

Suppl. Table 4. Characteristics of patient-reported outcome measures

INSTRUMENT NAME (ACRONYM)	PSYCHOMETRIC STUDIES	INSTRUMENT DEVELOPMENT PAPER	INSTRUMENT LANGUAGE(S) AVAILABLE	INSTRUMENT SUMMARY	SCORING METHOD
PSORIASIS-SPECIFIC MEASURES					
Children’s Scalpdex in Psoriasis (CSP)	Oostveen et al. [17]	Oostveen et al. [17]	Dutch English	<p>Measurement of patient-reported experiences with pediatric scalp psoriasis. Based on the patient-reported outcomes questionnaire for adults, Scalpdex^a</p> <p>22-item instrument composed of 3 major constructs: symptoms, functioning, and emotions. All items enquire about patient’s experience in the last 4 weeks</p> <p>Patients aged 6–12 may complete questionnaire with the assistance of a parent or guardian</p>	<p>Each item scored on a 5-point Likert scale (“never” = 0, “rarely” = 25, “sometimes” = 50, “often” = 75, “all the time” = 100)</p> <p>Item 19, “I feel that my knowledge about caring for my scalp psoriasis is adequate,” is reversed scored</p> <p>Global score is equal to the mean of responses to all items</p> <p>Lower scores are representative of better quality of life</p>
Simplified Psoriasis Index (SPI)	Van Geel et al. [18]	Chularojanamontri et al. ^b	Dutch English	<p>Measurement of patient-reported experiences with pediatric psoriasis. Consists of a Dutch translation of the saSPI questionnaire^b for adults with psoriasis with slight modifications to increase comprehension in children</p> <p>Composed of 3 sections: saSPI-s measures patient-reported disease severity by 10 anatomical locations SPI-p measures psychosocial impact according to a visual analog scale SPI-i measures history and interventions according to 4 items on disease course and 6 items on previous treatments</p> <p>Patients may complete questionnaire with the assistance of a parent or guardian</p>	<p>Global scores calculated for each independent domain: saSPI-s domain score (range 0–50) is calculated by multiplying a composite psoriasis extent score (range 0–10) by an overall average severity score (range 0–5). Composite psoriasis extent score rated on a 3-point scale (0 = absent or minimal, 0.5 = noticeable, 1 = extensive) for each body area, with extra weight given to scalp, face, hands, feet, and anogenital skin. Higher scores indicate greater disease severity</p> <p>SPI-p domain score (range 0–10) calculated on a 0–10 Likert scale derived from a 10-cm visual analog scale. Higher scores indicate larger psychosocial impact</p> <p>SPI-i domain score (range 0–10) calculated by adding summing scores across items. Higher scores indicate more extensive treatment history</p>

DERMATOLOGY-SPECIFIC MEASURES

<p>Children's Dermatology Life Quality Index (CDLQI) Dutch version</p>	<p>Oostveen et al. [21] De Jager et al. [22] Van Geel et al. [23]</p>	<p>Lewis-Jones M.S. and Finlay A.Y.^c</p>	<p>Afrikaans Arabic Bahasa Cantonese Chinese Croatian Czech Danish Dutch English Estonian Filipino Finish French German Greek Hebrew Hindi Hungarian Italian</p>	<p>Japanese Korean Latvian Norwegian Persian Polish Portuguese Romanian Russian Slovak Serbian Spanish Swedish Taiwanese Thai Turkish Twi Ukrainian Yoruba</p>	<p>Measure of patient-reported psychosocial impact of pediatric psoriasis, ages 4–16 years</p> <p>10-item questionnaire with 6 domains: Symptoms and feelings (items 1 and 2) Leisure (items 4–6) School or holidays (item 7) Personal relationships (items 3 and 8) Sleep (item 9) Treatment (item 10)</p>	<p>Each item scored on a 4-point Likert scale (“not at all” = 0, “only a little” = 1, “quite a lot” = 2, “very much” = 3)</p> <p>Global score (range 0–30) is calculated by summing individual item scores</p> <p>Domain scores may also be calculated: Symptoms and feelings (0–6) Leisure (0–9) School or holidays (0–3) Personal relationships (0–6) Sleep (0–3) Treatment (0–3)</p> <p>Severity banding (effect on child's life) is assigned for the following scores^d: 0–1 = no effect 2–6 = small effect 7–12 = moderate effect 13–18 = very large effect 19–30 = extremely large effect</p> <p>Interpretation of incorrectly completed items: If one question unanswered, assign score of 0 to that item If ≥2 questions unanswered, questionnaire is not scored If both parts of question 7 completed, count the higher of the two scores</p>
<p>Children's Dermatology Life Quality Index (CDLQI) Swedish version</p>	<p>Ganemo et al.[24]</p>					
<p>Children's Dermatology Life Quality Index (CDLQI) English version</p>	<p>Langley et al. [25]</p>					

<p>Children's Dermatology Life Quality Index (CDLQI) Cartoon version</p>	<p>Langley et al. [25]</p>	<p>Holme et al.^e</p>	<p>Afrikaans Bahasa Danish Dutch English French</p>	<p>German Hungarian Italian Japanese Romanian</p>	<p>Measure of patient-reported psychosocial impact of pediatric psoriasis. Identical to original CDLQI developed by Lewis-Jones and Finaly^c with addition of graphics to improve comprehension in younger children</p> <p>10-item questionnaire with 6 domains: Symptoms and feelings (items 1 and 2) Leisure (items 4–6) School or holidays (item 7) Personal relationships (items 3 and 8) Sleep (item 9) Treatment (item 10)</p> <p>Patients aged 4–7 may complete questionnaire with the assistance of a parent or guardian</p>	<p>Each item scored on a 4-point Likert scale (“not at all” = 0, “only a little” = 1, “quite a lot” = 2, “very much” = 3)</p> <p>Global score (range 0–30) is calculated by summing individual item scores</p> <p>Domain scores may also be calculated: Symptoms and feelings (0–6) Leisure (0–9) School or holidays (0–3) Personal relationships (0–6) Sleep (0–3) Treatment (0–3)</p> <p>Severity banding (effect on child's life) is assigned for the following scores^d: 0–1 = no effect 2–6 = small effect 7–12 = moderate effect 13–18 = very large effect 19–30 = extremely large effect</p> <p>Interpretation of incorrectly completed items: If one question unanswered, assign score of 0 to that item If ≥2 questions unanswered, questionnaire is not scored If both parts of question 7 are completed, count the higher of the two scores</p>
--	----------------------------	---------------------------------	---	---	--	--

GENERIC, NON-DERMATOLOGIC MEASURES

Pediatric Quality of Life Inventory (PedsQL)	Langley et al. [25]	Varni et al. ^f	Afrikaans	Konkani	Measure of patient-reported health-related quality of life in both healthy and ill children and adolescents. Designed to measure core dimensions defined by the World Health Organization with the addition of role functioning (school)	Each item is administered on a 5-point Likert scale (“never” = 0, “almost never” = 1, “sometimes” = 2, “often” = 3, “almost always” = 4). Each item is then reverse scored, transforming the 0–4 scale to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0)			
			Arabic	Korean					
			Belarusian	Latvian					
			Bengali	Lithuanian					
			Bosnian	Malay					
			Bulgarian	Marathi					
			Cantonese	Norwegian					
			Catalan	Polish			23-item questionnaire with 4 subscales:	Physical functioning summary score is calculated as the sum of all items over the number of items answered in the physical functioning scale	
			Chinese (Mandarin)	Portuguese					Physical functioning (8 items)
			Croatian	Romanian					Emotional functioning (5 items)
			Czech	Russian					Social functioning (5 items)
			Danish	Serbian					School functioning (5 items)
			Dutch	Sesotho			Four age-specific versions available: age 4, ages 5–7, ages 8–12, and ages 13–17	Psychosocial health summary score is calculated as the sum of all items over the number of items answered in the emotional, social, and school functioning scales	
			English	S’gaw					
			Estonian	Karen					
			Farsi	Sinhalese			Two administration formats available:	Total scale score is calculated by dividing the sum of all items over the number of items answered	
			Finnish	Slovak					
			French	Slovenian			The Child Self-Report	If >50% of items are missing, the scale score is not calculated	
			Galician	Spanish			The Parent Proxy Report		
			Georgian	Swedish					
			German	Tagalog					
			Greek	Tamil					
			Hebrew	Telugu					
			Hiligaynon	Thai					
			Hindi	Tongan					
			Hungarian	Turkish					
			Indonesian	Ukrainian					
			Italian	Urdu					
Japanese	Welsh								
Kinyarwanda	Xhosa								
	Zulu		Higher scores indicate better health-related quality of life						

saSPI-s, self-assessment Simplified Psoriasis Index – current severity domain; SPI-p, Simplified Psoriasis Index – psychosocial impact domain; SPI-I, Simplified Psoriasis Index – history and intervention domain.

^aChen SC, Yeung J, Chren MM: Scalpdex: a quality-of-life instrument for scalp dermatitis. *Arch Dermatol* 2002;138:803–807.

^bChularojanamontri L, Griffiths CE, Chalmers RJ: The Simplified Psoriasis Index (SPI): a practical tool for assessing psoriasis. *J Invest Dermatol* 2013;133:1956–1962.

^cLewis-Jones MS, Finlay AY: The Children’s Dermatology Life Quality Index (CDLQI): initial validation and practical use. *Br J Dermatol* 1995;132:942–949.

^dWaters A, Sandhu D, Beattie P, Ezughah F, Lewis-Jones S: Severity stratification of Children’s Dermatology Life Quality Index (CDLQI) scores. *Br J Dermatol* 2010;163:121.

^eHolme SA, Man I, Sharpe SL, Dykes PS, Lewis-Jones MS, Finlay AY: The Children’s Dermatology Life Quality Index: validation of the cartoon version. *Br J Dermatol* 2003;148:285–290.

^fVarni JW, Seid M, Rode CA: The PedsQL: measurement model for the pediatric quality of life inventory. *Med Care* 1999;37:126–139.