

ORIGINAL ARTICLE

CLINICAL STUDIES

Priority Clinical Actions for Outpatient Management of Nonhospitalized Traumatic Brain Injury

Noah D. Silverberg,^{1,*} Kathy Lee,² Ana Mikolić,¹ Mark T. Bayley,³ David L. Brody,⁴ E. Wesley Ely,⁵ Joseph T. Giacino,⁶ Cathra Halabi,⁷ Flora M. Hammond,⁸ Daniel A. Ignacio,⁹ Caterina Mosti,¹⁰ Joukje van der Naalt,¹¹ Monique R. Pappadis,¹² Olli Tenovu,¹³ Vincent Y. Wang,¹⁴ Monica Verduzco-Gutierrez,¹⁵ and Geoffrey T. Manley¹⁶; On behalf of the Action Collaborative on TBI Care**

Abstract

Outpatient care following nonhospitalized traumatic brain injury (TBI) is variable, and often sparse. The National Academies of Sciences, Engineering, and Medicine's 2022 report on *Traumatic Brain Injury: A Roadmap for Accelerating Progress* highlighted the need to improve the consistency and quality of TBI care in the community. In response, the present study aimed to identify existing evidence-based guidance and specific clinical actions over the days to months following nonhospitalized TBI that should be prioritized for implementation in primary care. In systematic literature searches, 17 clinical practice guidelines met our eligibility criteria and an additional expert consensus statement was considered highly relevant. We extracted 73 topics covered by one or more existing clinical practice guidelines. After removing redundant and out-of-scope topics, those deemed essential (not requiring prioritization), 42 topics were subjected to a prioritization exercise. Experts from the author group ($n = 14$), people with lived experience ($n = 112$), and clinicians in the community ($n = 99$) selected and ranked topics they considered most important. There were

¹University of British Columbia, Vancouver, Canada.

²Secretary of Defense for Health Readiness Policy and Oversight, Falls Church, Virginia, USA.

³UHN Toronto Rehabilitation Institute, Temerty Medicine, University of Toronto, Toronto, Canada.

⁴Uniformed Services University of the Health Sciences, Bethesda, Maryland, USA.

⁵Critical Illness, Brain Dysfunction, Survivorship (CIBS) Center, Vanderbilt University Medical Center, and the Tennessee Valley Veteran's Affairs Geriatric Research Education Clinical Center (GRECC), Nashville, Tennessee, USA.

⁶Department of Physical Medicine and Rehabilitation, Spaulding Rehabilitation Hospital and Harvard Medical School, Charlestown, Massachusetts, USA.

⁷Weill Institute for Neurosciences, University of California-San Francisco, San Francisco, California, USA.

⁸Department of Physical Medicine and Rehabilitation, Indiana University School of Medicine, Indianapolis, Indiana, USA.

⁹St. Jude Brain Injury Network, Fullerton California, USA.

¹⁰Department of Psychiatry and Behavioral Sciences, University of California-San Francisco, San Francisco, California, USA.

¹¹Department of Neurology, University Medical Center Groningen, University of Groningen, Groningen, the Netherlands.

¹²Sealy Center on Aging and Department of Population Health and Health Disparities, School of Public and Population Health, University of Texas Medical Branch, Galveston, Texas, USA.

¹³Division of Clinical Neurosciences, University of Turku, Turku, Finland.

¹⁴Department of Neurosurgery, Dell Medical School, University of Texas-Austin, Austin, Texas, USA.

¹⁵Department of Rehabilitation Medicine, University of Texas Health Science Center at San Antonio, San Antonio, Texas, USA.

¹⁶Zuckerberg San Francisco General Hospital and Trauma Center, University of California, San Francisco, San Francisco, California, USA.

**The Action Collaborative on TBI Care is an *ad hoc* activity convened under the auspices of the Forum on Traumatic Brain Injury at the National Academies of Sciences, Engineering, and Medicine. The work the collaborative produces does not necessarily represent the views of any one organization, the TBI Forum, or the National Academies and is not subjected to the review procedures of, nor is it a report or product of, the National Academies.

*Address correspondence to: Noah D. Silverberg, PhD, University of British Columbia, 2136 West Mall, Vancouver, British Columbia V6T 1Z4, Canada E-mail: noah.silverberg@ubc.ca

areas of agreement (e.g., early education was ranked highly by all groups) and discordance (e.g., people with lived experience perceived diagnostic tests/investigations as more important than the other groups). We synthesized the prioritization survey results into a top-10 list of the highest priority clinical actions. This list will inform implementation efforts aimed at improving post-acute care for nonhospitalized TBI.

Keywords: clinical practice guideline; craniocerebral trauma; priorities; survey; traumatic brain injury

Introduction

Traumatic brain injury (TBI) remains a leading cause of disability across the life span.¹ The majority of people with TBI require minimal to no inpatient hospital care. Outcomes from nonhospitalized TBI are variable, with persistent symptoms and disability in up to one-third of patients.² Despite considerable scientific advances, diagnosis, prognostication, treatment, and equitable care access pose ongoing challenges. Recognizing this, the U.S. Department of Defense funded the National Academies of Sciences, Engineering, and Medicine (National Academies, hereafter) to conduct a study to identify barriers and possible solutions for improving TBI care and research. After reviewing the scientific literature and hearing testimony from people with lived experience (PWLE) and others involved in TBI prevention, care, recovery, and research, the committee outlined eight recommendations in their 2022 report *Traumatic Brain Injury: A Roadmap for Accelerating Progress*.³ The National Academies subsequently established a Forum on TBI to facilitate implementation of these recommendations. An Action Collaborative on TBI Care was convened under the auspices of this Forum to compile and disseminate best practices and resources on symptom management, care models, patient/family/provider materials, and other information aimed at enhancing recovery in the period after TBI.

Action Collaborative members' work focused initially on adults with TBI who do not present to an emergency department or are discharged directly from the emergency department (i.e., *nonhospitalized*), but also applicable to people with TBI who are able to care for themselves at discharge from acute care. Most cases of nonhospitalized TBI would fulfill criteria for *mild* TBI.⁴ Because the National Academies TBI Roadmap report³ called for replacement of the "inaccurate and misleading" (pg. 5) convention to trichotomize TBI severity into mild, moderate, and severe, and the subsequent National Institutes of Health initiative to propose a new classification system,⁵ the Action Collaborative elected to not use the term mild TBI.

One of the key recommendations in the National Academies TBI Roadmap report³ was to "reduce unwarranted variability and gaps in administrative and clinical care guidance to ensure high-quality care for TBI" (pg. 6). Toward this end, members of the Action Collaborative on TBI Care formed a Working Group in December 2022 to

review the landscape of current clinical practice guidelines (CPGs) for managing TBI and to identify and synthesize the top-priority recommendations from those documents, at least some of which could be applied in primary care. The CPG Working Group focused on the post-acute phase (the days to ~6 months following injury) because this period was perceived to have the greatest variability and gaps in care, and complement efforts toward management of TBI as a chronic disease.⁶ Members of other Action Collaborative Working Groups are currently (1) developing updated patient-facing education materials, (2) proposing core elements of an interdisciplinary post-acute TBI clinic, and (3) identifying goals for TBI follow-up care.

Here we describe the CPG Working Group's process for identifying priority clinical actions for outpatient management of nonhospitalized TBI. The process involved extracting topics from existing CPGs; conducting prioritization surveys with experts, clinicians, and PWLE; and a final consolidation by consensus of CPG Working Group members. Identifying top priority clinical actions can inform the development of guidelines for implementation in primary care settings.

Methods

Identifying existing CPGs

The CPG Working Group was aware of recently performed systematic searches that had broader criteria than considered necessary for the present purpose. We decided it would more efficient to screen these search results rather than conduct a new (redundant) systematic search. We obtained the search results containing all included and ineligible articles from Sander et al,⁷ and all included articles from systematic reviews performed by Berrigan et al⁸ (updated to April 2021) and Lithopoulos et al⁹ (updated to October 2022).

The CPG Working Group created *a priori* inclusion/exclusion criteria for existing CPGs based on an adapted version of National Guideline Clearinghouse definition of a CPG¹⁰ and additional criteria for alignment with the scope of TBI Forum's Action Collaborative on TBI Care (see Supplementary Data S1). Two independent raters (pairs of CPG Working Group members) screened titles and abstracts, applying the eligibility criteria. Another pair of independent raters reviewed full-text reviews, with discrepancies resolved by a third (M.T.B.). We searched for additional CPGs and recent updates of

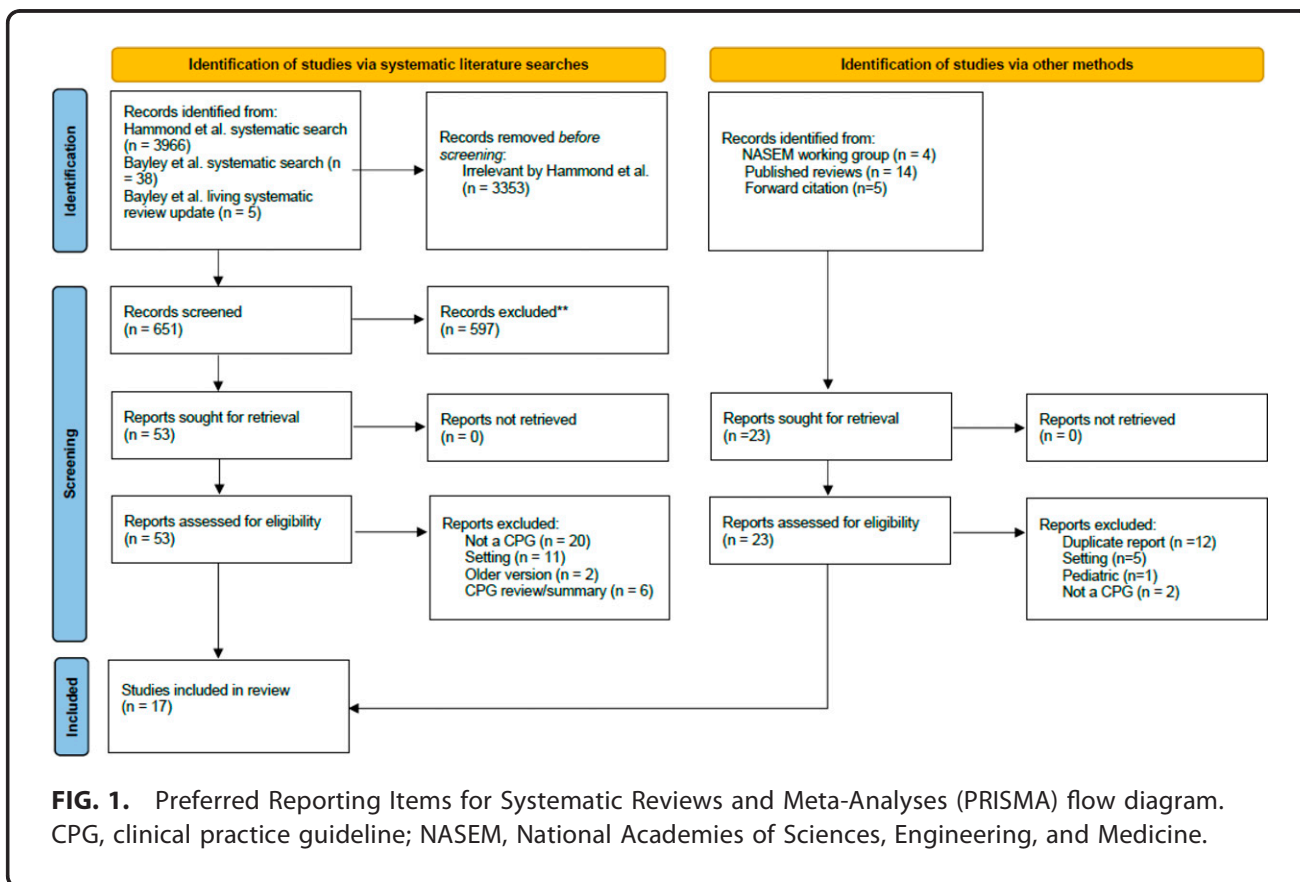


FIG. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. CPG, clinical practice guideline; NASEM, National Academies of Sciences, Engineering, and Medicine.

eligible CPGs from the reference lists of published reviews of CPGs^{11,12} and forward citation tracking of eligible CPGs. The number of articles excluded at each stage is reported in Figure 1.

The systematic search process yielded 17 eligible CPGs. The CPG Working Group decided to include the Concussion in Sport consensus statement¹³ because it was expected to have a major impact on clinical practice even though it did not meet our definition of a CPG and does not identify itself as a CPG. This addition raised the total to 18 eligible CPGs (listed in Supplementary Data S1).

Identified topics covered in eligible CPGs

Each of the 18 eligible CPGs was assigned to a CPG Working Group member (one extractor per CPG). The extractors' task was to complete a spreadsheet to mark which topics were covered in each CPG. The co-chairs (N.D.S. and K.L.) drafted an initial seed list of topics in CPGs and invited extractors to add topics covered in the CPG but not included in the seed list.

The extraction process identified 70 topics covered in eligible CPGs. Of these, three were determined to cover multiple distinct elements of care, and so were separated, resulting in a total of 73. This list of 73 topics was circulated to all CPG Working Group members, who were invited to add topics that they believed *should* be covered

in a CPG on nonhospitalized TBI but were not covered in previous CPGs. Seven new topics were added through this mechanism. Of the complete list of 80 topics, 19 were removed because they were out of scope (e.g., involved pre-hospital or hospital care) and another 16 were removed because they were redundant or could be integrated within another topic (e.g., return to driving was incorporated into return to activity).

Of the remaining 45 topics, three were excluded from the subsequent prioritization process because the CPG Working Group considered them *essential*, leaving 42 topics (Supplementary Data S1). These three essential topics were as follows: (1) confirm a diagnosis of TBI, (2) determine the severity of the TBI, and (3) determine if the patient requires assessment at an emergency department for possible life-threatening complications. In a later CPG Working Group meeting, after publication of the 2023 update of the National Institute for Health and Care Excellence (United Kingdom) guideline on TBI,¹⁴ which included a new recommendation (#1.4.12) on abuse/neglect as a possible cause of TBI, the CPG Working Group decided to add screening (and possible safeguarding) for abuse/neglect as a fourth essential topic. Finally, even though screening for social determinants of health had been included in the prioritization process, the CPG Working Group decided to add it as a fifth essential topic.

Public prioritization survey

To elicit input from the public, the CPG Working Group designed an anonymous survey modeled after the type used for “interim prioritization” in James-Lind Alliance Priority-Setting Partnerships, for example, see Ref.¹⁵ The survey asked respondents to self-identify as (1) a person who sustained a TBI, (2) a caregiver for a person with TBI, or (3) a health professional who provides TBI care. Respondents were then instructed to select up to 10 topics (from a list of 42) that are “most important” to include in a CPG for TBI and in a second step, rank order their selections. The survey included lay definitions of TBI and CPG. Finally, respondents entered their demographic characteristics. With branching logic, patients and caregivers responded to additional questions about the injury, most problematic symptoms, and care received. A draft of the survey was circulated to lay reviewers at the U.S. Department of Defense and a patient focus group involved in other activities of the Action Collaborative on TBI Care to get feedback and recommendations to improve readability. A copy of the final survey is provided in Supplementary Data S1. The survey was reviewed by the Institutional Review Board of the University of California, San Francisco (IRB#: 23-39445, Reference#: 387719) and determined to be exempt.

The survey was programmed into Qualtrics and distributed by email by staff and members of the TBI Forum to a list of professional and patient associations/organizations (primarily within the United States and Canada) compiled by the CPG Working Group. CPG Working Group members also shared the survey invitation within their professional networks and encouraged snowball sampling and social media promotion. Advertisements highlighted that the public survey was intended for “adults with TBI who do not require acute hospital care (mild TBI/concussion)” or “individuals with lived experience of mild TBI, including patients and their family members.” The English-language survey opened on November 14, 2023, with an advertised deadline of December 15, 2023. A Spanish-language version was open from February 22 to March 24, 2024 and then because of low engagement, extended to April 21, 2024, with additional promotion.

Expert prioritization survey

CPG Working Group members were invited by email to complete a copy of the same survey designed for the public, but with minor changes. This survey differed from the public survey in that respondents were explicitly asked to consider the following factors for determining the “importance” of topics: (1) prevalence of the problem/symptom, or the proportion of patients the topic applies to, (2) underuse, overuse, or misuse of the advice, diagnostic test, or intervention, (3) concerns about

practice variation, (4) costs associated with different practice options, (5) concerns (other than cost) about inequities in access to or delivery of diagnostic tests, interventions, or information, (6) likelihood that the guideline recommendation will be effective in influencing practice, (7) if consistently implemented, likelihood that the guideline recommendation will improve the quality of care and/or patient outcomes, and (8) quality of evidence supporting guideline recommendation. These criteria are based on the ADAPTE Manual and Resource Toolkit (Version 2.0, 2019, accessed from www.g-i-n.net June 18, 2023) and tailored for the present study. The expert survey was conducted from October to November 2023.

Statistical analysis

Rankings were reverse coded so that the highest rank (1) equals the highest score (10). Unranked topics were assigned a score of 0. We calculated an average of the reverse-coded rankings within each group. Higher mean item scores (maximum = 10) reflect topics that were ranked higher by more people. As a complementary metric of perceived importance, we also report the proportion of respondents in each group who included a given topic in their top 10, regardless of rank within top 10. Data are reported descriptively, except for a supplementary analysis in which we used independent samples *t*-tests to compare priority ratings in PWLE with lengthy versus no hospitalization for TBI.

Results

We received a total of 288 responses to the public prioritization survey, including 157 from PLWE (patients and caregivers) and 131 from clinicians. Of this response pool, 112 (71.3%) of PWLE provided valid data (i.e., selected at least one topic as important) and 99 (75.6%) clinicians provided valid data. Only 11 (3.8%) of the total responses and 6 (2.8%) of the valid responses were completed in Spanish. Participant characteristics are reported in Table 1. The majority of PWLE identified as women and White, reported having a college degree and an annual household income of at least \$50,000, and were from the United States. The sample of clinicians had a similar demographic profile but was more balanced on gender.

The majority of PWLE respondents (84 of 101; 83.2% of valid responses) reported on a TBI that occurred more than a year ago. Nearly a third of PWLE (30 of 99; 30.3% of valid responses) reported that the most recent TBI involved a hospital admission of more than seven nights (see Table 1). PWLE who reported on a TBI requiring hospitalization more than seven nights ($n = 30$) had similar ratings to those reporting on nonhospitalized TBIs ($n = 53$) for their highest priority topics, including computed tomography (Q1), magnetic resonance imaging (MRI) (Q2), neuropsychological assessment (Q5),

Table 1. Demographics of Survey Respondents

Variable	CPG working group (n = 14)	PWLE (n = 112)	Clinicians (n = 99)
Location			
United States	9	79	59
Caribbean	0	2	0
Canada	3	11	25
South America	0	2	0
Europe	2	3	4
Africa	0	0	1
Asia	0	2	0
Oceania	0	3	2
Missing	0	10	8
Gender			
Woman	7	71	47
Man	6	22	40
Gender fluid	0	5	0
Non-binary	0	1	0
Transgendered	0	1	0
Prefer not to say or missing	1	12	12
Age group			
18–24	0	3	4
25–34	3	13	8
35–44	4	20	26
45–54	2	31	18
55+	5	31	35
Missing	0	14	8
Race			
White	9	76	62
Black	1	8	4
Latino/Hispanic	1	3	2
Asian/Asian American	2	5	10
Indigenous/Native American	0	3	1
Other	1	1	5
Prefer not to say or missing	0	16	15
Highest education attainment			
Less than high school	—	3	—
High school diploma	—	1	—
Some college, no degree	—	22	—
Bachelor's degree	—	30	—
Graduate/professional degree	—	41	—
Missing	—	16	—
Recency of TBI			
Within the past year	—	17	—
1–4 years ago	—	34	—
5–10 years ago	—	24	—
More than 10 years ago	—	26	—
Missing	—	11	—
Admitted to hospital for most recent TBI			
Yes, for >7 nights	—	30	—
Yes, for 0–7 nights	—	16	—
No	—	50	—
Unsure	—	3	—
Missing	—	13	—
Required neurosurgery for most recent TBI			
Yes	—	15	—
No	—	29	—
Unsure	—	3	—
Not applicable (not admitted)	—	50	—
Missing	—	15	—
Household income			
Under \$25,000	—	11	—
\$25,000 to \$49,999	—	9	—
\$50,000 to \$99,999	—	20	—
\$100,000 and over	—	36	—
Prefer not to say or missing	—	36	—

(continued)

Table 1. (Continued)

Variable	CPG working group (n = 14)	PWLE (n = 112)	Clinicians (n = 99)
Health specialty/discipline			
Neurologist	4	—	16
Neurosurgeon	1	—	8
Physiatrist/rehabilitation medicine	3	—	6
Primary care/family physician	0	—	4
Emergency medicine physician	0	—	3
Sports medicine physician	0	—	3
Psychiatrist	0	—	1
Occupational therapist	0	—	16
Speech-language pathologist	0	—	12
Physical therapist	0	—	8
Neuropsychologist	2	—	4
Other	4	—	12
Missing	0	—	6
Primary work location			
Academic medical center	8	—	37
Outpatient rehabilitation clinic	1	—	25
Veterans Health/military facility	2	—	8
Other	4	—	20
Missing	0	—	9
Years of clinical experience			
Less than 1	0	—	6
1–5 years	2	—	13
5–10 years	3	—	11
10–15 years	1	—	7
More than 15 years	6	—	53
Missing or not applicable	2	—	9

CPG, clinical practice guideline; PWLE, people with lived experience; TBI, traumatic brain injury.

and computerized cognitive testing (Q6), all $p < 0.05$. However, PWLE respondents who had experience with a TBI involving lengthy hospitalization rated early education (Q12) as significantly more important than those who had experience with a nonhospitalized TBI [$M = 4.20$, $SD = 3.7$ vs. $M = 1.7$, $SD = 2.9$; $t(81) = 3.43$, $p = 0.0009$].

Neurologists, occupational therapists, and speech-language pathologists were the most represented disciplines. The majority of clinicians were senior (independent practice >15 years) and worked at an academic medical center or outpatient rehabilitation clinic. Virtually all clinicians reported caring for adults in the general population and a substantial portion reported providing care to athletes ($n = 45$; 46%) and/or military service members or veterans ($n = 29$; 30%). The results of the public prioritization survey are presented in Table 2, specifically, respondents' rankings for topics that the expert group ranked within the top 10, and their own top 10 ranked topics.

All 17 CPG Working Group members were invited to complete the expert survey, and 14 did. Their characteristics are also reported in Table 1 and results in Table 2. There were seven topics rated in the top 15 by all three groups (rows colored green) and an additional six topics rated in the top 15 by two groups (rows colored orange). Within the latter category, there were some marked

Table 2. Prioritization Survey Results

Topic	Expert working group (n = 14)			PWLE (n = 112)			Clinicians (n = 99)		
	Rank	Score ^a	% top10 ^b	Rank	Score	% top10	Rank	Score	% top10
Q8. Guidance on rest and when to return to usual daily activities, such as driving, school/work, sport or recreation	1	7.71	93%	6	1.98	31%	1	3.39	44%
Q12. Providing education to the patient/family about traumatic brain injury, such as typical symptoms and how to cope with them	2	4.64	71%	2	2.38	42%	3	2.47	39%
Q27. First-line treatments for post-traumatic headache	3	4.07	93%	30	0.51	12%	6	1.89	37%
Q11. Prioritizing which symptoms to treat first (e.g., those symptoms that are easiest to treat and thought to impact other symptoms)	4	3.93	43%	13	1.32	18%	4	2.07	28%
Q4. Recommendations on when to return for follow-up medical visits	5	3.64	50%	15	1.07	16%	12	1.50	24%
Q18. Screening for mental health disorders and first-line intervention for mental health disorders (e.g., depression, anxiety, post-traumatic stress disorder)	6	3.57	57%	9	1.56	28%	11	1.51	30%
Q24. When to refer a patient to a specialist provider or interdisciplinary clinic that specializes in brain injury	7	3.29	64%	7	1.90	30%	8	1.77	33%
Q17. Screening for health conditions that could complicate recovery (comorbid medical disorders such as obstructive sleep apnea and endocrine disorders)	8	2.57	43%	28	0.54	11%	24	0.85	14%
Q14. Assessing a patient's risk for slow recovery or long-lasting symptoms	9	2.50	36%	10	1.55	26%	2	2.95	47%
Q10. Use of post-concussion symptom checklists (in initial evaluation and ongoing visits to monitor recovery)	10	2.9	21%	14	1.21	21%	20	1.06	15%
Q5. When to refer for a detailed evaluation of thinking skills such as concentration, memory, and reaction time (neuropsychological assessment)	24	0.43	14%	1	2.82	38%	5	2.01	34%
Q2. When to order a brain scan to view small areas of damage (magnetic resonance imaging scan of the brain)	19	0.71	14%	3	2.38	29%	9	1.69	21%
Q1. When to order a brain scan to assess bigger or more obvious damage (computed tomography of the head)	19	0.71	7%	4	2.17	23%	25	0.92	24%
Q6. Assessing thinking skills (e.g., concentration, memory, and reaction time) with an in-office test done on the computer (computerized neurocognitive battery)	42	0.00	0%	5	2.12	32%	7	1.84	34%
Q25. Choosing a treatment designed to improve overall post-concussion symptoms	18	1.00	14%	8	1.59	26%	10	1.58	27%

PWLE, people with lived experience; Green, topics rated in the top 15 by all three groups; Orange, topics rated in the top 15 by two groups; Red, topics rated in the top 15 by one group.

^aRankings were reverse coded so that 1 (highest ranking) = 10 (highest score), unranked topics were assigned a score of 0, and an average was calculated across respondents in each group. Higher scores (maximum = 10) reflect topics that were ranked higher by more people.

^bThe proportion of respondents who included this topic in their top 10 (regardless of rank within top 10).

discrepancies between groups. For example, PWLE and clinicians both rated neuropsychological assessment and computerized cognitive testing as very high priorities, whereas experts ranked these topics as 24th and 42nd out of 42. Only two topics were rated in the top 15 by one group and neither of the other two groups (rows colored red): screening for health condition that could complicate recovery, and when to order a brain scan.

Finally, the CPG Working Group integrated the survey results from the PWLE and clinicians with their own to create a “top 10” list of priority topics. They started by including all topics ranked highly by at least two groups (*n* = 14; green and yellow rows of Table 2) and those topics deemed essential by the CPG Working Group before the prioritization surveys (*n* = 5), leading to a list of 19 topics (Table 3—left column). The CPG Working Group then consolidated topics that could be covered in a single recommendation. For example, three topics were assessments/diagnostic tests/investigations intended to clarify how TBI affected brain structure and function, and

so were condensed into a single topic. After seven iterations, the CPG Working Group reached unanimous consensus on a final “top 10” list (Table 3—right column).

Discussion

Many people with TBI do not receive follow-up care,^{16,17} or receive inadequate or inappropriate care, predisposing them to suboptimal recovery and chronic disability.³ This may be especially true in marginalized and minoritized groups.^{18,19} CPGs can reduce the variability in care by synthesizing empirical evidence and translating them into actionable recommendations. Quality CPGs for TBI exist, but most target subpopulations (e.g., athletes with sport-related concussion¹³) or specific providers (e.g., physical therapists¹⁶) or the emergency department/acute care hospital setting.^{14,20,21} None are ideally suited for clinicians in the general community, where the greatest variability in TBI care practices likely exists.³ The comprehensiveness (voluminousness) of prior CPGs

Table 3. Top 10 Priority Topics for a Clinical Practice Guideline on Management of Nonhospitalized Traumatic Brain Injury

<i>Priority clinical actions based on surveys</i>	<i>Final list of top priority clinical actions</i>
1. Confirming the diagnosis of TBI	1. Confirming the diagnosis of TBI and determining whether emergency department evaluation is required
2. Determining the severity of the TBI	2. Requesting assessments/investigations to characterize the effects of TBI
3. Determining if an emergency department assessment for possible life-threatening complications is required	3. Screening for social determinants of health, including abuse/neglect as a suspected cause of TBI
4. Safeguarding measures when abuse/neglect is a cause of TBI	4. Providing guidance on rest and when to return to usual daily activities
5. Screening for social determinants of health	5. Providing education to the patient/family
6. Providing education to the patient/family	6. Assessing a patient's risk for slow recovery or long-lasting symptoms and providing recommendations on when to return for follow-up medical visits
7. Guidance on rest and when to return to usual daily activities	7. Prioritizing which symptoms to treat first
8. Assessing a patient's risk for slow recovery or long-lasting symptoms	8. Providing first-line treatments for post-traumatic headache
9. Recommendations on when to return for follow-up medical visits	9. Screening for mental health disorders and providing first-line intervention for mental health disorders
10. Use of post-concussion symptom checklists	10. Recommending when to refer a patient to a specialist provider or interdisciplinary clinic that specializes in brain injury
11. Assessing thinking skills (e.g., concentration, memory, and reaction time) with an in-office test done on the computer (computerized neurocognitive battery)	
12. When to refer for a detailed evaluation of thinking skills such as concentration, memory, and reaction time (neuropsychological assessment)	
13. When to order a brain scan to view small areas of damage (magnetic resonance imaging scan of the brain)	
14. Prioritizing which symptoms to treat first	
15. Screening for mental health disorders and first-line intervention for mental health disorders	
16. First-line treatments for post-traumatic headache	
17. Investigations to characterize the effects of TBI	
18. When to refer a patient to a specialist provider or interdisciplinary clinic that specializes in brain injury	
19. Choosing a treatment designed to improve overall post-concussion symptoms	

TBI, traumatic brain injury.

may also limit their implementation in primary care.²² The CPG Working Group of the TBI Forum's Action Collaborative on TBI care therefore sought to identify the *highest priority* clinical actions in the days to months following nonhospitalized TBI, with input from PWLE and clinicians in the community.

Several prioritization survey findings were noteworthy. There was fair agreement between PWLE, clinicians, and the CPG Working Group that follow-up care should include early education, guidance on return to activity, and assessing risk for prolonged recovery and the need for return visits and referral to specialty TBI services. Interestingly, the three surveyed groups also agreed that screening and initiating treatment for mental health complications were a priority, which aligns with evidence on the high incidence and impact of psychiatric comorbidity on TBI recovery.^{23–27} There were also areas of disagreement. Of the five most highly ranked topics by PWLE, four concerned assessments/diagnostic tests/investigations to characterize the effects of TBI on brain structure and function, or in other words, to help answer the question “how has my brain been injured?” Clinicians similarly valued these kinds of assessments. The large representation of occupational therapists and speech-language therapists in this sample, who are often providers of cognitive assessment, may partly explain this finding. However, the CPG Working Group did not rank assessments among their highest priorities. Debriefing in the CPG Working Group meetings suggested a primary reason—a low likelihood of results that would change clinical management. For example,

MRI in patients with persisting symptoms following TBI not requiring hospitalization will usually show no traumatic intracranial abnormalities^{28,29} or abnormalities that do not alter the treatment plan. That said, confirming an absence or presence of TBI-related pathology on MRI may be helpful in some clinical contexts.

The top 10 topics listed in Table 3 are not implementation-ready. While they highlight important content areas for TBI outpatient care, they do not provide specific guidance on what actions clinicians should take, when to take them, and with whom. Development of these topics into a new CPG could achieve that necessary specificity. We only included prior CPGs that were published in English, which is a limitation. Another limitation of the present study is underrepresentation of certain regions (outside of the United States) and demographic groups (e.g., Black and Latino/Hispanic respondents) in the public survey. The public survey also did not specify a time frame after TBI to consider when identifying their priorities. The priorities in the acute stage post-injury may not have been captured well, as the vast majority of PWLE group referred to the injury sustained >1 year ago. Moreover, despite our attempts to advertise the public survey as for PWLE with “mild TBI/concussion,” a proportion of respondents likely experienced more severe TBIs, given that 30% were hospitalized for more than 7 days and 15% required neurosurgery. This may have contributed to differences in priorities between the surveyed groups, although we found evidence of this for early education only. Primary care physicians were not well-represented in the clinician

survey sample. They provide the majority of post-acute TBI care and so should be engaged in future CPG development and implementation efforts.

The CPG Working Group is now in the process of writing a new CPG by translating each of the 10 priority topics identified in the present study into actionable recommendations based on syntheses of existing CPGs. We acknowledge that merely publishing a new CPG will not markedly enhance TBI care without theory and evidence-informed implementation efforts.^{22,30} Moreover, widespread adoption of a new CPG could potentially exacerbate rather than reduce care variability, particularly by recommending interventions that are costly or otherwise inaccessible in some communities. Attention to health inequity considerations in the CPG design will be essential to avoid that unintended outcome.^{31,32}

The top 10 priority clinical actions identified here overlap with the top 10 research priorities identified in the recent James-Lind Alliance Priority-Setting Partnership on concussion.¹⁵ For example, early referral to TBI specialty care and treatments for post-traumatic headache appear in both lists. That PWLE and clinicians in both priority setting efforts identified similar areas of importance provides reassuring convergence. The fact that the James-Lind Alliance Priority-Setting Partnership aimed to identify the most important *unanswered* research questions, however, raises a concern that there may be insufficient evidence to write strong recommendations on these topics.

Conclusions

The present study scoped existing CPGs that covered, at least in part, outpatient care for nonhospitalized TBI, compiled a comprehensive list of topics covered in those CPGs, and then gathered input from experts, PWLE, and clinicians to refine the top 10 priorities for implementation. Another key contribution of the present study was to show how perceptions of importance aligned and differed between these groups. Including perspectives from PWLE in the CPG development process is critical to ensure that their needs are effectively addressed in outpatient TBI care.

Transparency, Rigor, and Reproducibility

The study protocol was not preregistered. The analyses were descriptive. No null hypothesis testing was planned or performed, and accordingly, the sample size was pragmatic rather than based on power calculations. Data were acquired from October 2023 to March 2024. The surveys are made available as supplementary material, to support reproducibility. De-identified data from this study will be made available (as allowable according to IRB standards) by emailing the corresponding author.

Acknowledgments

The authors wish to acknowledge Moriah Cogan for operational support for the Action Collaborative, Scott Hamilton

for providing input on the public survey, and Eloisa Martinez for translating the public survey into Spanish.

Authors' Contributions

N.D.S. and K.L. co-led the Working Group, liaising with G.M., leader of the Action Collaborative. N.D.S. prepared the first draft of the article. A.M., M.T.B., E.W.E., J.T.G., C.H., F.M.H., D.A.I., C.M., J.V.D.N., M.R.P., O.T., V.W., and M.V.G. participated in Working Group activities, including the study design and data collection and interpretation. All authors critically reviewed and approved the article.

Members of the Action Collaborative on TBI Care:

Amy Markowitz, University of California-San Francisco; Caterina Mosti, University of California-San Francisco; Cathra Halabi, University of California-San Francisco; Christopher Giza, University of California-Los Angeles; Daniel Ignacio, St. Jude Brain Injury Network; David Brody, Uniformed Services University of Health Sciences; David Okonkwo, University of Pittsburgh; Flora Hammond, Indiana University; Gavin Attwood, Brain Alliance of Colorado; Geoffrey Manley, University of California-San Francisco; Javier Cardenas, University of West Virginia; Jeff Bazarian, University of Rochester; Joel Scholten, US Department of Veteran Affairs; John Corrigan, Ohio State University; Joseph Giacino, Spaulding Rehabilitation Hospital and Harvard Medical School; Joukje van der Naalt, University of Groningen; Katherine Lee, MS, Secretary of Defense for Health Readiness Policy and Oversight; Kelly Sarmiento, MPH, Centers of Disease Control and Prevention; Laura B. Ngwenya, University of Cincinnati; Mark Bayley, University of Toronto; Mayur Patel, American College of Surgeons Committee on Trauma and Vanderbilt University Medical Center; Michael Huang, University of California-San Francisco; Michael McCrea, Medical College of Wisconsin; Monica Verduzco-Gutierrez, University of Texas Health Science Center at San Antonio; Monique Pappadis, University of Texas Medical Branch; Moriah Cogan, University of California-San Francisco; Noah Silverberg, University of British Columbia; Odette Harris, Stanford University; Olli Tenovuo, University of Turku; Rachel Lazarus, AARP; Raymond Raven, OSS Health Network; Rebecca Wolfkiel, National Association of State Head Injury Administrators; Scott Hamilton; Steven Flanagan, NYU Langone; Christina L. Master, Children's Hospital of Philadelphia and University of Pennsylvania Perelman School of Medicine; Vincent Wang, University of Texas-Austin; Wesley Ely, Vanderbilt University Medical Center.

Author Disclosure Statement

N.D.S. has received research operating funds from multiple granting agencies (Canada Foundation for Innovation, Canadian Institutes of Health Research,

Mitacs, Ontario Brain Institute, U.S. Department of Defense, WorkSafeBC, VGH+UBC Hospital Foundation) for research related to TBI diagnosis, prognosis, and treatment. He has received speaker fees for providing continuing medical education on these topics. He serves as chair of the American Congress of Rehabilitation Medicine's Brain Injury Special Interest Group Task Force on mild TBI (unpaid). He has served as an expert panel member for the Living Concussion Guidelines and as an external reviewer for other clinical practice guidelines on concussion/TBI (unpaid). He has provided expert testimony and medical-legal consulting in the past 5 years (<10% of total income). K.L. reports no conflicts of interest. A.M. has received a fellowship from the University of British Columbia (UBC) Institute of Mental Health (IMH) Marshall Fellows Program. M.T.B. reports no conflicts of interest. D.L.B. is an employee of the U.S. Dept. of Defense. Research currently funded by the Department of Defense. Equity in Inner Cosmos LLC. Royalties from Sales of Concussion Care Manual (Oxford University Press). Honoraria from Mary Ann Liebert, Inc. Publisher of *Journal of Neurotrauma* for services as Editor-in-Chief. Consulting for Pfizer Inc, Intellectual Ventures, Signum Nutralogix, Kypha Inc, Sage Therapeutics, iPerian Inc, Navigant, Avid Radiopharmaceuticals (Eli Lilly & Co), the St Louis County Public Defender, the U.S. Attorney's Office, the St Louis County Medical Examiner, GLG, and Stemedica. He has provided expert testimony and medical-legal consulting in over 50 cases (<1% of total income). None of these entities was directly involved in the present work. E.W.E. discloses that he receives ongoing funding from the Veterans Affairs and the National Institutes of Health. He received honoraria within the past 3 years from Pfizer for continuing medical education lectures he gave at international medical conferences that received Pfizer's sponsorship. He does not have any formal consultancies or stock investment to disclose with any industry groups or companies. J.T.G. reports grant funding from the National Institute of Neurological Disorders and Stroke, Department of Defense, National Institute on Disability, Independent Living, and Rehabilitation Research for research related to TBI diagnosis, prognosis, treatment, and outcome. He also receives research support from the Barbara Epstein Foundation and SameYou Foundation. He occasionally receives honoraria from academic institutions and medical centers for training seminars concerning the Coma Recovery Scale—Revised. He serves on the Scientific Advisory Boards of the Traumatic Brain Injury Model System National Data and Statistical Center and the Neurocritical Care Society's Curing Coma Campaign. He has provided medicolegal consultation within the last 3 years (<10% of total income). C.H. has received research support from the Pac12 Student Health and

Wellbeing Initiative for concussion recovery, the Weill Institute for Neurosciences Neurohub for stroke recovery, and UC Noyce Initiative for stroke rehabilitation, unrelated to the current work. Dr. Halabi has also received research support from the National Institute on Deafness and Other Communication Disorders for aphasia recovery after stroke, also unrelated to the current work. F.M.H. has served on scientific advisory boards for Avanir and Otsuka, and received funding to her academic institution from the National Institute on Disability Independent Living and Rehabilitation Research, National Institutes of Health, Department of Defense, Patient Centered Outcomes Research Institute. D.A.I. reports no conflicts of interest. C.B.M. reports no conflicts of interest and no financial disclosures. J.V.D.N. reports no conflicts of interest. M.R.P. has received ongoing research funding to her institution from the National Institutes of Health/ National Institute on Aging and the National Institute on Disability, Independent Living, and Rehabilitation Research. She serves as a consultant for TIRR Memorial Hermann, Craig Hospital, and Indiana University. O.T. has received research funding for TBI research from the EU Commission, Business Finland, and several Finnish foundations supporting scientific research. He has received speaker fees for providing continuing medical education on these topics from the Brain Injury Society of Finland and several Finnish universities and hospitals. He has served as chair of Finnish Traumatic Brain Injury Guidelines (unpaid) and participated in the development of Scandinavian guidelines on TBI as a member of the Scandinavian Neurotrauma Committee (unpaid). He has been a member of the expert panel preparing an European Consensus Panel Recommendation for patients with TBI of GCS13-15, work supported by Abbott. He has provided expert testimony and medicolegal consulting for the past 20 years (<10% of total income). He has received consultation fees from NeuroTrauma Sciences, LLC. V.W. has no financial disclosure and no conflict of interest. M.V.G. discloses she has received ongoing AHRQ grant funding for Long COVID. She has received honoraria from AbbVie, Merz, Revance, and Ipsen for speaking or consulting work on spasticity. She is on the board of the Association of Academic Physiatrists (unpaid). She has provided expert testimony and medical-legal consulting in the past 5 years (<10% of total income). K.B. reports no conflicts of interest. G.T.M. discloses research grants from the U.S. Department of Defense, the National Institutes of Health/ National Institute of Neurological Disorders and Stroke, U.S. Department of Energy, the National Football League (NFL) Scientific Advisory Board, NeuroTrauma Sciences, and Abbott Laboratories. Dr. Manley is currently a member of the steering committee for an NIH-NINDS initiative

for improved characterization/nomenclature of TBI and a member of the NASEM TBI Forum.

Funding Information

The Action Collaborative on TBI Care is funded by generous donations from an anonymous donor, the Weill Family Foundation, and the Maurice Marciano Family Foundation.

Supplementary Material

Supplementary Data S1

References

- Maas AIR, Menon DK, Manley GT, et al. InTBR Participants and Investigators. Traumatic brain injury: Progress and challenges in prevention, clinical care, and research. *Lancet Neurol* 2022;21(11):1004–1060; doi: 10.1016/s1474-4422(22)00309-x
- Cancelliere C, Verville L, Stubbs JL, et al. Post-concussion symptoms and disability in adults with mild traumatic brain injury: A systematic review and meta-analysis. *J Neurotrauma* 2023;40(11–12):1045–1059; doi: 10.1089/neu.2022.0185
- National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Board on Health Sciences Policy; Committee on Accelerating Progress in Traumatic Brain Injury Research and Care. Traumatic Brain Injury: A Roadmap for Accelerating Progress. Washington, DC: National Academies of Sciences Engineering; 2022.
- Silverberg ND, Iverson GL, Cogan A, et al. ACRM Mild TBI Diagnostic Criteria Expert Consensus Group. The American Congress of Rehabilitation Medicine Diagnostic Criteria for Mild Traumatic Brain Injury. *Arch Phys Med Rehabil* 2023;104(8):1343–1355; doi: 10.1016/j.apmr.2023.03.036
- National Institute of Neurological Disorders and Stroke. NINDS TBI Classification and Nomenclature Workshop. Available from: <https://www.ninds.nih.gov/news-events/events/ninds-tbi-classification-and-nomenclature-workshop> [Last accessed: October 3 2024].
- Interagency Rehabilitation and Disability Research Portfolio. BeHEALTHY: Chronic Disease Management for Traumatic Brain Injury (Project number 90DPHF0006; Agency: NIDILRR). 2023. Available from: <https://irad.nih.gov/project/behealthy-chronic-disease-management-traumatic-brain-injury-tbi-2> [Last accessed: July 26 2024].
- Sander AM, Pappadis MR, Bushnik T, et al. An umbrella review of self-management interventions for health conditions with symptom overlap with traumatic brain injury. *J Head Trauma Rehabil* 2024;39(2):140–151; doi: 10.1097/HTR.0000000000000863
- Berrigan L, Marshall S, McCullagh S, et al. Quality of clinical practice guidelines for persons who have sustained mild traumatic brain injury. *Brain Inj* 2011;25(7–8):742–751; doi: 10.3109/02699052.2011.580317
- Lithopoulos A, Bayley M, Curran D, et al. Protocol for a living systematic review for the management of concussion in adults. *BMJ Open* 2022; 12(7):e061282; doi: 10.1136/bmjopen-2022-061282
- National Guideline Clearinghouse. Definition of a clinical practice guideline 2023. Available from: <https://www.ahrq.gov/gam/summaries/inclusion-criteria/index.html> [Last accessed: May 10 2023].
- Lee SY, Amatya B, Judson R, et al. Clinical practice guidelines for rehabilitation in traumatic brain injury: A critical appraisal. *Brain Inj* 2019; 33(10):1263–1271; doi: 10.1080/02699052.2019.1641747
- Silverberg ND, Iaccarino MA, Panenka WJ, et al. American Congress of Rehabilitation Medicine Brain Injury Interdisciplinary Special Interest Group Mild TBI Task Force. Management of concussion and mild traumatic brain injury: A synthesis of practice guidelines. *Arch Phys Med Rehabil* 2020;101(2):382–393; doi: 10.1016/j.apmr.2019.10.179
- Patricios JS, Schneider KJ, Dvorak J, et al. Consensus statement on concussion in sport: The 6th International Conference on Concussion in Sport—Amsterdam, October 2022. *Br J Sports Med* 2023;57(11):695–711; doi: 10.1136/bjsports-2023-106898
- National Institute for Health and Care Excellence. Head Injury: Assessment and Early Management. NICE Guideline [NG232]. NICE; 2023.
- Osmond MH, Legace E, Gill PJ, et al. Canadian Traumatic Brain Injury Research Consortium. Partnering with patients, caregivers, and clinicians to determine research priorities for concussion. *JAMA Netw Open* 2023; 6(6):e2316383–e2316383; doi: 10.1001/jamanetworkopen.2023.16383
- Seabury SA, Gaudette É, Goldman DP, et al. TRACK-TBI Investigators. Assessment of follow-up care after emergency department presentation for mild traumatic brain injury and concussion: Results from the TRACK-TBI Study. *JAMA Netw Open* 2018;1(1):e180210–e180210; doi: 10.1001/JAMANETWORKOPEN.2018.0210
- Bazarian JJ, McClung J, Cheng YT, et al. Emergency department management of mild traumatic brain injury in the USA. *Emerg Med J* 2005; 22(7):473–477; doi: 10.1136/emj.2004.019273
- Saadi A, Bannon S, Watson E, et al. Racial and ethnic disparities associated with traumatic brain injury across the continuum of care: A narrative review and directions for future research. *J Racial Ethn Health Disparities* 2022;9(3):786–799.
- Johnson LW, Diaz I. Exploring the social determinants of health and health disparities in traumatic brain injury: A scoping review. *Brain Sci* 2023;13(5):707.
- Valente JH, Anderson JD, Paolo WF, et al. Members of the American College of Emergency Physicians Clinical Policies Committee (Oversight Committee). Clinical policy: Critical issues in the management of adult patients presenting to the emergency department with mild traumatic brain injury: Approved by ACEP Board of Directors, February 1, 2023 Clinical Policy Endorsed by the Emergency Nurses Association (April 5, 2023). *Ann Emerg Med* 2023;81(5):e63–e105; doi: 10.1016/j.annemergmed.2023.01.014
- Gil-Jardine C, Payen JF, Bernard R, et al. Management of patients suffering from mild traumatic brain injury 2023. *Anaesth Crit Care Pain Med* 2023;42(4):101260; doi: 10.1016/j.accpm.2023.101260
- Wang T, Tan JB, Liu XL, et al. Barriers and enablers to implementing clinical practice guidelines in primary care: An overview of systematic reviews. *BMJ Open* 2023;13(1):e062158; doi: 10.1136/bmjopen-2022-062158
- Zahniser E, Nelson LD, Dikmen SS, et al. TRACK-TBI Investigators. The temporal relationship of mental health problems and functional limitations following mTBI: A TRACK-TBI and TED Study. *J Neurotrauma* 2019; 36(11):1786–1793; doi: 10.1089/neu.2018.6172
- Lamontagne G, Belleville G, Beaulieu-Bonneau S, et al. Anxiety symptoms and disorders in the first year after sustaining mild traumatic brain injury. *Rehabil Psychol* 2022;67(1):90–99.
- Stein MB, Jain S, Giacino JT, et al. TRACK-TBI Investigators. Risk of post-traumatic stress disorder and major depression in civilian patients after mild traumatic brain injury: A TRACK-TBI Study. *JAMA Psychiatry* 2019; 76(3):249–258; doi: 10.1001/jamapsychiatry.2018.4288
- Hellewell SC, Beaton CS, Welton T, et al. Characterizing the risk of depression following mild traumatic brain injury: A meta-analysis of the literature comparing chronic mTBI to non-mTBI populations. *Front Neurol* 2020;11:350.
- Bryant RA, O'Donnell ML, Creamer M, et al. The psychiatric sequelae of traumatic injury. *Am J Psychiatry* 2010;167(3):312–320; doi: 10.1176/appi.ajp.2009.09050617
- Panwar J, Hsu CCT, Tator CH, et al. Magnetic resonance imaging criteria for post-concussion syndrome: A study of 127 post-concussion syndrome patients. *J Neurotrauma* 2020;37(10):1190–1196; doi: 10.1089/neu.2019.6809
- Ashina H, Christensen RH, Al-Khazali HM, et al. White matter hyperintensities and cerebral microbleeds in persistent post-traumatic headache attributed to mild traumatic brain injury: A magnetic resonance imaging study. *J Headache Pain* 2023;24(1):15; doi: 10.1186/s10194-023-01545-w
- Pereira VC, Silva SN, Carvalho VKS, et al. Strategies for the implementation of clinical practice guidelines in public health: An overview of systematic reviews. *Health Res Policy Syst* 2022;20(1):13; doi: 10.1186/s12961-022-00815-4
- Shaver N, Bennett A, Beck A, et al. Health equity considerations in guideline development: A rapid scoping review. *CMAJ Open* 2023;11(2):E357–E371; doi: 10.9778/cmajo.20220130
- Pottie K, Welch V, Morton R, et al. GRADE equity guidelines 4: Considering health equity in GRADE guideline development: Evidence to decision process. *J Clin Epidemiol* 2017;90:84–91; doi: 10.1016/j.jclinepi.2017.08.001