

Occupational Therapy Guideline: Additional file 2

A. Assessment form	Validated for the EB population	Age range			Benefits	Limitations
		Infant (0-12 months)	Child (1 year - pre-pubescent)	Adult (post-pubescent)		
Quality of Life Evaluation in Epidermolysis Bullosa (QOLEB)¹⁶	Validated on patients with EB	No	Yes	Yes	Useful for all EB subtypes	Children under 10 may need caregiver assistance to complete
Child Occupational Self-Assessment (COSA)²⁹	Not validated on patients with EB	No	6-17 years	No	A self-report of occupational competence and value for everyday activities that uses visual cues for rating	Can be used for younger children depending on their maturity or with caregiver assistance as needed.
COSA adapted for persons with EB³⁰					a modified version for children with EB	
Pediatric Reported Outcomes Measurement Information System (PROMIS)³¹	Not validated on patients with EB	No	8-17 years	Yes	An NIH supported group of self-report scales that include upper extremity skills and activities of daily living that can be web-based	Developed in English and research of validity and reliability performed in the United States
Functional Independence Measure for	Not validated on patients with EB	Yes	Yes	No	An assessment using observation and interview on 18	More difficult to rate younger children 2-4 years

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Children (WeeFim)³²					items to measure functional performance in self-care, mobility, and cognition.	
Hawaii Early Learning Profile (HELP)³³	Not validated on patients with EB	Yes	0-6 years	No	A checklist designed to assess function in 6 areas of development including fine and gross motor skills and adaptive/self-help areas Translated into 8 languages	No peer-reviewed publications evaluating the reliability or validity were located

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B. Standardized assessments of fine motor skill	Validated for the EB population	Age range			Benefits	Limitations
		Infant (0-12 months)	Child (1 year - pre-pubescent)	Adult (post-pubescent)		
Iscor EB ²⁴	Validated in children with EB	No	1-17 years	18- 50 years	A questionnaire developed for persons with EB includes use of hands as an outcome in their assessment ²⁴	There is a more recent reference for the Iscor EB ²⁵ , published in 2018 that was not appraised as publication occurred after appraisal process for OT CPG was completed ²⁵
Abilhand-Kid ²²	Validated in children with EB	No	6-15 years	No	A questionnaire assessing manual dexterity, upper extremity function and various ADL functions	Based on patient and caregiver perceived difficulties
Abilhand-adults ³⁷	Not validated on patients with EB	No	No	16 -80 years		
Patient Reported Outcomes Measure (PROMIS) ³⁸	Not validated on patients with EB	No	Adolescent to young adult	Yes	An NIH supported group of self-report scales that include upper extremity skills and activities of daily living that can be web-based for adults	Validity and reliability studies on young adults

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Sensory Profile (SP)³⁹	Not validated on patients with EB	No	5-10 years	No	A group of questionnaires with three main sections; sensory processing modulation, and behavioural and emotional responses	used primarily by English speaking countries
Sensory Processing Measure (SPM)³⁹	Not validated on patients with EB	No	5-12 years	No	A questionnaire to be filled out by caregivers, main classroom teacher, and other school personnel assessing social participation, praxis, and sensory processing issues	Used primarily by English speaking countries
Peabody Developmental Motor Scales (PDMS)⁴⁰	Not validated on patients with EB	Yes	Birth-71 months	No	Fine motor subtests provide objective information to supplement the entire evaluation and support the need for therapy services	May not be sensitive enough to detect deficits with mild impairment

References here and not from the main body of text

37. Simone A, Roja V, Tesio L, Perucca L. Generic ABILHAND questionnaire can measure manual ability across a variety of motor impairments. *Int J Rehabil Res.* 2011;34:131-140.

38. Howell C, Gross H, Reeve B, DeWalt D, Huang I. Known-groups validity of the Patient-Reported Outcomes Measurement Information System (PROMIS) in adolescents and young adults with special healthcare needs. *Qual Life Res.* 2016;25:1815-1823.

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39. Brown T, Morrison I, Stagnitti K. The convergent validity of two sensory processing scales used with school-age children: Comparing the Sensory Profile and the Sensory Processing Measure. *N Z J Occup Ther.* 2010;57:56-65.
40. Van Hartingsveldt MJ, Cup EH, Oostendorp RA. Reliability and validity of the fine motor scale of the Peabody Developmental Motor Scales–2. *Occup Ther Int.* 2005;12:1–13.