

Multidisciplinary Team Development of a Pediatric Hemorrhagic Stroke Outcomes Toolkit: A Focus on Child, Family, and Contexts

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pediatric stroke

Toolkit

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Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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pediatric stroke

Toolkit

Abstract

Hemorrhagic stroke accounts for half of incident strokes in children yet remains understudied. Clinical and research teams assessing recovery from pediatric hemorrhagic stroke are limited because commonly used outcome measures may not be meaningful to the care team, educators, and foremost the child and family. The current paper serves as a model for bringing together multiple disciplines for shared purposes of better assessing child recovery and development after hemorrhagic stroke over time, advocating for child- and family-centered care, and facilitating discourse in the community of those caring for children with pediatric hemorrhagic stroke. The purpose of this work is to describe our guiding principles and the process of our team's development of a toolkit that emphasizes inclusion of the patient and family perspective of recovery in the home, school, and community contexts. We provide the toolkit and an example of specific outcome measures selected to address unique aims of a research project. The toolkit is intended to be a living platform for further evolution of outcome measures for pediatric hemorrhagic stroke. As such, we hope it will be a dynamic document that serves the ongoing and future clinical and research needs of the multidisciplinary professional teams providing holistic care after a pediatric hemorrhagic stroke.

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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pediatric stroke

Introduction

Stroke during childhood has the potential to cause permanent disabilities, resulting in new or emerging cognitive challenges, motor deficits, psychosocial impacts, and impairment in bodily functions.¹ While outcomes after pediatric stroke are variable, resultant deficits often have a significant impact on a child's overall function and can impede ability to perform age-appropriate activities of daily living and social participation. These disabilities may change school function, with an impact on learning and academic performance. An estimated one-third to one-half of children with stroke later require assistance in school and/or attend a specialized education program.² A central focus in rehabilitation after childhood stroke is re-integration into the child's natural environments (academic, social, family), and particularly return to school.^{3,4}

The field of pediatric stroke research began in the early 2000's and has benefitted from international and multidisciplinary collaboration.^{5,6} Historically, a majority of this international collaborative research has focused on ischemic rather than hemorrhagic stroke. Yet these stroke types differ in etiology, acute management, and approach to secondary stroke prevention. Although lessons learned from ischemic stroke research may inform studies of outcome in hemorrhagic stroke, there are unique characteristics of hemorrhagic stroke that need to be considered. For example, hemorrhagic stroke may result in higher burden of disability (neurological and psychological) as measured by Disability-Adjusted Life Years,⁷ and in higher mortality rates than ischemic stroke.⁸ However, study of outcomes of hemorrhagic stroke across domains and contexts, particularly in the long term, is limited. Care models for pediatric hemorrhagic stroke require a collaborative effort of multiple disciplines including: neurology; neurosurgery; neuroradiology; interventional radiology; psychiatry and rehabilitation medicine; neuropsychology and psychology; occupational, physical, and speech/language therapy; and social work.

pediatric stroke

Toolkit

A multidisciplinary review and discussion of pediatric stroke outcome measures with a focus on hemorrhagic stroke are important for the advancement of pediatric stroke care.

Purpose, Goals and Objectives

The purpose of this work is to describe our multidisciplinary team's process of generating a toolkit of outcome measures that highlight the child and family perspectives of recovery from hemorrhagic stroke over time in real-life contexts, including home and school. Reliable and valid outcome measures specific to hemorrhagic stroke are lacking. While the few outcome measures available and validated for ischemic stroke have the potential to capture some of the unique aspects of hemorrhagic stroke recovery as well, none are validated for patient centered or patient reported outcomes in either population. We initially aimed to develop a relatively narrow battery of outcome measures to address research questions for a specific pediatric hemorrhagic stroke study. During that process, we found that few outcome measures were validated for or used in pediatric hemorrhagic stroke research. Those that were available were focused on disability ratings that did not capture how well or poorly children interacted within their family and community. Assessment of child and family centered outcomes is, however, an important component of care management for multidisciplinary teams.

Patient and Family Centered Outcome Measures

The World Health Organization defines outcome as a “change in the health of an individual, group of people, or population that is attributable to an intervention or series of interventions.”⁹ After a change in health, outcome measures are used to assess current level of function, monitor changes in the condition over time, and prognosticate future level of function.¹⁰ Outcome assessment provides critical data to track recovery and development across patients and over time. According to the framework of the International Classification of Functioning, Disability and Health, outcome measures may be focused on impairments, activity limitations, and/or participation restrictions.¹¹ Each of these domains of outcome

pediatric stroke

Toolkit

assessment may include specific areas such as cognitive (intellectual, language, visual-perceptual, executive functions), social-emotional, motor, adaptive functioning, as well as quality of life. In developing our toolkit, we first sought to include a breadth of outcome measures that could address each of these domains and measure recovery within each domain.

Outcome measures are meaningful to patients, families and clinicians when they relate to a child's *real-life contexts* such as home, school, or community. Therefore, outcome assessments conducted in research and clinical settings alone may not be relevant or applicable to recovery in real-life contexts. Examples of child- or family-informed and contextually anchored outcome measures include the Participation and Environment Measure for Children and Youth (PEM-CY)¹², and the Behavior Rating Inventory of Executive Functions (BRIEF/BRIEF2)^{13,14}, which includes versions for child, parents and teachers as informants. We considered inclusion of patient-or family-centric outcome measures informed by the child, parents, and teacher perspectives as essential components of the toolkit to improve clinical care and ongoing research.

Pediatric Stroke Outcome Measures- Current Knowledge and Gaps

Pediatric stroke rehabilitation should focus on recovery that optimizes health and uses integrative multidisciplinary approaches.^{3,15,16} The outcomes measures should thus be clinically meaningful to a multidisciplinary stroke care team (medical, behavioral health, rehabilitation), educators, and foremost the child and family.

A systematic review by Yale et al.¹⁷ examined pediatric stroke outcomes. After analysis of 116 studies that utilized 95 unique outcome measures, the authors noted the most frequently used outcome measures focused on global disability or motor impairments and served a specific medical purpose. Their synthesis of the characteristics of these 95 measures revealed a paucity of stroke outcome

pediatric stroke

Toolkit

measures focusing on behavioral and cognitive function, patient and family perspectives, real-life contexts (e.g., home, school, community), and quality of life. In addition, the authors found a lack of reliable and valid outcome measures specific to children with hemorrhagic stroke and infrequent use of outcome measures to monitor recovery over time. This systematic review provides a description of characteristics and shortcomings of outcome measures in current use; however, it does not include recommendations for specific instruments in pediatric stroke care.

In another recent review, Felling et al.¹⁸ suggested a roadmap for outcome assessment and management during the different phases (acute, subacute, chronic) after pediatric stroke. The authors identified critical information to be gathered at each stage. In the acute phase, indicators of global function are recommended. During the subacute phase, additional screening in motor, language, cognitive, behavior and emotional domains should be completed. During the chronic phase, comprehensive neuropsychological evaluations repeated over time are recommended.¹⁸ This review provides general guidance about types of outcomes at different stages after pediatric stroke, although did not recommend specific outcome measures other than the Pediatric Stroke Outcome Measure (PSOM). While the PSOM is a useful rating scale for clinicians, it cannot be easily used to describe outcomes to children or families.

In a related review, Feldman et al.¹⁹ described the quality and feasibility of most frequently used pediatric stroke outcome measures in seven domains (global performance, motor, cognitive, language, behavioral/emotional, and adaptive function, as well as quality of life) and proposed a toolkit of measures that ranked high in quality of psychometric properties in each domain. However, the authors did not review whether the outcome measures included family/child perspectives or daily life contexts such as home, school and community. Krivitzky et al.²⁰ reviewed recent advances in neuropsychological outcomes and interventions for pediatric stroke, with a focus on cognitive and socio-emotional

pediatric stroke

Toolkit

outcomes. While the authors did not make recommendations for specific measures, they noted the need for more in-depth study of socio-economic and familial factors such as parental stress and resiliency as contributors to stroke recovery and outcome.

Together these recent reviews did not specifically address outcomes in pediatric hemorrhagic stroke, or address shortcomings in the current use of the outcome measures available. In particular, they did not prioritize patient and family perspectives or real-life context measures. Therefore, our team aimed to fill these gaps of prior studies and devise a comprehensive toolkit of pediatric stroke outcome measures for consideration in clinical and research applications.

The current paper serves as a model for bringing together multiple disciplines for the shared purpose of assessing a child's recovery after hemorrhagic stroke over time, across real-life contexts, and advocating for child- and family-centered care. This model contributes to facilitating discourse in the community of those caring for children with pediatric hemorrhagic stroke. We aligned with guidelines that recommend a multidisciplinary team approach for assessment and monitoring of key domains of child development after pediatric stroke and other brain injuries.^{16, 21-23} We describe the process of developing a toolkit for pediatric hemorrhagic stroke outcome measures. The toolkit is intended to promote a multi-method, multi-informant approach of outcomes assessment that includes the child's and family's perspectives, and utilizes observations from different social contexts. This approach has been widely used in behavioral research and practice.²⁴ We expect the toolkit to evolve with continued revision and input; therefore, this paper is intended to focus on the process of *how* the toolkit was developed and how it can continue to be useful for client-family care, clinical and research purposes. We intend this to facilitate discourse in the community of those caring for children with pediatric hemorrhagic stroke.

Methods

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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pediatric stroke

Toolkit

Outcome Measures Task Force

An Outcome Measures Task Force was formed from the American Heart Association (AHA) Bugher Center of Excellence in Hemorrhagic Stroke research team. Our team drew together expertise from a total of four pediatric stroke centers and universities in the U.S. and consisted of 9 members, including 2 stroke neurologists, a neuroradiologist, a stroke neuropsychologist, a physical therapist, an occupational therapist, and 3 clinical research assistants. Each member has expertise in the areas of pediatric stroke, pediatric outcome measurement and child & family centered care. The purpose of the Outcome Measures Task Force was to identify outcome measures in a broad scope of domains that include assessment of home/school/community function through a patient-and family-perspective.

Toolkit Design and Process

The Outcome Measures Task Force developed the toolkit through an organized, iterative, and collaborative process of bi-monthly, multi-site video conference remote meetings and in-person discussions. Our team communicated frequently between meetings via email and generated shared folders of working documents and resources. Consensus building was grounded on respect for interprofessional collaboration, diverse perspectives, shared values, and a common vision for promoting best practices in pediatric stroke care. As new information arose, we returned to our initial goals and continually revised our work. As we gathered results from the outcome measures gathered for other projects in our research grant, we re-assessed our work. This process began in the Fall of 2020 and is ongoing. Our guiding principles focused on a holistic approach with the patient and family as primary stakeholders. Although we did not gather input from patients and families directly during the design process of the toolkit, part of the future directions for our research includes a qualitative study of patients'/families' perspectives.

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

www.pediatricstrokejournal.com

pediatric stroke

Toolkit

Other fields have documented team process approaches to establish toolkits to address clinical or research gaps.^{25,26} We used these models to address the shortcomings in the current literature. We began by first identifying a broad set of pediatric hemorrhagic stroke outcome measures and then creating a toolkit for clinicians and researchers that describes the pertinent characteristics of each measure. Our team's process was focused on the unique considerations of recovery from hemorrhagic stroke in partnership with children and families.

An overarching goal was to develop a broader resource of commonly used pediatric stroke outcome measures consistent with patient- and family-centered needs that could be used for both research and clinical purposes.

Results

Timeline

Our collaboration evolved through several phases. The timeline of the task force activities is depicted in **Figure 1**.

FIGURE 1 here

Figure 1. Timeline of Task Force Activities. AHA: American Heart Association. (Xmind software was used to create Figure 1).

Outcome Measures Toolkit

The outcome measures toolkit resource (**Table 1**) is organized so that research teams can identify domains and associated measures of outcome and select those most relevant for a specific research question. It is intended as a set of proven instruments rather than an extensive catalogue of all available measures and should be used only within the context of a *multidisciplinary team of qualified professionals*. This toolkit is informed by current literature and expert consensus. None of the outcome

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

www.pediatricstrokejournal.com

pediatric stroke

Toolkit

measures have been specifically validated or normed for hemorrhagic stroke, given the paucity of outcome studies in this population. However, many of the measures have been selected based on their use in prior pediatric stroke research, as denoted in Tables 1 & 2. Several measures require the expertise of neuropsychologists and rehabilitation specialists for administration, data processing, quality control, as well as analysis and interpretation. Some outcome measures assess general functioning such as the PSOM.²⁷ Other outcome measures assess specific domains of function and are organized accordingly: general cognitive ability, attention, executive function, language, visual-spatial, gross motor, fine motor, sensory motor, adaptive, and socio-emotional function. Organization into these categories allows the toolkit user to see options for assessment of specific outcomes, or consider combination of outcome measures to create a multi-faceted profile. The scope of the toolkit is broad and emphasizes measures that support child-and family-centered decision making of the stroke care team^{28,29} including self- and parent report of outcomes and in the contexts of home, school and community settings.

The toolkit is structured to display the pertinent details of each outcome measure including the name, age range, the source of information, and a link to further details. Psychometric properties including reliability and validity are noted when available for a measure in the general population. It provides approximate time required to administer, the required professional qualifications to administer and interpret, and languages available. However, many of the measures can be completed in a shorter time than listed in the tables because they are completed in parallel. For example, the PSOM, Modified Rankin Scale (mRS), and King's Outcome Scale for Childhood Head Injury (KOSCHI) are typically recorded after a brief neurologic history and physical exam, which may take 5-20 minutes. However, after the history and exam, each of these scales can be scored in 1-2 minutes, so the total time is not additive. These elements allow users to select the most feasible set of measures for different clinical or research purposes.

Bugher Project Outcome Protocol Example

As an example of how the pediatric outcome measures toolkit resource can be used, we describe its application in selecting outcomes for two separate projects based on unique research questions and design needs. The first research project required a targeted set of repeatable instruments for a small number of pediatric hemorrhagic stroke patients, including both in-person assessment and measures that can be completed remotely. The second research project was a registry study, which required assessments that could be abstracted from the chart across a large number of sites but could not accommodate in-person assessments. See **Table 2** for a comprehensive summary of the larger toolkit applied for both research projects and **Figure 2** for an outline of the outcome measures and their domains.

FIGURE 2 here

Figure 2. AHA Bugher Project Outcome Measures Toolkit Diagram. PSOM: Pediatric Stroke Outcome Measure (Short Neuro Exam); mRS: Modified Rankin Scale; Seizure Form: Follow-up Seizure Form; KOSCHI: King's Outcome Scale for Childhood Head Injury; RRQ: Pediatric Stroke Recurrence and Recovery Questionnaire; PROMIS: Patient-Reported Outcome Measurement Information System; BRIEF-2: Behavior Rating Inventory of Executive Function-Second Edition; PEM-CY: Participation and Environment Measure for Children and Youth; SDH: Social Determinants of Health; NIH: National Institutes of Health; Grip Strength: Grip Strength Test; Pegboard: 9-Hole Pegboard Dexterity Test; 2min Walk: 2-Minute Walk Endurance Test; 4m Walk: 4-Meter Walk Gait Speed Test; DCCS: Dimensional Change Card Sort Test; Flanker: Flanker Inhibitory Control and Attention Test; PSMT: Picture Sequence Memory Test; PVT: Picture Vocabulary Test. (Xmind software was used to create Figure 2).

Our research outcome measure selection criteria included several elements: (1) an evidence-based battery covering several domains and aspects of patient and family functioning; (2) use of measures that are standardized and provide age reference norms; (3) consideration of short administration time –

pediatric stroke

Toolkit

being sensitive to patient and family burden and fatigue as they recover; (4) measures that are repeatable to track progress over time; (5) informed by patient and family voice and context where appropriate; (6) can be administered by a trained research coordinator under the supervision of the appropriate licensed professional for each outcome domain (e.g., neurologists, neuropsychologists, and rehabilitation specialists such as physical and occupational therapists) reducing cost and clinician time.

Preliminary Observations

The outcome measures for the AHA Bugher Project are administered to pediatric study participants and their parents during the initial admission and at follow-up visits. The outcome measures for this study are completed within a 1.5 hour study visit. The clinician reported measures, including the PSOM, mRS, and KOSCHI, are recorded after routine clinical neurological exams. Families also have the option to complete questionnaires either online or in-person and in English or Spanish.

As the AHA Bugher Project continues, we are gaining insight into the feasibility of our outcome measure selections for the first project with iterative adjustments to the methods of administering the outcome measures. Our neuropsychologist and rehabilitation specialists have trained and supervise the study coordinator on test administration and behavioral techniques to solicit optimal engagement and cooperation. Administering the outcome measures in the inpatient or outpatient setting has presented unique opportunities and challenges. We have noted that some of the younger study participants have difficulty completing all of the outcomes in one session due to decreased attention or distracting factors. Older participants, in general, are better able to complete the battery within the optimal 45 minute to 1 hour time period. Some children may be too fatigued to undergo assessment and complete rating scales. The rating scales may be completed at the family's convenience online and over a period of time in proximity to the study visit. During inpatient admissions, outcome assessments can be broken into several shorter sessions to accommodate study participants' needs, and the schedule of measurements

pediatric stroke

Toolkit

is coordinated with the medical team; the inpatient rehabilitation team plays an integral part in facilitating outcome assessment. For example, if there are safety concerns, the physical therapist administers the gait outcome measures with the research coordinator. For outpatient assessments, travel and parental time are some potential barriers for participation. As a result, partial completion of the battery may occur in the outpatient setting.

Discussion

Our collaborative, multidisciplinary process to develop a toolkit for pediatric stroke outcome measures with a focus on hemorrhagic stroke has been a team effort to begin to address unmet research and clinical needs. This process paper offers the pediatric stroke research and clinical communities a way forward to better understand and utilize outcome measures that are meaningful to patients and families. The toolkit is anchored in the current literature; however, it is not solely based on measures “most frequently used” but also from ranked measures based on prior expert consensus¹⁹. It was developed after an in-depth examination of gaps in outcome measure use identified in research based on a systematic review in hemorrhagic stroke¹⁷. Unique aspects of this toolkit are an emphasis on capturing patient and family perspectives of recovery in the home, school, and community contexts – missing or limited in the current literature. In addition, the toolkit, unlike other guidelines and resources, is intended to be a living document that can be expanded by the larger pediatric stroke community and thus serve the ongoing clinical and research needs of multidisciplinary professional teams providing holistic care after a pediatric hemorrhagic stroke.

As our understanding of child and family perspectives of recovery from and adjustment to pediatric stroke grows, so will our ability to identify and design meaningful outcome measures to guide research and care management. Likewise, with an increased charge to build multidisciplinary teams and

pediatric stroke

Toolkit

collaborations to foster holistic care, we must strive to select outcomes from various domains to capture recovery and function with a contextually relevant lens. Important to the assessment of outcome is *not* the use of a specific measure itself but the interpretation in the context of a child's environment by the appropriate experts from medical, psychological and rehabilitative disciplines that will enhance our knowledge and care.

The process of developing this resource illuminated several lessons learned. We were initially surprised by the limited use of family- and child-centered outcome measures by research teams. . The paucity of outcome measures that are reliable and valid for our patient population with pediatric hemorrhagic stroke was striking. When viewing outcome measures through a health equity lens, it was difficult to identify tools that were appropriate for diverse settings (with various cultures, languages, and resources). We learned the importance of a collaborative team approach of experts from multiple disciplines for not only selection of outcome measures, but for developing a thoughtful and comprehensive battery of assessments along with guidelines for administration, analysis, and interpretation of these measures. It is our aim that these considerations will carry forward and can be adapted by other research and clinical care teams.

Limitations

We acknowledge several limitations of our process. The prescribed research aims of our task force that necessitated compilation of very targeted measures. The focus on a North-American context and perspective for the development of this outcome measures toolkit limits its generalizability to global settings. Further, families and caregivers were not directly consulted in the development of this toolkit. Rather, measures were selected based on expert opinion and years of experience with outcomes measures in the pediatric stroke population. In addition, years of collective work with families and reflection upon hearing their nuanced stories and lived experiences were at the forefront of this

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

www.pediatricstrokejournal.com

pediatric stroke

Toolkit

interdisciplinary team's discussions, which fueled the toolkit development. Currently available outcome measures for the pediatric stroke population have limitations themselves including lack of reference norms; lack of validation in the pediatric stroke population as a whole (not only hemorrhagic); lack of validation in other languages; and lack of feasibility related to cost, necessary training, and time requirements. While we developed this toolkit with pediatric hemorrhagic stroke-related research questions in mind, we do not assert that the proposed outcomes toolkit is comprehensive or applicable to hemorrhagic stroke alone.

Future Directions

The outcome measures toolkit could be disseminated as a living document to the pediatric stroke community, not as a set list, but as an evolving tool that is updated, revised, and expanded by the clinical and research community on an ongoing basis as new measures and evidence emerge. Future research aimed at understanding the lived experience of hemorrhagic stroke patients and their families as the potential for adding critical insight into how these outcome measures are meaningful. The plan for dissemination of the toolkit will be made collaboratively with those who are committed to innovation and evolution in pediatric hemorrhagic stroke care management. Possibilities to explore include: solicitation of new toolkit content at national and international stroke conferences; monitoring of the toolkit content by a task force within an organization focused on pediatric stroke; gathering of new content from an online tool such as Google forms; and refinement of content based on feedback gathered through conferences, organization portals, and multidisciplinary expert input. We have purposefully strayed from the typical process of publishing a fixed toolkit; rather, we have chosen to offer a living resource to the pediatric stroke community so that it can evolve through the community's input.

The stated vision of the International Pediatric Stroke Organization (IPSO) is "a world in which international, multidisciplinary collaborations advance the understanding, care, and outcomes of

pediatric stroke

Toolkit

childhood cerebrovascular disease.”³⁰ This framework could guide the development of future outcome measures that better fill the gaps in the range of currently available measures. Opportunities for researchers and clinicians to converse about outcome assessment choices can inform protocols and standards of care management. Through IPSO and other collaborations, we hope to engage in further conversations with the aim to bring together diverse perspectives.

Conclusion

We conducted a comprehensive evaluation of outcome measures and developed the toolkit shared here to support best practices in pediatric stroke research and clinical care. The focus of the toolkit is on feasible measures that capture information meaningful to children and their families. By focusing on measures of function in real-life contexts and across multiple domains, this toolkit is a unique contribution to the pediatric stroke field. We hope this toolkit will evolve through iterative versions based on the input from the pediatric stroke community.

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Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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Author Contributions

All authors conceived and designed the study. KCN, LGH, CKF, and CM designed the toolkit. KCN, LGH, and CM drafted the manuscript. SM generated figures and tables, and provided editorial support. All authors reviewed and edited the manuscript.

Conflicts of Interest

The authors do not have any conflicts of interest.

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pediatric stroke

Toolkit

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pediatric stroke

Toolkit

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www.pediatricstrokejournal.com

pediatric stroke

Toolkit

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pediatric stroke

Toolkit

Appendix 1

Investigators of the AHA-Bugher Pediatric Hemorrhagic Stroke Research Center of Excellence: Abla A (University of Miami), Chowdhury SS (University of California San Francisco), Cook D (University of California San Francisco), Dlamini N (The Hospital for Sick Children, Toronto), Fox CK (University of California San Francisco), Fullerton HJ (University of California San Francisco), Gupta N (University of California San Francisco), Hess L (Dominican University of California), Hetts S (University of California San Francisco), Kim H (University of California San Francisco), McCulloch C (University of California San Francisco), Mrakotsky C (Boston Children's Hospital/Harvard Medical School), Mukherjee P (University of California San Francisco), Narsinh K (University of California San Francisco), Nelson J (University of California San Francisco), Nesbit C (University of California San Francisco/San Francisco State University), Nowakowski T (University of California San Francisco), Roland J (Washington University in St. Louis), Saloner D (University of California San Francisco), Schollenberger J (University of California San Francisco), Sojoudi A (University of California San Francisco), Weinsheimer S (University of California San Francisco), Winkler E (University of California San Francisco)

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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Toolkit

Table 1. Outcome Measures Toolkit Resource

Physician/Clinician Reported Outcome Measures										
Global Outcomes/Medical										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Pediatric Stroke Outcome Measure (PSOM) [†]	Measures neurological deficit post ischemic stroke in the areas of sensorimotor, language, cognitive/behavior function	0-18	20	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	4.66 out of 5	PSOM
Modified Rankin Scale (mRS) [†]	Global outcome rating for patients with stroke, assesses degree of disability (no symptoms to severe disability)	No age requirements	5-15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	2.33 out of 5	mRS
King's Outcome Scale for Childhood	Global rating of injury severity and recovery after brain injury in children, assesses degree of	2-16 <i>(May be used in children)</i>	15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	3 out of 5	KOSCHI

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Head Injury (KOSCHI) [†]	severity/recovery (death to good recovery)	<i>under 2 yrs</i>		<input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input type="checkbox"/> Other		Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No			
Pediatric National Institutes of Health Stroke Scale (PedNIHSS) [†]	Measures level of severity of pediatric ischemic stroke (consciousness, visual, motor, sensation, language)	2-18	15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	Not ranked	PedNIHSS
Patient and Family Reported Outcome Measures										
Medical/Physical Recovery										
Pediatric Stroke Recurrence and Recovery Questionnaire (RRQ) [†]	Measures neurological deficit post ischemic stroke in the areas of sensorimotor, language, cognitive/behavior. PSOM converted to a telephone interview	0-18	20	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	4 out of 5	RRQ

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Patient Reported Outcome Measurement Information System (PROMIS)	<ul style="list-style-type: none"> • <i>Fatigue</i> • <i>Pain – Interference</i> • <i>Sleep-Related Impairment</i> • <i>Sleep Disturbance</i> 	5-18+ 1-18+	2-19 2-8 2 2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Pain: Home, Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Quality of Life in Neurological Disorders (Neuro-QOL)	<ul style="list-style-type: none"> • <i>Fatigue</i> 	8-18+	2-4	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and Spanish versions	4 out of 5	Neuro-QOL Self-Report or Parent Proxy Measure Neuro-QOL Adult Measure
Motor										
Patient Reported Outcome	<ul style="list-style-type: none"> • <i>Physical Function: Mobility</i> 	5-18+	2-9	<input type="checkbox"/> Clinician	<input checked="" type="checkbox"/> English	Mobility, Upper Extremity	Requirements for purchase <input type="checkbox"/> Yes	No cost for	4 out of 5	PROMIS Parent

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Toolkit

Measurement Information System (PROMIS)	<ul style="list-style-type: none"> • <i>Physical Function: Upper Extremity</i> • <i>Physical Activity</i> • <i>Strength Impact</i> 	1-17 5-17	2	<input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Physical Function, Strength: Home	<input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	English and some Spanish versions		Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Quality of Life in Neurological Disorders (Neuro-QOL)	<ul style="list-style-type: none"> • <i>Upper Extremity – Fine Motor, ADL</i> • <i>Lower Extremity – Mobility</i> 	8-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Activities of daily living: Home	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and Spanish versions	4 out of 5	Neuro-QOL Self-Report or Parent Proxy Measure Neuro-QOL Adult Measure

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Emotional/Social										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Patient Reported Outcome Measurement Information System (PROMIS)	<ul style="list-style-type: none"> • <i>Emotional Distress - Anxiety</i> • <i>Emotional Distress - Depressive Symptoms/ Depression</i> • <i>Global Health: Overall evaluation of physical, mental and social health</i> • <i>Peer Relationships</i> 	1-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Peer Relationships and Global Health: Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
		1-17	2							
Quality of Life in Neurological Disorders (Neuro-QOL)	<ul style="list-style-type: none"> • <i>Anxiety</i> • <i>Depression</i> • <i>Social Relations-Interaction with Peers</i> 	8-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Social Relations: Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and Spanish versions	4 out of 5	Neuro-QOL Self-Report or Parent Proxy Measure Neuro-QOL Adult Measure
		8-17	2							
Children's Depression Inventory 2	Assesses cognitive, affective and behavioral	7-17	15	<input type="checkbox"/> Clinician	<input checked="" type="checkbox"/> English	School, Social	Requirements for purchase <input checked="" type="checkbox"/> Yes	Yes	3.66 out of 5	CDI 2

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

(CDI 2)	signs of depression in children and adolescents			<input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input type="checkbox"/> Spanish <input type="checkbox"/> Other		<input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No			
Beck Depression Inventory (BDI-2)	Measures severity of depression in adolescents and adults	13-80	5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Social	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	BDI-2
Multidimensional Anxiety Scale for Children (MASC 2)	Assesses symptoms of anxiety disorders in youth	8-19	15	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	Social	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	MASC 2

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Behavioral/Cognitive										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Behavior Assessment System for Children (BASC-3)	Broadband assessment of behavior and emotional function and adjustment in children and adolescents. Includes problem scales and adaptive skills	2-25	10-30	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	BASC-3
Behavior Rating Inventory of Executive Function – Preschool Version (BRIEF-P) [†]	Executive function and self-regulation in pre-school aged children. Includes Inhibitory Self-Control Index, Flexibility Index, and Emergent Metacognition Index	2-5.9	10-15	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	BRIEF-P
Behavior Rating Inventory of Executive Function (BRIEF-2) [†]	Executive function and self-regulation in children and teens. Includes Behavioral Regulation Index, Emotional Regulation Index and Cognitive Regulation Index	5-18	10	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes	Yes	4.33 out of 5	BRIEF-2

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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				<input checked="" type="checkbox"/> Teacher			<input type="checkbox"/> No			
Quality of Life in Neurological Disorders (Neuro-QOL)	• <i>Cognitive function</i>	8-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and Spanish versions	4 out of 5	Neuro-QOL Self-Report or Parent Proxy Measure Neuro-QOL Adult Measure
Conners 3 rd Edition (Conners 3)	Screening for attention problems. Scoring option for the DSM-5 Symptom Scales with a focus on ADHD and associated features	6-18	5-20	<input type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	Conners 3
National Institute for Children's Health Quality (NICHQ) Vanderbilt Assessment Scales	Screening for ADHD diagnosis in children	6-12	15-20	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	School, Home	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	No	3.66 out of 5	NICHQ Vanderbilt Assessment Scales

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Sensory Profile 2	Evaluates sensory processing patterns in the context of home, school, and community-based activities	0-14	5-20	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	Sensory Profile 2
Sensory Processing Measure Second Edition (SPM-2)	Measures sensory integration and processing difficulties in multiple environments	0.3-87	20-30 (each main form) 10 (each environment form)	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, School	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	SPM-2
Adaptive/Independence										
Participation and Environment Measure for Children and Youth (PEM-CY)	Evaluates participation in the home, at school, and in the community, alongside environmental factors within each of these settings	5-17	30	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	Yes	Not ranked	PEM-CY

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Pediatric Quality of Life Inventory (PedsQL) [†]	Health related quality of life. Scales include physical, emotional, social, and school functioning	2-18	5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	School	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	4 out of 5	PedsQL
Adaptive Behavior Assessment System (ABAS-3)	Assesses adaptive skills across the life span	0-89	15-20	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.66 out of 5	ABAS-3
School Function Assessment (SFA)	Evaluates participation, support needs, and performance of functional, nonacademic tasks and activities that affect academic and social aspects of school environment	Kindergarten – Grade 6	5-10	<input type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	School, Social, Home	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	Yes	Not ranked	SFA

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Functional Independence Measure for Children (WeeFIM II) [†]	Measures functional ability that documents self-care, functional mobility, and cognitive abilities	0.5-7 7+ in children with disabilities & delays in functional development	10	<input checked="" type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	Activities of daily living: Home, Social	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	WeeFIM II
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Pediatric Evaluation of Disability Inventory (PEDI)	Measures capability and performance of self-care, mobility and social function	0.5 -7 or children whose functional abilities are lower than those of 7yr- olds without disabilities	45-60	<input checked="" type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	Activities of daily living: Social	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	PEDI
Performance Based Outcome Measures										

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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Motor										
NIH Toolbox– Motor Battery	<ul style="list-style-type: none"> • <i>Grip Strength Test</i>² (upper extremity strength) • <i>9-hole Pegboard Dexterity Test</i>² (fine motor dexterity) • <i>2-Minute Walk Endurance Test</i> (overall fitness and endurance) • <i>Standing Balance Test</i> (balance) • <i>4-Meter Walk Speed Test</i> (locomotion) 	3+ 7+	3 4 4 7 3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	Yes	Not ranked	NIH Toolbox - Motor Battery
6 Minute Walk Test	Aerobic capacity and endurance	2-12 18-65+	<10	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	3 out of 5	6 Minute Walk Test
10 Meter Walk Test	Walking speed over a short distance	2-64	5	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	Not ranked	10 Meter Walk Test

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Peabody Developmental Motor Scales, Third Edition (PDMS-3)	Assesses gross and fine motor skills. Subtests include: body control, body transport, object control, hand manipulation, eye-hand coordination	0-5	60-90	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	PDMS-3
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Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Bruininks-Oseretsky Test of Motor Proficiency (BOT-2)	Measures gross and fine motor skills. Subtests include: fine motor precision, fine motor integration, manual dexterity, bilateral coordination, balance, running speed and agility, upper-limb coordination, strength	4-21	15-60	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.33 out of 5	BOT-2
Gross Motor Function Measure (GMFM-88 & GMFM-66)	Assesses gross motor function in 5 dimensions, including, lying /rolling, sitting, crawling/kneeling, standing, walking/running/jumping	0.4 – 16	45-60 <i>(GMFM-88)</i> 20-30 <i>(GMFM-66)</i>	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	No	4.33 out of 5	GMFM-88 & GMFM-66
General Cognitive Ability/Broadband Developmental Measures										
Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV)	Measures cognitive development and intellectual ability in preschoolers and young children	2-7	30-60	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	WPPSI-IV

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Toolkit

Wechsler Intelligence Scale for Children (WISC-V) [†]	Measures intellectual ability and 5 cognitive domains that impact performance in children	6-16	60	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	WISC-V
Wechsler Abbreviated Scale of Intelligence (WASI-II) [†]	Measures general cognitive/ intellectual ability in clinical, educational, and research settings across the life span	6-90	15-30	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	WASI-II
Wechsler Adult Intelligence Scale (WAIS-IV)	Measures general cognitive/ intellectual ability in adults	16-90	60-90	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	WAIS-IV

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Toolkit

NEPSY-II	Assesses executive function/attention, language, memory/learning, sensorimotor functioning, visuospatial processing, and social perception	3-16	45-60 (<i>General Assessment</i>) 90-180 (<i>Full Assessment</i>)	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	NEPSY-II
Attention/Executive Functions										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
NIH Toolbox-Cognition Battery	<ul style="list-style-type: none"> • <i>Dimensional Change Card Sort Test</i> (cognitive flexibility and attention) • <i>Flanker Inhibitory Control and Attention Test</i> (inhibitory control and attention) 	4+	4 3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox - Cognition Battery
Delis-Kaplan Executive Function System (D-KEFS)	Assesses key components of executive functions in verbal and visual domains	8-89	90	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes	Yes	3.66 out of 5	D-KEFS

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Toolkit

				<input type="checkbox"/> Teacher			<input type="checkbox"/> No			
Test of Everyday Attention for Children, Second Edition (TEA-Ch2)	Measures attention	5-15	35-55	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.66 out of 5	TEA-Ch2
Memory										
NIH Toolbox-Cognition Battery	<ul style="list-style-type: none"> Picture Sequence Memory Test (nonverbal memory) 	3+	7	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox-Cognition Battery
California Verbal Learning Test (CVLT-C/CVLT-3)	Verbal auditory learning and memory <ul style="list-style-type: none"> CVLT-C: Children's version CVLT-3: Adult version 	5-16 16-90	35-40	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.66 out of 5	CVLT-C CVLT-3

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Children's Memory Scale (CMS)	Comprehensive learning and memory assessment for verbal and visual domains	5-16	30	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	CMS
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Pediatr Stroke. 2024;9: 76-130

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pediatric stroke

Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Wechsler Memory Scale, Fourth Edition (WMS-IV)	Measures verbal and visual memory and working memory	16-90	120	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.33 out of 5	WMS-IV
Child and Adolescent Memory Profile (ChAMP)	Assesses visual and verbal memory	5-21	30-40 (Full Assessment) 10-15 (Screening Index)	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.33 out of 5	ChAMP
Language										
NIH Toolbox-Cognition Battery	<ul style="list-style-type: none"> Picture Vocabulary Test (receptive vocabulary) 	3+	3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4 out of 5	NIH Toolbox-Cognition Battery

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

							Free online training			
Clinical Evaluation of Language Fundamentals (CELF-5)	Measures semantics, morphology, syntax and pragmatics of language	5-21	30-45	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.66 out of 5	CELF-5
Peabody Picture Vocabulary Test, Fifth Edition (PPVT-5)	Receptive vocabulary	2.5-90+	10-15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.66 out of 5	PPVT-5
Expressive Vocabulary Test, Third Edition (EVT)	Expressive vocabulary	2.5-90+	10-15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	3.66 out of 5	EVT-3

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Toolkit

Token Test for Children (TTC-2)	Receptive language	3-12	15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	TTC-2
Visual-Spatial/Nonverbal										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
NIH Toolbox-Cognition Battery	<ul style="list-style-type: none"> Visual Reasoning Test (nonverbal reasoning) 	4+	7	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox - Cognition Battery
Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (BEERY VMI)	Assesses integration of visual and motor abilities	2-99	10-15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes	Yes	3.66 out of 5	BEERY VMI

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

				<input type="checkbox"/> Teacher			<input type="checkbox"/> No			
Rey-Osterrieth Complex Figure Test and Recognition Trial (RCFT)	Visuospatial organization and memory	6-89	45	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	RCFT
Academic Achievement										
Wechsler Individual Achievement Test, Fourth Edition (WIAT-4)	Academic achievement including comprehensive listening, speaking, reading, writing, and math skills	4-50	45-120	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.66 out of 5*	WIAT-4
<p>^a Outcome measure language is based on available language versions listed on the test vendor's website. Further language versions may be available through other resources.</p> <p>^b Outcome measures should always be administered with appropriate training and supervision by qualified professionals as determined by legal and ethical guidelines and the research or clinical team based on project, institutional or patient population considerations. Training information is available through the outcome measures website.</p> <p>^c The reliability, validity and feasibility ranking is based on the outcomes measure score that was assigned by Feldman SJ, Beslow LA, Felling RJ, et al.¹⁹ in their Pediatric Neurology article titled, <i>Consensus-Based Evaluation of Outcome Measures in Pediatric Stroke</i>. Ranking score defined: 5=Highly recommend, 4=Recommend, 3=Recommend, nonpreferred, 2=Unable to recommend at this time, 1=Do not recommend.</p> <p>¹ The administration of outcome measures requires specific professional qualifications for certain measures (cognitive performance measures require a C-Level qualification including a state licensure and/or doctorate in psychology, education or related field with formal training in the ethical administration, scoring, and interpretation of clinical assessments); in general, it may vary based on legal and ethical requirements, best practices and in some instances, on institutional policies</p> <p>² The NIH Toolbox Grip Strength Test and 9-hole Pegboard Dexterity Test requires purchase of a dynamometer and a 9-hole peg board in addition to the NIH Toolbox subscription.</p>										

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

*Ranking provided for WIAT-III †Outcome measure has been used in a prior hemorrhagic stroke study, as identified in the systematic review by Yale, et.al.¹⁷

Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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Table 2. AHA Bugar Outcome Measures Table

Physician/Clinician Reported Outcome Measures										
Global Outcomes/Medical										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Pediatric Stroke Outcome Measure (PSOM) [†]	Measures neurological deficit post ischemic stroke in the areas of sensorimotor, language, cognitive/behavior function	0-18	20	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	4.66 out of 5	PSOM
Modified Rankin Scale (mRS) [†]	Global outcome rating for patients with stroke, assesses degree of disability (no symptoms to severe disability)	No age requirements	5-15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	2.33 out of 5	mRS

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Toolkit

King's Outcome Scale for Childhood Head Injury (KOSCHI) [†]	Global rating of injury severity and recovery after brain injury in children, assesses degree of severity/recovery (death to good recovery)	2-16 <i>(May be used in children under 2yrs)</i>	15	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	3 out of 5	KOSCHI
Follow-up Seizure Form ²	Seizure frequency and severity recorded by parents and pediatric neurologist	0-18	20	<input checked="" type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	Not ranked	None
Patient and Family Reported Outcome Measures										
Medical/Physical Recovery										
Pediatric Stroke Recurrence and Recovery Questionnaire (RRQ) [†]	Measures neurological deficit post ischemic stroke in the areas of sensorimotor, language, cognitive/behavior. PSOM converted to a telephone interview	0-18	20	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	No	4 out of 5	RRQ

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Patient Reported Outcomes Measurement Information System (PROMIS)										
Fatigue	Range of symptoms, from mild subjective feelings of tiredness to an overwhelming, debilitating, and sustained sense of exhaustion	5-18+	2-19	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Sleep-Related Impairment	Assesses perceptions of sleepiness during usual awake hours and reported impairments during the day associated with sleep problems or daytime sleepiness	1-18+	2	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure

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Toolkit

Sleep Disturbance	Perceived sleep quality, sleep onset (difficulties falling asleep), sleep continuity (difficulties staying asleep)	1-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Pain – Interference	Consequences of pain on relevant aspects of one's life	5-18+	2-8	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Home, Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Pain Intensity	Physical health and intensity of pain	18+	1	<input type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Home, Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Adult Measure

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Toolkit

Motor										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Patient Reported Outcomes Measurement Information System (PROMIS)										
Physical Function: Mobility	Activities of physical mobility such as getting out of bed or a chair to activities such as running	5-18+	2-9	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Physical Function	Self-reported capability rather than actual performance of physical activities.	18+	2-33	<input type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Home	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Adult Measure
Emotional/Social										
Patient Reported Outcomes Measurement Information System (PROMIS)										

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

Emotional Distress - Anxiety	Fear, anxious misery, hyperarousal, and somatic symptoms	1-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure
Emotional Distress - Depressive Symptoms/Depression	Negative mood, views of self, social cognition, and decreased positive affect	1-18+	2-5	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure PROMIS Adult Measure

pediatric stroke

Toolkit

Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
Patient Reported Outcomes Measurement Information System (PROMIS)										
Peer Relationships	Quality of relationships with friends and other acquaintances	1-17	2	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Parent Proxy Measure PROMIS Pediatric Measure
Ability to Participate in Social Roles and Activities	Perceived ability to perform one's usual social roles and activities	18+	2-7	<input type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Social	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	No cost for English and some Spanish versions	4 out of 5	PROMIS Adult Measure
Behavioral/Cognitive										
Behavior Rating Inventory of Executive Function – Preschool Version	Executive function and self-regulation in pre-school aged children. Includes Inhibitory Self-Control Index, Flexibility	2-5.9	10-15	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	Not ranked	BRIEF-P

pediatric stroke

Toolkit

(BRIEF-P) [†]	Index, and Emergent Metacognition Index			<input type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher			Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No			
Behavior Rating Inventory of Executive Function (BRIEF-2) [†]	Executive function and self-regulation in children and teens. Includes Behavioral Regulation Index, Emotional Regulation Index and Cognitive Regulation Index	5-18	10	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input checked="" type="checkbox"/> Self-report <input checked="" type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	Yes	4.33 out of 5	BRIEF-2
Adaptive/Independence										
Participation and Environment Measure for Children and Youth (PEM-CY)	Evaluates participation in the home, at school, and in the community, alongside environmental factors within each of these settings	5-17	30	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input checked="" type="checkbox"/> Other	Home, School, Community	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	Yes	Not ranked	PEM-CY
Socio-demographic/SES										
Social Determinants of Health Form ²	Parent questionnaire to record demographic, socio-economic information, family history, and barriers to healthcare	0-18	15	<input type="checkbox"/> Clinician <input checked="" type="checkbox"/> Caregiver <input type="checkbox"/> Self-report	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	Home, Community	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹	No	Not ranked	None

Pediatric Hemorrhagic Stroke Outcomes Toolkit

pediatric stroke

Toolkit

				<input type="checkbox"/> Teacher			<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No			
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Pediatric Hemorrhagic Stroke Outcomes Toolkit

Pediatr Stroke. 2024;9: 76-130

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Performance Based Outcome Measures										
Motor										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
NIH Toolbox-Motor Battery										
Grip Strength Test ³	Upper extremity strength	3+	3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	Yes	Not ranked	NIH Toolbox-Motor Battery
9-hole Pegboard Dexterity Test ³	Fine motor dexterity	3+	4	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	Yes	Not ranked	NIH Toolbox-Motor Battery

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pediatric stroke

Toolkit

2-Minute Walk Endurance Test	Overall physical fitness and endurance	3+	4	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	Yes	Not ranked	NIH Toolbox-Mot or Battery
4-Meter Walk Speed Test	Locomotion	7+	3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Requirements for administration ¹ <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Free online training	Yes	Not ranked	NIH Toolbox-Mot or Battery

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Cognitive										
Outcome Measure	Description/Domains	Age Range (Years)	Time to Administer (Minutes)	Reporter	Language ^a	Contexts	Qualifications ^b	Cost	Reliability, Validity and Feasibility Ranking ^c	Resource
NIH Toolbox-Cognition Battery										
Dimensional Change Card Sort Test (DCCS)	Cognitive flexibility and attention	4+	4	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox-Cognition Battery
Flanker Inhibitory Control and Attention Test	Inhibitory control and attention	4+	3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox-Cognition Battery

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Picture Sequence Memory Test (PSMT)	Episodic memory	3+	7	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox-Cognition Battery
Picture Vocabulary Test (PVT)	Receptive vocabulary	3+	3	<input checked="" type="checkbox"/> Clinician <input type="checkbox"/> Caregiver <input type="checkbox"/> Self-report <input type="checkbox"/> Teacher	<input checked="" type="checkbox"/> English <input checked="" type="checkbox"/> Spanish <input type="checkbox"/> Other	None	Requirements for purchase <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Requirements for administration ¹ <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Free online training	Yes	4 out of 5	NIH Toolbox-Cognition Battery
<p>^a Outcome measure language is based on available language versions listed on the test vendor's website. Further language versions may be available through other resources.</p> <p>^b Outcome measures should always be administered with appropriate training and supervision by qualified professionals as determined by legal and ethical guidelines and the research or clinical team based on project, institutional or patient population considerations. Training information is available through the outcome measures website.</p> <p>^c The reliability, validity and feasibility ranking is based on the outcomes measure score that was assigned by Feldman SJ, Beslow LA, Felling RJ, et al.¹⁹ in their Pediatric Neurology article titled, <i>Consensus-Based Evaluation of Outcome Measures in Pediatric Stroke</i>. Ranking score defined: 5=Highly recommend, 4=Recommend, 3=Recommend, nonpreferred, 2=Unable to recommend at this time, 1=Do not recommend.</p> <p>¹ The administration of outcome measures requires specific professional qualifications for certain measures (cognitive performance measures require a C-Level qualification including a state licensure and/or doctorate in psychology, education or related field with formal training in the ethical administration, scoring, and interpretation of clinical assessments); in general, it may vary based on legal and ethical requirements, best practices and in some instances, on institutional policies</p> <p>² These forms are unpublished and were developed by International Pediatric Stroke Study (IPSS) researchers for use in research studies</p> <p>³ The NIH Toolbox Grip Strength Test and 9-hole Pegboard Dexterity Test requires purchase of a dynamometer and a 9-hole peg board in addition to the NIH Toolbox subscription.</p> <p>⁴ Outcome measure has been used in a prior hemorrhagic stroke study, as identified in the systematic review by Yale, et al.¹⁷</p>										

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