Getting Answers about Concussions: CDC to Pilot a National Concussion Surveillance System

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Division of Unintentional Injury Prevention
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Learning Objectives

- Explain how Traumatic Brain Injury (TBI) surveillance data is currently captured, and understand its limitations
- Identify the goals of the pilot
- Outline how this data might be useful for you
TBI Surveillance Overview

- Purpose and Methodology
- Timeline and Implementation
- Survey Highlights
- Benefits
The Public Health Approach to Prevention

1. Define the Problem (Surveillance)
2. Identify Risk and Protective Factors
3. Develop & Test Prevention Strategies
4. Assure Widespread Adoption
Public Health Surveillance

Ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event to reduce morbidity and mortality and improve health.
Current Sources of Surveillance Data
National Electronic Injury Surveillance System-All Injury Program

- **NEISS-AIP**
  - Co-sponsored by CDC and CPSC since 2000
  - Captures all injury-related emergency department (ED) visits

- **Advantages**
  - National, representative, covers all ages
  - Identifies sports and recreation-related injuries

- **Limitations**
  - Only includes principal diagnoses and primary body part injured
  - ED visits only
  - Small samples sizes
NCAA Injury Surveillance Program

- National Collegiate Athletic Association Injury Surveillance Program (NCAA ISP)
  - Captures data describing injury trends in intercollegiate sports

- Advantages
  - Athlete exposures
  - Return to play information
  - Circumstances surrounding injury event

- Limitations
  - Only captures collegiate sports injuries
High School Reporting Information Online (RIO)

- **High School RIO**
  - Captures high school sport-related injuries

- **Advantages**
  - Nationally representative
  - Captures athlete exposures
  - Return to play information
  - Circumstances surrounding injury event

- **Limitations**
  - Restricted to high schools with certified athletic trainers
  - Only captures high school sports injuries
Purpose of the Surveillance System

RECOMMENDATION 1

“The Centers for Disease Control and Prevention, taking account of existing surveillance systems and relevant federal data collection efforts, should establish and oversee a national surveillance system to accurately determine the incidence of sports-related concussions…”

However, we will be able to do much more…

Purpose of the Surveillance System

Per the IOM report, we aim to:

- Provide national incidence estimates of sports-related concussions in youth
- Compare organized sports vs. non-organized sports vs. recreational activities
Purpose of the Surveillance System

The surveillance system will also be able to:

- Provide national incidence estimates of TBI overall
- Provide national estimates of TBI-related disability
- Provide comprehensive picture of healthcare utilization patterns for TBI
Methodology

- **Advantages**
  - Random digit dial
  - National, representative
  - Capable of capturing concussions
    - Outside of healthcare setting
    - Outside of organized sports
  - Possible to get high level of detail

- **Limitations**
  - Self or parent-proxy report
  - Declining response rates
Completed Tasks - Preparation

- Met internally to evaluate current and new data systems
- Consulted with internal CDC surveillance experts
- Identified candidate methods
- Consulted with external sports concussion surveillance experts
- Selected contractor
Current Tasks - Development

- Finalize survey
- Cognitive Testing
- Finalize pilot implementation plan, including sampling strategy
Future Tasks - Approval and Implementation

- OMB Review
- Conduct pilot
- Data cleaning and preparation
- Report pilot data
- Develop recommendations for national system
NCIPC identified and allocated a modest amount of funds to begin development of a pilot surveillance system.

Anticipate pilot to begin in 2017, and run for a full year. A full year lets us collect data on TBIs that may be affected by seasonality.

In the event that additional resources are received, CDC will be ready to start a full scale nationally representative survey.
Collecting data over time will enable us to:

- Monitor trends in TBI
- Assess whether prevention efforts are working
- Provide state specific information as these will likely require combining multiple years of data
Survey – High Level Description

Demographics/Health Information

Head/Neck Injury Last 12 Months

Symptomatology

Injury Mechanism

Medical Service Received

Post Injury

Lifetime TBI

Disability
Survey Highlights – Mechanisms

- Respondents are first asked about TBIs for which they were evaluated by a health care provider.

- Details
  - Setting
    - Inside/outside
    - Location
    - At work
  - Event
    - Broad mechanism
    - Conditions
    - Activity
Survey Highlights – Mechanisms

- Respondents are then prompted to recall other TBIs for which they did not seek care through a series of prompts
Survey Highlights – Post Injury

- Respondents are asked about their healthcare interactions after the injury

Details
- Initial evaluation
  - Location
  - Provider type
- Other care received
- Hospitalization
- Receipt of in-patient rehabilitation
- If applicable, why they did not seek care
Survey Highlights – Post Injury

- Respondents are asked about other experiences related to their recovery

Return to Work  Return to School  Return to Play
Survey Highlights – Post Injury

- **Return to Work**
  - Did the respondent miss work for wages or other responsibilities
  - For how long?
  - Have they returned?
Survey Highlights – Post Injury

- **Return to School**
  - Did the child miss school due to the injury?
  - For how long?
  - Did the provider make recommendations?

- **Communication**
  - Provider to school
  - Teachers

- **Accommodations**
  - Type
  - How long?
  - Was it what the child needed?
Survey Highlights – Post Injury

- **Return to Play**
  - Was the child removed from play?
  - Who removed them?
  - Have they returned?
    - When
    - Who made the decision
    - What type of provider was it
Survey Highlights – Disability

- Current disabilities

- Are the difficulties due to a head or neck injury?

- Were the difficulties made worse by the head or neck injury?

- Details
  - Deaf or hard of hearing
  - Blindness
  - Physical, mental, emotional condition
  - Difficulty walking or climbing stairs
  - Difficulty dressing or bathing
  - Difficulty doing errands
  - Unable to work
Benefits of the System

- **Incidence estimates**
  - Allocation of prevention resources
  - Targeting of prevention efforts

- **Healthcare utilization**
  - Understanding of barriers to care
  - Identification of clinical training needs

- **Recovery**
  - Understanding of TBI impact on returning to work
  - Identification of return to play patterns
  - Assessment of unmet needs for accommodations
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.