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APPENDIX S1

COSMIN criteria for good measurement properties

Measurement	Rating and Criteria
property Structural Validity	"+" CTT: CFA: CFI or TLI or comparable measure >0.95 OR RMSEA < 0.06 OR SRMR < 0.08 (1)
	IRT/Rasch: No violation of unidimensionality (2): CFI or TLI or comparable measure >0.95 OR RMSEA < 0.06 OR SRMR < 0.08 AND no violation of local independence: residual correlations among the items after controlling for the dominant factor < 0.20 OR Q3's < 0.37 AND no violation of monotonicity: adequate looking graphs OR item scalability >0.30 AND adequate model fit:
	IRT: χ2 >0.01
	Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z standardized values > -2 and < 2
	"?" CTT: Not all information for '+' reported
	IRT/Rasch: Model fit not reported
	"-" Criteria for '+' not met
Internal consistency	"+" At least low evidence (3) for sufficient structural validity (4) AND Cronbach's alpha(s) ≥ 0.70 for each unidimensional scale or subscale (5)
	"?" Criteria for "At least low evidence (3) for sufficient structural validity (4)" not met
	"-" At least low evidence (3) for sufficient structural validity (4) AND Cronbach's alpha(s) < 0.70 for each unidimensional scale or subscale (5)
Reliability	"+" ICC or weighted Kappa ≥ 0.70
	"?" ICC or weighted Kappa not reported
	"-" ICC or weighted Kappa < 0.70
Measurement error	"+" SDC or LoA < MIC
	"?" MIC not defined
	"-" SDC or LoA > MIC
Hypotheses testing	"+" The result is in accordance with the hypothesis (6)
for construct validity	"?" No hypothesis defined (by the review team)
	"-" The result is not in accordance with the hypothesis (6)
Cross-cultural validity\measurement	"+" No important differences found between group factors (such as age, gender, language) in multiple group factor analysis OR no important DIF for group factors (McFadden's R ² < 0.02)
invariance	"?" No multiple group factor analysis OR DIF analysis performed
	"-" Important differences between group factors OR DIF was found
Criterion validity	+" Correlation with gold standard ≥ 0.70 OR AUC ≥ 0.70
	"?" Not all information for '+' reported
	"-" Correlation with gold standard < 0.70 OR AUC < 0.70
Responsiveness	"+" The result is in accordance with the hypothesis OR AUC ≥ 0.70
	"?" No hypothesis defined (by the review team)
	"-" The result is not in accordance with the hypothesis7 OR AUC < 0.70

Ratings: "+" = sufficient, "-" = insufficient, "?" = indeterminate

AUC = area under the curve, CFA = confirmatory factor analysis, CFI = comparative fit index, CTT = classical test theory, DIF = differential item functioning, ICC = intraclass correlation coefficient, IRT = item response theory, LoA = limits of agreement, MIC = minimal important change, RMSEA: Root Mean Square Error of Approximation, SEM = Standard Error of Measurement, SDC = smallest detectable change, SRMR: Standardized Root Mean Residuals, TLI = Tucker-Lewis index. The criteria are based on Terwee et al.(252) and Prinsen et al.(253)

Notes.

- 1) To rate the quality of the summary score, the factor structures should be equal across studies.
- 2) Unidimensionality refers to a factor analysis per subscale, while structural validity refers to a factor analysis of a (multidimensional) patient-reported outcome measure
- 3) As defined by grading the evidence according to the GRADE approach.
- 4) This evidence may come from different studies.
- 5) The criteria 'Cronbach alpha < 0.95' was deleted, as this is relevant in the development phase of a PROM and not when evaluating an existing PROM.
- 6) The results of all studies should be taken together and it should then be decided if 75% of the results are in accordance with the hypotheses

Description of Validation Methods

Factor structure and dimensionality

Unidimensionality means that the instrument has only one construct or dimension (latent trait) and thus one single common factor accounts for all item covariances and all the items measure exactly the same concept¹. The unidimensionality of an instrument is normally assessed by confirmatory factor analysis (CFA), exploratory factor analysis (EFA), parallel analysis, or Rasch analysis (item response theory)¹⁻³. It explains the correlations among groups of variables or factors. There are two basic types of factor analysis: EFA, a data-driven approach with no *a priori* assumptions of the number of factors specified, and CFA, requires specifying a specific number of factors as well as the pattern of loadings of the measured variables on the common factors⁴⁻⁵.

The Rasch model⁶ is a probabilistic model used for measuring the ability of an individual based on their performance on a set of items. The model assumes that the probability of a correct response to an item or task depends only on the ability of the individual and the difficulty of the item. Key features include unidimensionality, local independence (each item response is assumed to be independent of the response to any other item, conditional on the individual's ability), and monotonicity (the probability of a correct response is assumed to increase monotonically with ability).

Test-retest reliability

Test-retest reliability is a measure of the consistency or stability of a test or measurement over time, assessed by administering the same test or measure to the same group of individuals on two different occasions, and then correlating the scores obtained at the two time points. If a test is measuring a stable characteristic or trait, then the scores obtained at the two time points should be highly correlated^{2,7}. Conversely, if the scores are not highly correlated, it may indicate that the test is not measuring a stable trait, or that there is too much error in the measurement to allow for consistent results over time. The test–retest reliability is a measure of the relationship between two variables and can be thus measured in many ways e.g. paired sample t-test, Pearson's or Spearman's correlation coefficient and intraclass correlation coefficient (ICC) or internal consistency reliability (ICR). The ICC⁸ however, is accepted as the preferred method for measuring test–retest reliability because it provides information about both the systematic and random differences in test scores⁹.

Internal consistency reliability

Internal consistency reliability is a measure of the consistency or reliability of a set of items in a domain that are intended to measure the same underlying construct or concept^{5,10}. A questionnaire is considered to be internally consistent when there is a high correlation among the scores of items. Internal consistency reliability is often assessed using Cronbach's alpha coefficient, which is the mean of correlations of items in a scale after adjusting for the number of items and the internal-structure of tests¹¹ and ranges from 0 to 1. A higher alpha coefficient indicates a higher level of internal consistency among the items. The alpha coefficient can be used to determine if the items are measuring the same construct, or if they are measuring multiple constructs. According to Streiner and Norman⁵, the minimum requirement for an instrument to be internally consistent is a value of 0.70.

Responsiveness to change

Responsiveness to change¹², or sensitivity, refers to a measure's ability to detect meaningful changes in a construct over time or in response to an intervention or treatment. A measure with good responsiveness to change should be able to detect changes (improvement or deterioration) in the construct being measured that are significant and relevant to the individual or group being studied¹³. Longitudinal studies are needed to determine whether a measure is responsive to changes or differences in health status in patients for whom a change is expected to occur. To assess responsiveness, some criterion is needed to identify whether patients have changed (either improved or deteriorated) over time. These criteria, or anchors, may be clinical endpoints, clinician ratings), patient-rated global improvement or other PROs with established responsiveness, or some combination. There are several statistical methods used to assess the responsiveness to change of a measure, including paired sample t-test, effect size, standardized response mean (SRM), and other responsiveness statistics. These methods compare the magnitude of change on the measure to the variability of scores in the sample being studied.

Known Group Analysis

Known group analysis is a type of construct validity that measures an instrument's ability to detect hypothesized differences among distinct (independent) groups. Groups are generally defined using another independent measure¹⁴ e.g. PASI score of psoriasis severity divided into different grades. Group differences are then determined using a statistical test. The effect size can also be determined¹⁵.

Differential item functioning (DIF)

DIF is a statistical method to determine if an item is functioning differently for respondents from one group to another group, after controlling for differences between the groups for the underlying trait ^{16,17}. Specifically, DIF is used to detect if an item is biased towards certain groups of individuals, such as those of different genders, races, or ethnicities and its examination can be used to evaluate cross-cultural equivalence of an instrument ¹⁶. DIF occurs when individuals from different groups, who have the same level of ability or trait being measured, have different probabilities of answering an item correctly, leading to inaccurate test scores and biased interpretations of test results. Uniform DIF occurs when an item is biased in the same direction and to the same degree for all groups of individuals being compared whereas occurs when an item is biased to a different degree for different groups of individuals being compared.

References for Description of Validation Methods

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DLQI Validation Studies: Search strategy

Keywords: DLQI Dermatology Life Quality Index validation or response rates or factor structure or dimensionality or test-retest or reliability or internal consistency or responsiveness or score banding or banding or clinical meaning or content validity or criterion validity or construct validity or known group validity or MID or minimal important difference or MCID or minimal clinically important difference or MCD or minimal clinical difference or correlation or item response theory or Rasch or graded response or partial credit or ICC or item characteristic curve or category response curve or item information or person-item or item difficulty or item severity or IRT or differential item functioning or Cronbach or inter-class correlation or ICC or classical test theory or EFA or exploratory

factor analysis or CFA or confirmatory factor analysis or bifactor or tscore or t-score or item discrimination or translation or cross cultural

Study type: adaptive clinical trial or case reports or clinical study or clinical trial, all or clinical trial or controlled clinical trial or equivalence trial or evaluation study or multicenter study or observational study or randomized controlled trial or validation study

SR3 Ovid MEDLINE(R) ALL 1946 to December 31, 2022

1	DLQI.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-
	heading word, keyword heading word, organism supplementary concept word, protocol supplementary
	concept word, rare disease supplementary concept word, unique identifier, synonyms]
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	heading word, floating sub-heading word, keyword heading word, organism supplementary concept word,
	protocol supplementary concept word, rare disease supplementary concept word, unique identifier,
	synonyms]
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4	limit 3 to english
5	limit 4 to yr="1946 - 2022"
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	clinical trial or equivalence trial or evaluation study or multicenter study or observational study or randomized
	controlled trial or validation study)
7	(validation or response rates or factor structure or dimensionality or test-retest or reliability or internal
	consistency or responsiveness or score banding or banding or clinical meaning or content validity or criterion
	validity or construct validity or known group validity or MID or minimal important difference or MCID or
	minimal clinically important difference or MCD or minimal clinical difference or correlation or item response
	theory or Rasch or graded response or partial credit or ICC or item characteristic curve or category response
	curve or item information or person-item or item difficulty or item severity or IRT or dif or differential item
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	analysis or CFA or confirmatory factor analysis or bifactor or tscore or t-score or item discrimination or
	translation or cross cultural).mp. [mp=title, abstract, original title, name of substance word, subject heading
	word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol
	supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
8	6 and 7

SR3 Embase Classic+Embase 1947 to Dec 31 2022

1	DLQI.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-
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	heading word, floating sub-heading word, keyword heading word, organism supplementary concept word,
	protocol supplementary concept word, rare disease supplementary concept word, unique identifier,
	synonyms]

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	controlled trial or validation study)
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	consistency or responsiveness or score banding or banding or clinical meaning or content validity or criterion
	validity or construct validity or known group validity or MID or minimal important difference or MCID or
	minimal clinically important difference or MCD or minimal clinical difference or correlation or item response
	theory or Rasch or graded response or partial credit or ICC or item characteristic curve or category response
	curve or item information or person-item or item difficulty or item severity or IRT or differential item
	functioning or Cronbach or inter-class correlation or ICC or classical test theory or EFA or exploratory factor
	analysis or CFA or confirmatory factor analysis or bifactor or tscore or t-score or item discrimination or
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	candidate term word]
6	4 and 5
7	limit 6 to yr="1946 - 2022"
8	limit 7 to english
9	limit 8 to (article and journal)

SR3 CINAHL Plus with Full Text EBSCO Host 31-12-22

F =	
S1	"DLQI" Expanders - Also search within the full text of the articles; Apply equivalent subjects.
	Search modes - Boolean/Phrase
S2	"Dermatology Life Quality Index" Also search within the full text of the articles; Apply equivalent subjects.
	Search modes - Boolean/Phrase
S3	S1 Or S2
S4	validation or response rates or factor structure or dimensionality or test-retest or reliability or internal
	consistency or responsiveness or score banding or banding or clinical meaning or content validity or criterion
	validity or construct validity or known group validity or MID or minimal important difference or MCID or
	minimal clinically important difference or MCD or minimal clinical difference or correlation or item response
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	analysis or CFA or confirmatory factor analysis or bifactor or tscore or t-score or item discrimination or
	translation or cross cultural Expanders - Also search within the full text of the articles; Apply
	equivalent subjects
S5	S3 AND S4
S6	Narrow by Language: - english
S7	PY <= 2022
S8	S6 AND S7

Notes: CINAHL Plus with Full Text EBSCO Host has no way to limit study type

SR3 Web of Science 31-12-22

1	(ALL=(DLQI))
2	ALL=("Dermatology Life Quality Index")
3	#1 OR #2
4	ALL=(validation or "response rates" or "factor structure" or dimensionality or "test-retest" or reliability or
	"internal consistency" or responsiveness or "score banding" or banding or "clinical meaning" or "content
	validity" or "criterion validity" or "construct validity" or "known group validity" or MID or "minimal important
	difference" or MCID or "minimal clinically important difference" or MCD)
5	ALL=("minimal clinical difference" or correlation or "item response theory" or Rasch or "graded response" or
	"partial credit" or ICC or "item characteristic curve" or "category response curve" or "item information" or
	"person-item" or "item difficulty" or "item severity" or IRT or dif or "differential item functioning" or Cronbach
	or "inter-class correlation" or ICC or "classical test theory")
6	ALL=(EFA or "exploratory factor analysis" or CFA or "confirmatory factor analysis" or "bifactor" or tscore or "t-
	score" or "item discrimination" or translation or "cross cultural")
7	#4 or #5 or #6
8	#3 and #7
9	Refined by English

Notes: Web of Science has no way to limit by age or study type

SR3 SCOPUS 31-12-22

1	TITLE-ABS-KEY (dlqi)
2	TITLE-ABS-KEY ("Dermatology Life Quality Index")
3	TITLE-ABS-KEY (dlqi OR "Dermatology Life Quality Index")
4	TITLE-ABS-KEY(validation OR "response rates" OR "factor structure" OR dimensionality OR test-retest OR reliability OR "internal consistency" OR responsiveness OR "score banding" OR banding OR "clinical meaning" OR "content validity" OR "criterion validity" OR "construct validity" OR "known group validity" OR MID OR "minimal important difference" OR MCID OR "minimal clinically important difference" OR MCD OR "minimal clinical difference" OR correlation OR "item response theory" OR Rasch OR "graded response" OR "partial credit" OR ICC OR "item characteristic curve" OR "category response curve" OR "item information" OR "person-item" OR "item difficulty" OR "item severity" OR IRT OR dif OR "differential item functioning" OR Cronbach OR "inter-class correlation" OR ICC OR "classical test theory" OR EFA OR "exploratory factor analysis" OR CFA OR "confirmatory factor analysis" OR bifactor OR tscore OR t-score OR "item discrimination" OR translation OR "cross cultural")
5	TITLE-ABS-KEY ((dlqi OR "Dermatology Life Quality Index") AND (validation OR "response rates" OR
	"factor structure" OR dimensionality OR test-retest OR reliability OR "internal consistency" OR
	responsiveness OR "score banding" OR banding OR "clinical meaning" OR "content validity" OR
	"criterion validity" OR "construct validity" OR "known group validity" OR mid OR "minimal important
	difference" OR mcid OR "minimal clinically important difference" OR mcd OR "minimal clinical
	difference" OR correlation OR "item response theory" OR rasch OR "graded response" OR "partial
	credit" OR icc OR "item characteristic curve" OR "category response curve" OR "item information" OR
	"person-item" OR "item difficulty" OR "item severity" OR irt OR dif OR "differential item functioning"
	OR cronbach OR "inter-class correlation" OR icc OR "classical test theory" OR efa OR "exploratory
	factor analysis" OR cfa OR "confirmatory factor analysis" OR bifactor OR tscore OR t-score OR "item

discrimination" OR translation OR "cross cultural")) AND (LIMIT-TO (PUBSTAGE, "final")) AND (LIMIT-TO (DOCTYPE, "ar")) AND (LIMIT-TO (LANGUAGE, "English"))

SR3 APA PsycInfo 1860 to 31 Dec 2022

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	concept word, rare disease supplementary concept word, unique identifier, synonyms]
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	heading word, floating sub-heading word, keyword heading word, organism supplementary concept word,
	protocol supplementary concept word, rare disease supplementary concept word, unique identifier,
	synonyms]
3	1 or 2
4	(validation or response rates or factor structure or dimensionality or test-retest or reliability or internal
	consistency or responsiveness or score banding or banding or clinical meaning or content validity or criterion
	validity or construct validity or known group validity or MID or minimal important difference or MCID or
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	curve or item information or person-item or item difficulty or item severity or IRT or diff or differential item
	functioning or Cronbach or inter-class correlation or ICC or classical test theory or EFA or exploratory factor
	analysis or CFA or confirmatory factor analysis or bifactor or tscore or t-score or item discrimination or
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	word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol
	supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5	3 and 4
6	limit 5 to (adaptive clinical trial or case reports or clinical study or clinical trial, all or clinical trial or controlled
	clinical trial or equivalence trial or evaluation study or multicenter study or observational study or randomized
	controlled trial or validation study)
7	limit 6 to english
8	limit 7 to yr="1860 - 2022"

DLQI Validation Studies: Definitions of Validation, Quality of Life (QoL), Patient Reported Outcome (PRO), and measures included and excluded in the study

Quality of life (QoL) is a multidimensional concept that refers to an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards" and is affected by a person's physical health and psychological state [1]. It can therefore be assumed that the assessment of QoL should consider aspects of physical health, psychological state, level of autonomy, social relationships, beliefs, and relationship to salient features of the environment [2].

From: Quality of life assessment instruments for adults: a systematic review of population-based studies. Pequeno et al. Health and Quality of Life Outcome. 18, Article number: 208 (2020).

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A visual analogue scale (VAS) alone should not be considered a QoL tool e.g. EQ5D VAS (unless it is presented with the full EQ5D questionnaire). Most dermatology severity scales are not QoL e.g. PASI, EASI, PGA, SCORAD, POEM.

A patient-reported outcome (PRO) is "any report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else" (FDA. Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. Rockville, MD; 2009. http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf).

PRO QoL Measures Included in the study

5-D itch scale
6 item stigmatization scale
12-Item Pruritus Severity Scale (12-PSS)
5D-pruritus scale
Angioedema Quality of Life Questionnaire (AE-QoL)
Beck Depression Inventory (BDI)
Brief Illness Perception Questionnaire (Broadbent)
Chemotherapy-induced Alopecia Distress Scale (CADS)
Cardiff Acne Disability Index (CADI)
Center for Epidemiologic Studies-Depression scale (CES-D)
Condyloma acuminata QoL (CECA10)
Cutaneous Sarcoidosis Activity and Morphology Instrument (CSAMI)
World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)
Dysmorphic concern prevalence and associations with clinical variables (DCQ)
Feeling of Stigmatization Questionnaire 33-item - Ginsberg
Frankfurt Body Concept Scale (FKKS)
General Health Questionnaire (GHQ-12, GHQ-28)
Hand Eczema Extent Score (HEES)
Hand-foot syndrome (HFS)-specific quality of life (QOL)
Health Assessment Questionnaire-Disability Index (HAQ-DI)
Hidradenitis Suppurativa Quality of Life (HiSQOL)
Hospital Anxiety and Depression Scale (HADS)
Interaction Anxiousness Scale (IAS)
Impact of Psoriasis Questionnaire (IPSO)
Internalized Stigma Scale (ISS)
Lymphatic Filariasis Quality of Life Questionnaire (LFSQQ)
Patient Generated Index (PGI)
Patient Health Questionnaire (PHQ-9)
Patient Reported Outcomes Measurement Information System (PROMIS) sleep disturbance and related
impairment
Psoriasis Disability Index (PDI)
Psoriasis Life Stress Inventory (PLSI)

Quality of Life in Hand Eczema Questionnaire (QoLHEQ)

Quick Inventory of Depressive Symptomatology-Self Report - QIDS-SR16

Revised Illness Perception Questionnaire (IPQ-R)

Rheumatoid Arthritis Impact of Disease (RAID)

Sarcoidosis Activity and Severity Index (SASI)

Sheehan Disability Scale (SDS)

Shirom Melamed Burnout Measure (SMBM)

Short Form 36 (SF-36)

Skindex-29

Social Appearance Anxiety Scale (SAAS)

Stigma Assessment and Reduction of Impact Scale (SARI)

Vitiligo Impact Scale-22 (VIS-22)

Vitiligo-specific quality of life instrument (VitiQoL)

WHO Well Being Index (WHO-5)

Zung Self-rating Depression Scale

Measures (not QoL but may be PRO) excluded in the study

6 item stigmatization scale

Angioedema Activity Score (AAS)

Arizona Sexual Experience Scale (ASEX)

Body Surface Area (BSA)

CIASsification for Psoriatic ARthritis (CASPAR)

Composite Psoriatic Disease Activity Index (CPDAI)

Culture Free Self-Esteem Inventory - Adult Version (CFSEI-AD)

Culture Free Self-Esteem Inventory - Adult Version (CFSEI-AD) - measures perception of self

Disease Activity index for Psoriatic Arthritis (DAPSA)

Eczema Area and Severity Index (EASI)

Glasgow Ultrasound Enthesis Scoring System (GUESS)

Hand Eczema Extent Score (HEES)

Hidradenitis Suppurativa (HS) Hurley Stages

Hidradenitis suppurativa Investigator Global Assessment (HS-IGA)

Investigator Global Assessment (IGA)

Itch Numeric Rating Scale (Itch NRS)

ItchApp - Pruritus

Madrid Sonographic Enthesitis Index Scoring System (MASEI)

Medical Outcomes Study Sleep Problem Index II

Mishel Uncertainty in Illness Scale-Community form (MUIS-C)

Patient Global Assessment (PtGA)

Patient Oriented Eczema Measure (POEM) Peak pruritus Numerical Rating Scale (NRS) Person-Centered Dermatology Self-Care Index (PeDeSI) Physician Global Assessment (PGA) Private Body Consciousness subscale (PBS subscale) Pruritus and Symptoms Assessment for Atopic Dermatitis (PSAAD) Psoriasis Area Severity Index (PASI) Psoriasis Epidemiology Screening Tool (PEST) Psoriasis Life Stress Inventory (PLSI) Psoriasis Symptom Inventory (PSI) Psoriasis Symptoms and Impacts Measure (P-SIM) Psoriasis Symptoms and Signs Diary (PSSD) Rosenberg's measure of self-esteem (RES) Stigmatisation and Psoriasis Questionnaire (SEQ) Scoring Atopic Dermatitis index (SCORAD) Simplified Psoriasis Index (SPI) Six Area Six Sign Atopic Dermatitis (SASSAD) Spielberger State-Trait Anxiety Index (STAI, SA, TA) Symptom Check List-90 (SCL-90R) (psychological distress) Temperament and Character Inventory (TCI) Tokyo University Egogram (TEG) Urticaria Control Test (UCT)