

# Let's Talk about TBI



In 2018, researchers from Johns Hopkins University in collaboration with the Brain Injury Association of Maryland brought together a diverse group of TBI (Traumatic Brain Injury) stakeholders. They included people with TBI, caregivers involved in the care of people with TBI, non-physician clinicians (such as occupational therapists, physical therapists, speech language therapists, mental health therapists), program coordinators and mental health administrators to discuss TBI mental health research. The project was funded by Patient Centered Outcomes Research Institute (PCORI) JUU #7136

The purpose of the discussions was to help shape patient-centered research and policies to better meet the mental health needs of individuals with TBI and their families. The discussion was guided by four main questions.

1

What are common barriers and facilitators experienced in the management of neuropsychiatric problems after TBI?



2

What are the important and needed research topics pertaining to TBI mental health that should be investigated further?

3

What are the strategies that can keep a TBI stakeholder group active and invested in TBI mental health care so that patient centered research can continue?

4

What are the important and needed policy changes that can improve TBI mental health care in the US?



## Perceived stigma

People with neuropsychiatric symptoms after TBI are often treated as “crazy/bad/impaired” by family, friends and even clinicians who are not knowledgeable in TBI

**Educate family members;** Help connect people with TBI to others who have the potential to understand them. Respect individuals with TBI as people with difficulties rather than disabled or impaired

## Poor insurance coverage

Inadequate insurance coverage specifically for neuropsychiatric symptoms after TBI

**Educate insurers** and incentivize clinicians to provide more services

## Management starts in acute trauma period

Education on neuropsychiatric symptoms to be provided in the acute trauma period in emergency rooms and acute care facilities. Acute care facilities to develop long-term rehabilitation plans that include education and management of neuropsychiatric symptoms

**Address, educate and guide family members** on management of problematic behaviors. Discharge materials to include literature on TBI and resource guide

## Minimizing caregiver burden

Caregivers are burdened and overwhelmed by neuropsychiatric symptoms that arise following TBI. Addressing this with a comprehensive caregiver plan is beneficial

**Create a caregiver plan**

**BARRIERS**

**FACILITATORS**