National Concussion Surveillance System
Pilot Summary

Background

Traumatic brain injuries (TBIs) are a significant public health concern in the United States. However, existing national TBI estimates likely underestimate TBI burden considerably. Estimates using healthcare administrative data only capture information on the number of emergency department (EDs) visits and hospitalizations that are identified as TBI-related. A 2016 study in a pediatric healthcare system found that nearly 80% of evaluated concussions, commonly referred to as mild TBIs, were treated outside of the hospital setting.[1] Since many children do not seek care for a TBI or seek care for a TBI outside of the ED, hospital-based incidence estimates may fail to capture more than 80% of pediatric concussions.

A 2014 Institute of Medicine report, "Sports-Related Concussions in Youth: Improving the Science, Changing the Culture,"[2] recognized the gaps in TBI surveillance and recommended that CDC "establish and oversee a national surveillance system to accurately determine the incidence of sports-related concussions, including those in youth ages 5 to 21." CDC examined new and existing methodologies to address the gaps in TBI surveillance in general, and youth sports concussion in particular. CDC pilot-tested a National Concussion Surveillance System (NCSS) using a random-digit dial telephone survey of U.S. households in 2018-2019.

Purpose

The primary goals of the NCSS pilot were to:

Evaluate
the methodology of collecting self-reported TBI information

Validate
a TBI case definition

Methodology

The NCSS pilot used computer-assisted telephone interviewing to gather information on head injuries experienced in the preceding 12 months. Data were collected on adults and their children (ages 5-17 years). Adolescents (aged 13–17 years) whose parent was interviewed were also interviewed separately about head injuries they experienced in the preceding 12 months. Preliminary results classified a respondent as having experienced a TBI if they reported a hit to the head plus at least one TBI sign or symptom, such as loss of consciousness or nausea/vomiting.

Completed surveys were obtained from:

10,130
Adults

3,557
Children
(via adult proxy)

198
Adolescents

8.4%
Overall combined response rate

Beyond the Pilot

In keeping with the IOM recommendation, and with the desire to capture TBIs among adults, the primary goals of an ongoing NCSS are to:

- Produce nationally representative estimates of TBI in children and adults, inclusive of all causes, and,
- Capture detailed information on the cause, nature, and extent of the injury

1. Arbogast KB, Curry AE, Pfeiffer MR, et al. Point of health care entry for youth with concussion within a large pediatric care network. JAMA Pediatr. 2016;179(7):e160294
2. Institute of Medicine (IOM) and National Research Council (NRC). 2014. Sports-related concussions in youth: Improving the science, changing the culture. Washington, DC: The National Academies Press.

Preliminary Results

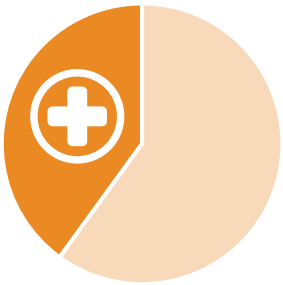
Among **adults** who responded to the survey:

1 in 8

reported experiencing a TBI in the preceding 12 months

40% with TBI were evaluated for their injury

Falls, motor vehicle crashes, and sport/recreational activities were the leading causes of TBI among adults.



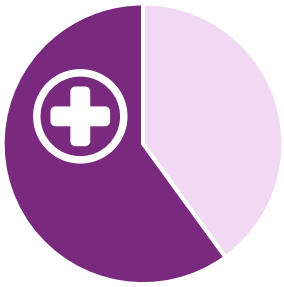
Among **children and adolescents** who responded:

1 in 10

reported experiencing a TBI in the preceding 12 months

60% with TBI were evaluated for their injury

Sport/recreational activities were the leading causes of TBI among children and adolescents (more than 65%).



Among all survey respondents, those who reported seeking care were equally likely to report being initially evaluated for their injury at the time the injury occurred (such as on the sideline of a game or at the scene of a car crash) as they were to report receiving care in the ED. The primary reason respondents reported for not seeking care after a TBI was that they did not believe the injury was serious (81%).

The NCSS pilot was successful in capturing TBIs not counted through ED-based estimates:

- **Adult** respondents reported **more than 30 times** as many TBIs in the past 12 months compared to estimates using ED data from national datasets.
- **Children and adolescents** reported **approximately 17 times** as many TBIs in the past 12 months compared to estimates using ED from national datasets.

The NCSS pilot addressed the IOM recommendation and demonstrated the feasibility of administering a household survey to capture TBIs for use in surveillance. Use of a household survey allowed important contextual information about the injury circumstances, injury impact, and care received to be collected.

Recommendations for Continuing the NCSS

Due to declining response rates among telephone surveys, continuing the NCSS on an annual or biannual basis would require modifications to the survey methodology. The preferred methodology for a future NCSS data collection is to use an address-based probability (ABS) sampling methodology. This methodology uses a United States Postal Service-compiled list of U.S. addresses to randomly send letters to households requesting participation in the survey. These letters provide potential respondents with an option to complete the survey via three modalities: 1) a paper/pencil survey returned via postage-paid envelope, 2) a web-based survey, or 3) a telephone survey in which the respondent would contact a call center to participate.

An ongoing NCSS would provide the first-ever comprehensive national estimates of TBI in the United States, identify trends and populations at higher risk, and provide critical information about the effectiveness of prevention efforts. A fully supported system would also make it possible to provide state-level estimates.

Centers for Disease Control and Prevention
National Center for Injury Prevention and Control

More information on NCSS can be found at www.cdc.gov/TraumaticBrainInjury