SEMMELWEIS EGYETEM
DOKTORI ISKOLA

Ph.D. értekezések

2994.

SZABÓ ÁKOS

Bőrgyógyászat és Venerológia című program

Programvezető: Dr. Sárdy Miklós, egyetemi tanár
Témavezető: Dr. Rencz Fanni, egyetemi tanár

Use and measurement properties of dermatology-specific health-related quality of life measures and their modifications

PhD thesis

Ákos Szabó

Semmelweis University

Doctoral School of Semmelweis University, Rácz Károly Conservative Medicine Division

Supervisor: Fanni Rencz, M.D., Ph.D.

Official reviewers: András Inotai, Pharm.D., Ph.D. habil.
Eszter Baltás, M.D., Ph.D., habil.

Head of the Complex Examination Committee: Zoltán Vokó, D.Sc.

Members of the Complex Examination Committee: Csaba Dózsa, Ph.D. habil.
Béla Tamási, Ph.D.

Budapest

2024

CONTENTS

1. Introduction 5

1.1. Health-related quality of life (HRQoL) 8

1.2. Measurement of HRQoL 9

1.2.1. Generic HRQoL questionnaires 10

1.2.2. Dermatology-specific HRQoL questionnaires 10

1.3. Clinical use of HRQoL measurement in dermatology 14

1.4. Use of HRQoL data in guidelines in dermatology 15

1.5. Validation of HRQoL measures 16

1.6. Modifications of HRQoL questionnaires 18

2. Objectives 20

2.1. Modified versions and alternative scoring methods of DLQI 20

2.2. Comparison of the measurement performance of dermatology-specific HRQoL outcomes (DLQI, DLQI-R and Skindex-16) 20

3. Results 21

3.1. Results of Modified versions and alternative scoring methods of DLQI 22

3.1.1. Inclusion of relevant studies 22

3.1.2. Studied questionnaires and scorings 27

3.1.3. Methodological quality of studies (COSMIN criteria) 33

3.1.4. Measurement properties of DLQI modifications (Terwee criteria) 34

3.2. Results of comparison of the measurement performance of dermatology-specific HRQoL outcomes (DLQI, DLQI-R and Skindex-16) 35

3.2.1. Characteristics of the study population 35

3.2.2. Descriptive results of the outcome measures 35

3.2.3. Ceiling and floor effects 37

3.2.4. Informativity 41
3.2.5. Convergent and known-group validity 42
3.2.6. Subgroup analysis 44
3.2.7. Summary of the results 44
4. Discussion 45
4.1. Modified versions and alternative scoring methods of DLQI 45
4.2. Comparison of the measurement performance of dermatology-specific questionnaires (DLQI, DLQI-R and Skindex-16) 48
5. Conclusions 52
6. Summary 53
7. References 54
8. Bibliography of own publications 75
8.1. Publications related to this thesis 75
8.1.1. International peer reviewed journals 75
8.1.2. Conference presentations and posters 75
8.2. Publications not related to this thesis 76
8.2.1. International peer reviewed journals 76
8.2.2. Hungarian peer-reviewed journals 77
8.2.3. Conference presentations and posters 77
9. Acknowledgments 79
10. List of tables and figures 80
11. Appendices 82

List of abbreviations

AD	atopic dermatitis
BSA	Body Surface Area
COI	Cost of illness
CDLQI	Children's Dermatology Life Quality Index
CE	Ceiling effect
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
DLQI	Dermatology Life Quality Index
DLQI-R	DLQI-Relevant
EMMI	Ministry of Human Resources / Emberi Erőforrások Minisztériuma
FDA	United States Food and Drug Administration
FDLQI	Family Dermatology Life Quality Index
FE	Floor effect
GQ	Global Question
H’	Shannon’s index for absolute informativity
HE	hand eczema
HRQoL	Health Related Quality of Life
HS	hidradenitis suppurativa
HUI	Health Utilities Index
J’	Shannon’s evenness index for relative informativity
LY-DLQI	Last-year Dermatology Life Quality Index

NHIF	National Health Insurance Fund / Nemzeti Egészségbiztosítási Alapkezelő
NHP	Nottingham Health Profile
NNGYK	National Center for Public Health and Pharmacy / Nemzeti Népegészségügyi és Gyógyszerészeti Központ
NRR	'Not relevant' response
OGYÉI	National Institute of Pharmacy and Nutrition / Országos Gyógyszerészeti és Élelmezés-egészségügyi Intézet
PASI	Psoriasis Area and Severity Index
PG-VAS	Patient's global assessment visual analogue scale
PRO	Patient Reported Outcome
PROMIS	Patient-Reported Outcomes Measurement Information System
QALY	Quality-adjusted life year
QWB	Quality of Well-Being scale
RE	Relative efficiency
SD	Standard deviation
SF-36	Short Form-36 Health Survey
SIP	Sickness Impact Profile
T-QoL	Teenager's Quality of Life
WHO	World Health Organization
WHO-5	World Health Organization 5 well-being index
WoS	Web of Science

1. Introduction

Due to technological advancements and health and social developments in countries worldwide, life expectancy has significantly increased. This transformation of life phases presents new challenges to societies in the 21st century, and a considerable rise in healthcare costs has accompanied these innovations. This situation places an enormous burden on governments as social security expenditures gradually increase, and the range of available pharmaceutical products and active substances continues to expand [1]. Clinical and financial protocols regulate the provision of the health services in most developed countries, including Hungary. More than the mere diagnosis may be required to qualify for specific treatments, which encompass higher-cost technologies. Consequently, specific health outcomes, such as disease severity and health-related quality of life (hereinafter: HRQoL) measured by standardized instruments, have become significant factors in making clinical and financing decisions [2-4]. Often meeting a specific level of disease severity or HRQoL impairment is a prerequisite to be eligible for certain health interventions.

Skin diseases are among the most prevalent diseases, with over 3,000 known skin conditions worldwide [5]. Both acute (e.g., infections) and chronic skin diseases (e.g., atopic dermatitis or psoriasis) often have a substantial negative effect on patients' lives which cause a significant burden directly for the patients and indirectly for their families. In general, few skin diseases shorten one's life; however, they could have a major impact on the patients' HRQoL [6-9]. Based on the evaluation of the Global Burden of Disease Study, skin diseases were ranked the 7th largest nonfatal disease burden worldwide in 2019 [10]. Therefore, improving patients' life HRQoL is one of the fundamental aims of healthcare [11,12].

The burden of disease can be defined as the total consequences, encompassing health or social aspects as well as costs to the patients or the society, caused by chronic skin diseases and other health problems [13]. The most obvious burden is the physical symptoms of skin disease, which can be associated with itching, burning, irritation, scaling of the skin, and pain, among others. Several skin conditions affect the visible areas of the body, such as the hands, fingers, face, or scalp, potentially leading to

embarrassment, lower self-esteem and self-confidence, contributing to the consequences of stigmatisation or discrimination. The lack of self-confidence due to the appearance of the skin may lead to problems with social relationships and a significant reduction in social participation (leisure activities, social events), which may also give rise to mental problems (anxiety, depression, shame or suicidal thoughts) [14-18].

Another burden identified is the difficulties related to work, as illness (physician's visits or treatment) can lead to a loss of working time for people with skin disease, resulting in sick leave (absenteeism). Chronic skin problems can also negatively impact work performance (presenteeism) and may lead to early retirement from work [19-21]. Furthermore, many high-risk occupations are unsuitable for individuals with chronic skin conditions due to occupational diseases connected to the skin condition, such as being unable to expose their hands to water or wear necessary work clothing [22].

In understanding the financial burden of diseases, it is important to quantify the cost-of-illness (hereinafter: COI) associated with each condition. COI studies provide information from the societal perspective on encompassing direct medical costs (e.g., physician's visits, treatments, drugs, medicines, transportation) and indirect financial burdens (i.e., work productivity loss) [3,23]. Moreover, suppose the patient is no longer able to fully care for themselves, in that case, caregiving costs can also become a significant financial burden for the patient and their family or the social care system (direct nonmedical costs) [24,25].

Several COI studies have been conducted across various diseases in the Central and Eastern European countries. However, due to the variations in costing methodology, the transferability from one country to another may be limited [26]. Over the past 10 years, four studies have investigated the COI associated with chronic skin diseases in Hungary [27-30].

Table 1 presents annual per-patient expenses associated with specific dermatological conditions. For instance, in the case of psoriasis, the most important driver of costs is biological therapy (direct medical cost), while in atopic dermatitis and hidradenitis suppurativa, productivity loss (indirect cost) dominates among the cost items. This reflects that the more common use of biologics in psoriasis has led to a reduction in indirect costs.

Table 1 – Summary table of Hungarian cost of illness studies in dermatology [27-30]

	Beretzky et al. 2023[28]	Gáspár et al. 2021[30]	Brodszky et al. 2020[29]	Balogh et al. 2014[27]
Chronic skin disease	atopic dermatitis	hidradenitis suppurativa	pemphigus	psoriasis
Years of data collection	2018 - 2021	2017 - 2019	2014 - 2017	2012 - 2013
Year of cost calculation	2020	2019	2017	2012
Sample size	218	200	109	200
Female (%)	58%	39%	64%	32%
Biological therapy (%)	2%	16%	0%	52%
Mean age in years (SD)	31 (12)	37 (12)	57 (15)	51 (13)
Mean DLQI (SD)	13 (8)	12 (8)	6 (7)	6 (7)
Productivity losses	Mean annual per-patient costs in EUR and its relative frequencies (%)			
absenteeism	1,047 (24%)	1,599 (24%)	1,263 (32%)	307 (3%)
presenteeism	1,262 (29%)	1,781 (26%)	274 (7%)	948 (10%)
Direct medical costs	1,136 (26%)	2,400 (35%)	1,690 (42%)	7,790 (84%)
Direct non-medical costs	747 (17%)	767 (11%)	860 (22%)	208 (2%)
Total annual cost	4,331 (100%)	6,791 (100%)	3,995 (100%)	9,254 (100%)

DLQI = Dermatology Life Quality of Index; SD = Standard deviation

1.1. Health-related quality of life (HRQoL)

In 1948, the World Health Organization stated, "*Health is a state of complete physical, mental and social well-being, not merely the absence of disease or disability."* [31] The definition of HRQoL specifically focuses explicitly on quality of life aspects relevant to health. Nevertheless, HRQoL remains a comprehensive and intricate concept lacking a universally accepted definition [32]. Most definitions highlight two facets of HRQoL. First, HRQoL is a multidimensional concept representing the patients' physical, functioning, social, or psychological aspects [33,34]. Second, HRQoL incorporates subjective and objective perspectives within each dimension [35]. The objective perspectives focus on an individual's capabilities, which are essential in determining health. The subjective assessment of HRQoL involves the personal individual experience of HRQoL. The differences in assessments contribute to the observation that individuals with the same objective health status may report significantly different subjective HRQoL [6,36].

The outcomes based on patients' subjective assessment of their health and illness belong to the so-called patient-reported outcomes (hereinafter: PROs). Over the recent decades, the measurement of HRQoL has gained increasing importance, which has led to the use of standardized questionnaires to measure HRQoL in various diseases, with subsequent adaptation into different languages, including Hungarian [37].

HRQoL was recognized in medical literature over 50 years ago and has become a pivotal outcome within healthcare. Thus, improving the HRQoL has become a crucial objective in modern societies, leading to the integration of HRQoL research into various scientific disciplines. Various models of HRQoL and new health indicators are being developed to investigate the factors that determine and influence HRQoL and their effects [4]. The definition also includes how individuals perceive their health status, react to it, and aspects of life that can significantly impact their health. Figure 1 presents the Wilson-Cleary model which determined all connections between HRQoL and which variables could affect a patient's health status [38].

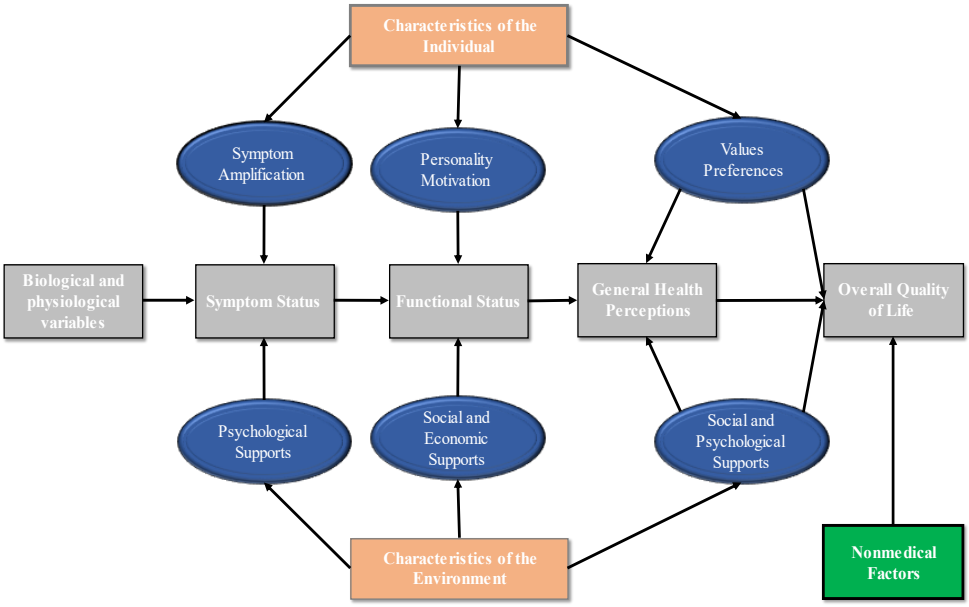


Figure 1 – Dimensions affecting a person's HRQoL, an adapted figure from Wilson and Cleary 1995 [38]

1.2. Measurement of HRQoL

HRQoL is typically measured using standardised questionnaires. In dermatology, HRQoL questionnaires may be grouped into generic, disease-specific, and dermatology-specific measures. When a questionnaire measures multiple HRQoL dimensions separately, it is called a profile-type measure. This approach offers the advantage of assessing specific interventions across various dimensions. In contrast, an index-type questionnaire focuses on overall health status and provides a specific numerical value to express it [39].

A specific type of HRQoL questionnaires, called preference-based measures allow the estimation of health utilities. Utilities represent an individual's preference for a health state and are measured on a scale anchored at zero and one. Full health is 1 on this scale, while 0 indicates health states as bad as being dead. In this context, it is important to highlight that negative utilities could occur, which are associated with health states worse than being dead [40-42]. Utility values are essential for calculating Quality-Adjusted Life Years (hereinafter: QALYs) in the context of cost-effectiveness analysis. The QALY represents a single composite indicator combining life expectancy (survival) and HRQoL

(utility) improvement. QALYs are employed to analyse the achievable maximum health benefits with the lowest economic investment, helping the decision-makers in selecting between various healthcare interventions [43-46].

1.2.1. Generic HRQoL questionnaires

Generic HRQoL instruments are designed to be relevant and suitable for diverse populations and various medical treatments or interventions, including the general population [47]. They focus on the overall aspects of health, such as pain, mobility, or depression, irrespective of the underlying disease or condition. Generic questionnaires offer comparability across different skin diseases and also allow comparison with non-dermatological conditions and the general population because of their universal nature. However, they may not be able to capture specific symptoms of skin diseases, such as itching, dry skin, lesions, or discolored skin patches.

Examples of generic HRQoL measures include the Short Form-36 Health Survey (SF-36), Nottingham Health Profile (NHP) or Sickness Impact Profile (SIP), and preference-based instruments, such as the Quality of Well-Being scale (QWB), Health Utilities Index (HUI), EQ-5D and Patient-Reported Outcomes Measurement Information System (PROMIS) Preference score [48-53].

1.2.2. Dermatology-specific HRQoL questionnaires

Dermatology-specific instruments are designed to focus on different HRQoL domains related to multiple skin diseases. Due to their specificity, dermatology-specific measures tend to have better sensitivity than generic ones. However, these instruments may not allow comparisons with non-dermatological diseases, and in some cases, they may not capture all relevant dimensions of HRQoL in a specific skin condition [39,54].

• *Dermatology Life Quality Index*

Dermatology Life Quality Index (hereinafter: DLQI) is a dermatology-specific HRQoL questionnaire designed for patients aged 16 years and older [55,56]. Its 10 items cover the following six aspects of HRQoL: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. The recall period for all items is

the last seven days. Eight out of the ten items of the DLQI use a five-point response scale ('not at all' or 'not relevant'=0, 'a little'=1, 'a lot'=2 and 'very much'=3), and two items use a four-point scale ('not at all'=0, 'a little'=1, 'a lot'=2 and 'very much'=3). From question three to ten of the DLQI, the responders may choose a 'not relevant' response option (hereinafter: NRR), when the item does not apply to them. In the original scoring of the questionnaire this answer is scored as equivalent to the 'not at all' option (scored as 0). Several previous studies have empirically demonstrated potential bias in scoring NRRs as they were 'not at all' responses, which may lead to the underestimation of the HRQoL of patients [57,58]. The total DLQI score, which ranges from 0 to 30, reflects the overall impact on HRQoL, with higher scores indicating a greater decrease in HRQoL. The DLQI questionnaire has been translated into over 115 languages and used in over 40 skin conditions worldwide. It is adopted in treatment or financial guidelines for biological treatments or in patient registries in over 45 countries [59].

• Dermatology Life Quality Index- Relevant

The Dermatology Life Quality Index-Relevant (hereinafter: DLQI-R) is an alternative scoring method of the DLQI developed by our research team in Hungary. This scoring modification adjusts the total DLQI score to the number of NRRs. Previous work has tested the measurement performance of the DLQI-R in atopic dermatitis, psoriasis, pemphigus, morphea, vitiligo, and hidradenitis suppurativa. In these studies, the DLQI-R showed similar or somewhat better convergent validity, responsiveness, and discriminatory power than the original DLQI questionnaire [57,58,60-65].

The DLQI-R score is calculated as follows:

$$\text{DLQI-R} = DLQI \times \frac{10}{10 - NRR}$$

NRR = Number of Not relevant responses

- ***Skindex-16***

Among members of the Skindex instrument family (Skindex-29, Skindex-17, Skindex-16, Skindex-mini), both the Skindex-16 and Skindex-17 questionnaires were developed based on the Skindex-29 [66]. For our comparative analysis, we opted to use the Skindex-16 as it was developed based on patient feedback, while the Skindex-17 was primarily based on a mathematical model (Rasch model) [67]. Furthermore, by reviewing the publications in the Pubmed online database, we observed that the Skindex-16 is more widely used than the Skindex-17, and therefore, we chose the Skindex-16. Skindex-16 is a dermatology-specific HRQoL questionnaire including 16 different items on three subscales about emotions, symptoms and functioning. Responses are transformed to a linear scale, ranging from 0 to 100 as the average of the three subscale scores. The recall period for all items is the last week. The questions can be rated on a bipolar scale from 0 to 6, where 0 indicates 'never bothered' and 6 indicates 'always bothered' [68,69]. The Skindex questionnaires have been validated in several skin conditions including atopic dermatitis, hand-foot syndrome, hidradenitis suppurativa, hyperhidrosis, psoriasis, rosacea or vitiligo [70-72], and are recommended for use in national treatment guidelines in a few countries [73-75].

Our research in this PhD thesis focused on two questionnaires (Skindex-16 and DLQI) and one alternative scoring method (DLQI-R). Both questionnaires have been validated earlier in Hungarian language [65,76]. The DLQI, DLQI-R, and Skindex-16 are compared in Table 2.

Table 2 – Characteristics of DLQI, DLQI-R and Skindex-16 [77]

	DLQI[55]	**DLQI-R [62]**[α]	**Skindex-16 [68]**			
Recall period	last week		last week			
Number of items	10		16			
Items	item 1 (itchy, sore, painful, stinging) item 2 (embarrassed, self-conscious) item 3 (shopping, home, garden) item 4 (clothing) item 5 (social, leisure) item 6 (sport) item 7 (working, studying) item 8 (interpersonal problems) item 9 (sexual difficulties) item 10 (treatment difficulties)		***Symptoms subscale*** item 1 (itching) item 2 (burning or stinging) item 3 (hurting) item 4 (skin irritation)	***Emotions subscale*** item 5 (persistence / reoccurrence) item 6 (worry) item 7 (appearance) item 8 (frustration) item 9 (embarrassment) item 10 (being annoyed) item 11 (feeling depressed)	***Functioning subscale*** item 12 (interactions with others) item 13 (desire to be with people) item 14 (show affection) item 15 (daily activities) item 16 (work or do what you enjoy)	
Type of response scale	severity (items 1-2), interference with functioning (items 3-10)		frequency			
Number of response options per item	4 (items 1-2) or 5 (items 3-10)		6 (all items)			
Response options	not relevant=0 (items 3-10) not at all=0 (all items) a little=1 (all items) a lot=2 (all items) very much=3 (all items)		7-point bipolar scale with endpoints ‘never bothered’ and ‘always bothered’ (scored 0-6)			
Scoring	$DLQI = \sum_{i=1}^{10} item_i$	DLQI-R= $DLQI \times \frac{10}{10-NRR}$	$\boldsymbol{Symptoms} = \sum_{i=1}^{4} item_i \times \frac{100}{6}$	$\boldsymbol{Emotions} = \sum_{i=5}^{7} item_i \times \frac{100}{6}$	$\boldsymbol{Functioning} = \sum_{i=12}^{5} item_i \times \frac{100}{6}$	$\boldsymbol{Total\ score} = \frac{Symptoms + Emotions + Functioning}{3}$
Score range	0-30		0-100			
Interpretation	Higher score indicates worse HRQoL		Higher score indicates worse HRQoL			

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; HRQoL = Health related quality of life; $item_i$ = the score on the *i*th item of the questionnaire; NRR = number of ‘not relevant’ responses.

[α]: Both DLQI and DLQI-R are based on the same DLQI questionnaire.

1.3. Clinical use of HRQoL measurement in dermatology

In dermatological clinical practice, the primary purpose of the assessment of HRQoL is to better understand the patients' subjective experience with their illness, which provides valuable information for the clinician. HRQoL information is useful to inform clinical decisions, support clinician-patient communication and improve the awareness of skin disease burden, among others (Table 3) [9,78].

Table 3 – Use of HRQoL measurement in dermatology, an adapted table from Finlay et al. 2017 [78]

Inform clinical decisions	Aid treatment decision taking
	Guideline use
	Shared decision taking
	Treatment goals
	Treatment adjustment at follow-up
	Discharge decisions
Clinician-patient communication	Clinician-patient relationship
	Clinician-patient enhanced dialogue
Awareness of skin diseases burden	Impact on clinician
	Impact on patient
Informing the consultation: information aid for prognosis, monitoring, screening, adherence and referral	Structured clinical assessment
	Prediction outcomes/prognosis
	Adherence/compliance
	Screening
	Monitoring of disease course
	Education
	Referral to other services
Clinical service administration	Guideline use/development
	Audit/Clinical audit
	Administration/policy

1.4. Use of HRQoL data in guidelines in dermatology

In both national and international guidelines and registries within the field of dermatology, there is an increasing trend toward adopting the DLQI. So far, more than 45 countries have been using the DLQI for these purposes. Overall, 18 European countries have included the DLQI in their guidelines, and 10 have incorporated it into their patient registries [59].

Table 4 – European countries using the DLQI in national guidelines or registries and for which disease, an adapted table from Singh, R., & Finlay, A. (2020) [59]

Country	Guideline	Registry	Disease(s)
Belgium	Yes	No	Psoriasis
Bulgaria	Yes	No	Psoriasis, HS, HE
Croatia	Yes	Unknown	Psoriasis
Czech Republic	Yes	Yes	Psoriasis
Denmark	Yes	Yes	Psoriasis
Finland	Yes	No registry	Psoriasis
France	Yes	Unknown	Psoriasis
Germany	Yes	Yes	Psoriasis, AD, HE
Hungary	Yes	No registry	Psoriasis
Italy	Yes	Yes	Psoriasis
Netherlands	Yes	Yes	Psoriasis
Poland	Yes	Unknown	Psoriasis
Portugal	Yes	Yes	Psoriasis
Romania	Yes	Unknown	Psoriasis
Slovenia	Yes	Yes	Psoriasis
Spain	Yes	Yes	Psoriasis
Sweden	Yes	Yes	Psoriasis
United Kingdom	Yes	Yes	Psoriasis. AD

AD = atopic dermatitis; HE = hand eczema; HS = hidradenitis suppurativa

In Europe, there is a consensus on defining plaque psoriasis severity using three clinical criteria [79]. The Psoriasis Area and Severity Index (hereinafter: PASI) is used to assess disease severity, the Body Surface Area (hereinafter: BSA) to express skin involvement

in terms of percentage of body surface area, and the DLQI to monitor dermatology-specific HRQoL.

In Hungary, the allocation of funding for medical treatments is determined by evaluating the QALY gain by the National Public Health and Pharmaceutical Centre (hereinafter: NNGYK) (formerly known: National Institute of Pharmacy and Nutrition OGYÉI) based on the Directive of the Ministry of Human Resources (hereinafter: EMMI) . Decision-makers for psoriasis treatment must adhere to the current funding protocol of the National Health Insurance Fund (NHIF). According to the current Hungarian funding protocol, systemic biological therapy may be initiated if PASI ≥ 15 or BSA ≥ 10 and DLQI ≥ 10 [80]. Adequate therapeutic response from initiation of treatment is assessed 12 to 16, defined as a 50% reduction in PASI or BSA and a reduction of at least 5 points in DLQI [80-82].

1.5. Validation of HRQoL measures

In recent decades, there has been a significant increase in the availability of HRQoL questionnaires, which provide a wide range of choices of appropriate instruments. The most important measurement properties of HRQoL questionnaires are described in Table 5 [83,84].

Table 5 – Key measurement properties of HRQoL questionnaires, an adapted from Terwee et al. 2007, Prinsen et al. 2018 and Rencz et al 2021 [83,85,86]

Measurement properties	**Definition**
Internal consistency	Items within a subscale/domain/scale measure the same construct.
Reliability	The capacity to differentiate between patients, even when there are measurement errors.
Measurement error	The degree to which scores on repeated measures closely align, indicating the absolute measurement error.
Test-retest reliability	The extent to which the questionnaire can consistently measure the construct it is intended to measure. For example, successive measurements using the same questionnaire should provide the same or very similar results with the same constructs (test-retest reliability).
Content validity	The content of the questionnaire is representative of the underlying theoretical framework or domain of interest.
Convergent and divergent validity	The questionnaire under examination and how effectively it aligns with or diverges from other valid existing questionnaires measuring a similar (convergent) or different (discriminant) construct.
Construct validity	The degree to which scores on a specific questionnaire align with other measures in a manner that is consistent with theoretically derived hypotheses regarding the concepts being measured.
Cross-cultural validity	The degree to which a scale exhibits similar performance when applied to a different skin type or ethnic group compared to its performance on the original skin type or ethnic group.
Responsiveness	The ability of a questionnaire to detect clinically significant changes over time.
Floor & ceiling effects	A significant proportion of respondents (15%) indicated the lowest or highest possible score.
Score interpretation	The process of assigning a qualitative meaning to numerical scores. For instance, on a 0-30-point scale, how many points considered poor or good. (According to Hongbo et al. interpretation of DLQI: 0–1: no effect on patient's life, 2–5: small effect on patient's life, 6–10: moderate effect on patient's life, 11–20: very large effect on patient's life, 21–30: extremely large effect on patient's life)[87]

1.6. Modifications of HRQoL questionnaires

Many dermatology-specific HRQoL questionnaires offer multiple versions. It is important to underscore that conducting a linguistic-cultural adaptation of an existing, validated HRQoL questionnaire is essential when the instrument is intended for application in a population distinct from the source population. However, translations and/or cultural adaptations cannot be considered a modification of the questionnaire [39,88].

A standard and validated questionnaire loses its validity immediately if a single character is changed in its content. Any modifications require re-validation, involving testing the measurement properties against established criteria (typically 8-10 measurement properties). Limited knowledge about other modifications does not necessarily mean they are of suboptimal quality; however, their use is cautioned until further validation is conducted.

Dermatology-specific instruments have a significant impact on the financial guidelines in dermatology. In certain instances, a modified questionnaire may lead to a different outcome from the actual result. Some non-validated modifications provide unreliable information. Consequently, individuals may receive treatment when it is not warranted, and patients who genuinely require treatment may be excluded due to inappropriate questionnaire selections [89-91]. Unvalidated modifications may also lead to manipulative practices in medical product labelling and reimbursement requests.

The copyright law protects the integrity of all standardised questionnaires against unauthorized individual objectives. Copyright holders could control access, modification, and translation of their instrument to ensure the validity and comparability of results, which may provide benefits over the developments [89,90,92]. The copyright owners have every right to prohibit any modifications however a new, well-founded scoring method or a bolt-on dimension may correct some potential bias in response options or improve the content validity of the original questionnaire and the help of these modifications can improve the measurement of HRQoL [62,93,94].

Modification may be directed at altering the content of the questionnaire, such as modifying response scales, reducing or increasing the number of questions (bolt-on, bolt-off, or bolt-on&offs), excluding particular dimensions, or adding new questionnaire items (e.g., skin irritation, self-confidence, sleep or energy dimensions were added to the original EQ-5D questionnaire) [17,95,96]. The introduction of different additional dimensions enhances content validity, allowing respondents to articulate their opinions on matters not initially addressed in the original questionnaire. Changing the existing wording of the instruments is also an opportunity to modify a measure by replacing the wording of an existing question in order to make it more understandable to a specific target group (children-specific instruments, like Children DLQI (CDLQI), Skindex-teen, EQ-5D-Y, and Teenager's Quality of Life (T-QoL)) [97-100], but also by changing the disease focus of the questionnaire (replacing the name of the skin with a specific disease or symptom). Furthermore, the recall period is another significant change, whereby the questionnaire compiler does not use the original recall of but shortens or lengthens the recall period [101]. Scoring methods are also modifications where the calculation rules or the scoring methods change, or response scale modifications result in different total scoring calculations.

2. Objectives

Our studies aimed to identify all – available at the time of research – modifications of DLQI and to compare measurement properties of dermatology-specific measures in patients with chronic skin conditions in Hungary. Our specific aims are described below.

2.1. Modified versions and alternative scoring methods of DLQI

The purpose of the research was the following:

1) To conduct a systematic review of the existing international literature and identify all modified questionnaire versions and alternative scoring methods of the DLQI.

2) To categorize all modifications and scoring methods.

3) To assess measurement properties of the modified DLQI versions.

2.2. Comparison of the measurement performance of dermatology-specific HRQoL outcomes (DLQI, DLQI-R and Skindex-16)

The objective of the cross-sectional study was the following:

1) To compare the measurement properties (floor and ceiling effect, informativity, convergent validity and validity between known groups) of three dermatology-specific HRQoL outcomes (DLQI, DLQI-R and Skindex-16) in a population-based sample of patients with chronic skin diseases.

3. Results

This chapter of the PhD thesis draws upon the results of two published articles of the candidate [77,85]:

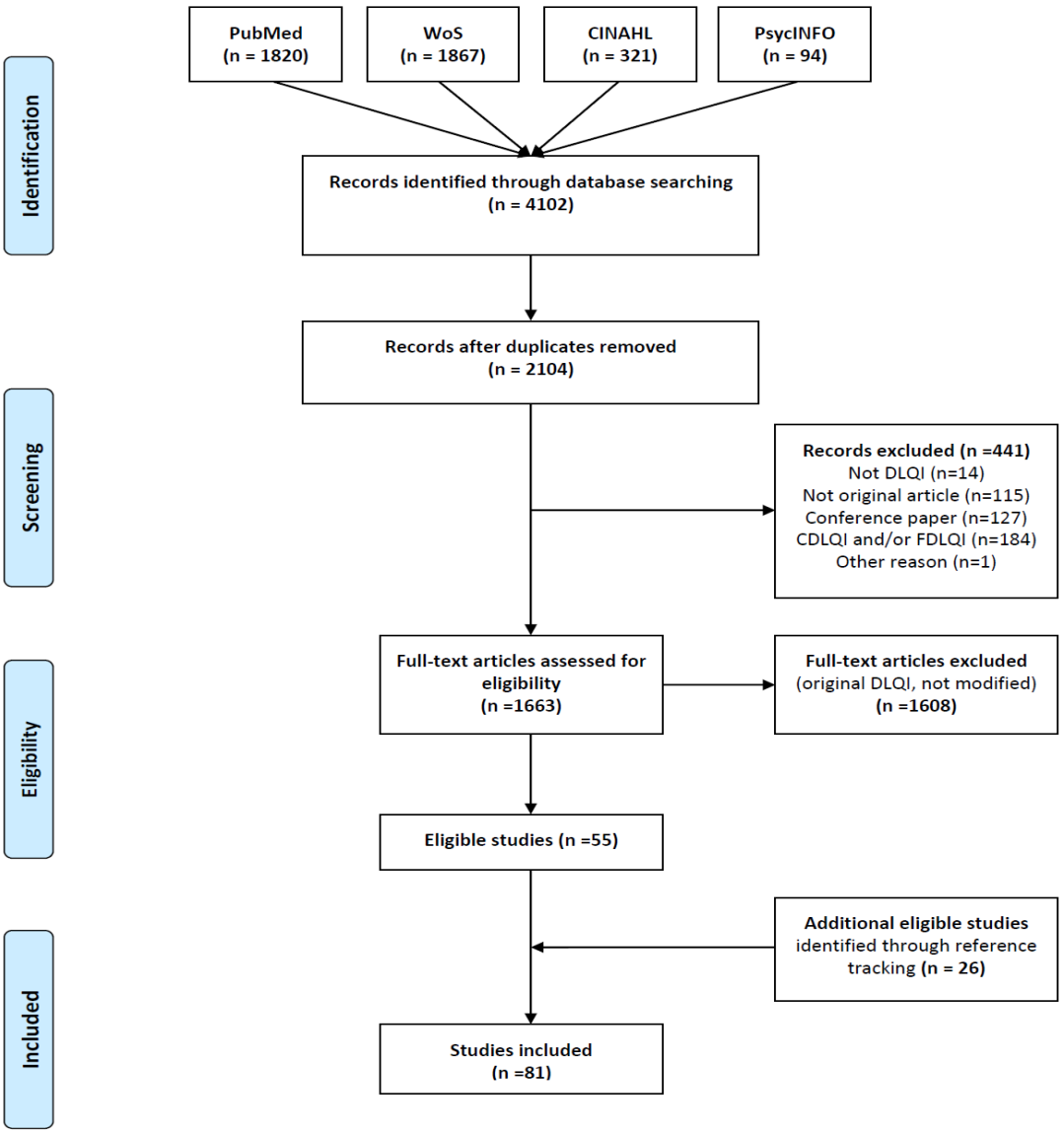
1. **Szabó Á**, Brodszky V, Rencz F. (2022) A comparative study on the measurement properties of Dermatology Life Quality Index (DLQI), DLQI-Relevant and Skindex-16. Br J Dermatol, 186: 485-495.

2. Rencz F, **Szabó Á**, Brodszky V. (2021) Questionnaire Modifications and Alternative Scoring Methods of the Dermatology Life Quality Index: A Systematic Review. Value Health, 24: 1158-1171.

3.1. Results of Modified versions and alternative scoring methods of DLQI

3.1.1. Inclusion of relevant studies

The electronic database search yielded 4,102 records, 1,663 of which were full-text articles retrieved, and 55 finally deemed eligible. The majority of full texts were excluded, as they used the original DLQI without any modifications in the questionnaire or its scoring. Further 26 eligible articles were identified by tracking the reference lists of included papers (n=12) and by searching Google Scholar (n=14). Thus, 81 articles reporting on 77 studies were included in this systematic review (Figure 2).



CDLQI = Children's Dermatology Life Quality Index; FDLQI = Family Dermatology Life Quality Index; DLQI = Dermatology Life Quality Index; WoS = Web of Science

Figure 2 – Study flow diagram [85]

To make a clear distinction, hereafter these are referred to as 'article' and 'study'. Citations for each study are provided in the Tables 6-10.

Sample sizes of the included studies varied widely, ranging from one to 9,845 patients. The cumulated sample size was 25,509 participants, 99% of which were patients and 1% healthy controls. A total of 47 different diagnoses/symptoms were studied (Table 6).

The most frequently studied diseases were psoriasis (n=16, 21%), acne (n=6, 8%), hirsutism (n=6, 8%), alopecia (n=5, 6%) and bromhidrosis (n=5, 6%).

Table 6 – Diagnoses/symptoms in which DLQI modifications were used [85]

	Studies (n)[a]	%	Patient number (n)[b]	%	Modifications (n)	%	References
Acne	6	8%	3721	15%	5	8%	[102-107]
Alopecia	5	6%	496	2%	5	8%	[106,108-111]
Asteatotic eczema	1	1%	5	<1%	1	2%	[112]
Atopic dermatitis	4	5%	335	1%	3	5%	[103,106,113,114]
Bromhidrosis	5	6%	494	2%	2	3%	[115-119]
Burn	1	1%	49	<1%	1	2%	[120]
Contact dermatitis	4	5%	1481	6%	4	7%	[106,121-123]
Cutaneous larva migrans	1	1%	91	<1%	2	3%	[124,125]
Darier's disease	1	1%	1	<1%	1	2%	[126]
Dermatitis (unspecified)	2	3%	1294	5%	2	3%	[103,106]
Discoid lupus	1	1%	7	<1%	1	2%	[106]
Eczema (unspecified)	2	3%	1287	5%	2	3%	[103,104]
Filarial lymphodema	2	3%	118	<1%	2	3%	[127,128]
Folliculitis	1	1%	1	<1%	1	2%	[104]
Hand eczema	2	3%	2319	9%	1	2%	[129,130]
Hidradenitis suppurativa	3	4%	264	1%	2	3%	[104,131,132]
Hirsutism	6	8%	293	1%	3	5%	[133-138]
Hyperhidrosis	4	5%	207	1%	2	3%	[104,139-141]
Leg ulcers	1	1%	17	<1%	1	2%	[106]
Lipodystrophia	1	1%	84	<1%	1	2%	[142]
Melasma	1	1%	8	<1%	1	2%	[106]
Morphea	1	1%	101	<1%	1	2%	[63]
Nodular prurigo	1	1%	6	<1%	1	2%	[106]
Obesity	1	1%	79	<1%	1	2%	[132]
Pachyonychia congenita	1	1%	76	<1%	1	2%	[143]
Pemphigus	2	3%	115	<1%	1	2%	[63,106]
Photoaging	1	1%	35	<1%	1	2%	[144]
Photodermatoses	3	4%	949	4%	3	5%	[145-147]
Pigment disorder (unspecified)	1	1%	2	<1%	1	2%	[104]
Port-wine stains	1	1%	197	1%	1	2%	[148]
Pruritus	4	5%	196	1%	3	5%	[112,114,149,150]
Psoriasis	16	21%	5188	20%	15	25%	[60,62,63,103,104,106,114,132,151-160]
Rosacea	1	1%	2	<1%	1	2%	[104]

	Studies (n)[a]	%	Patient number (n)[b]	%	Modifications (n)	%	References
Sarcoidosis	1	1%	1	<1%	1	2%	[104]
Scabies	2	3%	217	1%	4	7%	[161,162]
Scleroderma	1	1%	1	<1%	1	2%	[104]
Seborrheic dermatitis	2	3%	198	1%	2	3%	[112,163]
Sialorrhoea	2	3%	13	<1%	2	3%	[164,165]
Skin toxicity after chemotherapy	3	4%	547	2%	3	5%	[166-168]
Skin tumour (unspecified)	1	1%	4	<1%	1	2%	[104]
Tinea capitis	1	1%	10	<1%	1	2%	[106]
Tungiasis	1	1%	50	<1%	1	2%	[169]
Urticaria	4	5%	843	3%	4	7%	[103,106,114,170]
Vaginal candidiasis	2	3%	303	1%	2	3%	[171,172]
Vascular malformation	1	1%	20	<1%	1	2%	[160]
Vitiligo	3	4%	283	1%	3	5%	[148,173,174]
Warts	3	4%	312	1%	2	3%	[106,175,176]
Other (unspecified)	6	8%	2934	12%	5	8%	[103,104,106,112,177,178]
Healthy controls	3	4%	255	1%	3	5%	[106,125,143]
Total[c]	**77**		**25509**		**59**		

a: The papers by Kim et al. 2014 [153], 2015a [154] and 2015b [155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a[60] and 2019b [179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011 [124] and Shimogowara et al. 2013 [125] used the same dataset and therefore considered one study.

b: The patient populations of the Rencz et al. 2018 [62] and 2019[63] studies overlapped.

c: Figures in the number of studies and number of modifications columns do not add up as one study may have included patients with various diseases/symptoms.

Most study designs were cross-sectional studies (n=35, 45%), non-controlled clinical trials (n=19, 25%) or randomized controlled trials (n=11, 14%). The majority of studies included outpatients (n=64, 83%). Approximately one-third of the studies were multicentre (n=24, 31%) (Table 7).

Table 7 – Instrument administration characteristics of the studies [85]

	Studies (n)	%	References
Study design [b]			
case-control study	1	1%	[148]
case study	1	1%	[126]
cross-sectional	35	45%	[60,62,63,102-110,114,121,122,127,129,131,132,142,146,149,156,158,160-162,166,168,171,173,176-178] [151]
non-controlled clinical trial [a]	19	25%	[111,112,115,116,118,124,125,128,133,134,136-138,140,144,157,164,165,169,172]
non-randomized controlled trial	1	1%	[117]
prospective cohort	3	4%	[130,159,175]
randomized controlled trial [a]	11	14%	[60,113,119,120,135,139,145,150,163,167,170,179]
registry-based study	2	3%	[143,152]
retrospective cohort [a]	5	6%	[123,141,147,153-155,174]
Clinical settings [c]			
community-based [a]	4	5%	[124,125,128,162,169]
Inpatient	1	1%	[103,167]
in- and outpatient	2	3%	[62,63]
online survey	2	3%	[102,158]
outpatient [a]	64	83%	[60,104-108,110-123,126,127,129,131-140,142-145,147-150,152-157,159-161,163-166,168,170-179]
postal survey	5	6%	[109,141,146,151,158]
Number of centres			
single centre [a]	48	62%	[104,106,108,110-112,115-120,122,124-126,132-134,136,138-145,147,149,150,152,156,157,160-162,164-166,168,170,171,173-178]
multicentre [a]	24	31%	[60,62,63,103,105,107,113,114,121,123,127,129-131,135,137,146,148,151,153-155,159,163,167,172,179]
n/a	5	6%	[102,109,128,158,169]

a: The papers by Kim et al. 2014 [153], 2015a [154] and 2015b [155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a [60] and 2019b [179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011 [124] and Shimogowara et al. 2013 [125] used the same dataset and therefore considered one study.

b: The sum of the studies is 78, as Barbieri & Gelfand 2019 [60] reported results of two studies: a cross-sectional and a randomized controlled trial.

c: The sum of the studies is 78, as Meeuwis et al. 2011 [158] used both online and postal surveys.

n/a = not applicable

So far, modified DLQI questionnaires or scorings were used in 23 different languages, whereby English being the most common (n=23, 30%) (Appendix 1). The most frequently administered non-English questionnaires were Chinese, Danish, German, Japanese and Persian. The studies originated from 28 different countries. The most common were the UK (n=9, 12%) and China (n=8, 10%) (Appendix 2).

3.1.2. Studied questionnaires and scorings

The 77 studies contained information on overall 59 questionnaire or scoring modifications to the DLQI. Overall, seven (9%) studies used more than one questionnaire modification. The majority of the modifications were item modifications (n=30, 51%) or body part/disease/symptom specifications (n=28, 47%).

Overall, 15 (25%) different scoring modifications were identified, three (5%) of which were alternative scorings to the original DLQI questionnaire. Recall period was changed in 11 (19%) questionnaires to nine different time frames, the most frequent of which was last year (three questionnaire versions in n=9 studies). Other modification types included response scale changes (n=5, 8%), changes made to the target population (i.e. children) (n=4, 7%) and pictorial illustrations (n=2, 3%). A total of 10 (17%) modifications appeared in multiple studies: last year DLQI (n=7), bromhidrosis or hyperhidrosis-specific DLQI (n=6), hirsutism-specific DLQI (n=4), DLQI-R scoring (n=3), DLQI-Q1 (n=3), Pruritus-related quality of life Index (n=3), Before surgical treatment DLQI (n=2), Before Botox DLQI (n=2), Rasch-calibrated DLQI for hand eczema (n=2) and viral wart-specific DLQI (DLQI-VW) (n=2) (Table 8).

Table 8 – Categorisation of DLQI modifications [85]

	Studies (n)	%	Modifications (n)	%	References
Scoring modifications	**20**	**26%**	**16**	**27%**	
Alternative scoring for the original questionnaire [a]	8	10%	4	7%	[60,62,63,131,143,149,150,156,179]
Other changes in scoring	12	16%	12	20%	[103,121,127,129,130,132,151,165,167,170,173,174]
Item modifications	**29**	**38%**	**28**	**48%**	
Bolt-on	4	5%	4	7%	[106,112,136,152]
Bolt-on&off [a]	15	20%	17	29%	[121,122,124,125,132,138,143,161,162,165,169,173-176]
Bolt-off	10	13%	7	12%	[103,110,114,120,129,130,142,160,167,170]
Recall period modifications	**20**	**26%**	**11**	**19%**	
Before the Botox treatment	2	3%	1	2%	[126,141]
Before the surgical treatment	2	3%	1	2%	[116,117]
Generally	2	3%	1	2%	[175,176]
Last month	1	1%	1	2%	[128]
Last 2 months	1	1%	1	2%	[102]
Last 6 months	1	1%	1	2%	[121]
Last year[a]	9	12%	3	5%	[104,108,109,123,145-147,153-155,158]
Over your lifetime with psoriasis[a]	1	1%	1	2%	[153-155]
Nowadays compared with before the phototherapy	1	1%	1	2%	[174]
Change in existing items	**28**	**36%**	**20**	**34%**	
Change in one item	16	21%	11	19%	[102,113,115-119,126,139-142,148,157,175,176]
Change in more items	12	16%	9	15%	[103,111,132,138,143,151,159,161,162,165,169,178]
Response scale modifications	**10**	**13%**	**9**	**15%**	
Change related to NRR	6	8%	4	7%	[106,116,159,165,175,176]
Frequency responses	1	1%	2	3%	[132]
Rating scale	1	1%	1	2%	[121]
Other modifications	2	3%	2	3%	[173,174]
Disease/symptom/body part specification[c]	**30**	**39%**	**26**	**44%**	
Disease specification[a]	11	14%	10	17%	[102,107,111,128,132,143,153-155,169,171,175,176]
Symptom specification	14	18%	9	15%	[105,109,114,120,133-135,137,142,143,160,165,166,172]
Body part specification	8	10%	7	12%	[110,127,138,143,159,163,168]

	Studies (n)	%	Modifications (n)	%	References
Illustrations	**2**	**3%**	**2**	**3%**	
Illustrated questions	1	1%	1	2%	[177]
Illustrated response options	1	1%	1	2%	[169]
Changes in the target population	**4**	**5%**	**4**	**7%**	
Children	4	5%	4	7%	[124,125,161,162,169]

a: The papers by Kim et al. 2014 [153], 2015a [154] and 2015b [155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a [60] and 2019b [179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011 [124] and Shimogowara et al. 2013 [125] used the same dataset and therefore considered one study.***b:*** The sum of percentages is > 100%, as one questionnaire modification may contain more than one changes. For example, a bolt-off may also change the response scales of the questions etc.

Among item modifications, there were four (7%) bolt-ons, eight (14%) bolt-offs and 18 (31%) bolt-on&offs. The number of items in the modified questionnaires ranged between three and twenty (Appendix 3). The majority of bolt-on items concerned mental health or social life (Table 9).

Table 9 – DLQI bolt-on items [85]

Bolt-on items	Studies (n)	%	Modifications (n)	%	References
Daily activities	**7**	**37%**	**6**	**27%**	
Disease making the living area messy or smelly	1	5%	1	5%	[165]
Lost time due to skin disease/ time spent to apply treatment or make-up to camouflage lesions	5	26%	4	18%	[138,152,174-176]
Playing	1	5%	1	5%	[161]
Disease-specific symptoms	**2**	**11%**	**1**	**5%**	
Bleeding from warts	2	11%	1	5%	[175,176]
Pain due to warts	2	11%	1	5%	[175,176]
Functioning	**7**	**37%**	**6**	**9%**	
Coughing/choking	1	5%	1	5%	[165]
Sleeping[a]	4	21%	4	18%	[121,124,125,143,169]
Speaking	1	5%	1	5%	[165]
Walking	1	5%	1	5%	[169]
General health	**2**	**11%**	**2**	**9%**	
Civil rights equivalent to that of a healthy citizen's	1	5%	1	5%	[173]
General rating of health	1	5%	1	5%	[174]

Bolt-on items	Studies (n)	%	Modifications (n)	%	References
General rating of health compared with before the phototherapy	1	5%	1	5%	[174]
Influence on life	1	5%	1	5%	[174]
Mental health	**8**	**42%**	**8**	**36%**	
Anxiety	1	5%	1	5%	[106]
Being annoyed/irritable	1	5%	1	5%	[121]
Being frustrated	3	16%	2	9%	[121,175,176]
Being overwhelmed by the skin problem	1	5%	1	5%	[173]
Depression/inferiority complex	3	16%	3	14%	[106,121,161]
Effect on spirituality	1	5%	1	5%	[173]
Feeling uncomfortable	1	5%	1	5%	[121]
Getting upset	1	5%	2	9%	[132]
Insecurity/negative feelings	1	5%	1	5%	[174]
Worrying about infecting others	1	5%	1	5%	[121]
Social life	**9**	**47%**	**9**		
Being teased[a]	3	16%	3	14%	[124,125,161,162]
Fear of negative appraisal by others	2	11%	1	5%	[175,176]
Feeling stared at by people in the neighbourhood	1	5%	1	5%	[174]
Getting married	1	5%	1	5%	[173]
Interactions	1	5%	2	9%	[132]
Performing prayers publicly	1	5%	1	5%	[173]
Physical health and emotional problems inhibiting social activities with friends, family and others	1	5%	1	5%	[174]
Playing a role in finding new friends/relationship	1	5%	1	5%	[174]
Social exclusion	1	5%	1	5%	[169]
Therapy-related	**4**	**21%**	**3**	**14%**	
Alcohol/ medication use	1	5%	1	5%	[143]
Frustrated with current treatment	2	11%	1	5%	[175,176]
Frustrated with past treatment	2	11%	1	5%	[175,176]
Herbal medicine therapy	1	5%	1	5%	[112]
Work and financial problems	**5**	**26%**	**4**	**19%**	
Disease interferes with daily work	4	21%	2	9%	[121,143]
Financial problems/costs of disease/costs of treatment	2	11%	3	14%	[121,152,175,176]
Using hands at work	1	5%	1	5%	[121]
Worrying about being fired	1	5%	1	5%	[121]
Other (unspecified)	**2**	**11%**	**3**	**14%**	**[136,162]**

Bolt-on items	Studies (n)	%	Modifications (n)	%	References
Total	**19**		**21**		

a: The papers by Schuster et al. 2011[124] and Shimogowara et al. 2013 [125] used the same dataset and therefore considered one study.

Change in existing items occurred in 11 (19%) questionnaires. The most common changes to the existing DLQI items were that researchers changed the activities in each item to better fit their own research objectives.

Table 10 – The most common changes in existing DLQI items [85]

DLQI Item	Original wording	Wording changes	Studies (n)	%	Modifications (n)	%	References
Item 1	Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?	'***Itchy, sore, painful or stinging***' was changed to '***sweaty***'.	8	10%	2	3%	[116,118,119,126,139-141,147]
		'***Itchy, sore, painful or stinging***' was changed to '***drooling***'.	1	1%	1	2%	[165]
		'***Stinging***' was changed to '***burning***'.	1	1%	1	2%	[159]
		'***Stinging***' was changed to ***'irritation or oils on your scalp'.***	1	1%	1	2%	[111]
		'***If you have ingrown hair***' was added to the end of the question.	1	1%	1	2%	[138]
Item 2	Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?	'***Self conscious***' was changed to '***insecure***'.	1	1%	1	2%	[159]
		'***Frustration***' was added.	1	1%	1	2%	[111]
		'Self conscious' was changed to '***ashamed'***	3	4%	5	8%	[161,162,169]
Item 3	Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?	'***Garden***' was replaced by '**attending college or work**'.	1	1%	1	2%	[102]
		The word '***garden***' was removed.	1	1%	1	2%	[138]
Item 4	Over the last week, how much has your skin influenced the **clothes** you wear?	***'Hairstyle***' was added to the question.	1	1%	1	2%	[148]
		'***Clothing***' was replaced with ***'hairstyle***' and an extra sentence was added ***'Do you need to wear a hat, wig or***	1	1%	1	2%	[111]

DLQI Item	Original wording	Wording changes	Studies (n)	%	Modifications (n)	%	References
		special hair type to cover the thinner area?'.					
		'***Make-up***' was added to the question.	1	1%	1	2%	[165]
Item 5	Over the last week, how much has your skin affected any **social** or **leisure** activities?	'***Social or leisure***' was changed to '***spare-time***'.	1	1%	1	2%	[162]
		The word '***social***' was removed.	3	4%	4	7%	[132,162,169]
Item 6	Over the last week, how much has your skin made it difficult for you to do any **sport**?	'***Hobbies***' was added.	1	1%	1	2%	[111]
Item 7	Over the last week, has your skin prevented you from **working or studying**? If "No", over the last week how much has your skin been a problem at **work** or **studying**?	The word 'studying' or '***school***' was removed.	3	4%	3	5%	[157,161,162]
		The word '***work***' was removed or 'working or studying' was changed to 'school work'.	3	4%	3	5%	[161,162,169]
		The two separate questions were merged into one: ***'How much has your skin been a problem at work or studying?***'.	1	1%	1	2%	[116]
		The question was rephrased as ***'curtailed working or going out***'.	1	1%	1	2%	[165]
Item 8	Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?	The question was rephrased as ***'interfered with socializing with your spouse or friends?'***.	1	1%	1	2%	[165]
		'***Partner or any of your close friends or relatives***' was changed to '***relationships***'.	1	1%	2	3%	[132]
		'***Partner or any of your close friends or relatives***' was changed to '***friendships***'.	3	4%	3	5%	[161,162,169]
		'***Partner or any of your close friends or relatives***' was changed to '***social contacts***'.	2	3%	2	3%	[161,162]
		The question was rephrased as '***interfere with personal relationships***'.	2	3%	1	2%	[175,176]
Item 9	Over the last week, how much has your skin caused any **sexual difficulties**?	'***Sexual difficulties***' was changed to '***difficulties in your love life***'.	1	1%	1	2%	[159]
		'Sexual difficulties' was replaced by '***problems in close personal relationships***'.	1	1%	1	2%	[113]

DLQI Item	Original wording	Wording changes	Studies (n)	%	Modifications (n)	%	References
Item 10	Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?	'***Making your home messy***' was changed to '***interfering with your daily schedule***'.	1	1%	1	2%	[138]
		'***For example by making your home messy, or by taking up time'*** was removed.	1	1%	1	2%	[116]
		'***The treatment for your skin been, for example, by making your home messy or by taking up time***' was replaced with '***take care of your pachonychia congenita***'.	1	1%	1	2%	[143]
		'***Making your home messy, or by taking up time***' was changed to ***'making your clothing and other articles messy or by taking up time***'.	1	1%	1	2%	[159]
		The question was rephrased as ***'caused living area to be smelly and messy'.***	1	1%	1	2%	[165]
		'***Treatment***' was changed to ***'attempts to solve problems due to body changes'***.	1	1%	1	2%	[142]
All items	-	The items were rephrased into neutral frames, i.e. not to lead a respondent to consider this as a negative phenomenon.	1	1%	1	2%	[178]

3.1.3. Methodological quality of studies (COSMIN criteria)

The quality of measurement properties of all identified questionnaire modifications or scorings were evaluated according to the quality criteria adapted based on Terwee et al. and Prinsen et al. (Appendix 4). Overall, 29 (36%) of the included 81 articles presented information on the measurement properties of DLQI modifications according to the COSMIN checklist (Appendix 5). Overall, 25 (31%) publications applied classical test theory methods to evaluate measurement properties, three used item response theory [103,129,151] and one used both [143]. The overall methodological quality of the articles was generally weak. There were only three modifications that received at least one 'good' or 'excellent' rating. The most frequently assessed measurement properties were hypothesis testing (n=21, 26%), internal consistency (n=10, 12%) and criterion validity (n=6, 7%). Content validity (n=5, 6%), reliability (n=3, 4%), structural validity (n=3, 4%), cross-cultural validity (n=1, 1%) and responsiveness (n=1, 1%) were examined for a few questionnaires. There were no publications that reported measurement error.

3.1.4. Measurement properties of DLQI modifications (Terwee criteria)

Sixty-four (79%) of the included 81 articles presented information on the measurement properties of the questionnaire or scoring modification according to the Terwee criteria (n=29, 36% without floor and ceiling effects and interpretability). Internal consistency was rated as positive for four questionnaires and intermediate for nine others (Appendix 6). Cronbach's α and person separation index for these modified questionnaires ranged from 0.67 to 0.87 [102,106,107,114,127,143,148,160,176] and from 0.68 to 0.87, respectively[103,107,129,151]. Evidence on reliability was available for three articles, one was rated as positive while two of them were intermediate. Content validity was assessed for five articles (three positive and two intermediate). There was positive evidence for structural validity in two publications, intermediate in two publications and negative in two others. Construct validity was assessed for 22 articles (nine positive, seven intermediate and six negative). Good criterion validity was described for six publications, while only one article received negative rating. Responsiveness was tested only in one study with positive results for DLQI-R scoring. Evidence for floor and ceiling effects was reported for 24 (30%) articles, seven of which were rated as positive, 14 as intermediate and two as negative. Furthermore, in one article, the DLQI-R was rated as positive, while the DLQI-SF as intermediate for floor and ceiling effects. For interpretability, none of the articles were rated as positive, but a total of 47 (58%) were graded as intermediate.

3.2. Results of comparison of the measurement performance of dermatology-specific HRQoL outcomes (DLQI, DLQI-R and Skindex-16)

3.2.1. Characteristics of the study population

Mean age was 50.5±16.9 years (minimum 18, maximum 86 years). More than half of the sample were female (n=358, 57.9%) (Table 11). Patients self-reported a total of 49 different dermatological conditions, the most common of which were warts (n=143, 23.1%), eczema (n=140, 22.7%), onychomycosis (n=113, 18.3%), acne (n=83, 13.4%) and psoriasis (n=82, 13.2%). Moreover, in the open-ended text box, further 39 different skin conditions were indicated (n=102, 16.5%). Mean health status PG-VAS and WHO-5 well-being scores were 66.5±23.4 and 41.4±16.6, respectively.

3.2.2. Descriptive results of the outcome measures

The mean DLQI and DLQI-R scores were 3.76±5.03 and 4.11±5.34, respectively. Of the 618 patients, 230 (37.2%) marked at least one NRRs with the highest number of NRRs occurring in patients with rosacea (54.8%) and basal cell carcinoma (51.6%), while the fewest in patients with eczema (32.1%) and psoriasis (34.2%) (Table 11). Mean Skindex-16 subscale (functioning, emotions, symptoms) scores were 22.2±28.3, 35.9±30.4 and 30.0±28.6, respectively, and mean Skindex-16 total score was 29.4±26.6.

Table 11 – Characteristics of the study population [77]

Variables	n (%)	% of patients with ≥1 NRRs on the DLQI	Mean number of NRRs on the DLQI (SD)
Total sample	618 (100%)	37.2%	1.09 (2.04)
Sex			
Male	260 (42.1%)	38.8%	1.24 (2.29)
Female	358 (57.9%)	36.0%	0.97 (1.83)
Age groups (years)			
18 - 29	93 (15.0%)	23.7%	0.69 (1.63)
30 - 39	89 (14.4%)	39.3%	1.49 (2.59)
40 - 49	115 (18.6%)	38.3%	1.19 (2.25)
50 - 59	92 (14.9%)	29.4%	0.86 (1.93)
60+	229 (37.1%)	44.5%	1.13 (1.85)
Education			
Primary school	31 (5.0%)	51.6%	1.19 (1.85)
Secondary school	462 (74.8%)	36.6%	1.08 (2.06)
College / university	125 (20.2%)	36.0%	1.08 (2.18)
Marital status			
Married / domestic partnership	421 (68.1%)	33.0%	1.05 (2.16)
Single / divorced / widower	197 (31.9%)	46.2%	1.16 (1.75)
Net monthly household income (HUF)			
≤ 150 000	121 (19.6%)	45.5%	1.22 (2.02)
150 001-300 000	218 (35.3%)	37.6%	1.15 (2.10)
≥300 000	195 (31.6%)	28.2%	0.81 (1.90)
Don't know / refused to answer	84 (13.6%)	45.2%	1.37 (2.17)
Diagnoses			
warts	143 (23.1%)	37.8%	1.10 (2.12)
eczema	140 (22.7%)	32.1%	0.91 (1.96)
onychomycosis	113 (18.3%)	38.9%	1.23 (2.22)
acne	83 (13.4%)	34.9%	0.93 (1.53)
psoriasis	82 (13.2%)	34.2%	0.82 (1.66)
tinea pedis	46 (7.4%)	41.3%	0.85 (1.70)
basal cell carcinoma	31 (5.0%)	51.6%	1.26 (2.02)
rosacea	31 (5.0%)	54.8%	1.32 (1.89)
urticaria	22 (3.6%)	40.9%	0.77 (1.41)
herpes zoster	11 (1.8%)	36.4%	1.36 (2.66)
other	102 (16.5%)	42.6%	1.22 (2.05)

DLQI = Dermatology Life Quality Index; NRR = 'not relevant' response

3.2.3. Ceiling and floor effects

Ceiling effect was 0% for both the DLQI and DLQI-R total score and 1.1% for Skindex-16 total score. A high floor effect was observed for DLQI and DLQI-R (26.5%), whereas it was merely 11.8% for the Skindex-16 total score. Out of the 73 patients with Skindex-16 total score of zero, 14 (19.2%) reported problems on DLQI/DLQI-R. Out of the 164 patients with a DLQI and DLQI-R score of zero, 105 (64.0%) had a Skindex-16 total score higher than zero.

Both with DLQI (or DLQI-R) and Skindex-16, item-level ceiling effect was low, with the exception of item 5 (persistence/reoccurrence, 19.7%) of Skindex-16 (Table 12). Floor effect ranged between 39.3% and 70.2% for the DLQI items and between 27.5% and 57.6% for Skindex-16 items. Four of the five Skindex-16 items with matched 'severity' format DLQI pairs significantly reduced the presence of floor effect compared to the DLQI ($p<0.05$). All four Skindex-16 items with 'interference with functioning' format DLQI pairs reduced the presence of floor effect compared to the DLQI ($p<0.05$).

Table 12 – Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 [77]

DLQI / DLQI-R*			Skindex-16		
Items	**FE n (%)**	**CE n (%)**	**Items**	**FE n (%)**	**CE n (%)**
item 1 (itchy, sore, painful, stinging)	243 (39.3%)	22 (3.6%)	item 1 (itching)	192 (31.1%) α	53 (8.6%) β
			item 2 (burning or stinging)	305 (49.4%) α	28 (4.5%)
			item 3 (hurting)	313 (50.6%) α	25 (4.0%)
			item 4 (skin irritation)	216 (35.0%) α	50 (8.1%) β
item 2 (embarrassed, self-conscious)	316 (51.1%)	20 (3.2%)	item 9 (embarrassment)	308 (49.8%)	54 (8.7%) β
item 3 (shopping, home, garden)	434 (70.2%)	11 (1.8%)	item 15 (daily activities)	320 (51.8%) α	25 (4.0%) β
item 4 (clothing)	399 (64.6%)	20 (3.2%)	-	-	-
item 5 (social, leisure)	417 (67.5%)	13 (2.1%)	-	-	-
item 6 (sport)	381 (61.7%)	13 (2.1%)	-	-	-
item 7 (working, studying)	416 (67.3%)	20 (3.2%)	item 16 (work or do what you enjoy)	344 (55.7%) α	32 (5.2%) β
item 8 (interpersonal problems)	433 (70.1%)	8 (1.3%)	item 12 (interactions with others)	337 (54.5%) α	27 (4.4%) β
item 9 (sexual difficulties)	391 (63.3%)	8 (1.3%)	item 14 (show affection)	356 (57.6%) α	35 (5.7%) β
item 10 (treatment difficulties)	410 (66.3%)	5 (0.8%)	-	-	-
			item 5 (persistence / reoccurrence)	170 (27.5%)	122 (19.7%)
			item 6 (worry)	183 (29.6%)	96 (15.5%)
			item 7 (appearance)	193 (31.2%)	89 (14.4%)
			item 8 (frustration)	277 (44.8%)	54 (8.7%)
			item 10 (being annoyed)	193 (31.2%)	70 (11.3%)
			item 11 (feeling depressed)	280 (45.3%)	37 (6.0%)
			item 13 (desire to be with people)	333 (53.9%)	32 (5.2%)
			Symptoms subscale	148 (23.9%)	15 (2.4%)
			Emotions subscale	90 (14.6%)	18 (2.9%)
			Functioning subscale	256 (41.4%)	11 (1.8%)
DLQI / DLQI-R Total	164 (26.5%)	0 (0.0%)	Total	73 (11.8%) α	7 (1.1%) β

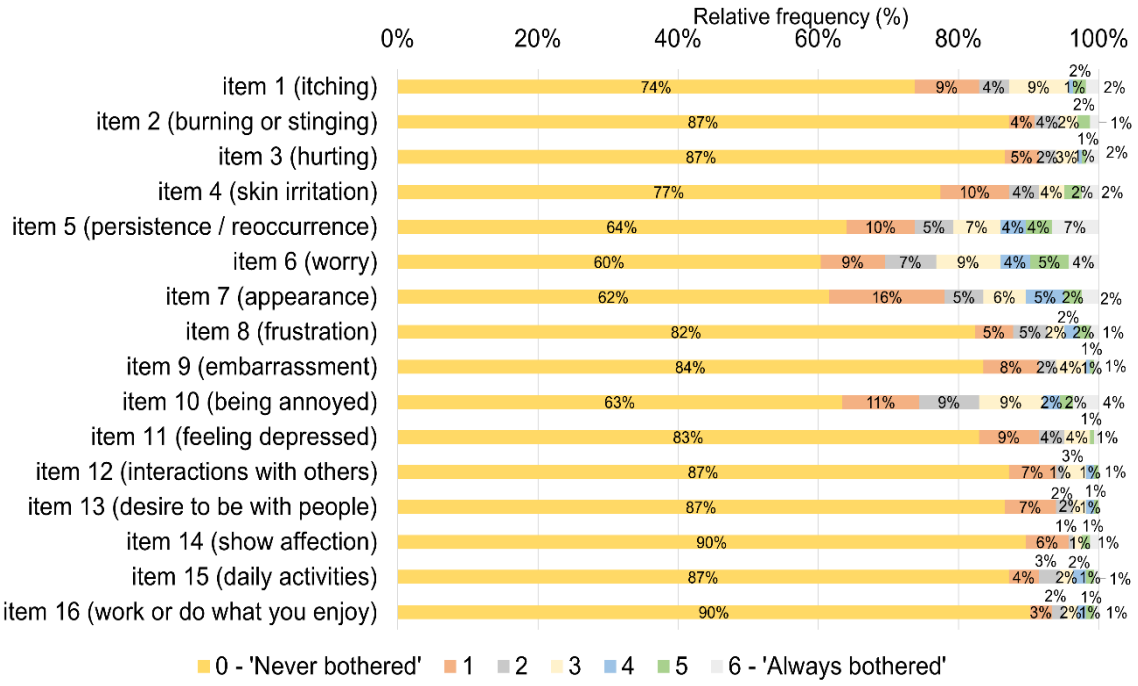
CE = ceiling effect; DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; FE =floor effect

* Theoretically, the ceiling effect for DLQI and DLQI-R total scores may be different; however, the sample included few patients with severe dermatological conditions, thus the two values were the same in this study.

α indicates a significant difference in floor effect between DLQI/DLQI-R and Skindex-16 ($p<0.05$).

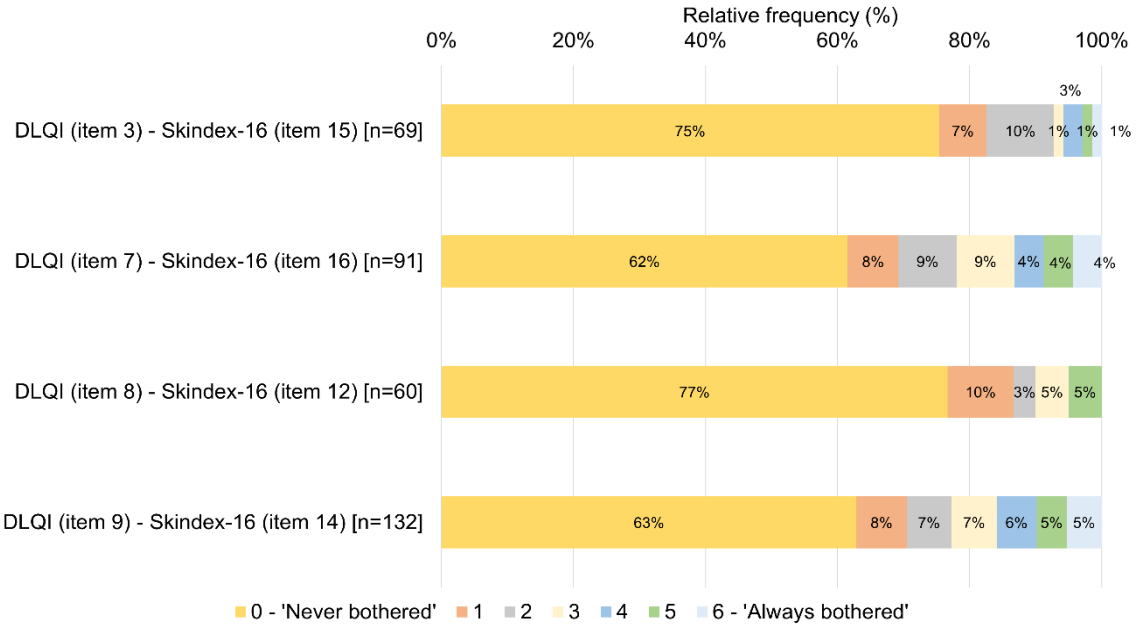
β indicates a significant difference in ceiling effect between DLQI/DLQI-R and Skindex-16 ($p<0.05$).

Overall, 17.3% to 40.1% of patients reporting ‘not at all’ in the nine matched items were bothered by some problems in Skindex-16 (Figure 3). Furthermore, 23.3%, 24.6%, 37.1% and 38.5% of patients marking a NRR in DLQI items 8 (interpersonal problems), 3 (shopping/home/garden), 9 (sexual difficulties) and 7 (working/studying), reported problems in their matched Skindex-16 items pairs, respectively (Figure 4).



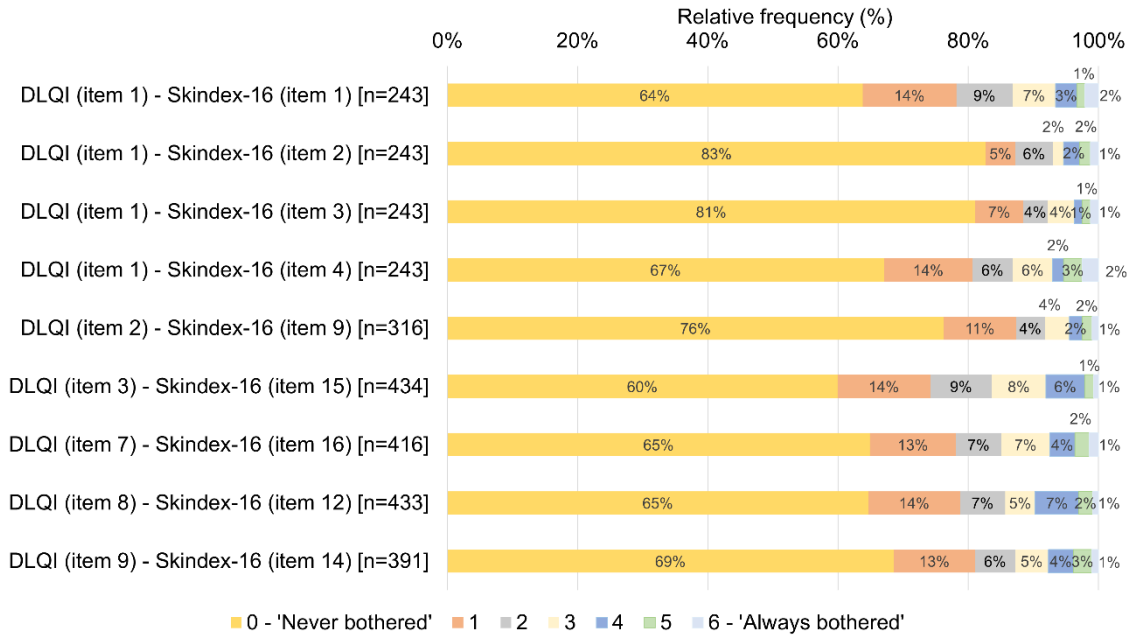
Percentages may not total 100 due to rounding.

Figure 3 – Distribution of Skindex-16 responses in patients with DLQI/DLQI-R score of zero [n=164] [77]



Percentages may not total 100 due to rounding.

Figure 4 – Skindex-16 responses of patients with 'not at all' responses on the DLQI (matched items) [77]



Percentages may not total 100 due to rounding.

Figure 5 – Skindex-16 responses of patients with NRR responses on the DLQI (matched items) [77]

3.2.4. Informativity

The average absolute informativity of the DLQI, DLQI-R and Skindex-16 were 1.07, 1.48 and 2.38, respectively (Table 13). The average relative informativity values for the DLQI, DLQI-R and Skindex-16 were 0.54, 0.66 and 0.85, respectively. Compared to the DLQI, we identified higher relative informativity with DLQI-R in all items with NRRs. Three of the five Skindex-16 items with matched 'severity' format DLQI pairs, and all four Skindex-16 items with 'interference with functioning' format DLQI pairs showed higher relative informativity than their DLQI or DLQI-R pairs.

Table 13 – Informativity of DLQI, DLQI-R and Skindex-16 [77]

DLQI/DLQI-R items	DLQI		DLQI-R		Skindex-16 items	Skindex-16	
	(H')	(J')	(H')	(J')		(H')	(J')
item 1 (itchy, sore, painful, stinging)	1.64	0.82	1.64	0.82	item 1 (itching)	2.64	**0.94** $^{\beta}$
					item 2 (burning or stinging)	2.28	0.81
					item 3 (hurting)	2.22	0.79
					item 4 (skin irritation)	2.58	**0.92** $^{\beta}$
item 2 (embarrassed, self-conscious)	1.54	0.77	1.54	0.77	item 9 (embarrassment)	2.27	**0.81** $^{\beta}$
item 3 (shopping, home, garden)	0.91	0.45	1.38	**0.59** $^{\alpha}$	item 15 (daily activities)	2.18	**0.78** $^{\beta}$
item 4 (clothing)	1.16	0.58	1.57	**0.68** $^{\alpha}$	-	-	-
item 5 (social, leisure)	1.12	0.56	1.48	**0.64** $^{\alpha}$	-	-	-
item 6 (sport)	0.81	0.41	1.52	**0.65** $^{\alpha}$	-	-	-
item 7 (working, studying)	0.85	0.43	1.41	**0.61** $^{\alpha}$	item 16 (work or do what you enjoy)	2.09	**0.74** $^{\beta}$
item 8 (interpersonal problems)	0.94	0.47	1.37	**0.59** $^{\alpha}$	item 12 (interactions with others)	2.12	**0.76** $^{\beta}$
item 9 (sexual difficulties)	0.81	0.40	1.50	**0.64** $^{\alpha}$	item 14 (show affection)	2.05	**0.73** $^{\beta}$
item 10 (treatment difficulties)	0.97	0.48	1.44	**0.62** $^{\alpha}$	-	-	-
					item 5 (persistence / reoccurrence)	2.68	0.95
					item 6 (worry)	2.67	0.95
					item 7 (appearance)	2.66	0.95
					item 8 (frustration)	2.41	0.86
					item 10 (being annoyed)	2.66	0.95
					item 11 (feeling depressed)	2.35	0.84
					item 13 (desire to be with people)	2.15	0.77
Total average	1.07	0.54	1.48	**0.66** $^{\alpha}$	Total average	2.38	0.85 $^{\beta}$

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; (H') = Shannon's index for absolute informativity; (J') = Shannon's evenness index for relative informativity

The theoretical maximum of H' for DLQI, DLQI-R and Skindex-16 was 2.00, 2.32 and 2.81, respectively.

$^{\alpha}$ indicates that J' of DLQI-R is higher than that of the DLQI

$^{\beta}$ indicates that J' of Skindex-16 is higher than those of DLQI and DLQI-R

3.2.5. Convergent and known-group validity

Most hypotheses regarding convergent validity of the three HRQoL outcomes were met. Skindex-16 subscale and total scores exhibited a strong correlation both with DLQI and DLQI-R scores (range of r_s=0.664 to 0.751) (Table 14). PG-VAS and WHO-5 scores showed weak negative correlations with all dermatology-specific HRQoL measures (range of r_s=-0.342 to -0.241). DLQI was able to better discriminate between known groups of patients based on overall HRQoL impairment (GQ rating), while both DLQI-R and Skindex-16 performed better than the DLQI for self-perceived health status (Table 15).

Table 14 – Spearman's correlations between outcome measures [77]

	DLQI	**DLQI-R**	**Skindex-16 Functioning**	**Skindex-16 Emotions**	**Skindex-16 Symptoms**	**Skindex-16 Total**	**PG-VAS**
DLQI (0-30)	-	-	-	-	-	-	-
DLQI-R (0-30)	0.984	-	-	-	-	-	-
Skindex-16 Functioning (0-100)	0.699	0.685	-	-	-	-	-
Skindex-16 Emotions (0-100)	0.678	0.664	0.797	-	-	-	-
Skindex-16 Symptoms (0-100)	0.700	0.683	0.727	0.752	-	-	-
Skindex-16 Total (0-100)	0.751	0.735	0.885	0.947	0.895		-
PG-VAS (0-100)	-0.333	-0.342	-0.320	-0.310	-0.266	-0.317	-
WHO-5 (0-100)	-0.314	-0.315	-0.241	-0.267	-0.270	-0.284	0.425

DLQI = Dermatology Life Quality Index; PG-VAS = Patient global assessment visual analogue scale; WHO-5 = World Health Organization 5 well-being index

All correlation coefficients were significant ($p<0.05$).

Table 15 – Known-group validity of the DLQI, DLQI-R and Skindex-16 [mean (SD)][77]

	Numbers of patients (%)	% of patients with ≥1 NRRs	DLQI (0-30)	DLQI-R (0-30)	Skindex-16 Functioning (0-100)	Skindex-16 Emotions (0-100)	Skindex-16 Symptoms (0-100)	Skindex-16 Total (0-100)
Self-perceived health status								
Very good	33 (5.3%)	36.4%	4.0 (7.8)	4.3 (7.9)	12.4 (28.0)	23.4 (29.4)	23.9 (30.9)	19.9 (27.4)
Good	198 (32.0%)	30.3%	2.5 (3.7)	2.7 (4.0)	15.2 (24.0)	28.6 (27.9)	23.4 (26.3)	22.4 (23.4)
Fair	264 (42.7%)	37.5%	3.6 (4.4)	3.9 (4.7)	22.9 (27.3)	35.8 (28.9)	29.4 (27.2)	29.4 (25.4)
Poor	107 (17.3%)	46.7%	5.6 (5.9)	6.1 (5.9)	31.9 (31.3)	49.1 (30.7)	41.8 (29.4)	40.9 (27.2)
Very poor	16 (2.6%)	56.2%	9.7 (8.4)	10.9 (9.6)	51.0 (36.4)	65.3 (37.2)	54.2 (34.4)	56.8 (34.9)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	13.1	15.0	12.1	14.2	11.1	15.0
RE	-	-	-	1.15	0.92	1.08	0.85	1.14
Overall skin-related HRQoL impairment (GQ rating)								
No effect	212 (34.3%)	40.1%	0.9 (1.7)	1.1 (2.2)	5.0 (13.3)	15.2 (19.3)	11.6 (18.3)	10.6 (14.5)
Small effect	163 (26.4%)	30.1%	2.8 (2.9)	3.0 (3.1)	20.6 (23.7)	33.5 (25.7)	30.7 (25.4)	28.3 (22.2)
Moderate effect	175 (28.3%)	41.1%	5.3 (4.5)	5.8 (4.9)	31.6 (29.1)	50.1 (27.9)	40.4 (26.4)	40.7 (24.3)
Very large effect	52 (8.4%)	38.5%	9.4 (6.3)	10.1 (6.6)	51.9 (31.4)	67.9 (24.9)	54.9 (30.3)	58.2 (24.6)
Extremely large effect	16 (2.6%)	25.0%	17.0 (9.4)	17.6 (9.5)	64.8 (32.3)	76.9 (24.6)	70.8 (29.4)	70.8 (27.4)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	118.7	111.7	68.6	88.0	64.3	95.6
RE	-	-	-	0.94	0.58	0.74	0.54	0.81

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index; GQ = Global Question; HRQoL= health related quality of life; NRR = 'not relevant' response; RE = relative efficiency

[α] Analysis of variance (ANOVA)

3.2.6. Subgroup analysis

With few exceptions, variations in measurement properties across the three subgroups of patients were overall small (Appendices 7-18). Floor effect for DLQI/DLQI-R total score ranged between 20.3% (chronic inflammatory skin diseases) to 29.1% (other conditions). In contrast, there was a very minor difference in floor effect for Skindex-16 total scores across the three condition groups (range 10.3% to 12.6%). Similarly, no substantial differences were found in informativity of DLQI, DLQI-R and Skindex-16 across the subgroups. Skindex-16 correlated strongly with DLQI and DLQI-R in all subgroups (range of r_s= 0.729 to 0.808). DLQI-R consistently improved relative efficiency of DLQI for self-perceived health status groups, but not for overall HRQoL impairment (GQ rating). In comparison, the performance of Skindex-16 was less systematic. It considerably improved relative efficiency for self-perceived health status in the 'other' group, while it was outperformed by both DLQI and DLQI-R for self-perceived health status in chronic inflammatory skin diseases and for GQ rating in infections.

3.2.7. Summary of the results

The systematic review of modifications and alternative scoring of the DLQI questionnaire reveals significant adaptations (n=59) across more than 40 skin conditions, yet often lacking validation. Notably, the most promising modifications are the DLQI-R and the "Last Year-DLQI," which asks about the previous one-year period, although validation remains sparse. In our comparative analysis, for the first time in Hungary, the measurement properties of the skin-specific questionnaires were investigated in several skin diseases not yet investigated (e.g., urticaria, rosacea), and the electronic Hungarian versions of the DLQI and Skindex-16 questionnaires were validated for the first time. Skindex-16 and DLQI-R generally outperformed the original DLQI. Nevertheless, the results of our study confirm that the Skindex-16 is more suitable than either the DLQI or the DLQI-R for measuring mild quality-of-life decline.

4. Discussion

We conducted a systematic literature review categorizing all DLQI modifications and evaluated the quality of each study. Additionally, we comprehensively analysed the measurement properties of two widely used dermatology-specific instruments (DLQI and Skindex-16) in a large population-based sample of patients with chronic skin conditions. Our studies were intended to support clinicians, researchers, and healthcare decision-makers regarding the selection of HRQoL instruments.

4.1. Modified versions and alternative scoring methods of DLQI

In this systematic review, we have identified 81 eligible articles that described 59 questionnaire modifications and alternative scorings of the DLQI. Based on our knowledge, such a substantial number of modifications to a questionnaire, either generic or disease-specific, is rare in HRQoL literature. These adaptations have been applied across a broad spectrum of over 40 distinct skin conditions, covering nearly all dermatological conditions. Notably, our findings reveal that approximately 2-4% of all published studies utilizing the DLQI have opted for some modified versions of the DLQI. On the one hand, this extraordinary array of modified questionnaire versions underscores the DLQI's global popularity and widespread use. On the other hand, it draws attention to potential limitations within the DLQI. The primary aim of employing modified questionnaire versions in many studies has been to enhance sensitivity in detecting treatment effects.

It is widely recognized that HRQoL questionnaires can lose their validity, comparability of scores, and reliability if even a single word is altered. The overall methodological quality of the studies included in our analysis exhibited heterogeneity, with the majority being assessed as weak. In some cases, the modifications implemented in the DLQI needed to be clarified. Furthermore, many of the studies provided limited coverage of the psychometric properties of each questionnaire. As a result, there is a notable absence of, or incomplete information regarding, the psychometric properties of the modified DLQI in the existing literature.

Most HRQoL surveys or questionnaires, including the DLQI, are protected by copyright to safeguard the developers' exclusive rights to their work. This includes activities such as reproducing, distributing, and creating derivative works, aiming to maintain the authenticity of the validated and authorized version of the original questionnaire [89,92]. Given that HRQoL measures frequently serve as endpoints in clinical trials, impact health-related decisions (e.g., treatment selection), influence reimbursement determinations, and contribute to labelling claims by regulatory bodies like the U.S. Food and Drug Administration (hereinafter: FDA) and the European Medicines Agency (EMA), upholding quality standards is crucial. This involves preserving the questionnaire's content, encompassing instructions, question-wording, order, response options, and recall period. Like other copyrighted HRQoL questionnaires, users are prohibited from altering the content, language, or question sequence in the DLQI without formal approval from the copyright holders, constituting a copyright infringement otherwise. The only exceptions are alternative scoring methods that adhere to the original questionnaire. Copyright holders are advised to actively monitor the questionnaire's usage to identify unauthorized modifications or use [90].

One noteworthy modification worth further investigation is the ‘last year DLQI’ (hereinafter: LY-DLQI), which extends the recall period from one week to one year while maintaining the integrity of the DLQI. So far, LY-DLQI has been employed in seven independent studies [104,108,123,145-147,158], and another four publications (2 independent studies) [109,153-155]have applied a one-year recall period in conjunction with other modifications. While an extended recall period might be suitable for conditions characterized by gradual changes in health status and intermittent symptoms, such as certain types of hair loss or many photodermatoses, it is not appropriate for most dermatological conditions where symptoms can vary more rapidly. Additionally, existing literature indicates that more extended recall periods may be more susceptible to recall bias [180-182]. Future validation studies are essential to evaluate the utility of the LY-DLQI, especially in conditions like alopecia and photodermatoses.

Another extensively studied alternative scoring system for the original DLQI is the DLQI-R, with 'R' standing for relevant. Five cross-sectional studies and a clinical trial have employed DLQI-R in patients with atopic dermatitis, vitiligo, psoriasis, pemphigus, and

morphea [62-65]. Compared to the original DLQI, DLQI-R has demonstrated improved informativity, responsiveness to change, and convergent validity with Psoriasis Area and Severity Index and EQ-5D-3L. It exhibits excellent criterion validity against the original DLQI and shows no floor/ceiling effects. It is advisable to gather additional evidence on the measurement properties of DLQI-R in various skin diseases to further evaluate its performance.

In 1995, an official and validated version for children, the Children's Dermatology Life Quality Index (hereinafter: CDLQI) [97,183], was published as a specific instrument to assess the impact of skin conditions on children. However, our systematic literature review identified five questionnaires that adapted the adult DLQI to assess the HRQoL impact of skin diseases in children. These modifications were implemented in patients with conditions like cutaneous larva migrans, scabies, and tungiasis [124,125,161,162,169]. However, it is important to mention that there are several child-specific HRQoL instruments exist such as CDLQI, Teenager's Quality of Life (T-QoL) and Skindex-teen which researchers could use to assess the HRQoL of children with dermatological conditions [99,100].

Notably, every modification made to the original questionnaire comes with a potential trade-off, as it may diminish the advantages of the original tool. Furthermore, poorly designed and non-validated questionnaires have the potential to compromise the outcomes of a study. Two future strategies can be considered to enhance the utility of modified DLQI questionnaires. First, it is crucial to emphasize the need for higher methodological standards in future studies that aim to modify the DLQI questionnaire. Adhering to rigorous research practices can improve the quality of the modifications. Second, rather than continually creating new DLQI modifications, researchers might find it beneficial to concentrate on refining and validating existing modifications. The collection of modifications provided in this PhD thesis serves as a resource to facilitate this effort, aiding in the selection of instruments that can be further validated and thus contribute to advancing research in the field.

A limitation of this systematic literature review is that a search strategy focused on the DLQI. While this focused approach was a reasonable choice, implementing a more sensitive filter, such as searching for all HRQoL studies in dermatology, could have

generated overwhelming results for full-text screening. As a result, there is a possibility that our study may have missed a few relevant studies featuring modified DLQI questionnaire versions that did not include explicit mentions of DLQI in their abstracts or keywords. To mitigate this limitation, we conducted reference tracking and supplemented our search using Google Scholar. This additional effort allowed us to identify and include 26 more studies, thus helping to address potential data gaps. Another limitation lies in the applicability of the COSMIN Risk of Bias and the Terwee et al. checklists [86], commonly employed to choose optimal outcome measures for clinical studies. These checklists appear less effective when assessing the methodological quality of studies reporting experimental questionnaire modifications. This is particularly relevant for modifications such as bolt-ons, recall period adjustments, and alternative scorings. Therefore, there is a need to develop specific guidelines and checklists tailored for assessing the quality of modifications to patient-reported outcome measures.

4.2. Comparison of the measurement performance of dermatology-specific questionnaires (DLQI, DLQI-R and Skindex-16)

This study is the first to offer a thorough, direct comparison of the measurement properties of three dermatology-specific HRQoL outcome measures (DLQI, DLQI-R, and Skindex-16). Among these measures, Skindex-16 exhibited superior item-level measurement properties, specifically in relation to floor effect and informativity, when compared to both DLQI and DLQI-R. Nonetheless, all three measures displayed similar levels of convergent validity with other measures and their ability to distinguish between known groups.

The difference in measurement performance between the DLQI and Skindex-16 could be attributed to the distinct areas of HRQoL captured. Skindex-16 contains several items that emphasize the mental and emotional aspects of dermatological disease, such as worrying, frustration, being annoyed or being depressed, which concepts entirely absent in DLQI. Conversely, Skindex-16 may not fully capture HRQoL aspects related to daily functioning, like clothing, sports, and treatment difficulties. Another difference between the examined measures is observed in the number of responses of DLQI and Skindex-16. While DLQI items typically offer four or five response options, Skindex-16 provides

seven response alternatives for each item. Previous research suggests that a higher number of response options, up to seven, can enhance the validity and reliability of an instrument [184]. It seems, however, that for reporting symptoms, both DLQI and Skindex-16 have their advantages. For painful, burning or stinging skin, the 'severity' format DLQI items showed a lower floor effect and improved relative informativity than Skindex-16. In contrast, for itching and skin irritation, the 'frequency' format Skindex-16 items performed better.

One of the most significant limitations of DLQI lies in the scoring of NRRs [185]. For DLQI items 3 (shopping, home, garden), 7 (working, studying), 8 (interpersonal problems), and 9 (sexual difficulties), approximately one-third of patients with NRRs reported problems on their corresponding Skindex-16 items. This suggests that the NRR option in DLQI combines elements from the other four response options, raising questions about the equivalence of 'not at all' and NRRs, as originally scored in DLQI. DLQI-R is an alternative scoring for the DLQI that offers an opportunity to correct the bias caused by NRRs. Validity of the DLQI-R has already been confirmed in patients with psoriasis, atopic dermatitis, pemphigus, morphoea, vitiligo, and hidradenitis suppurativa [57,58,60-64,179,185-189]. Moreover, a recent study provided empirical support for the improved measurement properties of the DLQI-R against DLQI using Rasch-analysis. In line with this, in the present study, DLQI-R outperformed the DLQI in nearly all measurement properties. While the DLQI-R scoring modification can enhance certain measurement properties of DLQI, it does not address the issues related to its content validity. The high frequency of NRRs reported across various diagnoses indicates problems with item relevance. Moreover, the relatively high floor effect highlights a content validity concern, implying that DLQI items may not effectively capture mild HRQoL problems. The numerous modifications made to the DLQI questionnaire, including the addition of 21 different bolt-ons (additional questionnaire items appended to the original DLQI), serve as evidence of its content validity issues [85]. However, it is worth noting that Skindex-16 (and other Skindex measures) may also suffer from content validity problems. In a recent qualitative study, patients with acne reported redundant items, uncertainties regarding the meaning of the 'never bothered' endpoint, and unlabelled response options, which may lead to arbitrary response choices [190].

Several limitations to our study should be taken into account. The first limitation is that we conducted our analysis on data from patients who self-reported their dermatological conditions, and we did not have access to clinical data regarding disease severity or health status. However, we aimed to maintain high data quality. The selection of 618 patient with self-reported, physician-diagnosed dermatological conditions from 2001 respondents involved several steps. Initially, respondents were asked to select from a drop-down list of diseases that included skin diseases and other common chronic diseases. An open-ended 'other' option allowed respondents to provide their own answers. Then, if the respondent ticked any of the pre-coded ten skin conditions, we asked them to specify which one they had been diagnosed with by a physician. To determine the final sample, our research team reviewed each respondent's answers in detail, one by one. Of note, our results align with previous research; the instruments we used demonstrated similar measurement properties to data recorded in clinical settings [65,71,187]. After reviewing the results of previous national and international data collections, we concluded that the face validity of our sample was also adequate. For example, the convergent validity of the questionnaires closely aligns with that reported in earlier HS and AD studies from Hungary [65,187]. The second limitation is that there was a limited number of patients with severe dermatological conditions, as represented by the relatively low mean scores for DLQI and Skindex-16. The third limitation is that the item pairs used for the item-level analyses when comparing DLQI/DLQI-R to Skindex-16 were not always completely identical in terms of content. For instance, item 9 of DLQI (sexual difficulties) was compared to item 14 of Skindex-16 (show affection), which may not be a perfect match. The fourth limitation is that the Skindex-16 total score lacks a well-established calculation method in the international literature. However, most previous studies used the arithmetic mean of the scores of the three subscales [65,69-71,187,191] to determine the total score, including the abovementioned Hungarian hidradenitis suppurativa and atopic dermatitis studies [65,187]. Hence, we have chosen to use this approach for comparability. Finally, because our study was cross-sectional, we were unable to assess the test-retest reliability or responsiveness of the instruments over time.

Our findings provide essential information about differences of dermatology-specific measures for making informed choices when selecting an instrument in clinical practice, research, treatment, and financial guidelines. DLQI is widely adopted in international and

national treatment guidelines for numerous skin conditions in almost 50 countries [59]. Meanwhile, the Skindex questionnaires are recommended to be used in only a few countries [73-75]. The measurement properties of dermatology-specific HRQoL instruments might vary depending on the specific skin condition, with one instrument being particularly suitable for one condition but not necessarily for others which is supported by our subgroup analysis. However, our finding suggests that in patients with mild symptoms, DLQI and DLQI-R might be less sensitive to minor impairments in HRQoL. In such cases, Skindex-16 could be a more appropriate decision. Further studies and analyses are warranted within specific skin conditions, preferably in clinical settings where severity assessments can be conducted to allow for more condition-specific assessments of validity.

5. Conclusions

In summary, our systematic review identified a range of questionnaire and scoring modifications applied to the DLQI. Our findings highlight that there is an incomplete understanding of the psychometric characteristics of the modified DLQI questionnaires. The limited information on measurement properties does not necessarily suggest poor measurement properties, but it is essential to underscore that most DLQI modifications lack robust empirical support. Further research is needed to establish the validity of these modified questionnaires in capturing HRQoL impairment associated with chronic dermatological conditions.

Based on the second research presented in this thesis, the DLQI and Skindex-16 cover similar but somewhat different areas of HRQoL and have different response scales responsible for the differences in their measurement performance. With few exceptions, the higher number of response options and their 'frequency' format in the Skindex-16 seem more useful to report the impact of the dermatological problem on patients' lives than the fewer and 'severity' or 'interference with functioning' format categories of the DLQI. Skindex-16 performs better at the item level, whereas DLQI seems superior as a scale. In most measurement properties, DLQI-R superseded the DLQI. Based on our findings, we recommend using DLQI-R or Skindex-16, depending on the purpose and needs of the study.

6. Summary

The DLQI is a widely used dermatology-specific measure to assess the HRQoL of patients with skin conditions. It has been used in a large number of observational studies, as an endpoint in clinical trials, patient registries, and for clinical and financial decision-making. Skindex-16 is another commonly used HRQoL instrument comparable to the DLQI in content, recall period, and length. This PhD thesis systematically reviewed modifications of the DLQI and compared the measurement properties of DLQI, DLQI-R, and Skindex-16.

In the first part of the thesis, a systematic literature review was conducted, and 81 studies were identified using 59 different questionnaire modifications of the DLQI. These modifications were examined 47 different diagnoses or symptoms from 28 countries. We have identified several DLQI modifications, encompassing various categories, with alternative score methods (DLQI-R), recall periods (DLQI-LY), disease/symptom/body part specifications, and bolt-ons/-offs being the most common. However, the evidence on the quality of measurement properties for these modifications was heterogeneous.

The second part of the PhD thesis compared several measurement properties of DLQI, DLQI-R, and Skindex-16 from 618 patients with dermatological conditions. Mean age was 50.5±16.9 years, 57.9% were female. Mean total of DLQI, DLQI-R and Skindex-16 scores were 3.76±5.03, 4.11±5.34 and 29.36±26.62, respectively. Of patients who obtained a 0 score on DLQI, 64% indicated problems on Skindex-16. Average relative informativity was the highest for Skindex-16 (0.85), followed by DLQI-R (0.66). DLQI-R and Skindex-16 could better discriminate between known groups of patients based on self-perceived health status.

This PhD thesis highlights the availability of numerous DLQI modifications, with incomplete psychometric validation for most. It also underscores the differences in measurement properties among dermatology-specific HRQoL measures. These findings provide valuable knowledge for selecting the most suitable instrument for clinical and research purposes in dermatology. Further research and validation efforts are essential in selected clinical populations for a more comprehensive understanding of these instruments and their modifications.

7. References

1. Pu L. (2021) Fairness of the Distribution of Public Medical and Health Resources. Front Public Health, 9: 768728.
2. Ahn CS, Gustafson CJ, Sandoval LF, Davis SA, Feldman SR. (2013) Cost effectiveness of biologic therapies for plaque psoriasis. Am J Clin Dermatol, 14: 315-326.
3. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. Methods for the Economic Evaluation of Health Care Programmes. Oxford University Press, 2005.
4. Haraldstad K, Wahl A, Andenæs R, Andersen JR, Andersen MH, Beisland E, Borge CR, Engebretsen E, Eisemann M, Halvorsrud L, Hanssen TA, Haugstvedt A, Haugland T, Johansen VA, Larsen MH, Løvereide L, Løyland B, Kvarme LG, Moons P, Norekvål TM, Ribu L, Rohde GE, Urstad KH, Helseth S. (2019) A systematic review of quality of life research in medicine and health sciences. Qual Life Res, 28: 2641-2650.
5. Bickers DR, Lim HW, Margolis D, Weinstock MA, Goodman C, Faulkner E, Gould C, Gemmen E, Dall T. (2006) The burden of skin diseases: 2004 a joint project of the American Academy of Dermatology Association and the Society for Investigative Dermatology. J Am Acad Dermatol, 55: 490-500.
6. Chen SC. (2012) Health-related quality of life in dermatology: introduction and overview. Dermatol Clin, 30: 205-208, xiii.
7. Chernyshov PV. (2019) The Evolution of Quality of Life Assessment and Use in Dermatology. Dermatology, 235: 167-174.
8. Hay RJ, Johns NE, Williams HC, Bolliger IW, Dellavalle RP, Margolis DJ, Marks R, Naldi L, Weinstock MA, Wulf SK, Michaud C, C JLM, Naghavi M. (2014) The global burden of skin disease in 2010: an analysis of the prevalence and impact of skin conditions. J Invest Dermatol, 134: 1527-1534.
9. Prinsen CAC, de Korte J, Augustin M, Sampogna F, Salek SS, Basra MKA, Holm EA, Nijsten TEC, Life TEToQo. (2013) Measurement of health-related quality of life in dermatological research and practice: outcome of the EADV Taskforce on Quality of Life. J Eur Acad Dermatol Venereol, 27: 1195-1203.

10. Institute for Health Metrics and Evaluation (IHME). (2020) Global Burden of Disease Study 2019 Available from https://www.healthdata.org/gbd/2019. Accessed: January 10, 2024.

11. Basra MK, Shahrukh M. (2009) Burden of skin diseases. Expert Rev Pharmacoecon Outcomes Res, 9: 271-283.

12. Richard MA, Paul C, Nijsten T, Gisondi P, Salavastru C, Taieb C, Trakatelli M, Puig L, Stratigos A. (2022) Prevalence of most common skin diseases in Europe: a population-based study. J Eur Acad Dermatol Venereol, 36: 1088-1096.

13. Hessel F. Burden of DiseaseBurdenof disease(s). In: Kirch W (ed.), Encyclopedia of Public Health. Springer Netherlands, Dordrecht, 2008: 94-96.

14. Wu JH, Cohen BA. (2019) The stigma of skin disease. Curr Opin Pediatr, 31: 509-514.

15. Kelly KA, Balogh EA, Kaplan SG, Feldman SR. (2021) Skin Disease in Children: Effects on Quality of Life, Stigmatization, Bullying, and Suicide Risk in Pediatric Acne, Atopic Dermatitis, and Psoriasis Patients. Children (Basel), 8: 1057.

16. Patel KR, Immaneni S, Singam V, Rastogi S, Silverberg JI. (2019) Association between atopic dermatitis, depression, and suicidal ideation: A systematic review and meta-analysis. J Am Acad Dermatol, 80: 402-410.

17. Szlávicz E, Szabó Á, Kinyó Á, Szeiffert A, Bancsók T, Brodszky V, Gyulai R, Rencz F. (2024) Content validity of the EQ-5D-5L with skin irritation and self-confidence bolt-ons in patients with atopic dermatitis: a qualitative think-aloud study. Qual Life Res, 33: 101-111.

18. Schmid-Ott G, Burchard R, Niederauer HH, Lamprecht F, Künsebeck HW. (2003) Stigmatisierungsgefühl und Lebensqualität bei Patienten mit Psoriasis und Neurodermitis [Stigmatization and quality of life of patients with psoriasis and atopic dermatitis]. Hautarzt, 54: 852-857.

19. Mattila K, Leino M, Mustonen A, Koulu L, Tuominen R. (2013) Influence of psoriasis on work. Eur J Dermatol, 23: 208-211.

20. Mustonen A, Mattila K, Leino M, Koulu L, Tuominen R. (2015) How much of the productivity losses among psoriasis patients are due to psoriasis. BMC Health Serv Res, 15: 87.

21. Péntek M, Beretzky Z, Brodszky V, Szabó JA, Kovács L, Kincses Á, Baji P, Zrubka Z, Rencz F, Gulácsi L. (2020) A magyarországi lakosság egészséggel összefüggő munkaképessége. Keresztmetszeti reprezentatív felmérés. [Health-related productivity of the Hungarian population. A cross-sectional survey]. Orv Hetil, 161: 1522-1533.

22. Dietz JB, Menné T, Meyer HW, Viskum S, Flyvholm M-A, Ahrensbøll-Friis U, John SM, Johansen JD. (2021) Degree of employment, sick leave, and costs following notification of occupational contact dermatitis—A register-based study. Contact Dermatitis, 84: 224-235.

23. Rashdan O, Brodszky V. (2020) Productivity Loss in Patients With Chronic Diseases: A Pooled Economic Analysis of Hungarian Cost-of-Illness Studies. Value Health Reg Issues, 22: 75-82.

24. Feldman SR, Burudpakdee C, Gala S, Nanavaty M, Mallya UG. (2014) The economic burden of psoriasis: a systematic literature review. Expert Rev Pharmacoecon Outcomes Res, 14: 685-705.

25. Rencz F, Brodszky V, Péntek M, Balogh O, Remenyik E, Szegedi A, Holló P, Kárpáti S, Jókai H, Herszényi K, Herédi E, Szántó S, Gulácsi L. (2014) Arthritis psoriaticával társuló középsúlyos és súlyos psoriasis betegségterhe Magyarországon [Disease burden of psoriasis associated with psoriatic arthritis in Hungary]. Orv Hetil, 155: 1913-1921.

26. Brodszky V, Beretzky Z, Baji P, Rencz F, Péntek M, Rotar A, Tachkov K, Mayer S, Simon J, Niewada M, Hren R, Gulácsi L. (2019) Cost-of-illness studies in nine Central and Eastern European countries. Eur J Health Econ, 20 (Suppl 1): 155-172.

27. Balogh O, Brodszky V, Gulácsi L, Herédi E, Herszényi K, Jókai H, Kárpáti S, Baji P, Remenyik É, Szegedi A, Holló P. (2014) Cost-of-illness in patients with moderate to severe psoriasis: a cross-sectional survey in Hungarian dermatological centres. Eur J Health Econ, 15 (Suppl 1): S101-109.

28. Beretzky Z, Koszorú K, Rencz F, Hajdu K, Borza J, Bodai K, Feifei X, Szegedi A, Sárdy M, Brodszky V. (2023) Societal costs and health related quality of life in adult atopic dermatitis. BMC Health Serv Res, 23: 859.

29. Brodszky V, Tamási B, Hajdu K, Péntek M, Szegedi A, Sárdy M, Bata-Csörgő Z, Kinyó Á, Gulácsi L, Rencz F. (2021) Disease burden of patients with pemphigus from a societal perspective. Expert Rev Pharmacoecon Outcomes Res, 21: 77-86.

30. Gáspár K, Gergely LH, Jenei B, Wikonkál N, Kinyó Á, Szegedi A, Remenyik É, Kiss N, Jin X, Sárdy M, Beretzky Z, Péntek M, Gulácsi L, Bánvölgyi A, Brodszky V, Rencz F. (2022) Resource utilization, work productivity and costs in patients with hidradenitis suppurativa: a cost-of-illness study. Expert Rev Pharmacoecon Outcomes Res, 22: 399-408.

31. World Health Organisation. (1948) The constitution of the World Health Organisation.

32. Fayers PM, Machin D. Quality of life: the assessment, analysis and interpretation of patient-reported outcomes. John Wiley & Sons, 2013.

33. de Wit M, Hajos T. Health-Related Quality of Life. In: Gellman MD, Turner JR (eds.), Encyclopedia of Behavioral Medicine. Springer New York, New York, NY, 2013: 929-931.

34. Spilker B. (1990) Quality of Life Assessments in Clinical Trials. Pp. 470; illustrated.) Raven Press: New York. 1990. Psychological Medicine, 20: 1010-1010.

35. Testa MA, Simonson DC. (1996) Assessment of quality-of-life outcomes. N Engl J Med, 334: 835-840.

36. van Cranenburgh OD, Prinsen CA, Sprangers MA, Spuls PI, de Korte J. (2012) Health-related quality-of-life assessment in dermatologic practice: relevance and application. Dermatol Clin, 30: 323-332, x.

37. Poór AK, Péntek M, Rencz F, Sárdy M, Holló P, Hidvégi B, Tamási B, Bali G, Remenyik É, Szegedi A. (2019) Az életminőség mérése a bőrgyógyászatban: hazai tapasztalatok. Bőrgyógyászati és Venerológiai Szemle, 95: 100-107.

38. Wilson IB, Cleary PD. (1995) Linking Clinical Variables With Health-Related Quality of Life: A Conceptual Model of Patient Outcomes. JAMA, 273: 59-65.

39. Inotai A, Kaló Z, Lovas K. Az egészségnyereség mérése-A betegek értékelése alapján. Springmed; 2014.

40. Torrance GW. (1986) Measurement of health state utilities for economic appraisal. J Health Econ, 5: 1-30.

41. Torrance GW. (1987) Utility approach to measuring health-related quality of life. J Chronic Dis, 40: 593-603.

42. Tsevat J. (2000) What do utilities measure? Med Care, 38: II160-164.

43. Beresniak A, Dupont D. (2016) Is there an alternative to quality-adjusted life years for supporting healthcare decision making? Expert Rev Pharmacoecon Outcomes Res, 16: 351-357.

44. Brazier J, Ratcliffe J, Saloman J, Tsuchiya A. Measuring and Valuing Health Benefits for Economic Evaluation. Oxford University Press, 2016.

45. Weinstein MC, Stason WB. (1977) Foundations of cost-effectiveness analysis for health and medical practices. N Engl J Med, 296: 716-721.

46. Weinstein MC, Torrance G, McGuire A. (2009) QALYs: the basics. Value Health, 12 (Suppl 1): S5-9.

47. Burström K, Johannesson M, Diderichsen F. (2006) A comparison of individual and social time trade-off values for health states in the general population. Health Policy, 76: 359-370.

48. Bergner M, Bobbitt RA, Carter WB, Gilson BS. (1981) The Sickness Impact Profile: development and final revision of a health status measure. Med Care, 19: 787-805.

49. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Amtmann D, Bode R, Buysse D, Choi S, Cook K, DeVellis R, DeWalt D, Fries JF, Gershon R, Hahn EA, Lai J-S, Pilkonis P, Revicki D, Rose M, Weinfurt K, Hays R. (2010) The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol, 63: 1179-1194.

50. Horsman J, Furlong W, Feeny D, Torrance G. (2003) The Health Utilities Index (HUI): concepts, measurement properties and applications. Health Qual Life Outcomes, 1: 54.

51. Kind P, Carr-Hill R. (1987) The Nottingham health profile: A useful tool for epidemiologists? Soc Sci Med, 25: 905-910.

52. Seiber WJ, Groessl EJ, David KM, Ganiats TG, Kaplan RM. (2008) Quality of well being self-administered (QWB-SA) scale. San Diego: Health Services Research Center, University of California, 41:

53. Ware JE, Jr., Sherbourne CD. (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care, 30: 473-483.

54. Both H, Essink-Bot ML, Busschbach J, Nijsten T. (2007) Critical Review of Generic and Dermatology-Specific Health-Related Quality of Life Instruments. J Invest Dermatol, 127: 2726-2739.

55. Finlay AY, Khan GK. (1994) Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. Clin Exp Dermatol, 19: 210-216.

56. Lewis V, Finlay AY. (2004) 10 years experience of the Dermatology Life Quality Index (DLQI). J Investig Dermatol Symp Proc, 9: 169-180.

57. Barbieri JS, Chiesa Fuxench ZC, Shin DB, Takeshita J. (2021) Frequency and influence of "not relevant" responses on the Dermatology Life Quality Index among adults with atopic dermatitis. Qual Life Res, 30: 1705-1713.

58. Barbieri JS, Gelfand JM. (2019) Influence of “Not Relevant” Responses on the Dermatology Life Quality Index (DLQI) for Patients With Psoriasis in the United States. JAMA Dermatol, 155: 743-745.

59. Singh RK, Finlay AY. (2020) Dermatology Life Quality Index use in skin disease guidelines and registries worldwide. J Eur Acad Dermatol Venereol, 34: e822-e824.

60. Barbieri JS, Gelfand JM. (2019) Evaluation of the Dermatology Life Quality Index scoring modification, the DLQI-R score, in two independent populations. Br J Dermatol, 180: 939-940.

61. Rencz F, Gergely LH, Wikonkál N, Gáspár K, Péntek M, Gulácsi L, Tamási B, Poór AK, Kinyó Á, Bali G, Hidvégi B, Sárdy M, Hajdu K, Szegedi A, Remenyik É, Bata-Csörgő Z, Holló P, Baji P, Brodszky V. (2020) Dermatology Life Quality Index (DLQI) score bands

are applicable to DLQI-Relevant (DLQI-R) scoring. J Eur Acad Dermatol Venereol, 34: e484-e486.

62. Rencz F, Gulacsi L, Pentek M, Poor AK, Sardy M, Hollo P, Szegedi A, Remenyik E, Brodszky V. (2018) Proposal of a new scoring formula for the Dermatology Life Quality Index in psoriasis. Br J Dermatol, 179: 1102-1108.

63. Rencz F, Gulácsi L, Péntek M, Szegedi A, Remenyik É, Bata-Csörgő Z, Bali G, Hidvégi B, Tamási B, Poór AK, Hajdu K, Holló P, Kinyó Á, Sárdy M, Brodszky V. (2020) DLQI-R scoring improves the discriminatory power of the Dermatology Life Quality Index in patients with psoriasis, pemphigus and morphea. Br J Dermatol, 182: 1167-1175.

64. Gupta V, Taneja N, Sati HC, Sreenivas V, Ramam M. (2021) Evaluation of 'not relevant' responses on the Dermatology Life Quality Index (DLQI) and the DLQI-R scoring modification among Indian patients with vitiligo. Br J Dermatol, 184: 168-169.

65. Koszorú K, Hajdu K, Brodszky V, Szabó Á, Borza J, Bodai K, Pónyai G, Szegedi A, Sárdy M, Rencz F. (2022) General and Skin-Specific Health-Related Quality of Life in Patients With Atopic Dermatitis Before and During the COVID-19 Pandemic. Dermatitis, 33: S92-S103.

66. Chren MM. (2012) The Skindex instruments to measure the effects of skin disease on quality of life. Dermatol Clin, 30: 231-6, xiii.

67. Nijsten TE, Sampogna F, Chren MM, Abeni DD. (2006) Testing and reducing skindex-29 using Rasch analysis: Skindex-17. J Invest Dermatol, 126: 1244-1250.

68. Chren MM, Lasek RJ, Sahay AP, Sands LP. (2001) Measurement properties of Skindex-16: a brief quality-of-life measure for patients with skin diseases. J Cutan Med Surg, 5: 105-110.

69. He Z, Lu C, Chren MM, Zhang Z, Li Y, Ni X, Buchtel VH, Ryan PF, Li GZ. (2014) Development and psychometric validation of the Chinese version of Skindex-29 and Skindex-16. Health Qual Life Outcomes, 12: 190.

70. Balkrishnan R, McMichael AJ, Camacho FT, Saltzberg F, Housman TS, Grummer S, Feldman SR, Chren MM. (2003) Development and validation of a health-related quality of life instrument for women with melasma. Br J Dermatol, 149: 572-577.

71. Gupta V, Sreenivas V, Mehta M, Khaitan BK, Ramam M. (2014) Measurement properties of the Vitiligo Impact Scale-22 (VIS-22), a vitiligo-specific quality-of-life instrument. Br J Dermatol, 171: 1084-1090.

72. Mikoshiba N, Yamamoto-Mitani N, Sato K, Asaoka Y, Ohki T, Ohata M, Miyashita M. (2015) Validation of the Japanese version of HFS-14, a disease-specific quality of life scale for patients suffering from hand-foot syndrome. Support Care Cancer, 23: 2739-2745.

73. Katoh N, Ohya Y, Ikeda M, Ebihara T, Katayama I, Saeki H, Shimojo N, Tanaka A, Nakahara T, Nagao M, Hide M, Fujita Y, Fujisawa T, Futamura M, Masuda K, Murota H, Yamamoto-Hanada K. (2020) Japanese guidelines for atopic dermatitis 2020. Allergol Int, 69: 356-369.

74. Nast A, Smith C, Spuls PI, Avila Valle G, Bata-Csörgö Z, Boonen H, De Jong E, Garcia-Doval I, Gisondi P, Kaur-Knudsen D, Mahil S, Mälkönen T, Maul JT, Mburu S, Mrowietz U, Reich K, Remenyik E, Rønholt KM, Sator PG, Schmitt-Egenolf M, Sikora M, Strömer K, Sundnes O, Trigos D, Van Der Kraaij G, Yawalkar N, Dressler C. (2020) EuroGuiDerm Guideline on the systemic treatment of Psoriasis vulgaris - Part 1: treatment and monitoring recommendations. J Eur Acad Dermatol Venereol, 34: 2461-2498.

75. van der Kraaij GE, Balak DMW, Busard CI, van Cranenburgh OD, Chung Y, Driessen RJB, de Groot M, de Jong E, Kemperman P, de Kort WJA, Karsch SA, Lamberts A, Lecluse LLA, van Lümig PPM, Menting SP, Prens EP, van den Reek J, Seyger MMB, Thio HB, Veldkamp WR, Wakkee M, Nast A, Jacobs A, Rosumeck S, Spuls Chair PI. (2019) Highlights of the updated Dutch evidence- and consensus-based guideline on psoriasis 2017. Br J Dermatol, 180: 31-42.

76. Herédi E, Rencz F, Balogh O, Gulácsi L, Herszényi K, Holló P, Jókai H, Kárpáti S, Péntek M, Remenyik É, Szegedi A, Brodszky V. (2014) Exploring the relationship between EQ-5D, DLQI and PASI, and mapping EQ-5D utilities: a cross-sectional study in psoriasis from Hungary. Eur J Health Econ, 15 Suppl 1: S111-119.

77. Szabó Á, Brodszky V, Rencz F. (2022) A comparative study on the measurement properties of Dermatology Life Quality Index (DLQI), DLQI-Relevant and Skindex-16. Br J Dermatol, 186: 485-495.

78. Finlay AY, Salek MS, Abeni D, Tomás-Aragonés L, van Cranenburgh OD, Evers AW, Jemec GB, Linder D, Manolache L, Marrón SE, Prinsen CA, Susitaival P, Chernyshov PV. (2017) Why quality of life measurement is important in dermatology clinical practice: An expert-based opinion statement by the EADV Task Force on Quality of Life. J Eur Acad Dermatol Venereol, 31: 424-431.

79. Pathirana D, Ormerod AD, Saiag P, Smith C, Spuls PI, Nast A, Barker J, Bos JD, Burmester GR, Chimenti S, Dubertret L, Eberlein B, Erdmann R, Ferguson J, Girolomoni G, Gisondi P, Giunta A, Griffiths C, Hönigsmann H, Hussain M, Jobling R, Karvonen SL, Kemeny L, Kopp I, Leonardi C, Maccarone M, Menter A, Mrowietz U, Naldi L, Nijsten T, Ortonne JP, Orzechowski HD, Rantanen T, Reich K, Reytan N, Richards H, Thio HB, van de Kerkhof P, Rzany B. (2009) European S3-guidelines on the systemic treatment of psoriasis vulgaris. J Eur Acad Dermatol Venereol, 23 Suppl 2: 1-70.

80. Finlay AY. (2005) Current severe psoriasis and the Rule of Tens. Br J Dermatol, 152: 861-867.

81. Emberi Erőforrások Minisztériuma. (2023) Egészségügyi szakmai irányelv – Az egészség-gazdaságtani elemzések készítéséhez és értékeléséhez. Available from https://kollegium.aeek.hu/Iranyelvek/. Accessed: January 7, 2024. Egészségügyi Közlöny.

82. Nemzeti Egészségbiztosítási Alapkezelő. (2023) NEAK közlemény finanszírozási eljárásrendekről. Available from https://www.neak.gov.hu/pfile/file?path=/felso_menu/szakmai_oldalak/finanszirozasi_protokollok/neak-kozlemeny-a-finanszirozasi-eljarasrendekrol-teljes---&inline=true. Accessed: January 7, 2024.

83. Prinsen CAC, Mokkink LB, Bouter LM, Alonso J, Patrick DL, de Vet HCW, Terwee CB. (2018) COSMIN guideline for systematic reviews of patient-reported outcome measures. Qual Life Res, 27: 1147-1157.

84. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. (2007) Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol, 60: 34-42.

85. Rencz F, Szabó Á, Brodszky V. (2021) Questionnaire Modifications and Alternative Scoring Methods of the Dermatology Life Quality Index: A Systematic Review. Value Health, 24: 1158-1171.

86. Terwee CB, Prinsen CAC, Chiarotto A, Westerman MJ, Patrick DL, Alonso J, Bouter LM, de Vet HCW, Mokkink LB. (2018) COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res, 27: 1159-1170.

87. Hongbo Y, Thomas CL, Harrison MA, Salek MS, Finlay AY. (2005) Translating the science of quality of life into practice: What do dermatology life quality index scores mean? J Invest Dermatol, 125: 659-664.

88. Rothman M, Burke L, Erickson P, Leidy NK, Patrick DL, Petrie CD. (2009) Use of existing patient-reported outcome (PRO) instruments and their modification: the ISPOR Good Research Practices for Evaluating and Documenting Content Validity for the Use of Existing Instruments and Their Modification PRO Task Force Report. Value Health, 12: 1075-1083.

89. Anfray C, Arnold B, Martin M, Eremenco S, Patrick DL, Conway K, Acquadro C, on behalf of the IT, Cultural Special Interest G. (2018) Reflection paper on copyright, patient-reported outcome instruments and their translations. Health and Quality of Life Outcomes, 16: 224.

90. Finlay AY. (2015) ©Copyright: why it matters. Br J Dermatol, 173: 1115-1116.

91. Finlay AY. (2017) Broader concepts of quality of life measurement, encompassing validation. J Eur Acad Dermatol Venereol, 31: 1254-1259.

92. Anfray C, Emery MP, Conway K, Acquadro C. (2012) Questions of copyright. Health Qual Life Outcomes, 10: 16.

93. Mulhern BJ, Sampson C, Haywood P, Addo R, Page K, Mott D, Shah K, Janssen MF, Herdman M. (2022) Criteria for developing, assessing and selecting candidate EQ-5D bolt-ons. Qual Life Res, 31: 3041-3048.

94. Swinburn P, Lloyd A, Boye KS, Edson-Heredia E, Bowman L, Janssen B. (2013) Development of a Disease-Specific Version of the EQ-5D-5L for Use in Patients Suffering

from Psoriasis: Lessons Learned from a Feasibility Study in the UK. Value Health, 16: 1156-1162.

95. Rencz F, Mukuria C, Bató A, Poór AK, Finch AP. (2022) A qualitative investigation of the relevance of skin irritation and self-confidence bolt-ons and their conceptual overlap with the EQ-5D in patients with psoriasis. Qual Life Res, 31: 3049-3060.

96. Finch AP, Brazier J, Mukuria C. (2020) Selecting Bolt-on Dimensions for the EQ-5D: Testing the Impact of Hearing, Sleep, Cognition, Energy, and Relationships on Preferences Using Pairwise Choices. Med Decis Making, 41: 89-99.

97. Lewis-Jones MS, Finlay AY. (1995) The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. Br J Dermatol, 132: 942-949.

98. Wille N, Badia X, Bonsel G, Burström K, Cavrini G, Devlin N, Egmar AC, Greiner W, Gusi N, Herdman M, Jelsma J, Kind P, Scalone L, Ravens-Sieberer U. (2010) Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. Qual Life Res, 19: 875-886.

99. Basra MKA, Salek MS, Fenech D, Finlay AY. (2018) Conceptualization, development and validation of T-QoL((c)) (Teenagers' Quality of Life): a patient-focused measure to assess quality of life of adolescents with skin diseases. Br J Dermatol, 178: 161-175.

100. Smidt AC, Lai JS, Cella D, Patel S, Mancini AJ, Chamlin SL. (2010) Development and validation of Skindex-Teen, a quality-of-life instrument for adolescents with skin disease. Arch Dermatol, 146: 865-869.

101. Peasgood T, Caruana JM, Mukuria C. (2023) Systematic Review of the Effect of a One-Day Versus Seven-Day Recall Duration on Patient Reported Outcome Measures (PROMs). Patient, 16: 201-221.

102. Davern J, O'Donnell AT. (2018) Stigma predicts health-related quality of life impairment, psychological distress, and somatic symptoms in acne sufferers. PLoS One, 13: e0205009.

103. He Z, Lo Martire R, Lu C, Liu H, Ma L, Huang Y, Li Y, Sun L, Bai Y, Liu W, Zha X. (2018) Rasch Analysis of the Dermatology Life Quality Index Reveals Limited Application to Chinese Patients with Skin Disease. Acta Derm Venereol, 98: 59-64.

104. Esmann S, Jemec GB. (2010) Is the Dermatology Life Quality Index really time-sensitive? J Eur Acad Dermatol Venereol, 24: 621-622.

105. Hayashi N, Miyachi Y, Kawashima M. (2015) Prevalence of scars and "mini-scars", and their impact on quality of life in Japanese patients with acne. J Dermatol, 42: 690-696.

106. Jobanputra R, Bachmann M. (2000) The effect of skin diseases on quality of life in patients from different social and ethnic groups in Cape Town, South Africa. Int J Dermatol, 39: 826-831.

107. Takahashi N, Suzukamo Y, Nakamura M, Miyachi Y, Green J, Ohya Y, Finlay AY, Fukuhara S, Acne QOLQDT. (2006) Japanese version of the Dermatology Life Quality Index: validity and reliability in patients with acne. Health Qual Life Outcomes, 4: 46.

108. Chiang YZ, Bundy C, Griffiths CE, Paus R, Harries MJ. (2015) The role of beliefs: lessons from a pilot study on illness perception, psychological distress and quality of life in patients with primary cicatricial alopecia. Br J Dermatol, 172: 130-137.

109. Williamson D, Gonzalez M, Finlay AY. (2001) The effect of hair loss on quality of life. J Eur Acad Dermatol Venereol, 15: 137-139.

110. Zbiciak-Nylec M, Wcislo-Dziadecka D, Brzezinska-Wcislo L, Smyla M, Miziolek B, Michalska-Bankowska A. (2015) The power of stereotypes. Findings of a pilot study on the psychosocial aspects and quality of life among patients with androgenetic alopecia. Post N Med Postepy Nauk Medycznych, 28: 181-185.

111. Zhuang XS, Zheng YY, Xu JJ, Fan WX. (2013) Quality of life in women with female pattern hair loss and the impact of topical minoxidil treatment on quality of life in these patients. Exp Ther Med, 6: 542-546.

112. Kondoh A, Ohta Y, Yamamoto K, Iwashita K, Umezawa Y, Matsuyama T, Ozawa A, Shinohara Y. (2005) Feasibility of modified DLQI-based questionnaires for evaluation of clinical efficacy of herbal medicine in chronic skin diseases. Tokai J Exp Clin Med, 30: 97-102.

113. Czech W, Brautigam M, Weidinger G, Schopf E. (2000) A body-weight-independent dosing regimen of cyclosporine microemulsion is effective in severe atopic dermatitis and improves the quality of life. J Am Acad Dermatol, 42: 653-659.

114. Zachariae R, Lei U, Haedersdal M, Zachariae C. (2012) Itch severity and quality of life in patients with pruritus: preliminary validity of a Danish adaptation of the itch severity scale. Acta Derm Venereol, 92: 508-514.

115. He J, Wang T, Dong J. (2012) A close positive correlation between malodor and sweating as a marker for the treatment of axillary bromhidrosis with Botulinum toxin A. J Dermatolog Treat, 23: 461-464.

116. He J, Wang T, Dong J. (2012) Excision of apocrine glands and axillary superficial fascia as a single entity for the treatment of axillary bromhidrosis. J Eur Acad Dermatol Venereol, 26: 704-709.

117. He J, Wang T, Zhang Y, Dong J. (2018) Surgical treatment of axillary bromhidrosis by combining suction-curettage with subdermal undermining through a miniature incision. J Plast Reconstr Aesthet Surg, 71: 913-918.

118. Van TN, Manh TN, Minh PPT, Minh TT, Huu ND, Cao KP, Huu QN, Cam VT, Huyen ML, Hau KT, Gandolfi M, Satolli F, Feliciani C, Tirant M, Vojvodic A, Lotti T. (2019) The Effectiveness of Local Surgical Technique in Treatment of Axillary Bromhidrosis. Open Access Maced J Med Sci, 7: 187-191.

119. Xie A, Nie L, Tan Q. (2014) Local injection of botulinum toxin A: an alternative therapy for axillary osmidrosis. J Dermatol, 41: 153-156.

120. Ebid AA, Ibrahim AR, Omar MT, El Baky AMM. (2017) Long-term effects of pulsed high-intensity laser therapy in the treatment of post-burn pruritus: a double-blind, placebo-controlled, randomized study. Lasers Med Sci, 32: 693-701.

121. Ayala F, Nino M, Fabbrocini G, Panariello L, Balato N, Foti C, Tosti A, Corazza M, Valsecchi RH, Gola M, Gallo R, Guarneri F, Pigatto PD, Cristaudo A, Schena D, Musumeci ML, Stingeni L, Lisi P. (2010) Quality of life and contact dermatitis: a disease-specific questionnaire. Dermatitis, 21: 84-90.

122. Holness DL. (2001) Results of a quality of life questionnaire in a patch test clinic population. Contact Dermatitis, 44: 80-84.

123. Simonsen AB, Sommerlund M, Deleuran M, Mortz CG, Johansen JD. (2015) Course of skin symptoms and quality of life in children referred for patch testing--a long-term follow-up study [published correction appears in Acta Derm Venereol. 2015 Jun 24;95(6):767-8]. Acta Derm Venereol, 95: 206-210.

124. Schuster A, Lesshafft H, Talhari S, Guedes de Oliveira S, Ignatius R, Feldmeier H. (2011) Life quality impairment caused by hookworm-related cutaneous larva migrans in resource-poor communities in Manaus, Brazil. PLoS Negl Trop Dis, 5: e1355.

125. Shimogawara R, Hata N, Schuster A, Lesshafft H, Guedes de Oliveira S, Ignatius R, Akao N, Ohta N, Feldmeier H. (2013) Hookworm-related cutaneous larva migrans in patients living in an endemic community in Brazil: immunological patterns before and after ivermectin treatmen. Eur J Microbiol Immunol (Bp), 3: 258-266.

126. Kontochristopoulos G, Katsavou AN, Kalogirou O, Agelidis S, Zakopoulou N. (2007) Letter: Botulinum toxin type A: an alternative symptomatic management of Darier's disease. Dermatol Surg, 33: 882-883.

127. Chandrasena TG, Premaratna R, Muthugala MA, Pathmeswaran A, de Silva NR. (2007) Modified Dermatology Life Quality Index as a measure of quality of life in patients with filarial lymphoedema. Trans R Soc Trop Med Hyg, 101: 245-249.

128. Yahathugoda TC, Weerasooriya MV, Samarawickrema WA, Kimura E, Itoh M. (2018) Impact of two follow-up schemes on morbidity management and disability prevention (MMDP) programme for filarial lymphedema in Matara, Sri Lanka. Parasitol Int, 67: 176-183.

129. Ofenloch RF, Diepgen TL, Weisshaar E, Elsner P, Apfelbacher CJ. (2014) Assessing health-related quality of life in hand eczema patients: how to overcome psychometric faults when using the dermatology life quality index. Acta Derm Venereol, 94: 658-662.

130. Apfelbacher CJ, Ofenloch RF, Weisshaar E, Molin S, Bauer A, Mahler V, Heinrich A, von Kiedrowski R, Schmitt J, Elsner P, Diepgen TL. (2019) Chronic hand eczema in Germany: 5-year follow-up data from the CARPE registry. Contact Dermatitis, 80: 45-53.

131. Butt M, Sisic M, Silva C, Naik HB, Esmann S, Jemec G, Kirby JS. (2019) The associations of depression and coping methods on health-related quality of life for those with hidradenitis suppurativa. J Am Acad Dermatol, 80: 1137-1139.

132. Storer MA, Danesh MJ, Sandhu ME, Pascoe V, Kimball AB. (2018) An assessment of the relative impact of hidradenitis suppurativa, psoriasis, and obesity on quality of life. Int J Womens Dermatol, 4: 198-202.

133. Alizadeh N, Ayyoubi S, Naghipour M, Hassanzadeh R, Mohtasham-Amiri Z, Zaresharifi S, Gharaei Nejad K. (2017) Can laser treatment improve quality of life of hirsute women? Int J Womens Health, 9: 777-780.

134. Conroy FJ, Venus M, Monk B. (2006) A qualitative study to assess the effectiveness of laser epilation using a quality-of-life scoring system. Clin Exp Dermatol, 31: 753-756.

135. Grant P. (2010) Spearmint herbal tea has significant anti-androgen effects in polycystic ovarian syndrome. a randomized controlled trial. Phytother Res, 24: 186-188.

136. Loo WJ, Lanigan SW. (2002) Laser treatment improves quality of life of hirsute females. Clin Exp Dermatol, 27: 439-441.

137. Maziar A, Farsi N, Mandegarfard M, Babakoohi S, Gorouhi F, Dowlati Y, Firooz A. (2010) Unwanted facial hair removal with laser treatment improves quality of life of patients. J Cosmet Laser Ther, 12: 7-9.

138. Wong SYC, Rivers JK. (2009) Does Laser and/or Electro-optical Synergy Technology for Removal of Unwanted Facial Hair Improve Women's Quality of Life? Journal of the Dermatology Nurses' Association, 1: 338-343.

139. Artzi O, Loizides C, Zur E, Sprecher E. (2017) Topical Oxybutynin 10% Gel for the Treatment of Primary Focal Hyperhidrosis: A Randomized Double-blind Placebo-controlled Split Area Study. Acta Derm Venereol, 97: 1120-1124.

140. Kouris A, Armyra K, Christodoulou C, Karimali P, Karypidis D, Kontochristopoulos G. (2014) Quality of Life in Patients with Focal Hyperhidrosis before and after Treatment with Botulinum Toxin A. ISRN Dermatol, 2014: 308650.

141. Tan SR, Solish N. (2002) Long-term efficacy and quality of life in the treatment of focal hyperhidrosis with botulinum toxin A. Dermatol Surg, 28: 495-499.

142. Blanch J, Rousaud A, Martinez E, De Lazzari E, Milinkovic A, Peri JM, Blanco JL, Jaen J, Navarro V, Massana G, Gatell JM. (2004) Factors associated with severe impact of lipodystrophy on the quality of life of patients infected with HIV-1. Clin Infect Dis, 38: 1464-1470.

143. Abbas M, Schwartz ME, Smith FJ, McLean WH, Hull PR. (2015) PCQoL: A Quality of Life Assessment Measure for Pachyonychia Congenita. J Cutan Med Surg, 19: 57-65.

144. Herane MI, Orlandi C, Zegpi E, Valdes P, Ancic X. (2012) Clinical efficacy of adapalene (differin((R))) 0.3% gel in Chilean women with cutaneous photoaging. J Dermatolog Treat, 23: 57-64.

145. Huang C, Yan S, Ren J, Xiang L, Hu Y, Kang K, Seite S. (2013) A quantitative assessment of the effects of formal sun protection education on photosensitive patients. Photodermatol Photoimmunol Photomed, 29: 261-265.

146. Jong CT, Finlay AY, Pearse AD, Kerr AC, Ferguson J, Benton EC, Hawk JL, Sarkany RP, McMullen E, Rhodes LE, Farr PM, Anstey AV. (2008) The quality of life of 790 patients with photodermatoses. Br J Dermatol, 159: 192-197.

147. Tan KW, Haylett AK, Ling TC, Rhodes LE. (2017) Comparison of Demographic and Photobiological Features of Chronic Actinic Dermatitis in Patients With Lighter vs Darker Skin Types. JAMA Dermatol, 153: 427-435.

148. Wang J, Zhu YY, Wang ZY, Yao XH, Zhang LF, Lv H, Zhang SP, Hu B. (2017) Analysis of quality of life and influencing factors in 197 Chinese patients with port-wine stains. Medicine (Baltimore), 96: e9446.

149. Panahi Y, Davoudi SM, Sadr SB, Naghizadeh MM, Mohammadi-Mofrad M. (2008) Impact of pruritus on quality of life in sulfur mustard-exposed Iranian veterans. Int J Dermatol, 47: 557-561.

150. Panahi Y, Sahebkar A, Amiri M, Davoudi SM, Beiraghdar F, Hoseininejad SL, Kolivand M. (2012) Improvement of sulphur mustard-induced chronic pruritus, quality of life and antioxidant status by curcumin: results of a randomised, double-blind, placebo-controlled trial. Br J Nutr, 108: 1272-1279.

151. Twiss J, Meads DM, Preston EP, Crawford SR, McKenna SP. (2012) Can we rely on the Dermatology Life Quality Index as a measure of the impact of psoriasis or atopic dermatitis? J Invest Dermatol, 132: 76-84.

152. Belcaro G, Luzzi R, Hu S, Cesarone MR, Dugall M, Ippolito E, Corsi M, Caporale S. (2014) Improvement in signs and symptoms in psoriasis patients with Pycnogenol(R) supplementation. Panminerva Med, 56: 41-48.

153. Kim GE, Seidler E, Kimball AB. (2014) The relative impact of psoriasis and obesity on socioeconomic and medical outcomes in psoriasis patients. J Eur Acad Dermatol Venereol, 28: 216-221.

154. Kim GE, Seidler E, Kimball AB. (2015) Effect of Age at Diagnosis on Chronic Quality of Life and Long-Term Outcomes of Individuals with Psoriasis. Pediatr Dermatol, 32: 656-662.

155. Kim GE, Seidler E, Kimball AB. (2015) A measure of chronic quality of life predicts socioeconomic and medical outcomes in psoriasis patients. J Eur Acad Dermatol Venereol, 29: 249-254.

156. Ljosaa TM, Stubhaug A, Mork C, Moum T, Wahl AK. (2013) Improvement in Psoriasis Area and Severity Index score predicts improvement in skin pain over time in patients with psoriasis. Acta Derm Venereol, 93: 330-334.

157. Malligarjunan H, Dayalan H, Gnanaraj P, Elango T, Subramanian S. (2011) Impact of propylthiouracil on quality of life in psoriasis patients. Indian J Med Sci, 65: 331-336.

158. Meeuwis KAP, de Hullu JA, van de Nieuwenhof HP, Evers AW, Massuger LF, van de Kerkhof PC, van Rossum MM. (2011) Quality of life and sexual health in patients with genital psoriasis. Br J Dermatol, 164: 1247-1255.

159. Mrowietz U, Macheleidt O, Eicke C. (2011) Effective treatment and improvement of quality of life in patients with scalp psoriasis by topical use of calcipotriol/betamethasone (Xamiol(R)-gel): results. J Dtsch Dermatol Ges, 9: 825-831.

160. Zachariae R, Zachariae CO, Lei U, Pedersen AF. (2008) Affective and sensory dimensions of pruritus severity: associations with psychological symptoms and quality of life in psoriasis patients. Acta Derm Venereol, 88: 121-127.

161. Nair PA, Vora RV, Jivani NB, Gandhi SS. (2016) A Study of Clinical Profile and Quality of Life in Patients with Scabies at a Rural Tertiary Care Centre. J Clin Diagn Res, 10: WC01-WC05.

162. Worth C, Heukelbach J, Fengler G, Walter B, Liesenfeld O, Feldmeier H. (2012) Impaired quality of life in adults and children with scabies from an impoverished community in Brazil. Int J Dermatol, 51: 275-282.

163. Lorette G, Ermosilla V. (2006) Clinical efficacy of a new ciclopiroxolamine/zinc pyrithione shampoo in scalp seborrheic dermatitis treatment. Eur J Dermatol, 16: 558-564.

164. Giess R, Naumann M, Werner E, Riemann R, Beck M, Puls I, Reiners C, Toyka KV. (2000) Injections of botulinum toxin A into the salivary glands improve sialorrhoea in amyotrophic lateral sclerosis. J Neurol Neurosurg Psychiatry, 69: 121-123.

165. Verma A, Steele J. (2006) Botulinum toxin improves sialorrhea and quality of living in bulbar amyotrophic lateral sclerosis. Muscle Nerve, 34: 235-237.

166. Komatsu H, Yagasaki K, Hamamoto Y, Takebayashi T. (2018) Falls and Physical Inactivity in Patients with Gastrointestinal Cancer and Hand-Foot Syndrome. Asia Pac J Oncol Nurs, 5: 307-313.

167. Peeters M, Siena S, Van Cutsem E, Sobrero A, Hendlisz A, Cascinu S, Kalofonos H, Devercelli G, Wolf M, Amado RG. (2009) Association of progression-free survival, overall survival, and patient-reported outcomes by skin toxicity and KRAS status in patients receiving panitumumab monotherapy. Cancer, 115: 1544-1554.

168. Yagasaki K, Komatsu H, Soejima K, Naoki K, Kawada I, Yasuda H, Hamamoto Y. (2018) Targeted Therapy-induced Facial Skin Toxicities: Impact on Quality of Life in Cancer Patients. Asia Pac J Oncol Nurs, 5: 172-177.

169. Wiese S, Elson L, Feldmeier H. (2018) Tungiasis-related life quality impairment in children living in rural Kenya. PLoS Negl Trop Dis, 12: e0005939.

170. Nettis E, Colanardi MC, Paradiso MT, Ferrannini A. (2004) Desloratadine in combination with montelukast in the treatment of chronic urticaria: a randomized, double-blind, placebo-controlled study. Clin Exp Allergy, 34: 1401-1407.

171. Bhute AA, Jha RK. (2016) Pharmacoepidemiological perspective of vaginal candidiasis: A cross sectional surveillance study among women of reproductive age group belonging to Wardha District, Maharashtra, India. Res J Pharm, Biol Chem Sci Research Journal of Pharmaceutical, Biological and Chemical Sciences, 7: 499-511.

172. Nguyen Y, Lee A, Fischer G. (2017) Quality of life in patients with chronic vulvovaginal candidiasis: A before and after study on the impact of oral fluconazole therapy. Australas J Dermatol, 58: e176-e181.

173. Borimnejad L, Parsa Yekta Z, Nikbakht-Nasrabadi A, Firooz A. (2006) Quality of life with vitiligo: comparison of male and female muslim patients in Iran. Gend Med, 3: 124-130.

174. Tjioe M, Otero ME, van de Kerkhof PC, Gerritsen MJ. (2005) Quality of life in vitiligo patients after treatment with long-term narrowband ultraviolet B phototherapy. J Eur Acad Dermatol Venereol, 19: 56-60.

175. Ciconte A, Campbell J, Tabrizi S, Garland S, Marks R. (2003) Warts are not merely blemishes on the skin: A study on the morbidity associated with having viral cutaneous warts. Australas J Dermatol, 44: 169-173.

176. Leow MQH, Oon HHB. (2016) The impact of viral warts on the quality of life of patients. Dermatological nursing, 15: 44-48.

177. Loo WJ, Diba V, Chawla M, Finlay AY. (2003) Dermatology Life Quality Index: influence of an illustrated version. Br J Dermatol, 148: 279-284.

178. Murray CS, Rees JL. (2010) How robust are the Dermatology Life Quality Index and other self-reported subjective symptom scores when exposed to a range of experimental biases? Acta Derm Venereol, 90: 34-8.

179. Barbieri JS, Gelfand JM. (2019) Responsiveness of the EuroQol 5-Dimension 3-Level instrument, Dermatology Life Quality Index (DLQI) and DLQI-Relevant for patients with psoriasis in the U.S.A. Br J Dermatol, 181: 1088-1090.

180. Haagsma JA, Spronk I, de Jongh MAC, Bonsel GJ, Polinder S. (2020) Conventional and retrospective change in health-related quality of life of trauma patients: an explorative observational follow-up study. Health Qual Life Outcomes, 18: 157.

181. Norquist JM, Girman C, Fehnel S, DeMuro-Mercon C, Santanello N. (2012) Choice of recall period for patient-reported outcome (PRO) measures: criteria for consideration. Qual Life Res, 21: 1013-1020.

182. Stull DE, Leidy NK, Parasuraman B, Chassany O. (2009) Optimal recall periods for patient-reported outcomes: challenges and potential solutions. Curr Med Res Opin, 25: 929-942.

183. Olsen JR, Gallacher J, Finlay AY, Piguet V, Francis NA. (2016) Quality of life impact of childhood skin conditions measured using the Children's Dermatology Life Quality Index (CDLQI): a meta-analysis. Br J Dermatol, 174: 853-861.

184. Lozano LM, García-Cueto E, Muñiz J. (2008) Effect of the number of response categories on the reliability and validity of rating scales. Methodology: European Journal of Research Methods for the Behavioral and Social Sciences, 4: 73-79.

185. Rencz F, Poór AK, Péntek M, Holló P, Kárpáti S, Gulácsi L, Szegedi A, Remenyik É, Hidvégi B, Herszényi K, Jókai H, Beretzky Z, Brodszky V. (2018) A detailed analysis of 'not relevant' responses on the DLQI in psoriasis: potential biases in treatment decisions. J Eur Acad Dermatol Venereol, 32: 783-790.

186. Barbieri JS, Shin DB, Syed MN, Takeshita J, Gelfand JM. (2020) Evaluation of the Frequency of "Not Relevant" Responses on the Dermatology Life Quality Index by Sociodemographic Characteristics of Patients With Psoriasis. JAMA Dermatol, 156: 446-450.

187. Gergely LH, Gáspár K, Brodszky V, Kinyó Á, Szegedi A, Remenyik É, Kiss NF, Bató A, Péntek M, Gulácsi L, Sárdy M, Bánvölgyi A, Wikonkál N, Rencz F. (2020) Validity of EQ-5D-5L, Skindex-16, DLQI and DLQI-R in patients with hidradenitis suppurativa. J Eur Acad Dermatol Venereol, 34: 2584-2592.

188. Tamási B, Brodszky V, Péntek M, Gulácsi L, Hajdu K, Sárdy M, Szegedi A, Bata-Csörgő Z, Kinyó Á, Rencz F. (2019) Validity of the EQ-5D in patients with pemphigus vulgaris and pemphigus foliaceus. Br J Dermatol, 180: 802-809.

189. Rencz F, Mitev AZ, Szabó Á, Beretzky Z, Poór AK, Holló P, Wikonkál N, Sárdy M, Kárpáti S, Szegedi A, Remenyik É, Brodszky V. (2021) A Rasch model analysis of two interpretations of 'not relevant' responses on the Dermatology Life Quality Index (DLQI). Qual Life Res, 30: 2375-2386.

190. Hornsey S, Stuart B, Muller I, Layton AM, Morrison L, King J, Thomas K, Little P, Santer M. (2021) Patient-reported outcome measures for acne: a mixed-methods validation study (acne PROMs). BMJ Open, 11: e034047.

191. Bató A, Brodszky V, Gergely LH, Gáspár K, Wikonkál N, Kinyó Á, Szabó Á, Beretzky Z, Szegedi A, Remenyik É, Kiss N, Sárdy M, Rencz F. (2021) The measurement

performance of the EQ-5D-5L versus EQ-5D-3L in patients with hidradenitis suppurativa. Qual Life Res, 30: 1477-1490.

8. Bibliography of own publications

8.1. Publications related to this thesis

8.1.1. International peer reviewed journals

Total IF: 15.456

1. **Szabó Á**, Brodszky V, Rencz F. (2022) A comparative study on the measurement properties of Dermatology Life Quality Index (DLQI), DLQI-Relevant and Skindex-16. Br J Dermatol, 186: 485-495. **(IF: 10.3) D1**

2. Rencz F, **Szabó Á**, Brodszky V. (2021) Questionnaire Modifications and Alternative Scoring Methods of the Dermatology Life Quality Index: A Systematic Review. Value Health, 24: 1158-1171. **(IF: 5.156) D1**

8.1.2. Conference presentations and posters

1. **Szabó Á**, Brodszky V, Rencz F. (2022) POSB379 Measurement Properties of DLQI, DLQI-R and Skindex-16: A Comparative Study. Value Health, 25: Supplement 1 p. S235.

2. **Szabó Á**, Brodszky V, Rencz F. (2021) Melyik a legjobb bőr-specifikus életminőség kérdőív? DLQI, DLQI-R és Skindex-16 összehasonlító elemzés. Bőrgyógy Venerol Sz, 97: 6 p.

3. Rencz F, **Szabó Á**, Brodszky V. (2020) 59-féle DLQI kérdőív létezik?!. Bőrgyógy Venerol Sz, 96: 6 p.

8.2. Publications not related to this thesis

8.2.1. International peer reviewed journals

Total IF: 30.686

1. Szlávicz E, **Szabó Á**, Kinyó Á, Szeiffert A, Bancsók T, Brodszky V, Gyulai R, Rencz F. (2024) Content validity of the EQ-5D-5L with skin irritation and self-confidence bolt-ons in patients with atopic dermatitis: a qualitative think-aloud study. Qual Life Res, 33: 101-111. **(IF: 3.5)**

2. Kuzmanovszki D, Kiss N, Tóth B, Tóth V, Szakonyi J, Lőrincz K, Hársing J, Kuroli E, Imrédi E, Kerner T, Patyánik M, Wikonkál NM, **Szabó Á**, Brodszky V, Rencz F, Holló P. (2023) Real-World Experience with Cemiplimab Treatment for Advanced Cutaneous Squamous Cell Carcinoma-A Retrospective Single-Center Study. J Clin Med, 12: 5966 **(IF: 3.9)**

3. Koszorú K, Hajdu K, Brodszky V, **Szabó Á**, Borza J, Bodai K, Pónyai G, Szegedi A, Sárdy M, Rencz F. (2022) General and Skin-Specific Health-Related Quality of Life in Patients With Atopic Dermatitis Before and During the COVID-19 Pandemic. Dermatitis, 33: S92-S103. **(IF: 5.2)**

4. Kuzmanovszki D, Kiss N, Tóth B, Kerner T, Tóth V, Szakonyi J, Lőrincz K, Hársing J, Imrédi E, Pfund A, **Szabó Á**, Brodszky V, Rencz F, Holló P. (2022) Anti-PD-1 Monotherapy in Advanced Melanoma-Real-World Data from a 77-Month-Long Retrospective Observational Study. Biomedicines, 10: 1737 **(IF: 4.7)**

5. Bató A, Brodszky V, Gergely LH, Gáspár K, Wikonkál N, Kinyó Á, **Szabó Á**, Beretzky Z, Szegedi A, Remenyik É, Kiss N, Sárdy M, Rencz F. (2021) The measurement performance of the EQ-5D-5L versus EQ-5D-3L in patients with hidradenitis suppurativa. Qual Life Res, 30: 1477-1490. **(IF: 3.440)**

6. Piros ÉA, **Szabó Á**, Rencz F, Brodszky V, Szalai K, Galajda N, Szilveszter B, Dósa E, Merkely B, Holló P. (2021) Impact of Interleukin-17 Inhibitor Therapy on Arterial Intima-media Thickness among Severe Psoriatic Patients. Life (Basel), 11: 919 **(IF: 3.253)**

7. Piros ÉA, **Szabó Á**, Rencz F, Brodszky V, Wikonkál N, Miheller P, Horváth M, Holló P. (2021) Anti-Interleukin-17 Therapy of Severe Psoriatic Patients Results in an Improvement of Serum Lipid and Inflammatory Parameters' Levels, but Has No Effect on Body Composition Parameters. Life (Basel), 11: 535 **(IF: 3.253)**

8. Rencz F, Mitev AZ, **Szabó Á**, Beretzky Z, Poór AK, Holló P, Wikonkál N, Sárdy M, Kárpáti S, Szegedi A, Remenyik É, Brodszky V. (2021) A Rasch model analysis of two interpretations of 'not relevant' responses on the Dermatology Life Quality Index (DLQI). Qual Life Res, 30: 2375-2386. **(IF: 3.440)**

8.2.2. Hungarian peer-reviewed journals

Total IF: 0.707

1. Galajda NÁ, Piros ÉA, Szalai K, Lukács A, Hon-Balla B, Kolonics MV, **Szabó Á**, Rencz F, Brodszky V, Miheller P, Wikonkál N, Holló P. (2023) IL-23/Th-17 útvonal: egy lehetséges közös nevező a pikkelysömör és kardiometabolikus társbetegségeinek kialakulásában. Bőrgyógy Venerol Sz, 99: 1 p. 17-24.

2. Szmirnova I, Szmirnov Gy, Rencz F, **Szabó Á**, Trimmel B, Németh Zs, Szabó Gy. (2020) Értelmi sérültek fogászati állapotának felmérése. Orv Hetil, 162: 42 p. 1698-1702. **(IF: 0.707)**

8.2.3. Conference presentations and posters

1. Oláh F, **Szabó Á**. (2023) A humán papillomavírus (HPV) elleni vakcina elfogadottsága, fizetési hajlandóság, HPV-ismeretek és egészségügyi tájékozottság Magyarországon.

2. **Szabó Á**, Brodszky V, Rencz F. (2023) Comparing EQ-5D-5L, PROPR SF-6D and TTO utilities in patients with chronic skin diseases. Semmelweis University PhD Scientific Days, Budapest.

3. **Szabó Á**, Brodszky V, Rencz F. (2022) SA72 Comparing EQ-5D-5L, Propr, Sf-6D and TTO Utilities in Patients With Chronic Skin Diseases. Value Health, 25: 12 S497.

4. **Szabó Á**, Brodszky V, Rencz F. (2022) Egészséghasznosság-mérési módszerek összehasonlítása krónikus bőrgyógyászati betegségekben. Bőrgyógy Venerol Sz, 98: 4 p.

5. Szlávicz E, **Szabó Á**, Kinyó Á, Szeiffert, A, Bancsok T, Brodszky V, Gyulai R, Rencz F. (2022) Az életminőség vizsgálata felnőttkori atópiás dermatitiszben. Bőrgyógy Venerol Sz, 98: 4 p.

6. Piros ÉA, **Szabó Á**, Rencz F, Brodszky V, Szalai K, Galajda NÁ, Szilveszter B, Dósa E, Merkely B, Holló P. (2021) Interleukin-17 Inhibitor Therapy on Arterial Intima-media Thickness among Severe Psoriatic Patients. J Invest Dermatol, 141: 10 Suppl. p. S156-S156.

7. Koszorú K, Hajdu K, Borza J, Bodai K, **Szabó Á**, Bató A, Szegedi A, Brodszky V, Rencz F, Sárdy M. (2021) 080 The impact of atopic dermatitis on health-related quality of life. J Invest Dermatol, 141: S162.

8. Rencz F, **Szabó Á**, Brodszky V. (2021) DLQI-R: az első 3 év tapasztalatai. Bőrgyógy Venerol Sz, 97: 6 p.

9. Koszorú K, Hajdu K, Borza J, Bodai K, **Szabó Á**, Bató A, Beretzky Zs, Blága K, Gergely LH, Kovács A, Pónyai Gy, Szegedi A, Brodszky V, Rencz F, Sárdy M. (2021) Az atopiás dermatitis betegségterhe. Bőrgyógy Venerol Sz, 97: 322 p.

10. Balázs PG, Brodszky V, Jenei B, **Szabó Á**, Gergely LH, Gáspár K, Kinyó Á, Wikonkál N, Szegedi A, Remenyik É, Kiss N, Sárdy M, Bánvölgyi A, Rencz F. (2020) PSY32 Health Utility Assessment By Composite Time Trade-Off in Patients with Hidradenitis Suppurativa. Value Health, 23: Suppl. 2 pp. S748.

11. Rencz F, Mitev AZ, **Szabó Á,** Beretzky Z, Poór AK, Holló P, Sárdy M, Kárpáti S, Szegedi A, Remenyik É, Brodszky V. (2020) PSY31 The Relevance of 'not Relevant' Responses on the Dlqi: A Rasch Analysis in Patients with Psoriasis. Value Health, 23: Suppl. 2 pp. S748.

9. Acknowledgments

I extend my heartfelt gratitude to Prof. Fanni Rencz (my supervisor, colleague, and mentor), whose unwavering guidance and support have been instrumental in shaping my academic journey since my master's degree. My supervisor's expertise, encouragement, and inspiration have fostered my dedication and attention to detail in my research and work. Together, we have navigated the intricate landscape of academia, adding numerous valuable contributions to the tapestry of knowledge. As I progress in my academic endeavours, I am equipped with the invaluable insights and wisdom gained under the tutelage of Professor Rencz, and I am eager to continue sewing new threads into the rich fabric of scientific exploration.

I would also like to thank Prof. Valentin Brodszky (my head of department) for making this research possible, reviewing my work, providing insightful remarks, and allowing me to teach at the Corvinus University of Budapest for three years. Moreover, I would also like to thank all my co-authors, fellow researchers, and colleagues for their support and invaluable contribution.

Last but not least, I am grateful to my partner/love who supports my education and career.

10. List of tables and figures

Tables

Table 1 – Own editing summary table of Hungarian cost of illness studies in dermatology [27-30] 7

Table 2 – Characteristics of DLQI, DLQI-R and Skindex-16 [77] 13

Table 3 – Use of HRQoL measurement in dermatology, an adapted table from Finlay et al. 2017 [78]..... 14

Table 4 – European countries using the DLQI in national guidelines or registries and for which disease, an adapted table from Singh, R., & Finlay, A. (2020) [59] 15

Table 5 – Key measurement properties of HRQoL questionnaires, an adapted from Terwee et al. 2007, Prinsen et al. 2018 and Rencz et al 2021 [83,85,86] 17

Table 6 – Diagnoses/symptoms in which DLQI modifications were used [85].....24

Table 7 – Instrument administration characteristics of the studies [85].....26

Table 8 – Categorisation of DLQI modifications [85] 28

Table 9 – DLQI bolt-on items [85].....29

Table 10 – The most common changes in existing DLQI items [85].....31

Table 11 – Characteristics of the study population [77].....36

Table 12 – Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 [77].....38

Table 13 – Informativity of DLQI, DLQI-R and Skindex-16 [77] 41

Table 14 – Spearman's correlations between outcome measures [77].....42

Table 15 – Known-group validity of the DLQI, DLQI-R and Skindex-16 [mean (SD)][77] 43

Figures

Figure 1 – Dimensions affecting a person's HRQoL, an adapted figure from Wilson and Cleary 1995 [38] 9

Figure 2 – Study flow diagram [85] 23

Figure 3 – Distribution of Skindex-16 responses in patients with DLQI/DLQI-R score of zero [n=164] [77] 39

Figure 4 – Skindex-16 responses of patients with ‘not at all’ responses on the DLQI (matched items) [77] 40

Figure 5 – Skindex-16 responses of patients with NRR responses on the DLQI (matched items) [77] 40

11. Appendices

List of appendices

Appendix 1 Modified DLQI language versions [85].....84

Appendix 2 Countries in which DLQI modifications have been used in published research [85] 85

Appendix 3 Number of items in DLQI modifications [85].....86

Appendix 4 Quality criteria of the measurement properties [85].....87

Appendix 5 Quality of design, methods and reporting on measurement properties [85] 89

Appendix 6 Quality of measurement properties of DLQI modifications [85] 95

Appendix 7 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77] 101

Appendix 8 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77] 102

Appendix 9 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [77].....103

Appendix 10 Informativity of DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77].....104

Appendix 11 Informativity of DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77] 105

Appendix 12 Informativity of DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [77].....106

Appendix 13 Spearman's correlations between outcome measures in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77] 107

Appendix 14 Spearman's correlations between outcome measures in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77] 108

Appendix 15 Spearman's correlations between outcome measures in other dermatological conditions (n=151) [77].....109

Appendix 16 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [mean (SD) scores] [77] 110

Appendix 17 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [mean (SD) scores] [77] 111

Appendix 18 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [mean (SD) scores] [77].....112

Appendix 1 Modified DLQI language versions [85]

Language	Studies (n)[a]	%	References
Afrikaans	1	1%	[106]
Arabic	1	1%	[120]
Chinese	8	10%	[103,111,115-117,119,145,148]
Danish	5	6%	[104,114,123,131,160]
Dutch	2	3%	[158,174]
English[a]	23	30%	[60,106,108,109,122,131,132,134-136,138,141,143,146,147,151,153-155,165,172,175-179]
French	1	1%	[163]
German	5	6%	[113,129,130,159,164]
Greek	2	3%	[126,140]
Hebrew	1	1%	[139]
Hindi	3	4%	[157,161,171]
Hungarian	2	3%	[62,63]
Irish	1	1%	[102]
Italian	4	5%	[118,121,152,170]
Japanese	5	6%	[105,107,112,166,168]
Norwegian	1	1%	[156]
Persian	5	6%	[133,137,149,150,173]
Polish	1	1%	[110]
Portuguese[a]	2	3%	[124,125,162]
Sinhala	2	3%	[127,128]
Spanish	2	3%	[142,144]
Swahili	1	1%	[169]
Xhosa	1	1%	[106]
Multiple languages (unspecified)	1	1%	[167]
Total	**77**	**104%[b]**	

a: The papers by Kim et al. 2014[153], 2015a[154] and 2015b[155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a[60] and 2019b[179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011[124] and Shimogowara et al. 2013[125] used the same dataset and therefore considered one study. ***b:*** The sum of percentages is higher than 100% as multiple language versions of the same questionnaire were applied in three studies [106,131,167].

Appendix 2 Countries in which DLQI modifications have been used in published research [85]

Country	Studies (n)	%	References
Australia	2	3%	[172,175]
Brazil[a]	2	3%	[124,125,162]
Canada	5	6%	[109,122,138,141,143]
Chile	1	1%	[144]
China	8	10%	[103,111,115-117,119,145,148]
Denmark	5	6%	[104,114,123,131,160]
France	1	1%	[163]
Germany	5	6%	[113,129,130,159,164]
Greece	2	3%	[126,140]
Hungary	2	3%	[62,63]
India	5	6%	[157,161,171]
Iran	1	1%	[133,137,149,150,173]
Ireland	3	4%	[102]
Israel	1	1%	[139]
Italy	4	5%	[118,121,152,170]
Japan	5	6%	[105,107,112,166,168]
Kenya	1	1%	[169]
Netherlands	2	3%	[158,174]
Norway	1	1%	[156]
Poland	1	1%	[110]
Saudi Arabia	1	1%	[120]
Singapore	1	1%	[176]
South Africa	1	1%	[106]
Spain	1	1%	[142]
Sri Lanka	2	3%	[127,128]
Tunisia	1	1%	[163]
United Kingdom	9	12%	[108,134-136,146,147,151,177,178]
United States[a]	5	6%	[60,131,132,153-155,165,179]
Multi-country (unspecified)	1	1%	[167]
Total	**77**	**103%[b]**	

a: The papers by Kim et al. 2014[153], 2015a[154]and 2015b[155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a[60] and 2019b[179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011[124] and Shimogowara et al. 2013[125] used the same dataset and therefore considered one study. ***b:*** The sum of percentages is higher than 100% as the study by Lorette&Ermosilla 2006[163] was conducted in France and Tunisia and the study by Butt et al. 2009 [74] in Denmark and the US.

Appendix 3 Number of items in DLQI modifications [85]

Number of items [a]	Studies (n) [b]	%	Modifications (n)	%	References
3	2	3%	2	3%	[110,167]
5	2	3%	3	5%	[161,170]
6	5	6%	6	10%	[129,130,132,162,169]
7	3	4%	1	2%	[114,120,160]
8	2	3%	3	5%	[103,124,125]
9	4	5%	2	3%	[142,149,150,156]
10	49	64%	33	56%	[60,62,63,102,104,105,107-109,111-113,115-119,122,123,126-128,131,133-135,137-141,145-148,151,153-155,157-159,163-166,168,171,172,177-179]
12	3	4%	3	5%	[106,143,152]
14	2	3%	2	3%	[136,174]
15	2	3%	1	2%	[175,176]
17	1	1%	1	2%	[173]
20	1	1%	1	2%	[121]
not reported	1	1%	1	2%	[144]
Total	**77**	**100%**	**59**	**100%**	

a: DLQI-SF and DLQI-Q1 were considered an alternative scorings of the 10-item original DLQI, not a 2-item or a 9-item questionnaire, respectively.

b: The papers by Kim et al. 2014 [153], 2015a [154]and 2015b [155] used the same dataset and therefore considered one study. The papers by Barbieri&Gelfand 2019a [60] and 2019b [179] used the same dataset and therefore considered one study. The papers by Schuster et al. 2011[124] and Shimogowara et al. 2013 [125] used the same dataset and therefore considered one study.

Appendix 4 Quality criteria of the measurement properties [85]

Measurement property	Quality criteria
Internal consistency	+ Factor analyses performed on adequate sample size (7 * no. items and >100) AND Cronbach's alpha(s) or Person Separation Index were calculated and range between 0.70 and 0.95; ? No factor analysis OR doubtful design or method; - Cronbach's alpha(s)/Person Separation Index <0.70 or >0.95, despite adequate design and method; 0 No information found on internal consistency.
Reliability	+ ICC or weighted Kappa>0.70 or Pearson's or Spearman's r >0.80; ? Doubtful design or method (e.g., time interval not mentioned); - ICC or weighted Kappa≤0.70 or Pearson's r or Spearman's r≤0.80, despite adequate design and method; 0 No information found on reliability.
Measurement error	+ MIC>SDC or MIC outside the LOA or convincing arguments that agreement is acceptable; ? Doubtful design or method or (MIC not defined AND no convincing arguments that agreement is acceptable); - MIC>SDC or MIC equals or inside LOA, despite adequate design and method; 0 No information found on agreement.
Content validity	+ A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection; ?A clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design or method; - No target population involvement; 0 No information found on target population involvement.
Structural validity	<u>CTT:</u> + Factors explain ≥ 50% of the variance - Factors explain < 50% of the variance' 0 No factor analysis has been carried out. <u>IRT/Rasch:</u> + No violation of unidimensionality: 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: $\chi 2$ >0.01; Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z-standardized values > -2 and <2 - Model fit not reported
Construct validity	+ Correlation with an instrument measuring the same construct ≥ 0.50 OR at least 75% of the results are in accordance with the hypotheses AND correlation with related constructs is higher than with unrelated constructs ? Solely correlations determined with unrelated constructs OR ≥ 50 but < 75% of the results are in accordance with the hypotheses - Correlation with an instrument measuring the same construct < 0.50 OR < 50% of the results are in accordance with the hypotheses OR correlation with related constructs is lower than with unrelated constructs 0 No information found on construct validity.

Measurement property	Quality criteria
Cross-cultural validity	+ No important differences found between group factors e.g. age, gender, language in multiple group factor analysis OR no important differential item functioning for group factors ? No multiple group factor analysis OR DIF analysis performed - Important differences between group factors or differential item functioning was found 0 No information found on cross-cultural validity.
Criterion validity	+ Convincing arguments that gold standard is ‘‘gold’’ and Pearson's or Spearman's correlation with gold standard >0.70; ? No convincing arguments that gold standard is ‘‘gold’’ OR doubtful design or method; - Pearson's or Spearman's correlation with gold standard ≤0.70, despite adequate design and method; 0 No information found on criterion validity.
Responsiveness	Correlation of changes with an instrument measuring change in the same construct ≥ 0.50 OR at least 75% of the results are in accordance with the hypotheses OR AUC ≥ 0.70 AND correlation of changes with related constructs is higher than with unrelated constructs ? Doubtful design or method - Correlation of changes with an instrument measuring change in the same construct < 0.50 OR < 75% of the results are in accordance with the hypotheses OR AUC < 0.70 OR correlation of changes with related constructs is lower than with unrelated constructs 0 No information found on responsiveness.
Floor &ceiling effects	+ <15% of the respondents achieved the highest or lowest possible scores; ? Doubtful design or method OR only ceiling or floor effect was reported, but not both; - ≥15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods; 0 No information found on interpretation.
Interpretability	+ Mean (SD) or median (IQR) scores presented of at least four relevant subgroups of patients and MIC defined; ? Doubtful design or method OR less than four subgroups OR no MIC defined; 0 No information found on interpretation.

Appendix 5 Quality of design, methods and reporting on measurement properties [85]

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
	'Before Botox' DLQI									
1	Tan & Solish 2002[141]	0	0	0	0	0	0	0	0	0
2	Kontochristopoulos et al. 2007[126]	0	0	0	0	0	0	0	0	0
	'Before surgical treatment' DLQI									
3	He et al. 2012[116]	0	0	0	0	0	0	0	0	0
4	He et al. 2018[117]	0	0	0	0	0	0	0	0	0
	Bromhidrosis or hyperhidrosis-specific DLQI									
1	Tan et al. 2002[141]	0	0	0	0	0	0	0	0	0
5	He et al. 2012[115]	0	0	0	0	0	0	0	0	0
6	Kouris et al. 2014[140]	0	0	0	0	0	0	0	0	0
7	Xie et al. 2014[119]	0	0	0	0	0	0	0	0	0
8	Artzi et al. 2017[139]	0	0	0	0	0	0	0	0	0
9	Van et al. 2019[118]	0	0	0	0	0	0	0	0	0
	Cutaneous larva migrans-specific DLQI (Adult)									
10	Schuster et al. 2011[124]	0	0	0	0	0	0	0	0	0
11	Shimogawara et al. 2013[125]	0	0	0	0	0	0	0	0	0
	Cutaneous larva migrans-specific DLQI (Child)									
10	Schuster et al. 2011[124]	0	0	0	0	0	0	0	0	0
11	Shimogawara et al. 2013[125]	0	0	0	0	0	0	0	0	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
	DLQI-Q1									
12	Panahi et al. 2008[149]	0	0	0	0	0	Fair	0	Fair	0
13	Ljossa et al. 2012[156]	Poor	0	0	0	0	Fair	0	0	0
14	Panahi et al. 2012[150]	0	0	0	0	0	0	0	0	0
	DLQI-R									
15	Rencz et al. 2018[62]	n/a	n/a	n/a	n/a	n/a	Fair	n/a	Fair	0
16	Barbieri & Gelfand 2019 [60]	n/a	n/a	n/a	n/a	n/a	Fair	n/a	0	0
17	Barbieri & G elfand 2019[179]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	Fair
18	Rencz et al. 2019[63]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	0
	DLQI-VW (viral wart-specific)									
19	Ciconte et al. 2003[175]	0	0	0	0	0	0	0	0	0
20	Leow & Oon 2016[176]	Poor	0	0	0	0	0	0	0	0
	Hirstutism-specific DLQI									
21	Conroy et al. 2006[134]	0	0	0	0	0	0	0	0	0
22	Grant 2010[135]	0	0	0	0	0	0	0	0	0
23	Maziar et al. 2010[137]	0	0	0	0	0	0	0	0	0
24	Alizadeh et al. 2017[133]	0	0	0	0	0	0	0	0	0
	Last year DLQI (LY-DLQI)									
25	Jong et al. 2008[146]	0	0	0	0	0	0	0	0	0
26	Esmann & Jemec 2010[104]	0	0	0	0	0	Fair	0	0	0
27	Meeuwis et al. 2011[158]	0	0	0	0	0	0	0	0	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
28	Huang et al. 2013[145]	0	0	0	0	0	0	0	0	0
29	Chiang et al. 2015[108]	0	0	0	0	0	Fair	0	Fair	0
30	Simonsen et al. 2015[123]	0	0	0	0	0	0	0	0	0
31	Tan et al. 2017[147]	0	0	0	0	0	0	0	0	0
	Pruritus-related quality of life Index									
32	Zachariae et al. 2008[160]	Poor	0	0	0	0	Fair	0	0	0
33	Zachariae et al. 2012[114]	Poor	0	0	0	0	Fair	0	0	0
34	Ebid et al. 2017[120]	0	0	0	0	0	0	0	0	0
	Psoriasis-specific last year DLQI									
35	Kim et al. 2014[153]	0	0	0	0	0	0	0	0	0
36	Kim et al. 2015[154]	0	0	0	0	0	Fair	0	0	0
37	Kim et al. 2015[155]	0	0	0	0	0	0	0	0	0
	Psoriasis-specific lifetime DLQI									
35	Kim et al. 2014[153]	0	0	0	0	0	0	0	0	0
36	Kim et al. 2015[154]	0	0	0	0	0	Fair	0	0	0
37	Kim et al. 2015[155]	0	0	0	0	0	0	0	0	0
	Rasch-calibrated DLQI for hand eczema									
38	Ofenloch et al. 2014[129]	Fair	0	0	0	Excellent	Fair	Excellent	Excellent	0
39	Apfelbacher et al. 2019[130]	0	0	0	0	0	0	0	0	0
	Drooling Impact Score									
40	Giess et. al. 2000[164]	0	0	0	0	0	0	0	0	0
41	Verma & Steele 2006[165]	0	0	0	0	0	0	0	0	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
	Questionnaires used in one study									
42	Czech et al. 2000[113]	0	0	0	0	0	0	0	0	0
43	Jobanputra & Bachmann 2000[106]	Poor	Fair	0	Fair	0	Fair	Fair	0	0
44	Holness 2001[122]	0	0	0	0	0	0	0	0	0
45	Williamson et al. 2001[109]	0	0	0	0	0	Poor	0	0	0
46	Loo & Lanigan 2002[136]	0	0	0	0	0	0	0	0	0
47	Loo et al. 2003[177]	0	0	0	0	0	0	0	Good	0
48	Blanch et al. 2004[142]	0	0	0	0	0	0	0	0	0
49	Nettis et al. 2004[170]	0	0	0	0	0	0	0	0	0
50	Kondoh et al. 2005[112]	0	0	0	0	0	0	0	0	0
51	Tjioe et al. 2005[174]	0	0	0	0	0	0	0	0	0
52	Borimnejad et al. 2006[173]	0	0	0	0	0	0	0	0	0
53	Lorette & Ermosilla 2006[163]	0	0	0	0	0	0	0	0	0
54	Takahashi et al. 2006[107]	Excellent	Fair	0	Fair	Excellent	Fair	0	0	0
55	Chandrasena et al. 2007[127]	Poor	0	0	0	0	Fair	0	0	0
56	Peeters et al. 2009[167]	0	0	0	0	0	Fair	0	0	0
57	Wong & Rivers 2009[138]	0	0	0	0	0	0	0	0	0
58	Ayala et al. 2010[121]	0	0	0	Fair	0	0	0	0	0
59	Murray & Rees 2010[178]	0	0	0	0	0	0	0	0	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
60	Malligarjunan et al. 2011[157]	0	0	0	0	0	Poor	0	0	0
61	Mrowietz et al. 2011[159]	0	0	0	0	0	0	0	0	0
62	Herane et al. 2012[144]	0	0	0	0	0	0	0	0	0
63	Twiss et al. 2012[151]	Fair	0	0	0	Fair	0	Fair	0	0
64	Worth et al. 2012 (adult)[162]	0	0	0	0	0	0	0	0	0
64	Worth et al. 2012 (child)[162]	0	0	0	0	0	0	0	0	0
65	Zhuang et al. 2013[111]	0	0	0	0	0	Fair	0	0	0
66	Belcaro et al. 2014[152]	0	0	0	0	0	0	0	0	0
67	Abbas et al. 2015[143]	Fair	Fair	0	Fair	Fair	0	0	Fair	0
68	Hayashi et al. 2015[105]	0	0	0	0	0	Poor	0	0	0
69	Zbiciak-Nylec et al. 2015[110]	0	0	0	0	0	0	0	0	0
70	Bhute & Jha 2016[171]	0	0	0	0	0	0	0	0	0
71	Nair et al. 2016 (adult)[161]	0	0	0	0	0	0	0	0	0
71	Nair et al. 2016 (child)[161]	0	0	0	0	0	0	0	0	0
72	Nguyen et al. 2017[172]	0	0	0	0	0	0	0	0	0
73	Wang et al. 2017[148]	Fair	0	0	0	Fair	0	0	0	0
74	Davern & O'Donnell [102]	Poor	0	0	0	0	Fair	0	0	0
75	He et al. 2018[103]	Fair	0	0	0	Fair	0	Fair	0	0
76	Komatsu et al. 2018[166]	0	0	0	0	0	0	0	0	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
77	Storer et al. 2018 (skin-specific)[132]	0	0	0	0	0	0	0	0	0
77	Storer et al. 2018 (obesity-specific)[132]	0	0	0	0	0	0	0	0	0
15	Rencz et al. 2018 (DLQI-SF)[62]	n/a	n/a	n/a	n/a	n/a	Fair	n/a	Fair	0
78	Wiese et al. 2018[169]	0	0	0	Poor	0	Fair	0	0	0
79	Yagasaki et al. 2018[168]	0	0	0	0	0	Fair	0	0	0
80	Yahathugoda et al. 2018[128]	0	0	0	0	0	0	0	0	0
81	Butt et al. 2019[131]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	0

n/a = not applicable (the original DLQI was used with an alternative scoring)

Appendix 6 Quality of measurement properties of DLQI modifications [85]

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
	'Before Botox' DLQI											
1	Tan & Solish 2002[141]	0	0	0	0	0	0	0	0	0	0	?
2	Kontochristopoulos et al. 2007[126]	0	0	0	0	0	0	0	0	0	0	0
	'Before surgical treatment' DLQI											
3	He et al. 2012[116]	0	0	0	0	0	0	0	0	0	+	0
4	He et al. 2018[117]	0	0	0	0	0	0	0	0	0	0	0
	Bromhidrosis or hyperhidrosis-specific DLQI											
1	Tan et al. 2002[141]	0	0	0	0	0	0	0	0	0	0	?
5	He et al. 2012[115]	0	0	0	0	0	0	0	0	0	?	?
6	Kouris et al. 2014[140]	0	0	0	0	0	0	0	0	0	0	?
7	Xie et al. 2014[119]	0	0	0	0	0	0	0	0	0	0	?
8	Artzi et al. 2017[139]	0	0	0	0	0	0	0	0	0	0	?
9	Van et al. 2019[118]	0	0	0	0	0	0	0	0	0	+	?
	Cutaneous larva migrans-specific DLQI (Adult)											
10	Schuster et al. 2011[124]	0	0	0	0	0	0	0	0	0	?	0
11	Shimogawara et al. 2013[125]	0	0	0	0	0	0	0	0	0	0	0
	Cutaneous larva migrans-specific DLQI (Child)											
10	Schuster et al. 2011[124]	0	0	0	0	0	0	0	0	0	?	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
11	Shimogawara et al. 2013[125]	0	0	0	0	0	0	0	0	0	0	0
	DLQI-Q1											
12	Panahi et al. 2008[149]	0	0	0	0	0	-	0	+	0	0	?
13	Ljossa et al. 2012[156]	?	0	0	0	0	-	0	0	0	0	?
14	Panahi et al. 2012[150]	0	0	0	0	0	0	0	0	0	0	?
	DLQI-R											
15	Rencz et al. 2018[62]	n/a	n/a	n/a	n/a	n/a	+	n/a	+	0	+	?
16	Barbieri & Gelfand 2019[60]	n/a	n/a	n/a	n/a	n/a	+	n/a	0	0	0	?
17	Barbieri & Gelfand 2019[179]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	+	+	?
18	Rencz et al. 2019[63]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	0	0	?
	DLQI-VW (viral wart-specific)											
19	Ciconte et al. 2003[175]	0	0	0	0	0	0	0	0	0	0	0
20	Leow & Oon 2016[176]	?	0	0	0	0	0	0	0	0	0	?
	Hirstutism-specific DLQI											
21	Conroy et al. 2006[134]	0	0	0	0	0	0	0	0	0	?	?
22	Grant 2010[135]	0	0	0	0	0	0	0	0	0	?	?
23	Maziar et al. 2010[137]	0	0	0	0	0	0	0	0	0	0	?
24	Alizadeh et al. 2017[133]	0	0	0	0	0	0	0	0	0	0	?
	Last year DLQI (LY-DLQI)											
25	Jong et al. 2008[146]	0	0	0	0	0	0	0	0	0	0	?

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
26	Esmann & Jemec 2010[104]	0	0	0	0	0	?	0	0	0	0	0
27	Meeuwis et al. 2011[158]	0	0	0	0	0	0	0	0	0	0	?
28	Huang et al. 2013[145]	0	0	0	0	0	0	0	0	0	0	?
29	Chiang et al. 2015[108]	0	0	0	0	0	?	0	+	0	+	?
30	Simonsen et al. 2015[123]	0	0	0	0	0	0	0	0	0	?	0
31	Tan et al. 2017[147]	0	0	0	0	0	0	0	0	0	?	?
	Pruritus-related quality of life Index											
32	Zachariae et al. 2008[160]	?	0	0	0	0	?	0	0	0	0	?
33	Zachariae et al. 2012[114]	?	0	0	0	0	?	0	0	0	0	?
34	Ebid et al. 2017[120]	0	0	0	0	0	0	0	0	0	0	?
	Psoriasis-specific last year DLQI											
35	Kim et al. 2014[153]	0	0	0	0	0	0	0	0	0	0	?
36	Kim et al. 2015[154]	0	0	0	0	0	+	0	0	0	0	?
37	Kim et al. 2015[155]	0	0	0	0	0	0	0	0	0	0	0
	Psoriasis-specific lifetime DLQI											
35	Kim et al. 2013[153]	0	0	0	0	0	0	0	0	0	0	?
36	Kim et al. 2014[154]	0	0	0	0	0	+	0	0	0	0	?
37	Kim et al. 2015[155]	0	0	0	0	0	0	0	0	0	0	0
	Rasch-calibrated DLQI for hand eczema											
38	Ofenloch et al. 2014[129]	?	0	0	0	?	?	-	+	0	0	0
39	Apfelbacher et al. 2019[130]	0	0	0	0	0	0	0	0	0	0	?

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
	Drooling Impact Score											
40	Giess et. al. 2000[164]	0	0	0	0	0	0	0	0	0	0	0
41	Verma & Steele 2006[165]	0	0	0	0	0	0	0	0	0	0	?
	Questionnaires used in one study											
42	Czech et al. 2000[113]	0	0	0	0	0	0	0	0	0	0	?
43	Jobanputra & Bachmann 2000[106]	?	?	0	+	0	+	+	0	0	?	?
44	Holness 2001[122]	0	0	0	0	0	0	0	0	0	0	0
45	Williamson et al. 2001[109]	0	0	0	0	0	+	0	0	0	?	0
46	Loo et al. 2002[136]	0	0	0	0	0	0	0	0	0	0	0
47	Loo et al. 2003[177]	0	0	0	0	0	0	0	+	0	0	0
48	Blanch et al. 2004[142]	0	0	0	0	0	0	0	0	0	0	0
49	Nettis et al. 2004[170]	0	0	0	0	0	0	0	0	0	0	?
50	Kondoh et al. 2005[112]	0	0	0	0	0	0	0	0	0	?	0
51	Tjioe et al. 2005[174]	0	0	0	0	0	0	0	0	0	?	0
52	Borimnejad et al. 2006[173]	0	0	0	0	0	0	0	0	0	0	0
53	Lorette & Ermosilla 2006[163]	0	0	0	0	0	0	0	0	0	?	?
54	Takahashi et al. 2006[107]	+	?	0	+	-	+	0	0	0	?	?
55	Chandrasena et al. 2007[127]	?	0	0	0	0	+	0	0	0	?	?

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
56	Peeters et al. 2009[167]	0	0	0	0	0	-	0	0	0	0	0
57	Wong & Rivers 2009[138]	0	0	0	0	0	-	0	0	0	0	0
58	Ayala et al. 2010[121]	0	0	0	?	0	0	0	0	0	0	0
59	Murray & Rees 2010[178]	0	0	0	0	0	0	0	0	0	0	0
60	Malligarjunan et al. 2011[157]	0	0	0	0	0	?	0	0	0	0	?
61	Mrowietz et al. 2011[159]	0	0	0	0	0	0	0	0	0	+	?
62	Herane et al. 2012[144]	0	0	0	0	0	0	0	0	0	0	0
63	Twiss et al. 2012[151]	+	0	0	0	?	0	-	0	0	0	0
64	Worth et al. 2012 (adult)[162]	0	0	0	0	0	0	0	0	0	-	?
64	Worth et al. 2012 (child)[162]	0	0	0	0	0	0	0	0	0	-	?
65	Zhuang et al. 2013[111]	0	0	0	0	0	-	0	0	0	0	?
66	Belcaro et al. 2014[152]	0	0	0	0	0	0	0	0	0	0	?
67	Abbas et al. 2015[143]	?	+	0	+	+	0	0	+	0	+	0
68	Hayashi et al. 2015[105]	0	0	0	0	0	+	0	0	0	0	?
69	Zbiciak-Nylec et al. 2015[110]	0	0	0	0	0	0	0	0	0	0	0
70	Bhute & Jha 2016[171]	0	0	0	0	0	0	0	0	0	0	0
71	Nair et al. 2016 (adult)[161]	0	0	0	0	0	0	0	0	0	?	0
71	Nair et al. 2016 (child)[161]	0	0	0	0	0	0	0	0	0	?	0

	Author, year	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Construct validity	Cross-cultural validity	Criterion validity	Responsiveness	Floor& ceiling effects	Interpretability
72	Nguyen et al. 2017[172]	0	0	0	0	0	0	0	0	0	+	?
73	Wang et al. 2017[148]	+	0	0	0	-	0	0	0	0	+	?
74	Davern & O'Donnell 2018[102]	?	0	0	0	0	-	0	0	0	0	0
75	Komatsu et al. 2018[166]	0	0	0	0	0	0	0	0	0	0	?
76	He et al. 2018[103]	+	0	0	0	+	0	0	0	0	0	0
77	Storer et al. 2018 (skin-specific)[132]	0	0	0	0	0	0	0	0	0	0	?
77	Storer et al. 2018 (obesity-specific)[132]	0	0	0	0	0	0	0	0	0	0	?
15	Rencz et al. 2018 (DLQI-SF)[62]	n/a	n/a	n/a	n/a	n/a	+	0	+	0	?	?
78	Wiese et al. 2018[169]	0	0	0	?	0	+	0	0	0	-	?
79	Yagasaki et al. 2018[168]	0	0	0	0	0	?	0	0	0	0	0
80	Yahathugoda et al. 2018[128]	0	0	0	0	0	0	0	0	0	0	?
81	Butt et al. 2019[131]	n/a	n/a	n/a	n/a	n/a	0	n/a	0	0	0	0

n/a = not applicable (the original DLQI was used with an alternative scoring); positive (+), intermediate (?), negative (-) or no information available (0).

Appendix 7 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77]

	DLQI / DLQI-R *		Skindex-16		
Items	**FE n (%)**	**CE n (%)**	**Items**	**FE n (%)**	**CE n (%)**
item 1 (itchy, sore, painful, stinging)	97 (31.2%)	14 (4.5%)	item 1 (itching)	74 (23.8%) $^{\alpha}$	35 (11.3%) $^{\beta}$
			item 2 (burning or stinging)	130 (41.8%) $^{\alpha}$	14 (4.5%)
			item 3 (hurting)	142 (45.7%) $^{\alpha}$	14 (4.5%)
			item 4 (skin irritation)	80 (25.7%) $^{\alpha}$	31 (10.0%) $^{\beta}$
item 2 (embarrassed, self-conscious)	148 (47.6%)	10 (3.2%)	item 9 (embarrassment)	146 (46.9%)	29 (9.3%) $^{\beta}$
item 3 (shopping, home, garden)	215 (69.1%)	4 (1.3%)	item 15 (daily activities)	142 (45.7%) $^{\alpha}$	13 (4.2%) $^{\beta}$
item 4 (clothing)	198 (63.7%)	10 (3.2%)	-	-	-
item 5 (social, leisure)	214 (68.8%)	4 (1.3%)	-	-	-
item 6 (sport)	199 (64.0%)	3 (1.0%)	-	-	-
item 7 (working, studying)	203 (65.3%)	6 (1.9%)	item 16 (work or do what you enjoy)	162 (52.1%) $^{\alpha}$	17 (5.5%) $^{\beta}$
item 8 (interpersonal problems)	217 (69.8%)	2 (0.6%)	item 12 (interactions with others)	156 (50.2%) $^{\alpha}$	14 (4.5%) $^{\beta}$
item 9 (sexual difficulties)	200 (64.3%)	6 (1.9%)	item 14 (show affection)	163 (52.4%) $^{\alpha}$	21 (6.8%) $^{\beta}$
item 10 (treatment difficulties)	203 (65.3%)	1 (0.3%)	-	-	-
			item 5 (persistence / reoccurrence)	68 (21.9%)	72 (23.2%)
			item 6 (worry)	89 (28.6%)	55 (17.7%)
			item 7 (appearance)	83 (26.7%)	49 (15.8%)
			item 8 (frustration)	125 (40.2%)	24 (7.7%)
			item 10 (being annoyed)	89 (28.6%)	33 (10.6%)
			item 11 (feeling depressed)	134 (43.1%)	20 (6.4%)
			item 13 (desire to be with people)	152 (48.9%)	13 (4.2%)
			Symptoms subscale	53 (17.0%)	8 (2.6%)
			Emotions subscale	40 (12.9%)	9 (2.9%)
			Functioning subscale	116 (37.3%)	4 (1.3%)
DLQI / DLQI-R Total	63 (20.3%)	0 (0.0%)	Total	32 (10.3%) $^{\alpha}$	3 (1.0%)

CE = ceiling effect; DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; FE =floor effect

* Theoretically, the ceiling effect for DLQI and DLQI-R total scores may be different; however, the sample included few patients with severe dermatological conditions, thus the two values were the same in this study.

α indicates a significant difference in floor effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

β indicates a significant difference in ceiling effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

Appendix 8 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77]

	DLQI / DLQI-R *		Skindex-16		
Items	**FE n (%)**	**CE n (%)**	**Items**	**FE n (%)**	**CE n (%)**
item 1 (itchy, sore, painful, stinging)	112 (41.2%)	8 (2.9%)	item 1 (itching)	90 (33.1%) $^{\alpha}$	22 (8.1%) $^{\beta}$
			item 2 (burning or stinging)	132 (48.5%) $^{\alpha}$	12 (4.4%)
			item 3 (hurting)	138 (50.7%) $^{\alpha}$	8 (2.9%)
			item 4 (skin irritation)	109 (40.1%)	22 (8.1%) $^{\beta}$
item 2 (embarrassed, self-conscious)	136 (50.0%)	8 (2.9%)	item 9 (embarrassment)	128 (47.1%)	25 (9.2%) $^{\beta}$
item 3 (shopping, home, garden)	192 (70.6%)	3 (1.1%)	item 15 (daily activities)	144 (52.9%) $^{\alpha}$	11 (4.0%) $^{\beta}$
item 4 (clothing)	169 (62.1%)	8 (2.9%)	-	-	-
item 5 (social, leisure)	178 (65.4%)	7 (2.6%)	-	-	-
item 6 (sport)	164 (60.3%)	6 (2.2%)	-	-	-
item 7 (working, studying)	184 (67.6%)	14 (5.1%)	item 16 (work or do what you enjoy)	157 (57.7%) $^{\alpha}$	14 (5.1%)
item 8 (interpersonal problems)	187 (68.8%)	5 (1.8%)	item 12 (interactions with others)	150 (55.1%) $^{\alpha}$	13 (4.8%)
item 9 (sexual difficulties)	167 (61.4%)	6 (2.2%)	item 14 (show affection)	160 (58.8%)	15 (5.5%) $^{\beta}$
item 10 (treatment difficulties)	179 (65.8%)	3 (1.1%)	-	-	-
			item 5 (persistence / reoccurrence)	79 (29.0%)	44 (16.2%)
			item 6 (worry)	82 (30.1%)	43 (15.8%)
			item 7 (appearance)	91 (33.5%)	39 (14.3%)
			item 8 (frustration)	123 (45.2%)	24 (8.8%)
			item 10 (being annoyed)	85 (31.3%)	32 (11.8%)
			item 11 (feeling depressed)	126 (46.3%)	14 (5.1%)
			item 13 (desire to be with people)	149 (54.8%)	17 (6.3%)
			Symptoms subscale	71 (26.1%)	6 (2.2%)
			Emotions subscale	41 (15.1%)	8 (2.9%)
			Functioning subscale	118 (43.4%)	6 (2.2%)
DLQI / DLQI-R Total	77 (28.3%)	0 (0.0%)	Total	32 (11.8%) $^{\alpha}$	3 (1.1%)

CE = ceiling effect; DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; FE =floor effect

* Theoretically, the ceiling effect for DLQI and DLQI-R total scores may be different; however, the sample included few patients with severe dermatological conditions, thus the two values were the same in this study.

α indicates a significant difference in floor effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

β indicates a significant difference in ceiling effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

Appendix 9 Ceiling and floor effects of DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [77]

	DLQI / DLQI-R *		Skindex-16		
Items	**FE n (%)**	**CE n (%)**	**Items**	**FE n (%)**	**CE n (%)**
item 1 (itchy, sore, painful, stinging)	61 (40.4%)	4 (2.6%)	item 1 (itching)	50 (33.1%)	9 (6.0%)
			item 2 (burning or stinging)	79 (52.3%) $^{\alpha}$	5 (3.3%)
			item 3 (hurting)	75 (49.7%) $^{\alpha}$	5 (3.3%)
			item 4 (skin irritation)	54 (35.8%)	12 (7.9%) $^{\beta}$
item 2 (embarrassed, self-conscious)	79 (52.3%)	6 (4.0%)	item 9 (embarrassment)	79 (52.3%)	13 (8.6%)
item 3 (shopping, home, garden)	103 (68.2%)	4 (2.6%)	item 15 (daily activities)	80 (53.0%) $^{\alpha}$	6 (4.0%)
item 4 (clothing)	93 (61.6%)	6 (4.0%)	-	-	-
item 5 (social, leisure)	99 (65.6%)	3 (2.0%)	-	-	-
item 6 (sport)	81 (53.6%)	6 (4.0%)	-	-	-
item 7 (working, studying)	99 (65.6%)	3 (2.0%)	item 16 (work or do what you enjoy)	77 (51.0%) $^{\alpha}$	8 (5.3%)
item 8 (interpersonal problems)	102 (67.5%)	2 (1.3%)	item 12 (interactions with others)	84 (55.6%) $^{\alpha}$	6 (4.0%)
item 9 (sexual difficulties)	87 (57.6%)	2 (1.3%)	item 14 (show affection)	88 (58.3%)	8 (5.3%)
item 10 (treatment difficulties)	92 (60.9%)	1 (0.7%)	-	-	-
			item 5 (persistence / reoccurrence)	42 (27.8%)	36 (23.8%)
			item 6 (worry)	40 (26.5%)	24 (15.9%)
			item 7 (appearance)	46 (30.5%)	23 (15.2%)
			item 8 (frustration)	67 (44.4%)	20 (13.2%)
			item 10 (being annoyed)	46 (30.5%)	20 (13.2%)
			item 11 (feeling depressed)	59 (39.1%)	11 (7.3%)
			item 13 (desire to be with people)	81 (53.6%)	8 (5.3%)
			Symptoms subscale	39 (25.8%)	1 (0.7%)
			Emotions subscale	20 (13.2%)	4 (2.6%)
			Functioning subscale	62 (41.1%)	3 (2.0%)
DLQI / DLQI-R Total	44 (29.1%)	0 (0.0%)	Total	19 (12.6%) $^{\alpha}$	1 (0.7%)

CE = ceiling effect; DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index-Relevant; FE =floor effect

* Theoretically, the ceiling effect for DLQI and DLQI-R total scores may be different; however, the sample included few patients with severe dermatological conditions, thus the two values were the same in this study.

α indicates a significant difference in floor effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

β indicates a significant difference in ceiling effect between DLQI or DLQI-R and Skindex-16 ($p<0.05$).

Appendix 10 Informativity of DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77]

DLQI/DLQI-R items	DLQI		DLQI-R		Skindex-16 items	Skindex-16	
	(H')	(J')	(H')	(J')		(H')	(J')
item 1 (itchy, sore, painful, stinging)	1.67	0.83	1.67	0.83	item 1 (itching)	2.74	0.97 β
					item 2 (burning or stinging)	2.45	0.87 β
					item 3 (hurting)	2.34	0.83
					item 4 (skin irritation)	2.73	0.97 β
item 2 (embarrassed, self-conscious)	1.60	0.80	1.60	0.80	item 9 (embarrassment)	2.34	0.83 β
item 3 (shopping, home, garden)	0.97	0.49	1.40	0.60 α	item 15 (daily activities)	2.32	0.83 β
item 4 (clothing)	1.19	0.59	1.58	0.68 α	-	-	-
item 5 (social, leisure)	1.13	0.56	1.41	0.61 α	-	-	-
item 6 (sport)	0.77	0.38	1.45	0.63 α	-	-	-
item 7 (working, studying)	0.87	0.44	1.43	0.62 α	item 16 (work or do what you enjoy)	2.19	0.78 β
item 8 (interpersonal problems)	0.99	0.50	1.36	0.58 α	item 12 (interactions with others)	2.24	0.80 β
item 9 (sexual difficulties)	0.90	0.45	1.53	0.66 α	item 14 (show affection)	2.20	0.78 β
item 10 (treatment difficulties)	1.04	0.52	1.45	0.62 α	-	-	-
					item 5 (persistence / reoccurrence)	2.70	0.96
					item 6 (worry)	2.67	0.95
					item 7 (appearance)	2.71	0.97
					item 8 (frustration)	2.51	0.89
					item 10 (being annoyed)	2.69	0.96
					item 11 (feeling depressed)	2.40	0.86
					item 13 (desire to be with people)	2.26	0.81
Total average	1.11	0.56	1.49	0.66 α	Total average	2.47	0.88 β

(H') = Shannon's index; (J') = Shannon's evenness index

α indicates that J' of DLQI-R is higher than that of the DLQI

β indicates that J' of Skindex-16 is higher than those of DLQI and DLQI-R

Appendix 11 Informativity of DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77]

DLQI/DLQI-R items	DLQI		DLQI-R		Skindex-16 items	Skindex-16	
	(H')	(J')	(H')	(J')		(H')	(J')
item 1 (itchy, sore, painful, stinging)	1.62	0.81	1.62	0.81	item 1 (itching)	2.61	0.93 β
					item 2 (burning or stinging)	2.29	0.82 β
					item 3 (hurting)	2.21	0.79
					item 4 (skin irritation)	2.48	0.88 β
item 2 (embarrassed, self-conscious)	1.50	0.75	1.50	0.75	item 9 (embarrassment)	2.33	0.83 β
item 3 (shopping, home, garden)	0.86	0.43	1.35	0.58 α	item 15 (daily activities)	2.15	0.76 β
item 4 (clothing)	1.17	0.59	1.61	0.69 α	-	-	-
item 5 (social, leisure)	1.12	0.56	1.53	0.66 α	-	-	-
item 6 (sport)	0.81	0.41	1.54	0.67 α	-	-	-
item 7 (working, studying)	0.88	0.44	1.42	0.61 α	item 16 (work or do what you enjoy)	2.04	0.73 β
item 8 (interpersonal problems)	0.95	0.47	1.41	0.61 α	item 12 (interactions with others)	2.11	0.75 β
item 9 (sexual difficulties)	0.80	0.40	1.53	0.66 α	item 14 (show affection)	2.02	0.72 β
item 10 (treatment difficulties)	0.92	0.46	1.44	0.62 α	-	-	-
					item 5 (persistence / reoccurrence)	2.67	0.95
					item 6 (worry)	2.66	0.95
					item 7 (appearance)	2.62	0.93
					item 8 (frustration)	2.40	0.86
					item 10 (being annoyed)	2.65	0.94
					item 11 (feeling depressed)	2.31	0.82
					item 13 (desire to be with people)	2.13	0.76
Total average	1.06	0.53	1.49	0.66 α	Total average	2.35	0.84 β

(H') = Shannon's index; (J') = Shannon's evenness index

α indicates that J' of DLQI-R is higher than that of the DLQI

β indicates that J' of Skindex-16 is higher than those of DLQI and DLQI-R

Appendix 12 Informativity of DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [77]

DLQI/DLQI-R items	DLQI		DLQI-R		Skindex-16 items	Skindex-16	
	(H')	(J')	(H')	(J')		(H')	(J')
item 1 (itchy, sore, painful, stinging)	1.63	0.82	1.63	0.82	item 1 (itching)	2.59	0.92 β
					item 2 (burning or stinging)	2.18	0.78
					item 3 (hurting)	2.24	0.80
					item 4 (skin irritation)	2.54	0.90 β
item 2 (embarrassed, self-conscious)	1.58	0.79	1.58	0.79	item 9 (embarrassment)	2.20	0.78
item 3 (shopping, home, garden)	1.03	0.51	1.46	0.63 α	item 15 (daily activities)	2.15	0.77 β
item 4 (clothing)	1.31	0.65	1.67	0.72 α	-	-	-
item 5 (social, leisure)	1.16	0.58	1.55	0.67 α	-	-	-
item 6 (sport)	0.93	0.47	1.68	0.72 α	-	-	-
item 7 (working, studying)	0.80	0.40	1.42	0.61 α	item 16 (work or do what you enjoy)	2.22	0.79 β
item 8 (interpersonal problems)	0.98	0.49	1.42	0.61 α	item 12 (interactions with others)	2.09	0.74 β
item 9 (sexual difficulties)	0.84	0.42	1.59	0.68 α	item 14 (show affection)	2.03	0.72 β
item 10 (treatment difficulties)	1.04	0.52	1.49	0.64 α	-	-	-
					item 5 (persistence / reoccurrence)	2.60	0.93
					item 6 (worry)	2.69	0.96
					item 7 (appearance)	2.67	0.95
					item 8 (frustration)	2.41	0.86
					item 10 (being annoyed)	2.68	0.95
					item 11 (feeling depressed)	2.48	0.88
					item 13 (desire to be with people)	2.16	0.77
Total average	1.13	0.57	1.55	0.69 α	Total average	2.37	0.84 β

(H') = Shannon's index; (J') = Shannon's evenness index

α indicates that J' of DLQI-R is higher than that of the DLQI

β indicates that J' of Skindex-16 is higher than those of DLQI and DLQI-R

Appendix 13 Spearman's correlations between outcome measures in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [77]

	DLQI (0-30)	**DLQI-R (0-30)**	**Skindex-16 Functioning (0-100)**	**Skindex-16 Emotions (0-100)**	**Skindex-16 Symptoms (0-100)**	**Skindex-16 Total (0-100)**	**PG-VAS (0-100)**
DLQI (0-30)	-	-	-	-	-	-	-
DLQI-R (0-30)	0.988	-	-	-	-	-	-
Skindex-16 Functioning (0-100)	0.705	0.697	-	-	-	-	-
Skindex-16 Emotions (0-100)	0.690	0.688	0.820	-	-	-	-
Skindex-16 Symptoms (0-100)	0.722	0.714	0.730	0.810	-	-	-
Skindex-16 Total (0-100)	0.757	0.751	0.894	0.957	0.915	-	-
PG-VAS (0-100)	-0.361	-0.367	-0.314	-0.292	-0.265	-0.306	-
WHO-5 (0-100)	-0.307	-0.319	-0.230	-0.267	-0.264	-0.275	0.417

DLQI = Dermatology Life Quality Index; PG-VAS = Patient global assessment visual analogue scale; WHO-5 = World Health Organization 5 well-being index

All correlation coefficients were significant ($p<0.05$).

Appendix 14 Spearman's correlations between outcome measures in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [77]

	DLQI (0-30)	**DLQI-R (0-30)**	**Skindex-16 Functioning (0-100)**	**Skindex-16 Emotions (0-100)**	**Skindex-16 Symptoms (0-100)**	**Skindex-16 Total (0-100)**	**PG-VAS (0-100)**
DLQI (0-30)	-	-	-	-	-	-	-
DLQI-R (0-30)	0.984	-	-	-	-	-	-
Skindex-16 Functioning (0-100)	0.694	0.678	-	-	-	-	-
Skindex-16 Emotions (0-100)	0.678	0.659	0.796	-	-	-	-
Skindex-16 Symptoms (0-100)	0.693	0.676	0.766	0.725	-	-	-
Skindex-16 Total (0-100)	0.748	0.729	0.891	0.941	0.892	-	-
PG-VAS (0-100)	-0.425	-0.445	-0.347	-0.377	-0.360	-0.390	-
WHO-5 (0-100)	-0.352	-0.356	-0.265	-0.278	-0.287	-0.303	0.490

DLQI = Dermatology Life Quality Index; PG-VAS = Patient global assessment visual analogue scale; WHO-5 = World Health Organization 5 well-being index

All correlation coefficients were significant ($p<0.05$).

Appendix 15 Spearman's correlations between outcome measures in other dermatological conditions (n=151) [77]

	DLQI (0-30)	DLQI-R (0-30)	Skindex-16 Functioning (0-100)	Skindex-16 Emotions (0-100)	Skindex-16 Symptoms (0-100)	Skindex-16 Total (0-100)	PG-VAS (0-100)
DLQI (0-30)	-	-	-	-	-	-	-
DLQI-R (0-30)	0.982	-	-	-	-	-	-
Skindex-16 Functioning (0-100)	0.750	0.732	-	-	-	-	-
Skindex-16 Emotions (0-100)	0.725	0.694	0.802	-	-	-	-
Skindex-16 Symptoms (0-100)	0.714	0.698	0.647	0.714	-	-	-
Skindex-16 Total (0-100)	0.808	0.782	0.883	0.944	0.862	-	-
PG-VAS (0-100)	-0.322	-0.330	-0.364	-0.365	-0.300	-0.359	-
WHO-5 (0-100)	-0.345	-0.327	-0.231	-0.352	-0.317	-0.330	0.447

DLQI = Dermatology Life Quality Index; PG-VAS = Patient global assessment visual analogue scale; WHO-5 = World Health Organization 5 well-being index

All correlation coefficients were significant ($p<0.05$).

Appendix 16 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in chronic inflammatory skin diseases (acne, eczema, psoriasis and rosacea) (n=311) [mean (SD) scores] [77]

	Numbers of patients (%)	% of patients with ≥1 NRRs	DLQI (0-30)	DLQI-R (0-30)	Skindex-16 Functioning (0-100)	Skindex-16 Emotions (0-100)	Skindex-16 Symptoms (0-100)	Skindex-16 Total (0-100)
Self-perceived health status								
Very good	16 (5.1%)	31.2%	2.7 (3.3)	3.3 (4.0)	11.5 (22.6)	28.4 (27.9)	27.1 (29.3)	22.3 (23.5)
Good	103 (33.1%)	32.0%	2.8 (4.0)	3.0 (4.3)	19.3 (26.9)	32.4 (30.3)	28.7 (28.8)	26.8 (26.6)
Fair	130 (41.8%)	33.8%	3.9 (4.4)	4.2 (4.7)	24.7 (28.6)	37.6 (28.6)	34.1 (26.7)	32.1 (25.8)
Poor	55 (17.7%)	45.5%	6.8 (6.5)	7.4 (6.4)	35.1 (32.3)	51.9 (31.4)	49.8 (27.9)	45.6 (27.5)
Very poor	7 (2.3%)	57.1%	6.6 (5.9)	7.5 (6.5)	38.1 (28.9)	54.8 (36.3)	42.3 (25.8)	45.0 (29.6)
p-value [α]	-	-	< 0.001	< 0.001	0.003	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	7.6	8.3	4.0	4.9	5,7	5.6
RE	-	-	-	1.10	0.53	0.64	0.75	0.74
Overall skin-related HRQoL impairment (GQ rating)								
No effect	89 (28.6%)	38.2%	0.8 (1.5)	0.9 (1.6)	5.2 (13.0)	14.4 (18.5)	13.0 (18.8)	10.9 (14.9)
Small effect	79 (25.4%)	30.4%	3.1 (3.1)	3.3 (3.3)	21.2 (23.8)	34.8 (25.8)	35.2 (26.1)	30.4 (22.8)
Moderate effect	101 (32.5%)	38.6%	5.1 (4.1)	5.7 (4.5)	30.8 (29.3)	48.8 (27.6)	43.0 (24.7)	40.9 (24.2)
Very large effect	35 (11.3%)	37.1%	9.4 (6.5)	10.1 (6.7)	51.9 (29.3)	67.9 (25.4)	57.7 (26.5)	59.2 (22.1)
Extremely large effect	7 (2.3%)	14.3%	14.0 (8.8)	14.2 (8.6)	74.3 (31.9)	83.0 (17.2)	80.4 (20.2)	79.2 (22.2)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	47.5	47.7	34.7	45.2	36.7	49.3
RE	-	-	-	1.00	0.73	0.95	0.77	1.04

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index; GQ = Global Question; HRQoL=health related quality of life; NRR = 'not relevant' response; RE = relative efficiency

α Analysis of variance (ANOVA)

Appendix 17 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in infections (herpes zoster, warts, onychomycosis and tinea pedis) (n=272) [mean (SD) scores] [77]

	Numbers of patients (%)	% of patients with ≥1 NRRs	DLQI (0-30)	DLQI-R (0-30)	Skindex-16 Functioning (0-100)	Skindex-16 Emotions (0-100)	Skindex-16 Symptoms (0-100)	Skindex-16 Total (0-100)
Self-perceived health status								
Very good	9 (3.3%)	33.3%	6.9 (12.4)	6.9 (12.4)	16.3 (33.0)	18.0 (30.9)	17.6 (30.2)	17.3 (31.2)
Good	74 (27.2%)	33.8%	2.0 (2.9)	2.1 (3.1)	11.5 (20.7)	26.1 (27.5)	17.8 (22.7)	18.5 (20.2)
Fair	123 (45.2%)	38.2%	3.3 (4.4)	3.7 (4.7)	22.5 (28.3)	35.0 (29.3)	28.8 (28.4)	28.8 (26.6)
Poor	56 (20.6%)	44.6%	5.0 (5.3)	5.6 (5.5)	29.0 (30.0)	45.9 (30.1)	38.6 (29.7)	37.8 (26.7)
Very poor	10 (3.7%)	40.0%	10.9 (8.0)	12.0 (9.4)	54.7 (35.9)	68.8 (34.9)	58.3 (36.9)	60.6 (34.7)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	9.9	10.6	7.4	7.7	7.9	9.1
RE	-	-	-	1.08	0.74	0.78	0.80	0.92
Overall skin-related HRQoL impairment (GQ rating)								
No effect	105 (38.6%)	41.0%	1.0 (1.7)	1.2 (2.5)	4.5 (12.9)	14.9 (18.5)	12.7 (19.5)	10.7 (14.2)
Small effect	72 (26.5%)	30.6%	3.0 (3.1)	3.3 (3.3)	23.9 (26.2)	35.6 (26.7)	29.0 (25.5)	29.5 (23.9)
Moderate effect	74 (27.2%)	43.2%	5.4 (4.4)	5.8 (4.6)	33.9 (29.1)	55.2 (28.2)	40.9 (28.7)	43.3 (25.0)
Very large effect	11 (4.0%)	36.4%	10.4 (6.2)	11.0 (6.7)	56.4 (35.8)	66.7 (24.7)	58.3 (32.1)	60.5 (27.2)
Extremely large effect	10 (3.7%)	30.0%	18.2 (9.6)	19.0 (9.8)	61.3 (31.5)	72.1 (27.5)	67.5 (31.9)	67.0 (29.1)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	66.2	59.7	31.8	41.4	25.3	41.3
RE	-	-	-	0.90	0.48	0.63	0.38	0.62

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index; GQ = Global Question; HRQoL=health related quality of life; NRR = 'not relevant' response; RE = relative efficiency

α Analysis of variance (ANOVA)

Appendix 18 Known-groups validity of the DLQI, DLQI-R and Skindex-16 in other dermatological conditions (n=151) [mean (SD) scores] [77]

	Numbers of patients (%)	% of patients with ≥1 NRRs	DLQI (0-30)	DLQI-R (0-30)	Skindex-16 Functioning (0-100)	Skindex-16 Emotions (0-100)	Skindex-16 Symptoms (0-100)	Skindex-16 Total (0-100)
Self-perceived health status								
Very good	10 (6.6%)	50.0%	4.5 (7.4)	4.9 (7.8)	15.0 (32.8)	23.6 (30.2)	28.8 (34.2)	22.4 (30.9)
Good	46 (30.5%)	34.8%	2.8 (4.4)	3.1 (4.7)	13.3 (21.0)	25.3 (22.9)	21.1 (22.5)	19.9 (19.8)
Fair	63 (41.7%)	36.5%	4.1 (4.8)	4.5 (5.3)	25.8 (26.9)	41.6 (31.3)	29.4 (28.5)	32.3 (25.2)
Poor	29 (19.2%)	75.9%	4.4 (3.2)	5.2 (3.7)	33.1 (30.8)	54.7 (24.9)	46.3 (27.7)	44.7 (23.4)
Very poor	3 (2.0%)	66.7%	17.7 (6.5)	20.1 (5.8)	88.9 (19.2)	98.4 (2.7)	81.9 (6.4)	89.7 (9.3)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	7.3	8.2	7.7	9.7	6.7	10.0
RE	-	-	-	1.12	1.05	1.33	0.91	1.37
Overall skin-related HRQoL impairment (GQ rating)								
No effect	48 (31.8%)	45.8%	0.6 (1.2)	0.8 (1.6)	4.9 (12.5)	16.1 (20.8)	8.6 (15.0)	9.9 (13.4)
Small effect	36 (23.8%)	38.9%	2.3 (2.1)	2.5 (2.4)	18.3 (22.3)	35.3 (27.6)	33.4 (26.4)	29.0 (21.7)
Moderate effect	44 (29.1%)	50.0%	6.0 (4.9)	6.8 (5.5)	34.3 (28.9)	49.9 (24.0)	43.6 (25.4)	42.6 (21.7)
Very large effect	20 (13.2%)	45.0%	10.0 (5.7)	11.0 (6.2)	52.8 (28.4)	72.5 (20.9)	51.0 (31.6)	58.8 (23.1)
Extremely large effect	3 (2.0%)	33.3%	12.3 (9.0)	12.5 (8.7)	51.1 (48.3)	71.4 (36.0)	47.2 (37.8)	56.6 (40.1)
p-value [α]	-	-	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001
F-statistic [α]	-	-	31.2	30.2	19.1	24.9	17.3	28.0
RE	-	-	-	0.97	0.61	0.80	0.55	0.90

DLQI = Dermatology Life Quality Index; DLQI-R = Dermatology Life Quality Index; GQ = Global Question; HRQoL=health related quality of life; NRR = 'not relevant' response; RE = relative efficiency

[α] Analysis of variance (ANOVA)