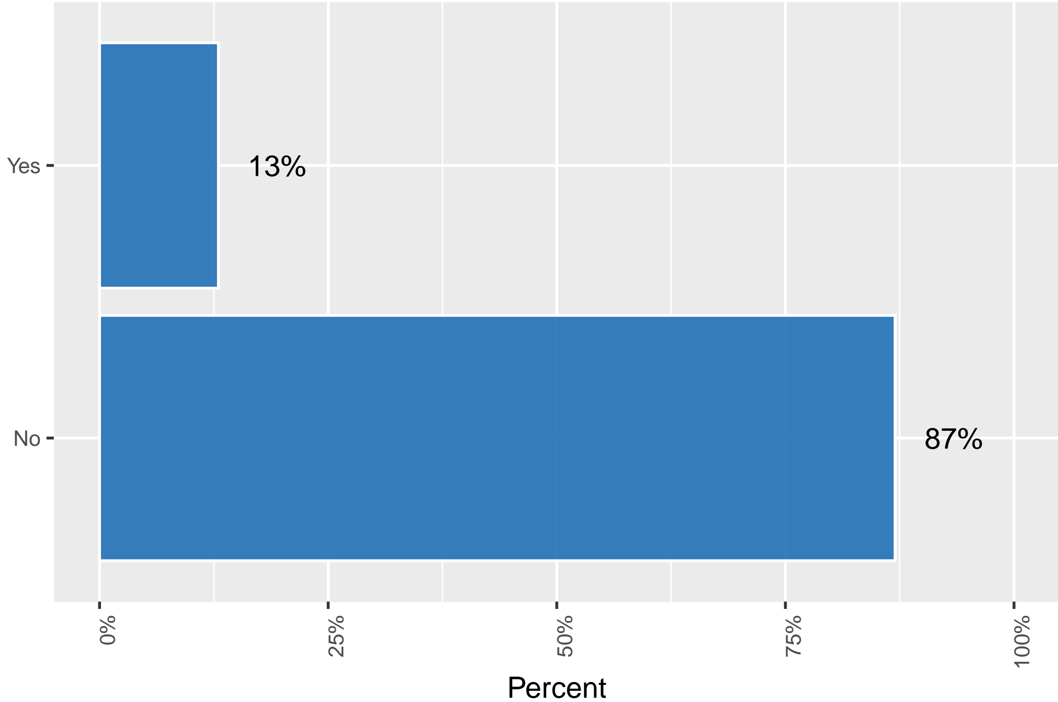
6.2.6 Diabetes / High Blood Sugar

6.2.6.1 Definition

Diabetes, high blood sugar, or sugar in the urine - Disease in which too little or no insulin is produced by the pancreas (Type 1) or insulin is produced but cannot be used normally by the body (Type 2)

Do NOT include Diabetes Insipidus, Pre-Diabetes (there's a difference between elevated and high blood sugar), or Gestational Diabetes.

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,**
DiabetesHighBloodSugarF, n (%)	2,823 (13)	528 (13)	532 (13)	521 (13)	431 (12)	432 (14)
Missing	1,108	225	238	179	181	140



95% of the interviewed people have valid data

6.2.7 Liver Disease

6.2.7.1 Definition

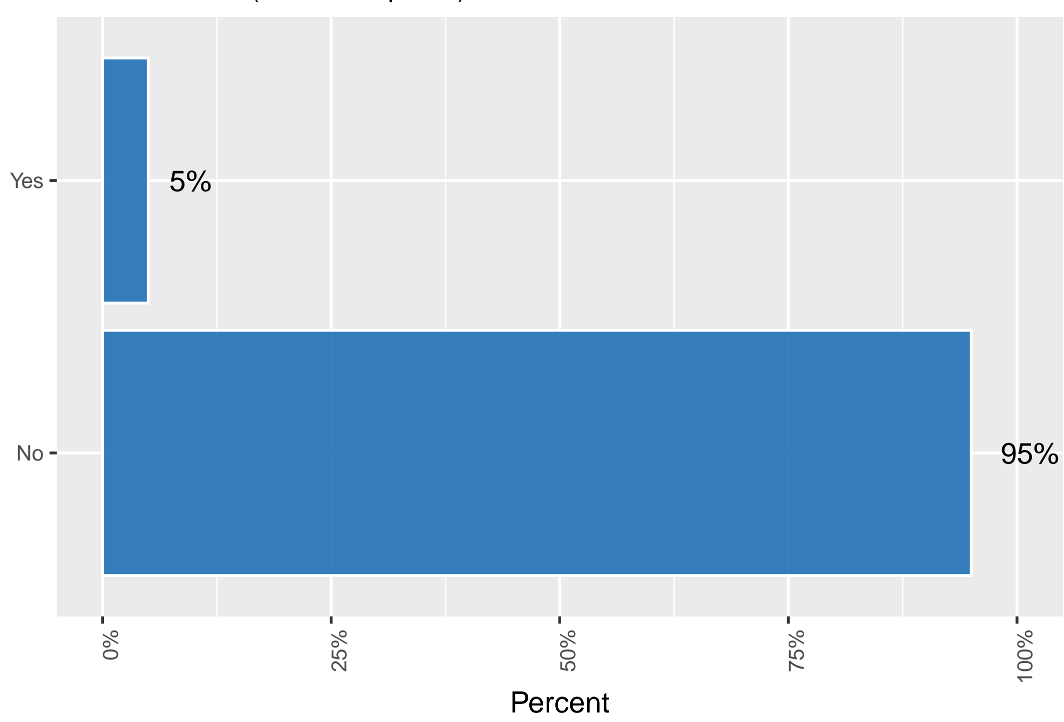
Liver disease (such as hepatitis) - Also includes liver cancer, alcohol related liver disease, autoimmune disorders, and genetic diseases.

INTERVIEWER: Include viral hepatitis (including hepatitis A, hepatitis B; and hepatitis C); autoimmune liver disease (including primary biliary cirrhosis; autoimmune hepatitis, sclerosing cholangitis); genetic liver diseases (including alpha-1-antitrysin deficiency, hemochromotosis, and Wilson's disease); drug- or medication-induced liver disease; alcoholic liver disease; non-alcoholic fatty liver disease; fatty liver disease; liver cancer; liver cyst; liver abscess; liver fibrosis; and liver cirrhosis.

INTERVIEWER: Do not include gallbladder disease; gallstones; or cholecystitis.

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Year 20
LiverDiseaseF, n (%)	1,062 (4.9)	179 (4.3)	205 (5.2)	185 (4.6)	152 (4.3)	149 (4.9)	118
Missing	1,183	242	257	187	195	148	

7. Liver disease (such as hepatitis)?



95% of the interviewed people have valid data

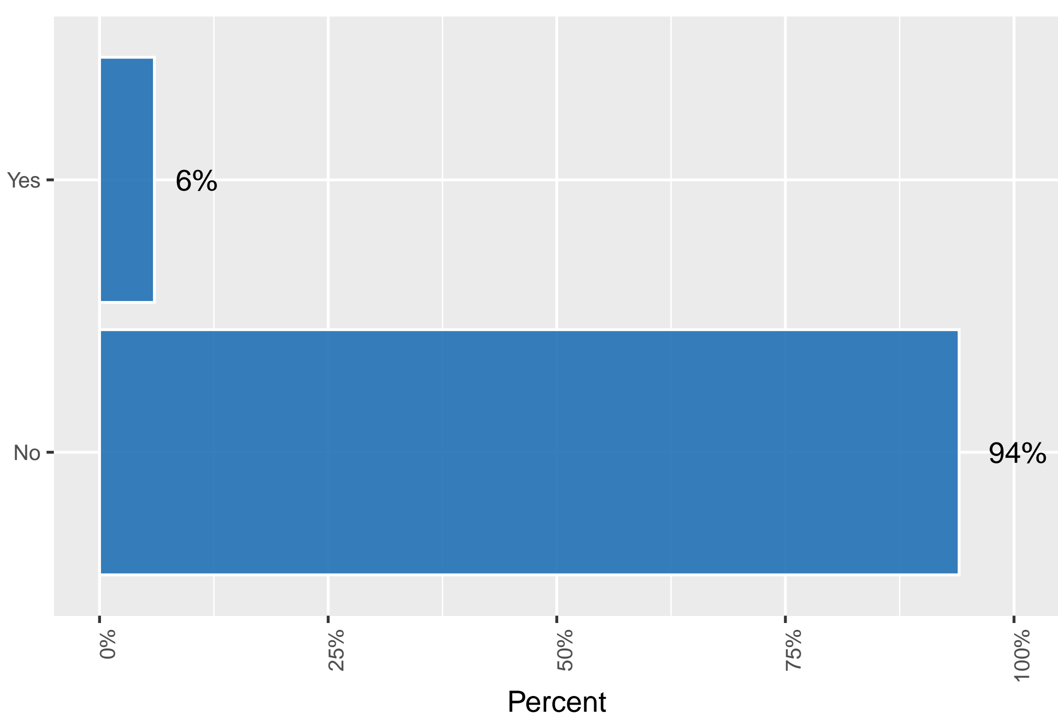
6.2.8 Rheumatoid Arthritis

6.2.8.1 Definition

Rheumatoid arthritis - An autoimmune disease characterized by chronic inflammation of joints

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172
RheumatoidArthritisF, n (%)	1,223 (5.7)	171 (4.1)	200 (5.1)	206 (5.2)	197 (5.6)	191 (6.3)

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172
Missing	1,268	262	275	203	206	159



94% of the interviewed people have valid data

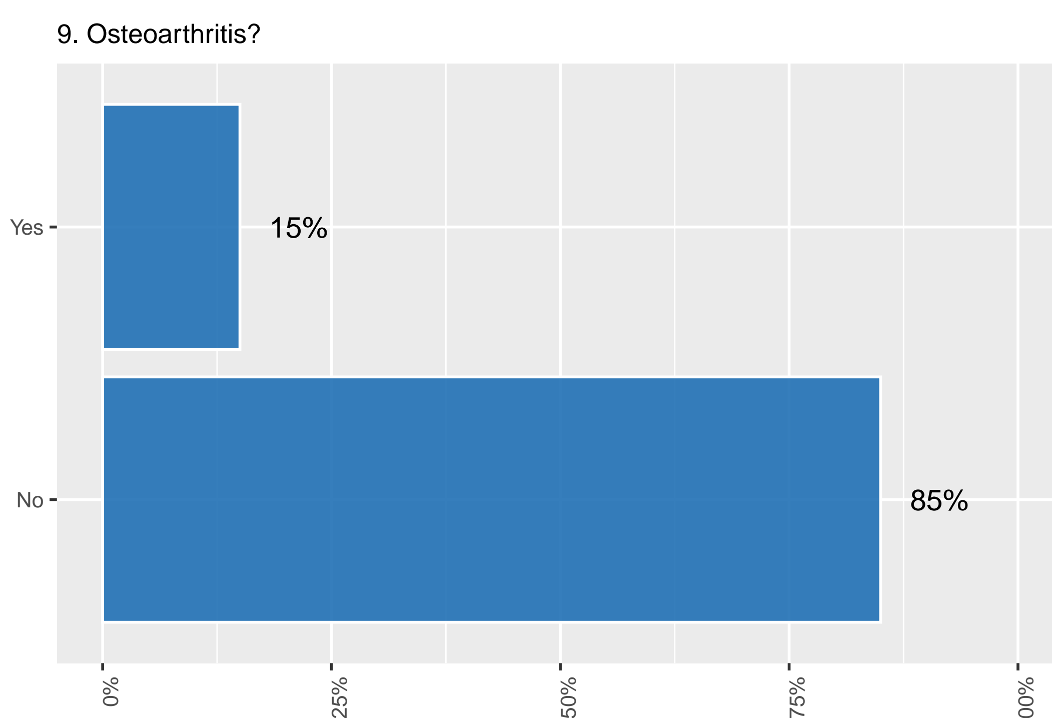
6.2.9 Osteoarthritis

6.2.9.1 Definition

Osteoarthritis - When the protective cartilage on the ends of bones wears down; sometimes called “old age” or “wear and tear” arthritis

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Year 20
OsteoarthritisF, n (%)	3,165 (15)	452 (11)	555 (14)	594 (15)	526 (15)	465 (15)	37
Missing	1,245	257	275	191	201	161	

9. Osteoarthritis?



95% of the interviewed people have valid data

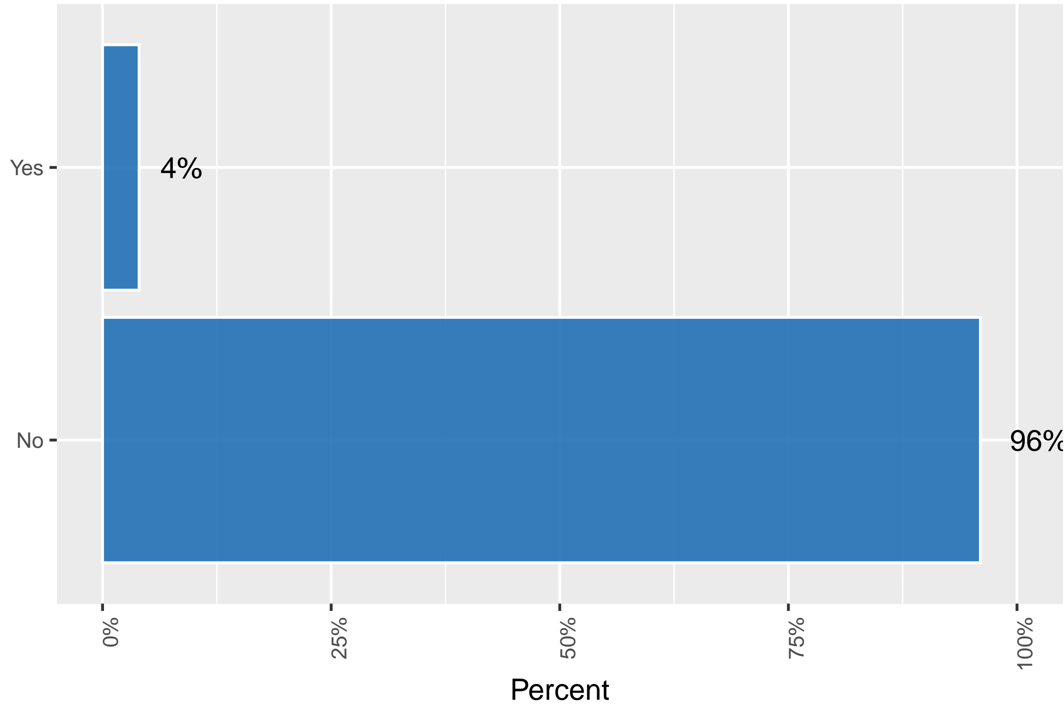
6.2.10 Dementia

6.2.10.1 Definition

Dementia of some kind, like Alzheimer's - Group of symptoms affecting memory, thinking, and social abilities enough to interfere with daily functioning; other examples are Lewy Body and frontotemporal dementia

INTERVIEWER: Though dementia generally involves memory loss, memory loss has different causes. Having memory loss alone doesn't mean it's dementia.

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,172**	**Year 20 N =**
DementiaF, n (%)	772 (3.6)	138 (3.3)	177 (4.5)	169 (4.2)	111 (3.1)	88 (2.9)	56 (3.0
Missing	1,221	253	274	196	201	145	79



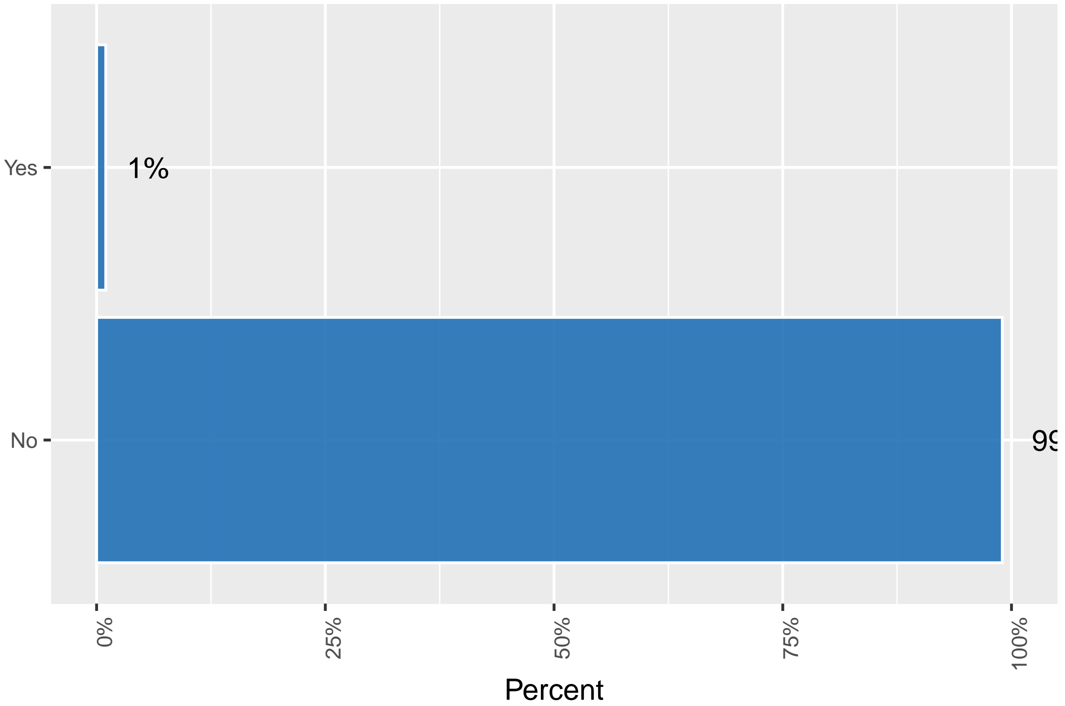
95% of the interviewed people have valid data

6.2.11 Movement Disorder

6.2.11.1 Definition

Movement Disorder like Parkinson's- Chronic progressive neurologic disease that can include tremor, slowness of movement, rigidity or stiffness, and problems with balance

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Y
MovementDisorderF, n (%)	192 (0.9)	52 (1.2)	57 (1.4)	35 (0.9)	18 (0.5)	15 (0.5)	
Missing	1,213	254	271	193	195	146	



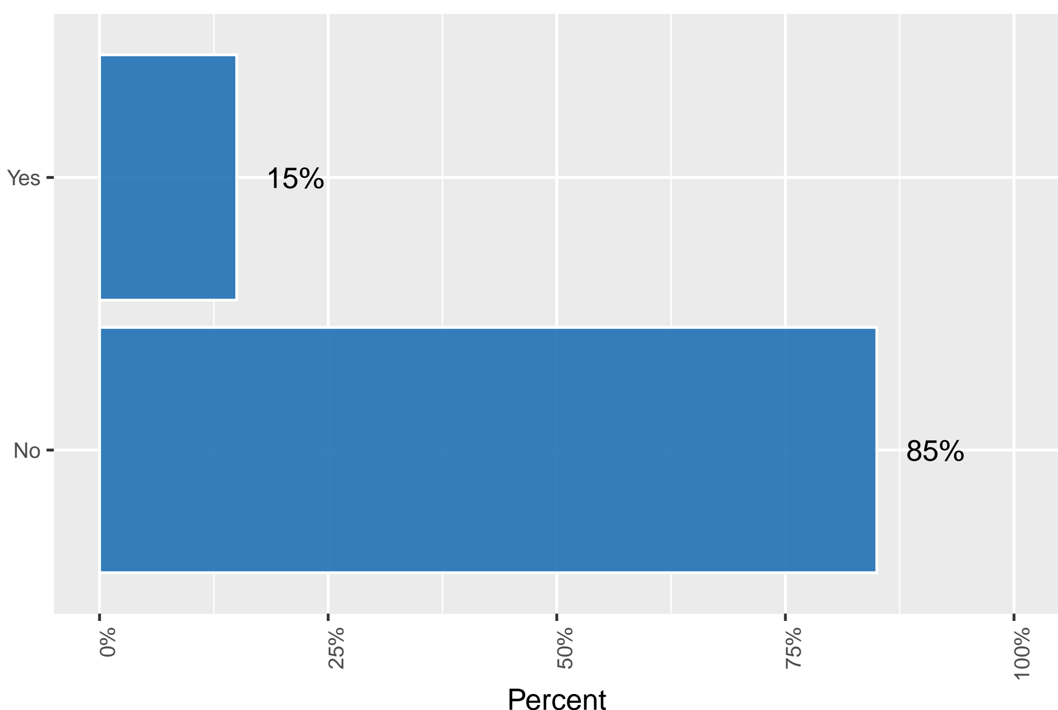
95% of the interviewed people have valid data

6.2.12 Panic Attacks

6.2.12.1 Definition

Panic attacks - A sudden feeling of acute and disabling anxiety. - Anxiety disorder that involves repeated episodes of sudden feelings of intense anxiety and fear or terror that peak within minutes

Characteristic	Overall N = 22,700	Year 1 N = 4,415	Year 2 N = 4,213	Year 5 N = 4,203	Year 10 N = 3,753	Year 15 N = 3,172	Year 20
PanicAttacksF, n (%)	3,298 (15)	526 (13)	662 (17)	707 (18)	499 (14)	479 (16)	29
Missing	1,237	263	270	199	194	152	



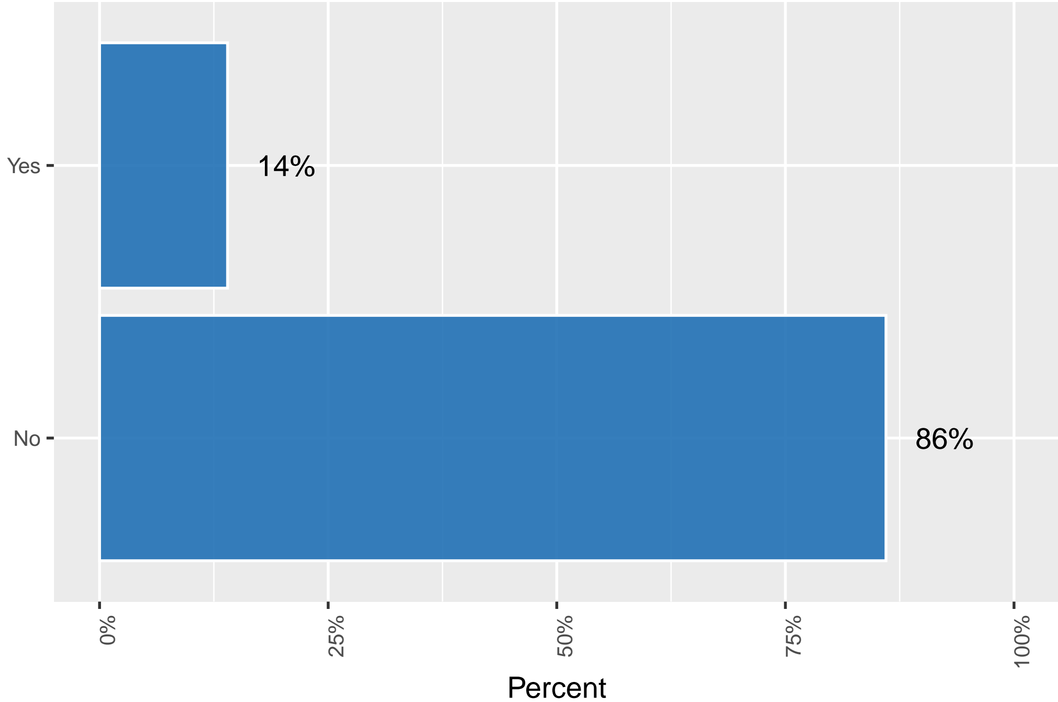
95% of the interviewed people have valid data

6.2.13 PTSD

6.2.13.1 Definition

Post-traumatic stress disorder (PTSD) - Mental health condition triggered by a terrifying event; symptoms may include flashbacks, nightmares, and severe anxiety

Characteristic	**Overall N = 22,700**	**Year 1 N = 4,415**	**Year 2 N = 4,213**	**Year 5 N = 4,203**	**Year 10 N = 3,753**	**Year 15 N = 3,172**	**Year 20 N =**
PTSDHlthF, n (%)	3,021 (14)	469 (11)	612 (16)	677 (17)	496 (14)	403 (13)	243 (1
Missing	1,267	259	276	206	204	158	90



94% of the interviewed people have valid data

7 Mood

Caution

:::t

7.1 Anxiety

7.1.0.1 Definition

The Generalized Anxiety Disorder 2-item (GAD-2) is a brief initial screening tool for generalized anxiety disorder.

The full Generalized Anxiety Disorder Scale is a 7-item scale validated as a screener for anxiety disorder.

Participants are asked how often they have been bothered by the first 2 items from the list below over the last 2 week. If either is endorsed, the remaining items are asked.

a. Feeling nervous, anxious or on edge

b. Not being able to stop or control worrying

c. Worrying too much about different things

d. Trouble relaxing

e. Being so restless that it is hard to sit still

f. Becoming easily annoyed or irritable

g. Feeling afraid as if something awful might happen

h. If you indicated any problems in the previous questions, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people

7.1.0.2 Form

[ ] Form 1
[X] Form 2

7.1.0.3 Source

Interview, Mail-Out (participant only)

7.1.0.4 Details

Interviewers should read the following introduction prior to administering the GAD: *"Over the LAST 2 WEEKS, how often have you been bothered by the following problems?"*

If either of the first 2 questions are coded either '1 - Several Days', '2 - More Than Half Of The Days', or '3 - Nearly Every Day', then proceed to ask the remaining GAD items.

If both of the first 2 questions are coded '0 - Not at all', code remaining GAD items as '81 - Not Applicable' and skip to next section of interview.

The GAD should not be administered to a significant other, or any other proxy. If the individual is unable to provide data, use code '82. Not Applicable: No data from person with TBI'.

Every effort should be made to obtain the GAD assessment, however, if any items can not be assessed, use code '99. Unknown'. Do not leave blanks.

7.1.0.5 Links

GAD-7 Spanish Translation

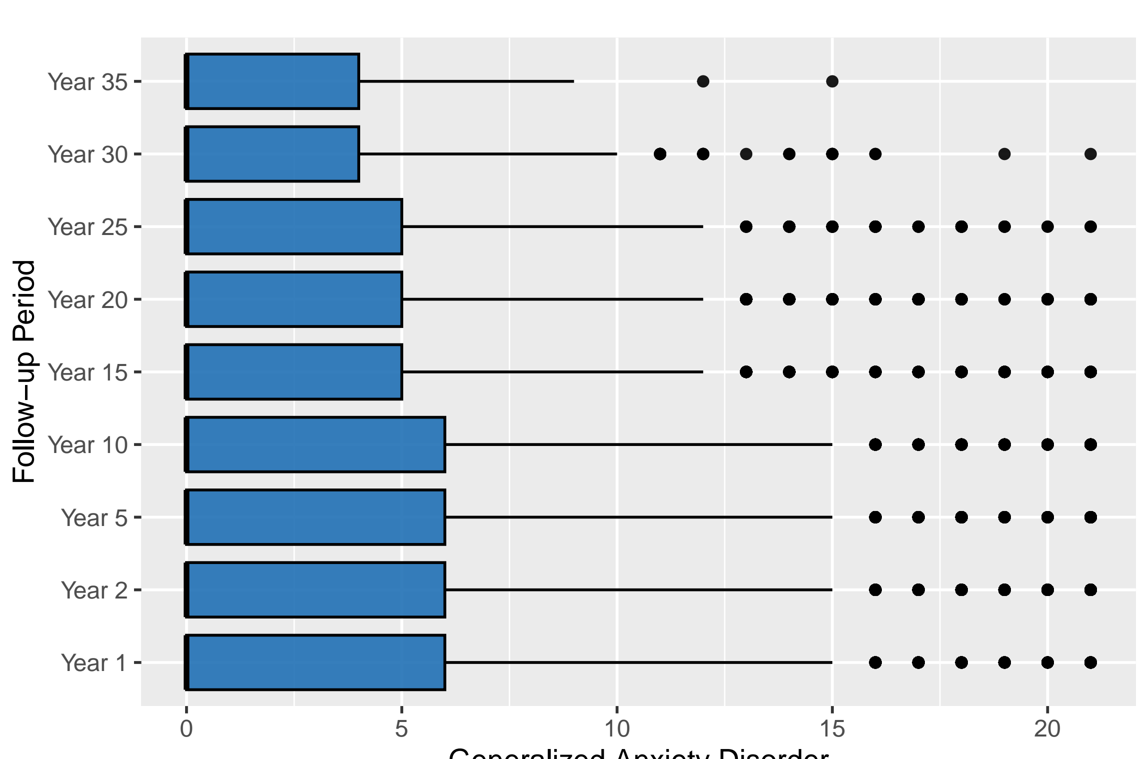
7.1.0.6 Characteristics

Participant responses to these variables may be affected by the COVID-19 pandemic starting in March of 2020.

On 4/1/2022, the GAD-2 Screener was implemented.

Generalized Anxiety Disorder

Characteristic	**Year 1** N = 6,874	**Year 2** N = 6,617	**Year 5** N = 6,449	**Year 10** N = 5,202	**Year 15** N = 3,51
GAD7TOTF					
N Non-missing	5,082	4,952	5,058	4,233	2,871
Mean (SD)	3.7 (5.4)	3.8 (5.4)	3.8 (5.4)	3.4 (5.1)	3.3 (5.2)
Median (Q1, Q3)	0.0 (0.0, 6.0)	0.0 (0.0, 6.0)	0.0 (0.0, 6.0)	0.0 (0.0, 6.0)	0.0 (0.0, 5.0)
Min, Max	0.0, 21.0	0.0, 21.0	0.0, 21.0	0.0, 21.0	0.0, 21.0
Missing	1,792	1,665	1,391	969	648



78% of the interviewed people have valid data

7.2 Depression

7.2.0.1 Definition

The Patient Health Questionnaire-2 (PHQ-2) is a brief initial screening tool for depression.

The Patient Health Questionnaire-9 (PHQ-9) contains is a 9-item, patient self-report depression assessment.

Participants are asked how often they have been bothered by the first 2 items from the list below over the last 2 week. If either is endorsed, the remaining items are asked.

a. Little Interest or pleasure in doing things
b. Feeling down, depressed, or hopeless
c. Trouble falling or staying asleep, or sleeping too much
d. Feeling tired or having little energy
e. Poor appetite or overeating
f. Feeling bad about yourself – or that you are a failure or have let yourself or your family down
g. Trouble concentrating on things, such as reading the newspaper or watching television
h. Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual
i. Thoughts that you would be better off dead, or of hurting yourself in some way
j. If you indicated any problems in the previous questions, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people

7.2.0.2 Form

[ ] Form 1
[X] Form 2

7.2.0.3 Source

Interview, Mail-Out (participant only)

7.2.0.4 Details

Interviewers should read the following introduction prior to administering the PHQ: “Over the LAST 2 WEEKS, how often have you been bothered by the following problems?”

If either of the first 2 questions are coded either ‘1 - Several Days’, ‘2 - More Than Half Of The Days’, or ‘3 - Nearly Every Day’, then proceed to ask the remaining PHQ items.

If both of the first 2 questions are coded ‘0 - Not at all’, code remaining PHQ items as ‘81 - Not Applicable’ and skip to next section of interview.

The PHQ should not be administered to a significant other, or any other proxy. If the individual is unable to provide data, use code ‘82. Not Applicable: No data from person with TBI’.

Every effort should be made to obtain the PHQ assessments, however, if any items can not be assessed, use code ‘99. Unknown’. Do not leave blanks.

7.2.0.5 Links

PHQ-9 Manual
PHQ-9 Spanish Translation

7.2.0.6 Reference

PHQ9 Pfizer

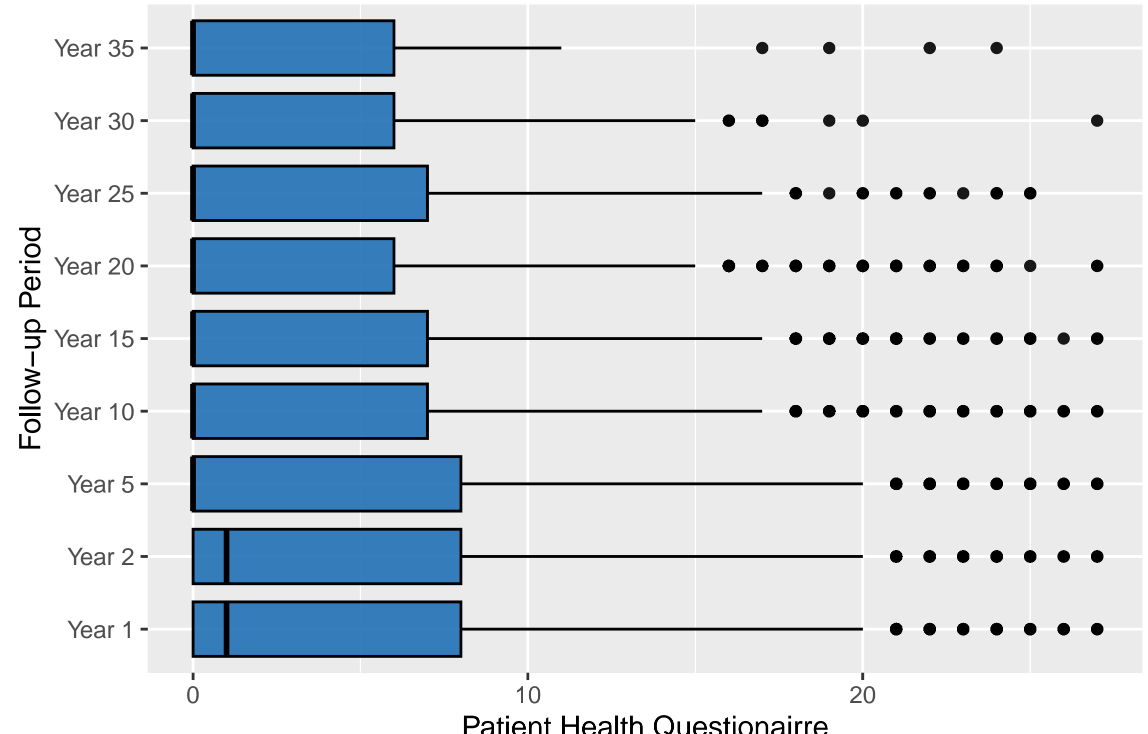
7.2.0.7 Characteristics

Participant responses to these variables may be affected by the COVID-19 pandemic starting in March of 2020.

On 4/1/2022, the PHQ-2 Screener was implemented.

Patient Health Questionaire

Characteristic	Year 1 N = 6,874	Year 2 N = 6,617	Year 5 N = 6,449	Year 10 N = 5,202	Year 15 N = 3,51
PHQ9TOTF					
N Non-missing	5,067	4,948	5,046	4,239	2,869
Mean (SD)	4.6 (6.2)	4.7 (6.2)	4.3 (6.1)	4.0 (5.9)	3.9 (5.7)
Median (Q1, Q3)	1.0 (0.0, 8.0)	1.0 (0.0, 8.0)	0.0 (0.0, 8.0)	0.0 (0.0, 7.0)	0.0 (0.0, 7.0)
Min, Max	0.0, 27.0	0.0, 27.0	0.0, 27.0	0.0, 27.0	0.0, 27.0
Missing	1,807	1,669	1,403	963	650



78% of the interviewed people have valid data

7.3 Satisfaction with Life Scale

7.3.0.1 Definition

The person with brain injury should rate his/her satisfaction with life at the time of the follow-up evaluation by indicating his/her level of agreement with the four questions below.

1. In most ways my life is close to my ideal.
2. The conditions of my life are excellent.
3. I am satisfied with my life.
4. So far I have gotten the important things I want in life.

For more information, see Links

7.3.0.2 Form

[ ] Form 1
[X] Form 2

7.3.0.3 Source

Interview, Mail-Out (Participant only)

7.3.0.4 Details

Do not embellish when obtaining this information.

If appropriate, when a participant questions what is meant by the word “ideal”, use the cue “best” or “best possible” or “whatever ideal means to you.”

7.3.0.5 Links

Introduction to the SWLS (COMBI)
SWLS Frequently Asked Questions/Tips (COMBI)
SWLS Spanish Translation

7.3.0.6 Reference

Diener E, Emmons R, Larsen J, Griffin S. (1985). The Satisfaction With Life Scale. J Personality Assessment, 49(1), 71-75.

Pavot W, Deiner E. (1993). Review of the Satisfaction With Life Scale. Psychological Assessment. 5(3), 164-172.

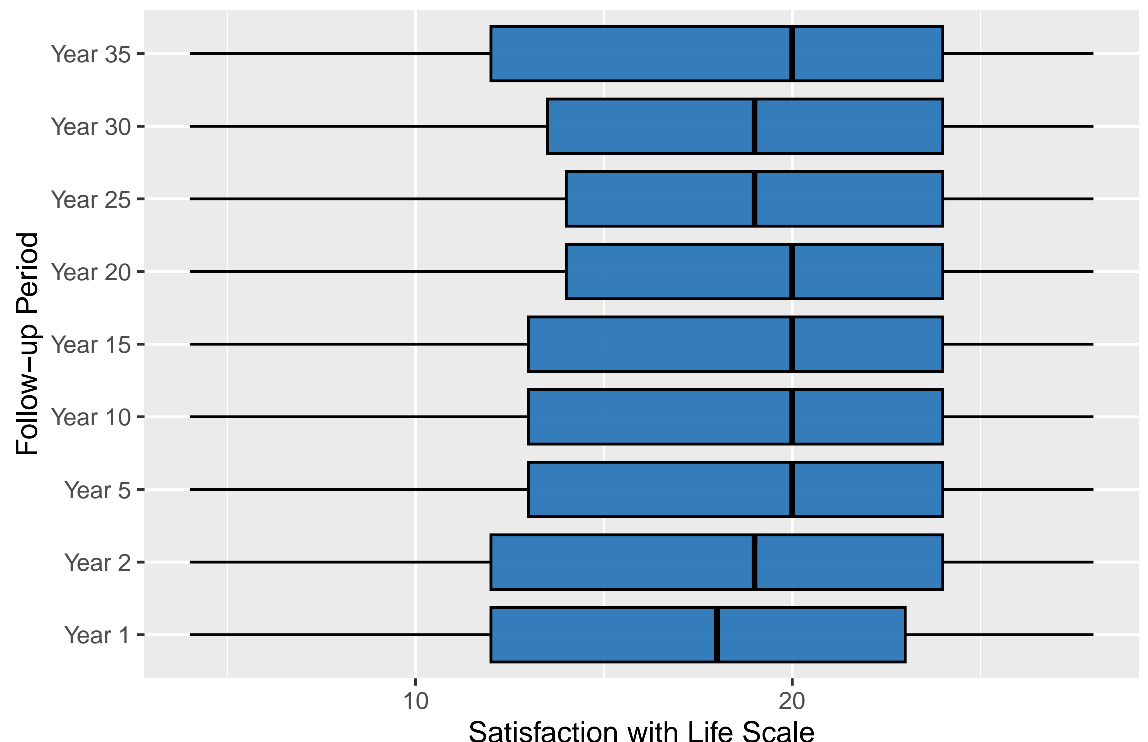
Satisfaction with Life Scale

Characteristic	**Year 1** N = 16,689	**Year 2** N = 14,818	**Year 5** N = 11,787	**Year 10** N = 8,062	**Year 15** N = 4
SWLSTOT4F					
N Non-missing	12,786	11,541	9,418	6,610	4,122
Mean (SD)	17 (7)	18 (7)	18 (7)	18 (7)	18 (7)
Median (Q1, Q3)	18 (12, 23)	19 (12, 24)	20 (13, 24)	20 (13, 24)	20 (13, 24
Min, Max	4, 28	4, 28	4, 28	4, 28	4, 28
Missing	3,903	3,277	2,369	1,452	862

7.3.0.7 Characteristics

In 2003, the TBIMS had difficulty obtaining this information (11% missing data). Five Model Systems had missing data rates of 10% or more. Data managers report that missing data are due to some persons with TBI being unable to provide information for the Form II, combined with the requirement that the SWLS must not be answered by anyone other than the person with TBI. A new code was been added to this item to identify these cases.

Participant responses to these variables may be affected by the COVID-19 pandemic starting in March of 2020.



79% of the interviewed people have valid data

8 Participation

8.1 PART

8.1.0.1 Definition

The Participation Assessment with Recombined Tools-Objective (PART-O) is an outcome scale measuring participation in the community. The PART-O consolidates questions from 3 commonly used instruments, and measures 3 domains of community participation post-rehabilitation: Productivity, Out and About, and Social Relations.

Form 1 - Only PART-O Productivity items and PART Volunteer are collected

8.1.0.2 Form

[X] Form 1
[X] Form 2

8.1.0.3 Details

See PART-O Manual link below for full administration and scoring guidelines.

8.1.0.4 Source

Interview, Mail-out (participant or proxy)

8.1.0.5 Links

PART-O Manual
PART-O Rasch Scoring_Malec et al 2016

Part Summary Statistic

Characteristic	**Year 1** N = 11,995	**Year 2** N = 11,233	**Year 5** N = 9,928	**Year 10** N = 7,644	**Year 15** N
Part Summary Statistic					
N Non-missing	11,482	10,704	9,499	7,325	4,6
Mean (SD)	1.59 (0.73)	1.64 (0.74)	1.69 (0.75)	1.75 (0.77)	1.74 (
Median (Q1, Q3)	1.58 (1.06, 2.10)	1.64 (1.09, 2.17)	1.70 (1.13, 2.25)	1.77 (1.18, 2.33)	1.75 (1.1
Min, Max	0.00, 4.13	0.00, 4.41	0.00, 3.97	0.00, 4.14	0.00,
Missing	513	529	429	319	20

8.1.0.6 Characteristics

On 10/01/2017 the code for refused and unknown were switched to conform to coding standards.

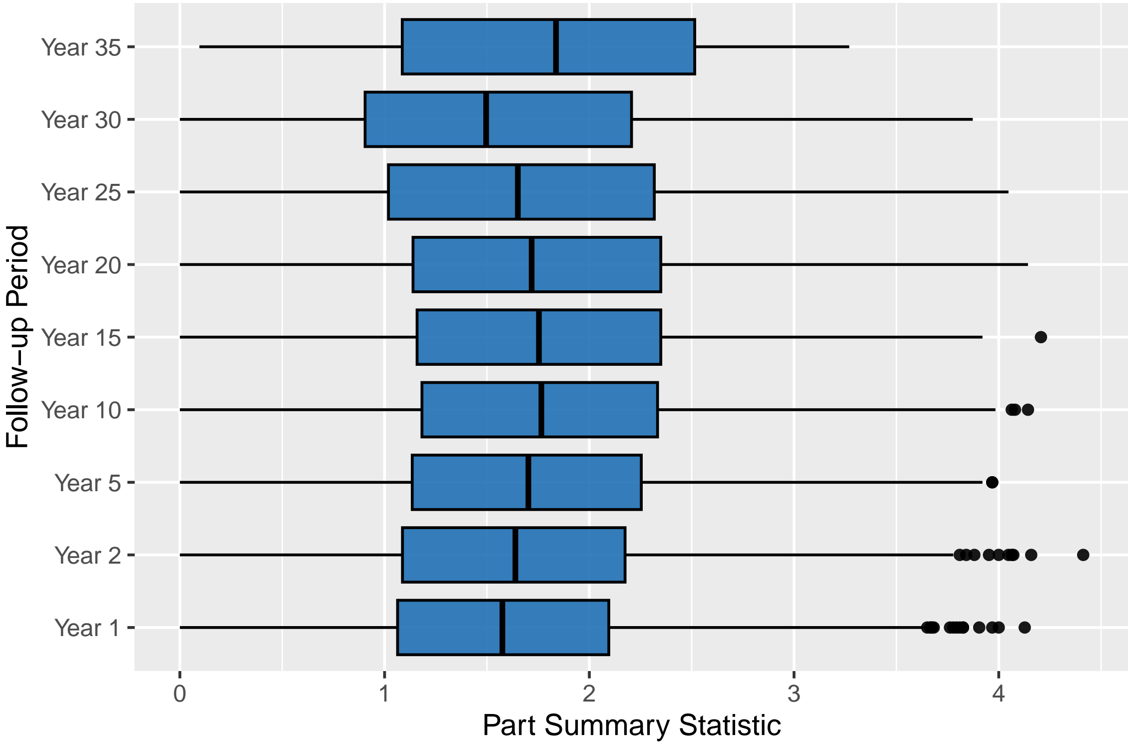
Participant responses to these variables may be affected by the COVID-19 pandemic starting in March of 2020.

The PART-O score can accommodate missing variables (a social score can be calculated if you have 3 of 5 variables), whereas the Rasch score needs complete data on all the measures (all variables need to have valid values). Therefore there are more missing Part-O Rasch calculated scores.

8.1.0.7 Training

Data Collectors should be familiar with the PART Training Manual (see Links) prior to administering the PART.

8.1.1 PART Summary



96% of the interviewed people have valid data

8.1.2 PART Out and About

8.1.2.1 Definition

Times per month out and about.

PRTVOL Prior to the injury, in a typical month, how many times do you do volunteer work?

PRTEatOutF: In a typical month, how many times do you eat in a restaurant?

PRTShopF: In a typical month, how many times do you go shopping? Include grocery shopping, as well as shopping for household necessities, or just for fun.

PRTPlaySportF: In a typical month, how many times do you engage in sports or exercise outside your home? Include activities like running, bowling, going to the gym, swimming, walking for exercise and the like.

Part OutAbout Subscale

Characteristic	**Year 1** N = 11,995	**Year 2** N = 11,233	**Year 5** N = 9,928	**Year 10** N = 7,644	**Year 15**
Part OutAbout Subscale					
N Non-missing	11,513	10,724	9,523	7,349	4,
Mean (SD)	1.42 (0.79)	1.47 (0.78)	1.50 (0.77)	1.53 (0.76)	1.50
Median (Q1, Q3)	1.43 (0.83, 2.00)	1.50 (0.93, 2.00)	1.54 (0.96, 2.00)	1.57 (1.00, 2.00)	1.50 (0.
Min, Max	0.00, 5.00	0.00, 4.71	0.00, 4.17	0.00, 4.29	0.00
Missing	482	509	405	295	1

PRTVolF: In a typical month, how many times do you do volunteer work?

PRTMovieF: In a typical month, how many times do you go to the movies?

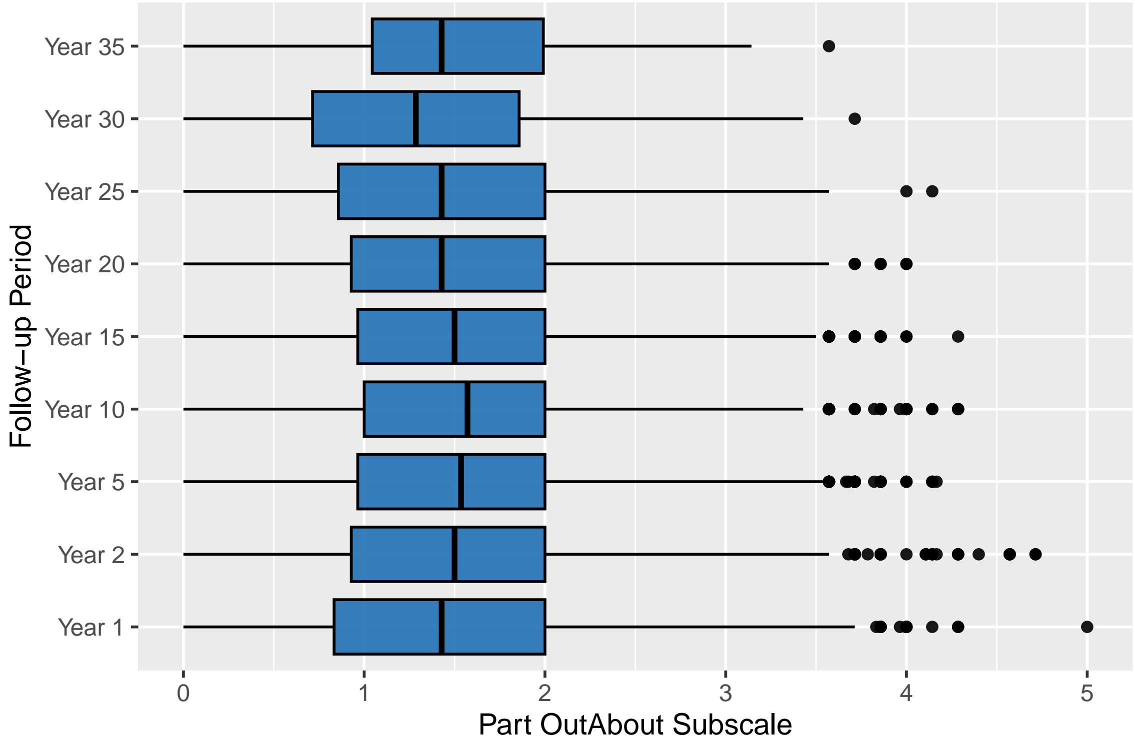
PRTWtchSportF: In a typical month, how many times do you attend sports events in person, as a spectator?

PRTReligionF: In a typical month, how many times do you attend religious or spiritual services? Include places like churches, temples and mosques.

8.1.2.2 Characteristics

Students who live in a dorm and eat in a dorm cafeteria would count as eating in a restaurant.

The volunteer item does not contribute to score for subscales.



96% of the interviewed people have valid data

8.1.3 PART Productivity

8.1.3.1 Definition

Hours per week engaged in productive activities. Productivity Items;

PRTHomeF: In a typical week, how many hours do you spend in active homemaking, including cleaning, cooking and raising children?

PRTSchoolF: In a typical week, how many hours do you spend in school working toward a degree or in an accredited technical training program, including hours in class and studying?

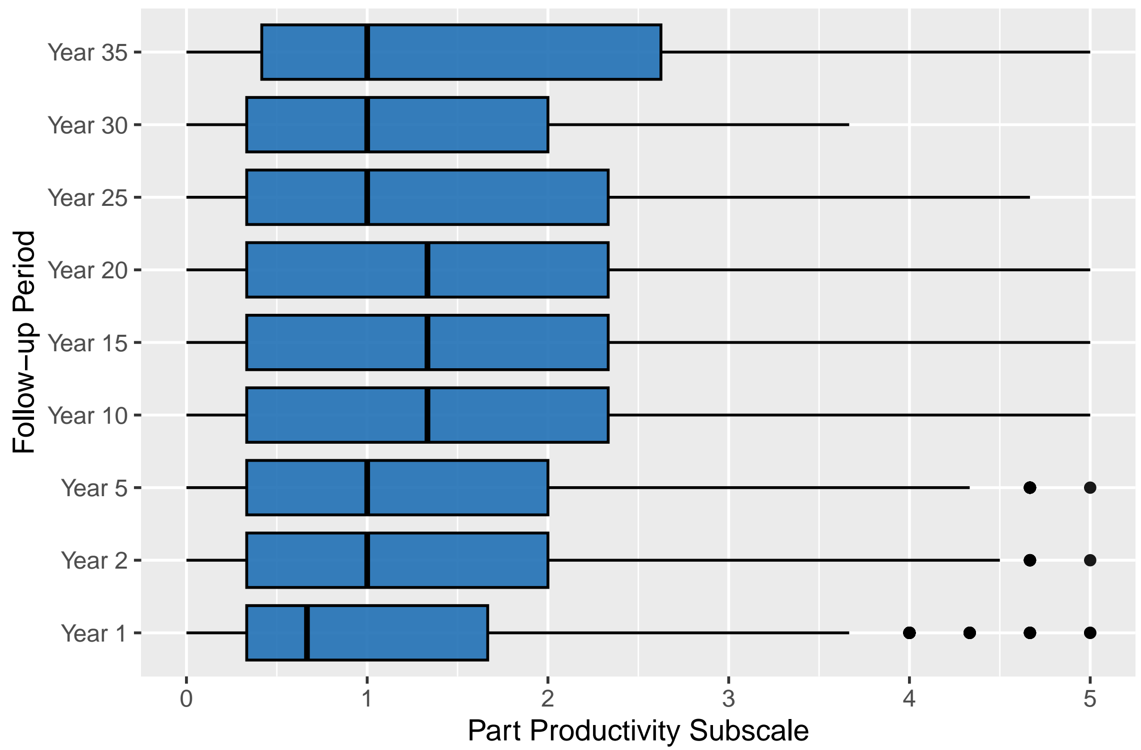
PRTWorkF: In a typical week, how many hours do you spend working for money, whether in a job or self-employed?

Part Productivity Subscale

Characteristic	**Year 1** N = 11,995	**Year 2** N = 11,233	**Year 5** N = 9,928	**Year 10** N = 7,644	**Year**
Part Productivity Subscale					
N Non-missing	11,669	10,862	9,651	7,427	
Mean (SD)	1.06 (0.97)	1.18 (1.00)	1.29 (1.02)	1.38 (1.03)	1.
Median (Q1, Q3)	0.67 (0.33, 1.67)	1.00 (0.33, 2.00)	1.00 (0.33, 2.00)	1.33 (0.33, 2.33)	1.33
Min, Max	0.00, 5.00	0.00, 5.00	0.00, 5.00	0.00, 5.00	0.
Missing	326	371	277	217	

8.1.3.2 Characteristics

Productivity items were added to Form 1 data collection on 4/1/2023



97% of the interviewed people have valid data

8.1.4 PART Social

8.1.4.1 Definition

Times per week engaged in social activities.

PRTSocFrndF: In a typical week, how many times do you socialize with friends, in person or by phone? Please do not include socializing with family members

PRTSocFamF: In a typical week, how many times do you socialize with family and relatives, in person or by phone?

PRTEmotSupF: In a typical week, how many times do you give emotional support to other people, that is, listen to their problems or help them with their troubles?

PRTInternetF: In a typical week, how many times do you use the Internet for communication with others? For example, text, email, virtual meetings, social media.?

8.1.4.2 Form

[ ] Form 1
[X] Form 2

8.1.4.3 Source

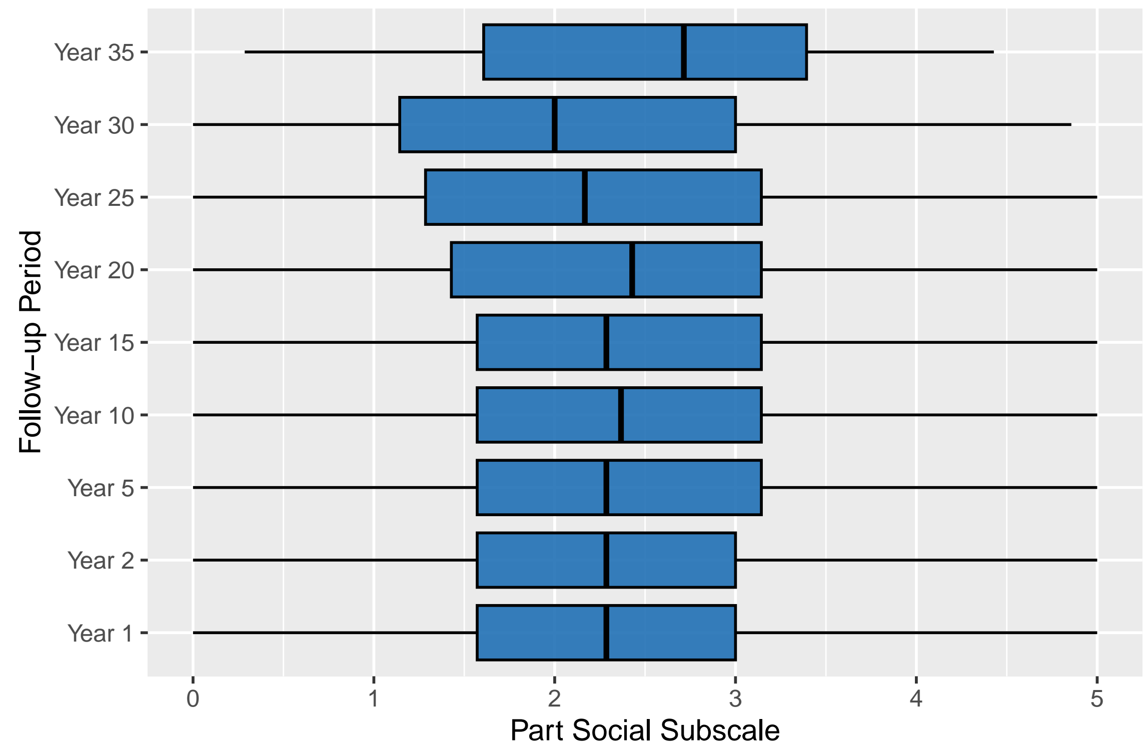
Form 2 - Interview, Mail-out (participant or proxy)

8.1.4.4 Characteristics

On 4/1/2022, the Internet question was updated from “In a typical week, how many times do you use the Internet for communication, such as for e-mail, visiting chat rooms or instant messaging?” to “In a typical week, how many times do you use the Internet for communication with others? For example, text, email, virtual meetings, social media.”

Part Social Subscale

Characteristic	**Year 1** N = 11,995	**Year 2** N = 11,233	**Year 5** N = 9,928	**Year 10** N = 7,644	**Year 15** N =
Part Social Subscale					
N Non-missing	11,517	10,747	9,540	7,354	4,640
Mean (SD)	2.26 (1.02)	2.25 (1.03)	2.27 (1.06)	2.33 (1.10)	2.32 (1.1
Median (Q1, Q3)	2.29 (1.57, 3.00)	2.29 (1.57, 3.00)	2.29 (1.57, 3.14)	2.37 (1.57, 3.14)	2.29 (1.57,
Min, Max	0.00, 5.00	0.00, 5.00	0.00, 5.00	0.00, 5.00	0.00, 5.0
Missing	478	486	388	290	185



96% of the interviewed people have valid data

8.1.5 Transportation

8.1.5.1 Definition

Indicates the primary mode of motorized vehicular transportation, according to the best source of information (person with brain injury unless unavailable or unreliable).

8.1.5.2 Form

[ ] Form 1
[X] Form 2

8.1.5.3 Source

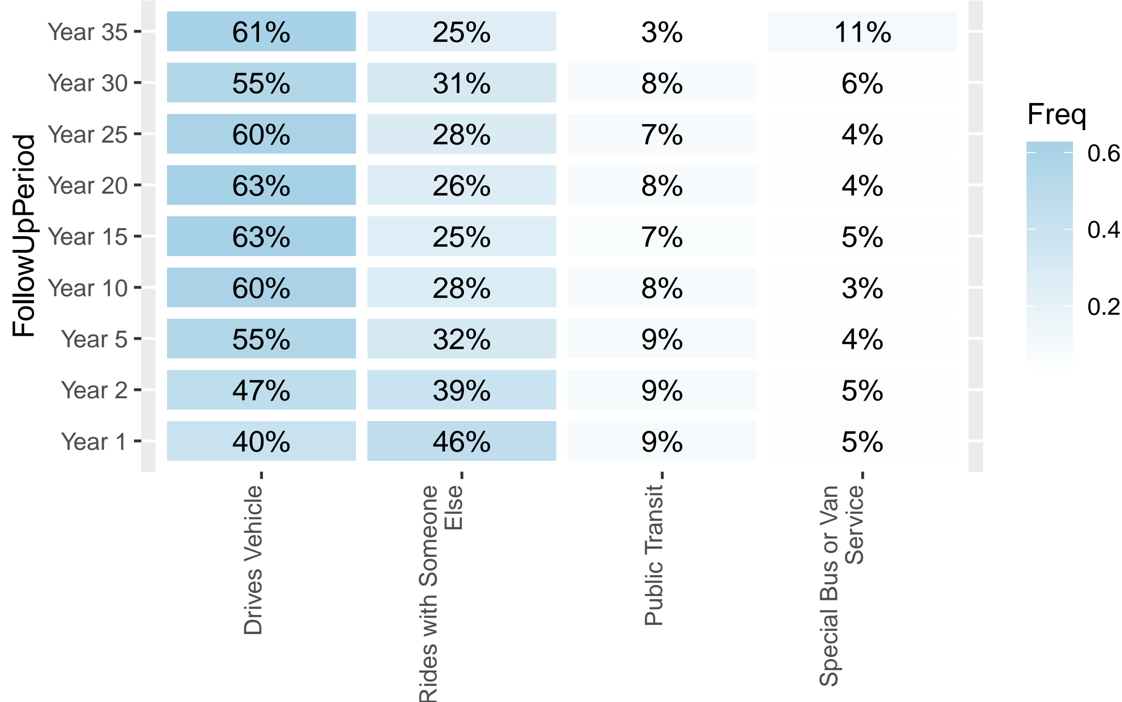
Form 2 - Interview, Mail-out (participant or proxy)

8.1.5.4 Details

Taxi, Uber and Lyft should be coded as 'Public Transit'.

Electric scooters/E-bikes, as well as motorized wheelchairs should be coded as 1- Drives Vehicle.

Characteristic	Overall N = 60,837	Year 1 N = 17,114	Year 2 N = 15,144	Year 5 N = 11,895	Year 10 N = 8,062	Year 15 N = 4,984
TransModeF, n (%)						
Drives Vehicle	29,311 (51)	6,499 (40)	6,753 (47)	6,251 (55)	4,674 (60)	3,009 (63)
Rides with Someone Else	20,991 (36)	7,498 (46)	5,599 (39)	3,590 (32)	2,161 (28)	1,215 (25)
Public Transit	5,133 (8.8)	1,447 (8.9)	1,359 (9.4)	1,074 (9.4)	649 (8.4)	343 (7.1)
Special Bus or Van Service	2,573 (4.4)	770 (4.7)	689 (4.8)	464 (4.1)	271 (3.5)	235 (4.9)
Missing	2,829	900	744	516	307	182



95% of the interviewed people have valid data

References

Corrigan, John D, Jeffrey P Cuthbert, Gale G Whiteneck, Marcel P Dijkers, Victor Coronado, Allen W Heinemann, Cynthia Harrison-Felix, and James E Graham. 2012. “Representativeness of the Traumatic Brain Injury Model Systems National Database.” *The Journal of Head Trauma Rehabilitation* 27 (6): 391–403.

Cuthbert, Jeffrey P, John D Corrigan, Gale G Whiteneck, Cynthia Harrison-Felix, James E Graham, Jeneita M Bell, and Victor G Coronado. 2012. “Extension of the Representativeness of the Traumatic Brain Injury Model Systems National Database: 2001 to 2010.” *The Journal of Head Trauma Rehabilitation* 27 (6): E15–27.