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## CDC's efforts to improve traumatic brain injury surveillance

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### Abstract

**Introduction**—Youth sports concussion has become a prominent public health issue due to growing concern about the risk of long-term health effects.

**Method**—A broad spectrum of stakeholders has convened to propose solutions, including a committee of the National Academy of Sciences (NAS) who systematically examined the issue and, in a 2014 report, made a series of recommendations to better address this public health problem.

**Results**—Among these recommendations, the NAS committee called for CDC to develop a plan for a comprehensive surveillance system to better quantify the incidence and outcomes of youth sports concussion among children 5 to 21 years of age. Since the release of the NAS report, CDC has taken action to address this recommendation and, in the process, develop strategies to improve traumatic brain injury (TBI) surveillance more broadly. The challenges outlined by the NAS committee with respect to producing comprehensive incidence estimates of youth sports concussion are not exclusive to youth sports concussion, but also apply to TBI surveillance overall. In this commentary, we will discuss these challenges, the process CDC has undertaken to address them and describe our plan for improving TBI and youth sports concussion surveillance.

### 1. Introduction

In recent years, youth sports concussion has become a prominent public health concern in the United States. Apprehension about the long-term effects of concussive and sub-concussive impacts has led to a wide range of responses including educational campaigns, increased research, rule changes among youth sports organizations, and the enactment of youth sports concussion laws in all 50 states. In 2013, the National Academy of Sciences (NAS), formerly the Institute of Medicine, examined this issue and produced a report, *Sports-related Concussions in Youth: Improving the Science, Changing the Culture*, describing the current state of scientific knowledge regarding youth sports concussion (Institute of Medicine (IOM) and National Research Council (NRC), 2014). The report outlines several recommendations to address knowledge gaps (Institute of Medicine (IOM)

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and National Research Council (NRC), 2014). Among them was a call for the Centers for Disease Control and Prevention (CDC) to design and implement a surveillance system that provides comprehensive incidence estimates of sports concussion among persons 5 to 21 years of age (Institute of Medicine (IOM) and National Research Council (NRC), 2014). In addition, the report includes a recommendation to collect data on the “cause, nature, and extent of the concussive injury” (1: p. 286), such as information related to the sport or activity in which the concussion was sustained, level of competition (e.g., recreational or competitive level), event type (i.e., practice or competition), impact location, nature of the injury (i.e., type of contact), and the signs and symptoms experienced. A concussion is considered a type of traumatic brain injury, on the mild end of the severity spectrum, and has been described as a “clinical syndrome of biomechanically induced alteration of brain function, typically affecting memory and orientation, which may involve loss of consciousness” (Giza, Kutcher, Ashwal, Barth, Getchius, & Gioia et al., 2013).

Since the release of the NAS report, CDC has considered the surveillance recommendation as a call to action, not only to provide incidence estimates for youth sports concussion but to improve TBI surveillance more broadly. In considering how to best address the NAS surveillance recommendation, it was clear that some of the gaps in current incidence estimates of youth sports concussion are similar to the gaps in current incidence estimates for TBI overall. In the interest of more efficiently utilizing resources, CDC quickly pivoted from the narrower request of better capturing incidence estimates of youth sports concussion to identifying how to better capture incidence estimates of TBI more broadly. This commentary discusses the current surveillance landscape and opportunities for improvement, including a strategy to obtain more comprehensive information about TBI and youth sports concussion.

## 2. The current surveillance landscape

To date, national TBI incidence estimates have been derived from administrative claims databases, such as those available through the Healthcare Cost and Utilization Project (HCUP). International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM) codes are used to identify TBI-related visits. For example, data obtained from HCUP's Nationwide Emergency Department Sample and HCUP's National Inpatient Sample are used by CDC to describe TBI-related ED visits and hospitalizations, respectively. Mortality data are obtained from vital statistics records using ICD-10 codes associated with TBI. Unfortunately, reliance on this method to describe TBI in the United States has at least 4 limitations: (1) ICD-9-CM codes have limited sensitivity and specificity and can lead to an undercount of TBI cases (Coronado et al., 2012; Leibson et al., 2011); (2) limited data elements in administrative databases do not permit comprehensive observation of factors associated with injury; (3) surveillance using this method excludes persons who receive outpatient care or persons who do not seek medical care; and (4) sports- and recreation-related (SRR) TBIs are difficult to abstract with ICD-9-CM-based external cause-of-injury codes (E-codes) (Centers for Disease Control and Prevention, 2011), as there are few codes to represent the vast number of SRR activities and they are often underutilized for claims purposes. Further, sports concussions are not able to be identified because the codes were not designed to definitively determine whether a TBI was sports-related. Similar limitations

apply to national estimates of TBI-related disability, as the most recent of these have been calculated using an extrapolation to the national level based on data from a single state (Selassie et al., 2008; Zaloshnja, Miller, Langlois, & Selassie, 2008). These limitations likely contribute to a significant underestimate of the number of TBIs that occur each year and the number of people living with a TBI-related disability.

National surveillance for sports concussion cannot be conducted using the aforementioned administrative databases. However, several ongoing data collection methods have been used to examine the incidence of SRR injuries. Currently, there are three large-scale surveillance systems that have been used to identify SRR injuries—High School Reporting Information Online (HS-RIO), the National Collegiate Athletic Association-Injury Surveillance Program (NCAA-ISP), and the National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP). HS-RIO and NCAA-ISP are web-based systems that allow athletic trainers to submit comprehensive information regarding an injured student athlete; examples of the type of information collected include the injury type, position played, and time elapsed before return-to-play. NEISS-AIP contains data on initial visits for injuries treated in a nationally representative sample of emergency departments (EDs) (Schroeder & Ault, 2001; HS-RIO and NCAA-ISP). Unlike HS-RIO and NCAA-ISP, NEISS-AIP includes data for persons of all ages and captures concussions sustained while engaged in a broader range of activities, including non-school-based organized sports and recreational activities (e.g., bicycling, playground activities, and “pick-up” games).

Although HS-RIO, NCAA-ISP, and NEISS-AIP have provided useful information about youth sports concussion, there are gaps in their ability to produce a comprehensive incidence estimate of SRR concussions. First, current trainer-based systems (HS-RIO and NCAA-ISP) are unable to capture SRR concussions sustained below the high school level and are unable to capture concussions sustained outside of organized, school-based sports (e.g., recreational leagues, “pick-up games”). Second, while many high school students participate in school-based athletic programs, this is not the case at the college level. Consequently, only a small fraction of sports-related concussions among college-aged students are captured by NCAA-ISP. Third, NEISS-AIP is limited to capturing SRR concussions that are the primary diagnosis in an ED setting. It has similar problems to the administrative healthcare datasets described earlier in that it does not capture SRR concussions for which people do not seek care or concussions initially treated in non-hospital settings.

### 3. Proposed method to address surveillance gaps

After a review of existing data sources, CDC concluded that a household survey has the most potential to sufficiently address key gaps in current TBI surveillance efforts. Specifically, CDC believes that a household survey is an efficient means to comprehensively capture TBIs that are not treated or are treated in non-hospital settings such as primary care, urgent care, and specialty care. Further, specific to SRR concussions, this method can comprehensively capture SRR concussions below the high school level and concussions that occur outside of organized, school-based settings. Finally, this methodology can be used to obtain needed information from respondents such as the circumstances of the TBI, recurrent TBI, the impact of the TBI, and care received post-TBI.

### 3.1. Household survey for traumatic brain injury

In collaboration with academic and federal partners with expertise in public health surveillance and TBI, CDC developed a survey that will be piloted as a random-digit-dial, household telephone survey. Survey interviewers will ask adult respondents whether they sustained a head injury within the past 12 months. If a head injury is reported, the respondent will be asked questions about signs and symptoms experienced due to the head injury. If one or more head injuries meet the case definition for TBI (including concussion), based on the signs and symptoms reported, the adult will be asked follow-up questions about the most recent TBI. Follow-up questions will elicit additional information such as the circumstances of injury and medical care received, including the setting where medical care was sought and the time elapsed between injury and medical evaluation. If a TBI is determined to be SRR, activity-specific information will be collected such as personal protective equipment used. In addition, adults will be asked if they are currently experiencing TBI-related disability. The disability questions are consistent with the questions used in the most recent Behavioral Risk Factor Surveillance System (BRFSS) survey (Courtney-Long et al., 2015) and assess the presence of physical or cognitive disabilities related to a head injury.

### 3.2. Flexibility of the proposed methodology

This particular methodology also has the flexibility to capture TBI and concussions among children and adolescents. The survey interviewer will ask adult respondents with children to serve as proxy reporters for those 5 to 17 years of age that reside in their home. Similar to adult respondents, they will be asked whether each child has had a head injury within the past 12 months. If a head injury is reported, the proxy reporter will be asked follow-up questions that mirror those asked of adults. Further, SRR-specific questions will also be asked when applicable, including questions about the process of returning to play and school. This methodology has the potential to address existing surveillance gaps and address the NAS recommendations.

It is also important to note that by utilizing a household survey for ongoing surveillance, CDC will have the flexibility to modify the survey from year to year. While the core questions that assess incidence should remain the same over time for comparability from year to year, the ability to add new questions provides an opportunity to monitor emerging concerns, or even specific research questions that can inform public health action.

### 3.3. Challenges of the proposed methodology

A household survey administered as a random-digit-dial, telephone survey is not without limitations. Response rates for telephone surveys have been decreasing over time (Groves, 2006) and the increased use of cell phones necessitates a complex dual-frame design that accounts for both landlines and cell phones (Center for Disease Control and Prevention, 2015; Greby et al., 2012).

Recall bias is a potential issue as it is optimal for information to be elicited about symptom presentation as soon as possible after a TBI (Rowhani-Rahbar, Chrisman, Drescher, Schiff, & Rivara, 2015). It may also be difficult for respondents to remember specific details about

injuries sustained over the course of a 12-month period or it may be challenging to recall how long ago events occurred (Gaskell, 2000). Another limitation for this type of injury is the lack of a validated, consensus case definition for TBI surveillance (Carman et al., 2015), creating the potential for false negatives and false positives. However, to be fair, this is a challenge for any surveillance effort, particularly those attempting to assess TBIs at the milder end of the severity spectrum.

Using adults as proxy reporters may result in inaccurate reporting of symptoms on behalf of children and adolescents. Researchers recommend that both the proxy reporter and the child be asked to report (Cantor et al., 2004; Sady, Vaughan, & Gioia, 2014). A recent study assessing agreement between young athletes and parents found there was substantial variability in the specific symptoms reported (Rowhani-Rahbar et al., 2015). This could lead to differential conclusions for the same TBI. There are also concerns that older children may not disclose symptoms and parents may have difficulty recognizing signs and symptoms in younger children.

To address a number of these concerns, the pilot study of CDC's household survey will: (1) not assess TBIs in children younger than 5 years of age; (2) directly interview adolescents 12 to 17 years of age to compare their responses with the information provided by their parent or guardian; (3) determine whether a 6-month reporting period results in enough TBI cases to produce stable incidence estimates. The comparison between parent or guardian and child reporting will suggest whether direct adolescent reporting should replace proxy reporting, complement proxy reporting, or be removed altogether, in the ongoing surveillance system. Despite these potential concerns about proxy reporting, it is also important to remember that TBIs captured by current surveillance systems almost entirely miss TBIs unknown to parents and guardians.

#### 4. Conclusion

Significant public health action has been undertaken to reduce the impact of TBI and youth sports concussion. However, these actions have been undertaken in the absence of comprehensive national incidence estimates that would permit a better understanding of the true scope of the problem. As a result, we do not know whether strategies aimed at preventing TBI have been effective. This also applies to youth sports concussion where public concern continues to grow and the potential health consequences are troubling. CDC has proposed a methodology to address the gaps in TBI surveillance, and is poised to pilot a national household survey aimed at providing the first comprehensive incidence estimates of TBI and youth sports concussion. Additionally, the survey will provide an estimate of TBI-related disability among adults as well as a comprehensive picture of healthcare utilization following TBI. The results of the pilot will be used to modify the methodology for the implementation of the surveillance system, contingent upon the allocation of resources. Moreover, the estimates derived from this proposed method will answer key questions that will inform public health action and the actions of the public.

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