



Response Evaluation In Neurofibromatosis Schwannomatosis INTERNATIONAL COLLABORATION

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Developing Endpoints Across Multiple Cognitive Domains

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Neurocognitive Outcomes Working Group



Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

Neurocognitive Outcomes Working Group

- Started 2011
- Goal to identify measures of cognition and psychosocial functioning for use in clinical trials
 - Well-designed measures (good psychometrics)
 - Easily administered in clinical trials setting
 - Previous use in clinical trials
 - Previous use with NF1
 - Availability in other languages
- Preschool subcommittee 2016
 - Lead: Bonnie Klein-Tasman



Relevant Domains

- Cognition
- Language
- Visual-spatial
- Memory
- Attention
- Executive functions
- Adaptive skills
- Academics
- Psychosocial
- Social skills
- Social cognition
- Computerized measures
- Global outcome measures

2016 Neurology supplement

Preschool- Upcoming Neurology supplement

Upcoming Neurology supplement



Traumatic Brain Injury Common Data Elements (CDE) Initiative

- Co-sponsored by NNDS, VA, NIDRR, DCoE, and DVBIC
- 8 working groups, including one focused on cognitive and psychological outcomes



TBI CDE Workgroup Method

- Subgroups for each cognitive domain working simultaneously
- Standardized search and review process
 - Each subgroup used similar search terms to find measures
 - Measures reviewed on same properties (similar to our CogRATE Form)
- For each cognitive domain, recommended measures organized into three tiers
 - Core: single, well-established measure
 - Supplemental: more in-depth assessment
 - Emerging: promising measures under development



Recommendations for outcome measures in pediatric TBI

Cognitive Domain	Core	Supplementary	Emerging
IQ	Wechsler Abbreviated Scale of Intelligence (WASI)	None	None
Executive Function	Delis-Kaplan Executive Function System (DKEFS) Verbal Fluency	<ol style="list-style-type: none"> 1. DKEFS Trail Making Test 2. Behavior Rating Inventory of Executive Function (BRIEF) 3. Contingency Naming Test 	<ol style="list-style-type: none"> 1. Test of Executive Control 2. Test of Strategic Learning 3. NIH Toolbox
Attention/Processing Speed	WISC/WPPSI Processing Speed	<ol style="list-style-type: none"> 1. Conners Continuous Performance Test 2. Test of Everyday Attention (TEA-Ch) 	<ol style="list-style-type: none"> 1. Flanker Test 2. NIH Toolbox



SPECIAL COMMUNICATION Arch Phys Med Rehab 2010;91:1650-1660

Recommendations for the Use of Common Outcome Measures in Traumatic Brain Injury Research

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JOURNAL OF NEUROTRAUMA 28:1– (XXX 2011)

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DOI: 10.1089/neu.2011.1838

Recommendations for the Use of Common Outcome Measures in Pediatric Traumatic Brain Injury Research

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Advantages of TBI CDE Model

- Efficient
- Tier groupings gives more guidance for primary and secondary study aims measures
- Future work will focus on updating recommendations



New Model

- Subgroups reviewing multiple domains concurrently
- Previous papers have focused on pediatric measures
 - Considering inclusion of adult measures (especially those that extend from childhood into adulthood)
 - Special section for infant/toddler measures
- Timeline
 - July 2020-February 2021
 - Adaptive
 - Psychosocial
 - Academics
 - Social Cognition
 - March 2021-October 2021
 - Language
 - Cognition
 - Executive Functions
 - Memory
 - November 2021-June 2022
 - Attention
 - Computerized Measures
 - Global Outcome Measures



Neurocognitive Committee

Chair

Jennifer Janusz

Committee Members

- Cynthia Campen
- Pete de Blank
- Allison de Castillo
- Kristina Haebich
- Kristi Hardy
- Kelly Janke
- Bonnie Klein-Tasman *
- Staci Martin
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- Carlos Prada
- Natalie Pride
- Tena Rosser
- Pete Stavinoha
- Heather Thompson
- Karin Walsh *
- Nicole Ullrich
- Pam Wolters

Patient Representatives

- Maureen Hussey
- Jessica Samblanet
- Connie Sorman

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