Improving Traumatic Brain Injury Care and Research
A Report From the National Academies of Sciences, Engineering, and Medicine

Traumatic brain injury (TBI) takes a substantial toll on health and health care costs in the US. Yet TBI is often unrecognized, misclassified, undertreated (especially in its longer-term manifestations), and, in proportion to its public health consequences, underresearched. Despite the dedication of an increasing number of professionals, disciplines, and organizations devoted to TBI care and research, including innovative programs for military service members and veterans, care often fails to meet the needs of affected individuals, families, and communities. The US lacks consolidated leadership for achieving improvements in TBI care and outcomes, and, partly as a result, it lacks a strategic plan for fostering change and overseeing progress. With stronger leadership and proper redesign, the health care system could reduce the morbidity and disability associated with TBI, while enhancing the effectiveness of TBI care.

These are among the conclusions of a National Academies of Sciences, Engineering, and Medicine report, Traumatic Brain Injury: A Roadmap for Accelerating Progress, written by an 18-member committee, which met over 15 months from 2020 to 2022, gathered testimony from more than 50 researchers, practitioners, patients, and families who experienced TBI and its sequelae, and analyzed evidence from peer-reviewed publications. While the report acknowledges the importance of prevention, its focus is on postinjury care. TBI encompasses injuries of vastly different severity and causation ranging from concussions during sports participation, to head trauma from falls in older adults, to skull fractures from automobile crashes, to penetrating wounds from projectiles and military combat, and to many other causes of neurotrauma. A consolidated registry is lacking, but data from 2009 and 2010 suggested that an estimated 4.8 million people were evaluated for TBI in US emergency departments each year, and data from 2013 suggested that TBI was diagnosed in approximately 2% of total emergency visits, hospitalizations, and deaths in the US.2,3 In 2017, TBI contributed to an estimated 224,000 hospitalizations and 61,000 deaths, and 2.5 million high school students reported having experienced at least 1 concussion.4,5 Worldwide, more than 55 million people are estimated to experience a "mild" TBI each year.6 TBI is more than an acute event. Although many individuals who experience a so-called mild TBI, such as a concussion, recover in weeks, others report ongoing symptoms for much longer.7 Many people who experience severe TBI are challenged with chronic, or even lifetime, morbidity and disability. The consequent physical and psychological effects and the economic costs for patients, families, and communities are high. An estimated 2.5 million caregivers in the US are supporting a family member with TBI.8 Lifetime financial costs in health care, lost income, and reduced quality of life are difficult to measure but have been estimated to be as high as $750 billion for the estimated 2 million people who experience TBI in the US each year.9

Despite its magnitude as a public health problem, TBI continues to be misunderstood and not optimally managed. Not all brain insults are identified or reported as such at the time of injury or during acute triage. The public, and many clinicians, may not realize that even the "mildest" TBIs can have downstream effects and could benefit from follow-up care, timely rehabilitation, and social and psychological support. TBI follow-up is often inadequate. Individuals with mild TBI may not receive a referral for follow-up or have no contact with a clinician after hospital discharge, even when they experience symptoms, and clinicians and patients may fail to realize that subsequent symptoms are connected to a prior TBI. Even when impairments from injury are evident, one estimate from 2012 suggested that only 13% to 25% of people with moderate, severe, or penetrating TBI received interdisciplinary inpatient rehabilitation.10 During its public workshops, the committee heard painful testimony from patients and families who, although grateful for superb acute care, felt lost and abandoned by the health care system in the months and years that followed, as they tried to cope with significant physical and psychological sequelae.

Part of the problem of underrecognition and under-treatment is that categorization of TBI as "mild," "moderate," and "severe" does not reflect the state of scientific knowledge. Injuries labeled as mild can have downstream morbidity, while severe cases may sometimes achieve levels of recovery that violate conventional wisdom. A more evidence-based approach, combining clinical presentation and the time-honored Glasgow Coma Scale score with advances in biomarkers and imaging, is needed to improve assessment, inform triage, and bolster treatment guidelines. By way of analogy, the report observes, "Today, one could not imagine classifying cancer as 'mild,' 'moderate,' and 'severe' for diagnosis, treatment, and prognosis."11 Rather than viewing TBI as an acute physiological event, the report proposes a "bio-psychosocial-ecological" model, using multiple lenses through which to appreciate the needs and condition of people living with TBI. That model highlights the importance of a system-wide health care approach able to anticipate and respond to needs in a coordinated fashion, with regular reassessment of care plans. It also emphasizes the importance of a focus on racial and socioeconomic equity. The report further recommends that the National Academies’ specifications for a "learning health care system" be applied to the approach to TBI care nationally, regionally, and locally. That requires...
a more complete, agile, and coordinated information system, including better methods to capture and integrate patient data across diverse prehospital, acute, and longer-term care settings. It also implies systemic leadership of TBI care that transcends organizational and disciplinary boundaries to ensure care coordination and secure handoffs over time and across care settings and geographies. The poignant accounts from patients with TBI and their families who feel lost and forgotten should become problems of the past.

To achieve improved TBI care, the committee arrived at 8 recommendations, briefly summarized here.

1. Update the TBI Classification Scheme. The NIH should convene a work group to develop and help promulgate a more precise and useful scheme. Clinicians should replace the “mild-moderate-severe” categorization with the actual Glasgow Coma Scale score, supplemented, if feasible and clinically indicated, with information from neuroimaging and biomarker measurements.

2. Manage TBI as a Chronic Condition. In all healthcare delivery sites, acute TBI care should be carefully integrated with reliable and timely multidisciplinary care to address physical, cognitive, and behavioral sequelae and comorbidities, both in the short term and in the longer run. Appropriate follow-up for longer-term needs should be ensured for all.

3. Consolidate and Support Clinical Practice Guidelines. Relevant professional bodies should bring together and rationalize clinical care guidelines for TBI, to reduce unwarranted variation and gaps in both care and administration. Payers, public and private, should bring their payment policies and benefit structures into better alignment with the knowledge of proper TBI care, especially for rehabilitation and long-term support.

4. Enhance Public and Professional Awareness. The Centers for Disease Control and Prevention, and others, should expand efforts to enhance public and professional understanding of the frequency, manifestations, causes, and long-term consequences of TBI. This should include professional training in TBI care and the implications of the bio-psycho-socio-ecological model.

5. Develop TBI Care Systems. Accrediting bodies and professional societies should establish and reinforce local and regional integrated care systems for TBI. Care standards should be included in trauma center verification systems, such as the one managed by the American College of Surgeons, as well as in assessments of integrated postacute and rehabilitation care, such as those promulgated by the Commission on Accreditation of Rehabilitation Facilities and, ideally, by the Joint Commission. The Centers for Medicare & Medicaid Services should support the creation of local and regional pilot programs for integrated TBI care.

6. Enhance TBI Data and a Learning Health System. The Department of Health and Human Services (HHS) should work with healthcare systems, electronic health record vendors, and owners of national and regional TBI registries and databanks to improve surveillance, standardized patient record information, and longitudinal TBI registries to better support integrated patient care and ongoing learning about care improvements.

7. Expand TBI Research. Investment in key TBI research questions could yield benefits in improved outcomes and lower health care costs. At present, TBI research investment is much lower than the morbidity and economic costs of TBI warrant. The report specifies 8 priority topics for expanded research.

8. Consolidate Leadership for National TBI Care Improvement. The secretary of HHS should establish a TBI task force to develop a strategic approach to implementing these recommendations and to monitor progress. A public-private coalition should be created to advance a framework for action.

Many clinicians will encounter patients with TBI in their careers, whether as caregivers in the acute phases of injury or in the distress of patients and families living with the downstream problems brought on by TBI. While much of this National Academies report speaks to policy makers, funders, organizations, and health care administrators, it also speaks to clinicians, who can realize significant gains through a better understanding of the presentations and consequences of TBI, and a wider perspective on what it means to care for people whose injuries are multidimensional and whose needs are lasting. Few conditions require for their successful management more interdisciplinary teamwork, coordination, proactivity, and patient-centeredness than TBI. This report calls for a wholesale reconsideration and redesign of TBI care from the examination room to the level of national policy to ensure the best care for all.

ARTICLE INFORMATION
Conflict of Interest Disclosures: None reported.

Additional Information: Dr Berwick chaired the Committee on Accelerating Progress in Traumatic Brain Injury Research and Care, which authored the NASEM report. Drs Bowman and Matney served as staff members. The report was sponsored by the US Department of Defense.

Additional Contributions: We acknowledge the contributions of the consensus committee that authored the NASEM report: Donald Berwick, MD, MPP; Jennifer Bogner, PhD; Matthew Fink, MD; Jessica Gill, RN, PhD; Odette Harris, MD, MPH; Sidney R. Hinds, MD; Frederick Korley, MD, PhD; Ellen Mackenzie, MSC, PhD; Geoffrey Manley, MD, PhD; Susan Margules, PhD; Christina L. Master, MD, MPH; Michael McCrea, PhD; Helene Moriarty, RN, PhD; Corinne Peek-Asa, MPH, PhD; Thomas Scala, MD; Eric Schoomaker MD, PhD; Martin Schreiber, MD, and Monica Vavilala, MD; NAM Fellow in Osteopathic Medicine Juleanne P. Sees, DO; and staff from the National Academies.

REFERENCES