

Table SIII. Validity and reliability tests of the Dutch QOLEB

	Dutch QOLEB	Conclusion
Validity tests		
Content validity	Not available	Addressed through forward-backward translation English QOLEB
Convergent validity	Skindex: $\rho_s = 0.86$ ($p < 0.01$)	Strong agreement
	SF-36 PCS: $\rho_s = -0.75$ ($p < 0.01$)	Agreement
	SF-36 MCS: $\rho_s = -0.43$ ($p < 0.01$)	Moderate agreement
Discriminative validity	$p = 0.002$	Significant
Reliability tests		
Internal consistency and construct validity	All EB subtypes: $\alpha = 0.905$	Excellent
	EBS: $\alpha = 0.88$	Good
	JEB: $\alpha = 0.85$	Good
	DDEB: $\alpha = 0.87$	Good
	RDEB: $\alpha = 0.94$	Excellent
Test-retest reliability	All EB subtypes: $\rho_s = 0.88$ ($p < 0.01$)	Strong agreement
	EBS: $\rho_s = 0.82$ ($p < 0.01$)	Strong agreement
	JEB: $\rho_s = 0.88$ ($p < 0.01$)	Strong agreement
	DDEB: $\rho_s = 0.82$ ($p < 0.01$)	Strong agreement
	RDEB: $\rho_s = 0.98$ ($p < 0.01$)	Very strong agreement

ρ_s : Spearman's rho correlation coefficient, α : Cronbach alpha, EBS: epidermolysis bullosa simplex; JEB: junctional epidermolysis bullosa; DDEB: dominant dystrophic epidermolysis bullosa; RDEB: recessive dystrophic epidermolysis bullosa; SF-36: Short Form-36; PCS: physical component summary; MCS: mental component summary.