

Berl, Madison M<sup>1</sup>; Carney, Allison<sup>2</sup>; Koop, Jennifer I.; Bearden, Donald; Bender, Heidi; Boyer, Katrina; Decrow, Amanda; Espe-Pfeifer, Patricia; Gabriel, Marsha; Hodges, Elise; Marshall, David; McNally, Kelly; Molnar, Andrew; Olsen, Emily; Ono, Kim; Patrick, Kristina; Paul, Brianna; Romain, Jonathan; Spat-Lemus, Jessica; Stilp, Rebecca LH; Wilkening, Greta; Zaccariello, Mike; Zelko, Frank; Perry, Scott

Children's National Hospital<sup>1</sup> and the Pediatric Epilepsy Research Consortium<sup>2</sup>

## BACKGROUND

- Guidelines and consensus statements related to pediatric epilepsy surgery are uniformly lacking high quality published outcome data to support clinical decisions that impact likelihood of seizure freedom and optimizing outcomes beyond seizures.
- We address this need by leveraging current successful efforts of the Pediatric Epilepsy Research Consortium (PERC), specifically the Surgery SIG, to establish a pediatric epilepsy surgical database by including neuropsychological outcome measures. Our initial aim was to finalize the data and methods for collection and establish an active collaborative network of pediatric epilepsy neuropsychologists whose engagement is critical for success.

## METHODS

### Participants:

Participants included pediatric neuropsychologists, neurologists, and other clinical research team members across 19 institutions (Figure 1)

### Procedures:

September 2020 was the start of efforts to standardize data collection through a commonly available online platform (REDCap) and scale for multi-institutional implementation. Over 9 months, activities included:

- Four group teleconference meetings (every 2-3 months). Group meetings had two meeting time options within days of each other
- One site specific teleconference meeting. and site-specific meetings were designed to include the site neuropsychologist and the site neurologist. Other personnel (e.g., research assistant) were encouraged to attend.
- Six individualized site trainings for training of personnel largely related to REDCap implementation at their local institution as well as crosswalking variables between existing databases and the new PERF database.
- Across months 5-9, activities included finalizing financial agreements, IRB approvals, opening the database for data entry.

We conducted two surveys:

- to determine which neuropsychological measures were used
- to assess impact of participation in the network.

**Analyses:** Descriptive statistics were conducted.



Figure 1. Participating Sites

## RESULTS

**Measures (1<sup>st</sup> survey):** Consistency in measures used across sites ranged from 0-100%. Measures were included if >50% of sites were using the measure or through an iterative discussion a measure was deemed important to keep (e.g., new measure, used at a site with many cases, use in children under age 3, etc.). Within 4 months, 33 measures were finalized for inclusion to cover all cognitive domains across infancy to at least 18 years (Table 2).

**Impact (2<sup>nd</sup> survey, 17 responses):** 69% of the neuropsychologists' caseload was primarily epilepsy. At 35% of sites, only one clinician sees all presurgical epilepsy patients. 76% of neuropsychologists were expected to do research but only 18% had funding to do so. Impact of the collaborative included adjusting protocols by adding measures or different norms; increasing confidence in the measures use; and 59% said they learned something new. 65% endorsed an impact on data management with 35% establishing a new local database. 100% believe they will be able to contribute data despite 47% also thinking there will be a barrier to overcome. 100% thought the meetings were worth the time and 94% endorsed an impact on their network of colleagues including 29% who improved their communication within their own epilepsy team.

Table 2. Neuropsychological measures included

Domain	Measure
Intellectual Functioning	Wechsler scales (WISC, WPPSI, WASI, WAIS)
	Differential Abilities Scales
	Bayley Scales of Infant and Toddler Development
Language	Mullen Scales of Early Learning
	NEPSY-II Comprehension of Instructions, Word Generation
	Boston Naming Test
	Expressive One Word Vocabulary Test
	Peabody Picture Vocabulary Test
Visual/Visual-Motor/Motor	Clinical Evaluation of Language Fundamentals
	DKEFS Verbal Fluency
	Beery Visual Motor Inventory
	Grooved Pegboard/Purdue/WRAVMA
	Judgement of Line Orientation Test
Attention/Executive Functioning	Rey-Osterreith Complex Figure
	Behavior Rating Inventory of Executive Functioning (age 2+)
	Delis-Kaplan Executive Functioning System (several subtests)
	Conners' Continuous Performance Test
Memory/Learning	Tower of London-DX
	Rey-Osterreith Complex Figure
	California Verbal Learning Test (Children, 2, 3)
	NEPSY-II Narrative memory, Memory for Designs
	Children's Memory Scale
	Child and Adolescent Memory Profile
Academic	Wechsler Memory Scale
	Wide Range of Memory and Learning, Second Edition
	Wechsler Individual Achievement Test
Social/Emotional	Wide Range Achievement Test
	Bracken (most commonly used preacademic assessment)
Adaptive Functioning	Child Behavior Checklist (age 1 1/2+)
	Behavior Assessment System for Children (age 2+)
	Child Depression Inventory
	Adaptive Behavior Assessment System (starts at birth)
	Vineland Adaptive Behavior Scales

## CONCLUSIONS

In less than a year, a comprehensive set of measures were finalized and ready for live data entry among 19 pediatric sites due to the collaboration of pediatric neuropsychologists experienced in working with epilepsy populations. Initial impact was high in several ways including standardizing clinical practice, improving database management, and enhancing professional communication and development. Importantly, all participants believed their participation was worth their time suggesting success not only in content but also efficiency despite having limited protected time to do the work. This work highlights that funded collaborative work enhances not only scientific progress but also professional development. Future work will include pilot studies to demonstrate the power of the database as well as larger grant submissions to promote the initial work.

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