

# Funding for the Centers for Disease Control and Prevention (CDC) National Concussion Surveillance System

#### What is the purpose of the National Concussion Surveillance System (NCSS)?

The Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 (Pub. Law 115-377) authorized \$5 million for the Centers for Disease Control and Prevention's (CDC) Injury Center to establish a National Concussion Surveillance System (NCSS) for purposes of capturing data to better understand the extent of TBI in children and adults nationally in order to better address primary prevention and to improve treatment and recovery after injury at the national, state, and community level.

### Why is the NCSS needed?

While TBIs are considered a significant public health issue in the United States, existing national TBI estimates underestimate the TBI burden considerably, as data that is captured pertain to the number of Emergency Department (ED) hospitalizations that are identified as TBI-related. CDC cites a 2016 study in a pediatric healthcare system that found nearly 80% of evaluated concussions and mild TBIs were treated outside of the hospital setting. Many individuals either do not seek care for concussions, or those who do are not reported inmost state data systems.

Treatment may first begin at the scene of injury or upon entry into the healthcare system, such as a physician's office, urgent care setting or hospital, then extended to rehabilitation professionals to help improve functioning. A 2014 Institute of Medicine report, "Sports-Related Concussions in Youth: Improving the Science, Changing the Culture," recommended that a national surveillance system be implemented in order to address the gaps with regard to existing data systems. While the IOM report focused on the need for data relating to sports-related concussions, data is needed to capture all incidences of concussions and TBIs that may be due to falls, motor vehicle crashes, work related injuries, domestic violence, and recreational injuries.

#### How would the data be collected?

The CDC Injury Center conducted a pilot to test the NCSS using a random-digit dial telephone survey of U.S. households in 2018-2019. The NCSS pilot used computer-assisted telephone interviewing to gather information on brain injuries experienced in the preceding 12 months. Data collected on adults and their children (ages 5-17 years). Adolescents (aged 13–17 years) whose parent was interviewed were also interviewed separately about brain injuries that 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.

The NCSS pilot found that adult respondents reported more than 30 times as many TBIs in the past 12 months compared to estimates using ED data from national datasets, while children and adolescents reported approximately 17 times as many TBIs in the past 12 months as compared to estimates using ED from national datasets.

Due to declining response rates among telephone surveys, CDC proposes NCSS data collection 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. The data would then be available for national, state and community entities to plan and coordinate prevention, treatment, and community services and supports.

## **Supporting Organizations**

AANS/CNS Joint Section on Neurotrauma & Critical Care

**ADvancing States** 

Alzheimer's Association

American Academy of Physical Medicine and Rehabilitation (AAPMR)

American Association of Neurological Surgeons

American Physical Therapy Association

Brain Injury Association of America

Concussion Legacy Foundation

Congress of Neurological Surgeons

Friends of TBI Model Systems

Injury Prevention Research Center at Emory

Matthew Gfeller Center, University of North Carolina at Chapel Hill

National Association of State Directors of Developmental Disabilities Services

National Association of State Head Injury Administrators

National Association of State Mental Health Program Directors

National Athletic Trainers' Association

National Disability Rights Network

North American Brain Injury Society

Safe Kids Worldwide

SCORE Program, Children's National Hospital

The Center on Brain Injury Research & Training at the University of Oregon

The National Concussion Management Center

United States Brain Injury Alliance (USBIA)

USA Field Hockey

**USA** Lacrosse

**USA Football** 

The National Association of State Head Injury Administrators (NASHIA) is a nonprofit organization comprised of State employees and others involved in service delivery to help individuals living with brain injury to live as independently as possible. NASHIA's mission is to assist States in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. For further information contact Zaida Ricker, NASHIA Governmental Relations, zricker@ridgepolicygroup.com, or Rebeccah Wolfkiel, NASHIA Executive Director, at <a href="mailto:executive-execut