



The National Institutes of Health
Pediatric Concussion Workshop
October 13-14, 2016

NIH Pediatric Concussion Workshop Executive Summary

Currently, several large longitudinal studies are aimed at better understanding the behavioral and physiological sequelae of concussion in military, civilian and athletic populations. These studies are designed to provide insight into the acute, sub-acute and chronic course of recovery from concussion. Though these efforts are likely to provide important insights for understanding the course of disease following concussion, none are focused on pediatric populations (i.e., pre-high school). Consequently, a considerable knowledge gap exists with regarding the course of recovery from concussion during critical neurodevelopmental stages. Because the rate of reported pediatric concussions has nearly doubled in the past decade, this knowledge gap presents a unique and compelling need for further research on pediatric concussion and its sequelae. Each year, an estimated 750,000 U.S. emergency department visits are accounted for by youth who present with symptoms of concussion. While most children experience a reduction in symptoms within 2 weeks of injury, up to 33% experience persistent affective, cognitive, somatic, and/or behavioral symptoms more than 28 days after injury. Despite calls from medical, athletic and public communities, no objective markers exist for monitoring and prognosticating the course of recovery in pediatrics. In response, the NIH sponsored a two-day workshop attended by approximately 130 researchers, clinicians, patients, parents, advocates and other stakeholders. The purpose of the workshop was to outline the state of the science in pediatric concussion; develop a list of research priorities to expedite the accumulation of evidence-based knowledge regarding pediatric concussion diagnosis, prognosis and recovery; and, provide evidence-based practices that could be useful to parents, patients, medical professionals and other stakeholders. The workshop agenda was developed by an international group of concussion experts and program officials from participating NIH Institutes and Centers (See Appendix A). To best propagate the information from this meeting, NIH provided a live videocast that can now be viewed at: [NIH Pediatric Concussion Workshop, Day 1](#) and [Day 2](#).

Dr. Walter Koroshetz, the Director of the National Institute for Neurological Disorders and Stroke (NINDS) opened the workshop with a welcoming message to the participants that outlined the NINDS' view of the challenges that may need to be addressed in pediatric concussion. This was followed by a patient's testimonial and a review of the Institute of Medicine (IOM) recommendations for youth sports concussion. The IOM's recommendation #2 was particularly pertinent: The National Institutes of Health and the Department of Defense should support research to: (1).establish objective, sensitive, and specific metrics and markers of concussion diagnosis, prognosis, and recovery in youth & (2).inform the creation of age-specific, evidence-based guidelines for the management of short-and long-term sequelae of concussion in youth.

The introductory talks on day 1 were followed by a series of review sessions. The first defined and described the current understanding of concussion's definition, diagnosis, pathophysiology, biomechanics and epidemiology. Subsequent review sessions focused on understanding the state of the science and identifying knowledge gaps in pediatric research and pediatric concussion, specifically. Several common themes arose from each of the sessions. Among the most prominent challenges in the field was simply defining "concussion". There are more than 30 clinical or consensus definitions of concussion in the literature which hampers diagnostics and comparison of findings across different studies. Speakers also identified a list of challenges that investigators face when trying to study pediatric populations in comparison to adults. In particular, developmental factors influence differences in cognitive, verbal and affective developmental trajectory, and this can complicate collection of both objective and self-report assessment of concussive symptoms in children. Moreover, little normative data exist for many of the most common diagnostic assessment tools used to diagnose concussion. The final review session provided attendees with a brief description of several large relevant, ongoing resources/studies that may provide either guidance or resources to studying concussion. These studies included NIH's Adolescent Brain Cognitive Development (ABCD) study that will follow 10,000 9-10 year olds for 10 years while measuring cognitive, behavioral and biomarker data. As well, the NINDS Transforming Research and Clinical Knowledge in Traumatic Brain Injury (TRACK-TBI) study which has a small pediatric arm (N=50) but developed a brief battery of assessments that can be feasibly done in an emergency room setting. Other studies included the

DoD/NCAA CARE Consortium that is studying 30,000+ collegiate athletes with a primary focus on understanding concussion and concussion risks. Finally, a representative from the Centers of Disease Control (CDC) provided information about the upcoming CDC youth concussion surveillance program.

The last component of the meeting was dedicated to breakout groups where attendees discussed the research gaps in pediatric concussion, developed a list of priorities, and suggested approaches that may accomplish the prioritized research objectives they created. Across the three breakout groups the following research priorities were considered of the highest priority:

Research Priorities for pediatric concussion:

- 1) Development of a multi-domain diagnostic and prognostic model to assist in predicting which children will suffer persistent symptoms.
- 2) Development of non-traditional / non-invasive biomarkers for diagnosis, prognosis and monitoring of concussion.
- 3) Understanding the interaction of sex and age as it relates to mechanism of injury, pathophysiology, symptom reporting and recovery.
- 4) Epidemiological understanding of the incidence of concussion across the pediatric age spectrum.
- 5) Development of a precision medicine approach for the treatment of pediatric concussion.
- 6) Understanding of the course of disease; i.e., long-term effects of concussion.
- 7) Investigation of the relationship between head impact exposure and psychosocial, biological and cognitive outcomes.

Breakout group experimental design and data collection recommendations for conducting studies in pediatric concussion.

In general: "Remember that if it can't be translated in the real world, it won't be useable!"

- Leverage current initiatives such as the NIH's ABCD study for normative data.
- Inclusion of Data Sharing and utilization of Common Data Elements and TBI relevant standard operating procedures.
- Include baseline measures of outcome measure when possible.
- Broad but brief assessment of multi-domain outcomes to include cognition, psychosocial, emotional, sleep, and somatic measures
- Demographics must include both males and females and should initially focus on pre-high school though data from all age groups are needed. If feasible, studies should avoid sampling biases such as including only sports-related concussions, and patients presenting at the ER

Breakout group suggestions for accomplishing these goals:

All groups thought the most appropriate approach would be either (1) a prospective longitudinal study of at risk children that collects behavioral and biological data similar to the ABCD effort, or (2) a cross-sectional approach with specified affected populations across age groups.

Appendix A

Organizing and Agenda Committee:

Committee Chair:

Jonathan Mink, MD, PhD, University of Rochester, NINDS Advisory Council Member

Committee:

Patrick Bellgowan, PhD, NIH/NINDS

Matthew Breiding, PhD, CDC

Ruth Brenner, MD, NIH/NICHD

BJ Casey, PhD, Yale University

Isabelle Gagnon, PhD, McGill University

Tom Hammeke, PhD, Medical College of Wisconsin

Ramona Hicks, PhD, One Mind for Research

Susan Weiss, PhD, NIH/NIDA

Roger Zemek, MD, Children's Hospital of Eastern Ontario

Supporting Institutes and Center:

National Institute of Neurological Disorders and Stroke (NINDS)

National Institute on Drug Abuse (NIDA)

National Center for Medical Rehabilitation Research (NCMRR)/*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)