

Suppl. Table 5. Summary of results from studies on the measurement properties of patient-reported outcome measures

INSTRUMENT (ACRONYM)	STUDY	MEASUREMENT PROPERTIES									
		INTERNAL CONSISTENCY	RELIABILITY (SAMPLE SIZE, TIME INTERVAL)	CONTENT VALIDITY	STRUCTURAL VALIDITY	HYPOTHESIS TESTING	CROSS-CULTURAL VALIDITY	CRITERION VALIDITY	RESPONSIVENESS	TOTAL AND SUBGROUP SCORE DISTRIBUTION	MID
Children's Scalpdex in Psoriasis (CSP)	Oostveen et al. [17]	Cronbach's α , subscales: Symptoms = 0.69 Functioning = 0.74 Emotions = 0.91	Not assessed	Items generated from Dutch translation of patient-reported outcome measure for adult scalp psoriasis, Scalpdex ^a Final item selection by expert panel of 2 dermatologists, 1 pediatric dermatologist, and 1 psychiatrist. Expert panel translated Scalpdex items into Dutch, modified items to be comprehensive to children, and performed final item reduction	CFA (rotation not reported) showed acceptable fit for 3-factor model Variance explained not reported	Spearman correlations (r) between CSP subscales and PaGA scalp: Symptoms, $r = 0.51$ Functioning, $r = 0.46$ Emotions, $r = 0.46$ All p values <0.001	Not assessed	Not assessed	Cohen's d (effect size), from baseline to 1–7 months, by subscale: Symptoms = 0.44 Functioning = 0.58 Emotions = 0.51	Baseline total score distribution of subscales per treatment response as measured by PaGA scalp, mean \pm SD: Worse ($n = 10$): Symptoms, 21.7 \pm 26.7 Functioning, 13.5 \pm 23.6 Emotions 21.1 \pm 22.3 Same ($n = 16$): Symptoms, 29.7 \pm 19.7 Functioning, 17.8 \pm 16.9 Emotions 25.0 \pm 16.2 Better ($n = 27$): Symptoms, 36.1 \pm 21.4 Functioning, 20.7 \pm 15.6 Emotions 27.1 \pm 18.3 Baseline total score distribution	Not reported

of subscales per treatment response as measured by PhGA scalp, mean \pm SD:

Worse ($n = 12$):
Symptoms, 22.9 \pm 25.4
Functioning, 16.2 \pm 22.4
Emotions 27.4 \pm 22.2

Same ($n = 15$):
Symptoms, 30.6 \pm 26.7
Functioning, 17.0 \pm 17.7
Emotions 24.5 \pm 19.7

Better ($n = 26$):
Symptoms, 35.9 \pm 17.1
Functioning, 20.4 \pm 15.4
Emotions 24.9 \pm 16.0

Simplified Psoriasis Index (SPI)	Van Geel et al. [18]	Not assessed	Not assessed	Not assessed	Not assessed	Spearman correlations (r) between saSPI-s and: CDLQI, $r = 0.64$ proSPI-s, $r = 0.67$	Not assessed	Spearman correlations (r) between: saSPI-s and PASI, $r = 0.69$ SPI-p and CDLQI, $r = 0.78$	Not assessed	Median saSPI-s (range), 3.5 (0–30) Median SPI-p (range), 3.0 (0–10) Histogram of saSPI-s and SPI-p response distributions with frequency of each	Not reported
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SPI-p and:
PASI, $r = 0.40$
proSPI-s, $r = 0.43$

were not
utilized

score presented in
psychometric
study

Spearman
correlations
(r) between
saSPI-s and
SPI-p, $r = 0.68$

All p values
<0.01

saSPI-s
scores >30
were not
utilized

Children's Life Quality Index (CDLQI) Dutch version	Oostveen et al. [21]	Not assessed	Not assessed	Not assessed	Not assessed	Pearson correlations (r) between CDLQI- Dutch version and PASI, $r = 0.31$ (p value = 0.001)	Not assessed	Not assessed	Pearson correlations (r) between Δ CDLQI and Δ PASI by treatment group: All treatments, $r = 0.48$ Topical, $r = 0.48$ Dithranol, $r = 0.46$ Systemic, $r = 0.55$ All p values <0.05	Baseline mean CDLQI \pm SD (range), 7.5 ± 5.0 (0–25) Baseline mean CDLQI scores by gender: Boys, 7.5 Girls, 7.6 (p value = 0.89) Baseline mean CDLQI \pm SD scores by age group: 12 years and under ($n = 68$), 7.0 ± 4.5 12 years and above ($n = 53$), 8.2 ± 5.6 (p value = 0.173)	Not reported
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Baseline mean CDLQI (95% CI) by treatment group:
 All treatments, 7.5 (6.5–8.5)
 Topical, 7.0 (5.8–8.2)
 Dithranol, 8.4 (6.4–10.6)
 Systemic, 9.0 (6.2–11.7)

De Jager et al. [22]	Not assessed	Not assessed	Not assessed	Not assessed	Spearman correlations (<i>r</i>) between CDLQI-Dutch version and: PASI, <i>r</i> = 0.47 (<i>p</i> value = 0.003) PGA, <i>r</i> = 0.51 (<i>p</i> value = 0.001)	Not assessed	Not assessed	Not assessed	Median CDLQI (IQR), 6 (5–9)	Not reported
Van Geel et al. [23]	Not assessed	Not assessed	Not assessed	Not assessed	Spearman correlations (<i>r</i>) between CDLQI-Dutch version and DLQI, <i>r</i> = 0.90 (<i>p</i> value <0.001)	Not assessed	Not assessed	Not assessed	Mean CDLQI ± SD, 6.61 ± 5.74 Percent study population with CDLQI score by severity band: 0–1 = 18% 2–6 = 43% 7–12 = 21% 13–18 = 14% 19–30 = 4%	Not reported

Children's Life Quality Index (CDLQI) Swedish Version	Ganemo et al. [24]	Not assessed	Not assessed	Not assessed	Not assessed	Spearman correlations (<i>r</i>), by age group, between CDLQI Swedish version and: DFI, 5–8 years old, <i>r</i> = 0.004 (<i>p</i> value <0.05) DFI, 5–16 years old, <i>r</i> = 0.04 (<i>p</i> value <0.05) DFI, 9–16 years old, <i>r</i> = 0.34 (<i>p</i> value >0.05)	Not assessed	Not assessed	Not assessed	Median CDLQI (range) by age group, 5–8 years old, 6 (2–11) 5–16 years old, 4 (0–24) 9–16 years old, 4 (0–24) Mean CDLQI ± SD by age group, 5–8 years old, 6.4 ± 3.6 5–16 years old, 5.05 ± 5.0 9–16 years old, 4.7 ± 5.3 Median CDLQI (range) in children with joint complaints (<i>n</i> = 4, 9–16 years old), 12 (0–24)	Not reported
Children's Life Quality Index (CDLQI) English and cartoon versions	Langley et al. [25]	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	CDLQI English version mean percent (median percent) improvement from baseline to week 12 by treatment group: Etanercept, 49.7 (66.7) Placebo, 17.6 (23.5) CDLQI cartoon version mean percent (median percent) improvement from baseline to week 12	CDLQI (English and cartoon versions) mean ± SD score at baseline: Etanercept group, 8.9 ± 6.0 Placebo group 10.0 ± 6.4 CDLQI (English and cartoon versions) median (range) score at baseline: Etanercept group, 7.0 (0–26.0)	MID = 2.5 Mean ΔCDLQI score from baseline to week 12 above MID for both etanercept group (5.4) and placebo group (3.1).

by treatment group: Etanercept, 55.7 (66.7) Placebo, 17.5 (0)	Placebo group, 9.5 (0–29.0)
CDLQI (English and cartoon versions) mean percent (median percent) improvement from baseline to week 2 by treatment group: Etanercept, 27.4 (33.3) Placebo, 8.0 (15.5) (<i>p</i> value = 0.0333)	CDLQI (English and cartoon versions) mean ± SD at 12 weeks, PASI 75 achieved, 9.7 ± 5.6 PASI 75 not achieved, 7.8 ± 6.4
CDLQI (English and cartoon versions) mean percent (median percent) improvement from baseline to week 12 by treatment group: Etanercept, 52.3 (66.7) Placebo, 17.5 (15.5)	CDLQI (English and cartoon versions) median (range) at 12 weeks, PASI 75 achieved, 9.0 (0– 23.0) PASI 75 not achieved, 5.5 (0– 26.0)
CDLQI (English and Cartoon versions) mean ± SD (median) change from baseline to week 12 by treatment group: Etanercept, 5.4 ± 5.6 (4.0) Placebo, 3.1 ± 5.1 (1.0)	
CDLQI (English and Cartoon versions) mean % (median %) improvement from baseline to week 12 by PASI,	

PASI 75 achieved, 75.1 (81.2)
 PASI 75 not achieved, 29.8 (46.4)
 PASI 50 achieved, 64.2 (75.0)
 PASI 50 not achieved, 26.5 (11.5)
 PASI 90 achieved, 80.3 (85.4)
 PASI 90 not achieved, 45.4 (60.8)

Pediatric Quality of Life Inventory (PedsQL)	Langley et al. [25]	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	<p>PedsQL mean ± SD (median) change from baseline to week 12 by treatment group: Etanercept, 6.8 ± 17.6 (3.3) Placebo, 3.8 ± 10.1 (0)</p> <p>PedsQL mean ± SD (median) change from baseline to week 12 by CDLQI response status for etanercept subgroup: <2.5 CDLQI change from baseline, 1.9 ± 8.3 (0) ≥2.5 CDLQI change from baseline, 10.3 ± 20.7 (7.6)</p>	<p>PedsQL mean ± SD score at baseline by treatment group: Etanercept, 74.8 ± 17.8 Placebo, 76.1 ± 16.9</p> <p>PedsQL median (range) score at baseline by treatment group: Etanercept, 77.2 (5.4–100) Placebo, 79.9 (30.4–100)</p> <p>PedsQL mean score at week 12 by treatment group: Etanercept, 81.7 Placebo, 79.8</p> <p>PedsQL mean ± SD at week 12 by PASI, PASI 75 achieved, 74.7 ± 17.4</p>	<p>MID = 4.4 (previously reported in separate study)^b</p> <p>Mean ΔPedsQL score from baseline to week 12 above MID for etanercept group (6.8) but below MID for placebo group (3.8)</p>
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PASI 75 not
achieved, 75.1 ±
18.5

PedsQL median
(range) at week
12 by PASI,
PASI 75
achieved, 77.2
(81.1-100)
PASI 75 not
achieved, 77.2
(5.4-98.9)

MID, minimal important difference; CSP, Children's Scalpdex in Psoriasis; CFA, confirmatory factor analysis; PaGA, Patient Global Assessment; PhGA, Physician Global Assessment; SPI, Simplified Psoriasis Index; saSPI-s, self-assessment Simplified Psoriasis Index – severity subscale; CDLQI, Children's Dermatology Life Quality Index; proSPI-s, professional-assessment Simplified Psoriasis Index – current severity domain; SPI-p, Simplified Psoriasis Index – psychosocial impact domain; PASI, Psoriasis Area and Severity Index; PGA, Physician's Global Assessment; IQR, interquartile range; DFI, Dermatitis Family Impact Questionnaire; PedsQL, Pediatric Quality of Life Inventory.

^aChen SC, Yeung J, Chren MM: Scalpdex: a quality-of-life instrument for scalp dermatitis. Arch Dermatol 2002;13):803–807.

^bVarni JW, Burwinkle TM, Seid M, Skarr D: The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr 2003;3:329–341.