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Patient-Reported Outcomes

Questionnaire Modifications and Alternative Scoring Methods of the Dermatology Life Quality Index: A Systematic Review



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ABSTRACT

Objectives: Dermatology Life Quality index (DLQI) is the most widely used health-related quality of life questionnaire in dermatology. Little is known about existing questionnaire or scoring modifications of the DLQI. We aimed to systematically review, identify, and categorize all modified questionnaire versions and scoring methods of the DLQI.

Methods: We performed a systematic literature search in PubMed, Web of Science, CINAHL, and PsychINFO. Methodologic quality and evidence of psychometric properties were assessed using the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) and Terwee checklists.

Results: The included 81 articles reported on 77 studies using 59 DLQI modifications. Modifications were used for a combined sample of 25 509 patients with 47 different diagnoses and symptoms from 28 countries. The most frequently studied diseases were psoriasis, hirsutism, acne, alopecia, and bromhidrosis. The modifications were categorized into the following non-mutually exclusive groups: bolt-ons or bolt-offs (48%), disease, symptom, and body part specifications (42%), changes in existing items (34%), scoring modifications (27%), recall period changes (19%), response scale modifications (15%), and illustrations (3%). The evidence concerning the quality of measurement properties was heterogeneous: 4 of 13 studies were rated positive on internal consistency, 1 of 3 on reliability, 3 of 5 on content validity, 9 of 22 on construct validity, 6 of 6 on criterion validity, and 1 of 1 on responsiveness.

Conclusion: An exceptionally large number of DLQI modifications have been used that may indicate an unmet need for adequate health-related quality of life instruments in dermatology. The psychometric overview of most questionnaire modifications is currently incomplete, and additional efforts are needed for proper validation.

Keywords: alternative scoring, bolt-on, Dermatology Life Quality Index, psoriasis, psychometrics, questionnaire modifications, skin disease, systematic review.

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Introduction

The Dermatology Life Quality Index (DLQI) was the first skin-specific health-related quality of life (HRQoL) questionnaire.¹ In the past 25 years since its publication, it has become by far the most frequently used instrument to measure HRQoL in dermatology.² It has been translated to >110 languages and now it is used in >40 skin conditions worldwide. Measurement properties of the DLQI, such as validity, reliability, and responsiveness to change were reported by more than a 100 independent studies.³ It is widely used in both clinical practice and research settings, including randomized controlled trials, patient registries, and national treatment and reimbursement guidelines.^{4–7}

Many generic or skin-specific HRQoL questionnaires have multiple versions developed by the copyright holders allowing physicians and researchers to decide upon which measure would be best suited for their purpose. These versions may differ in terms of their response scales (eg, the EQ-5D offers a 3-level

[EQ-5D-3L] and 5-level [EQ-5D-5L] version for adults),⁸ the number of questionnaire items (eg, Skindex-29, -16)⁹ or recall period (eg, Short-Form 36 [SF-36] is available in a chronic, 4-week and in an acute, 1-week format).¹⁰ In recent years, adding new “bolt-on” items to existing questionnaires has also become popular to develop disease-specific questionnaires and, as such, to improve sensitivity to change. For example, a psoriasis-specific version of the EQ-5D-5L questionnaire (EQ-PSO) has been developed by adding 2 additional dimensions, “skin irritation” and “self-confidence” to the existing 5 dimensions.^{11,12} Furthermore, alternative scoring algorithms are often created for HRQoL questionnaires, with the aim of improving psychometric properties or changing the weighting of items (eg, different ways of scoring are available for the SF-36).^{10,13–15}

Currently, the DLQI has one official version that has maintained its original form since 1994. Little is known about existing questionnaire modifications or scoring methods of the DLQI. Until now there has been no systematic review summarizing the attempts to

modify the DLQI. The present systematic review, therefore, aimed to (1) identify and categorize all modified questionnaire versions and scoring methods of the DLQI; (2) evaluate the measurement properties of these questionnaires and scorings, and (3) recommend validated tools for use in future research and clinical practice.

Methods

Description of DLQI

The DLQI was designed to be used in patients ≥ 16 years. It consists of 10 items that encompass the following 6 aspects of HRQoL: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment.¹ All questions have a 1-week recall period. The 10 items of the questionnaire are rated on a 4-point scale (“not at all” or “not relevant” = 0, “a little” = 1, “a lot” = 2 and “very much” = 3), yielding a total score of 0 to 30. A higher total score represents a greater impairment of HRQoL.

Design, Data Sources, Search Strategy

The protocol of this systematic review was registered in PROSPERO (<https://www.crd.york.ac.uk/prospero/>), under number CRD42020151988. MEDLINE via PubMed, PsycInfo, and CINAHL (via EBSCO) and the Web of Science were searched from January 1, 1994 (DLQI creation), to July 26, 2019. The search terms consisted of “Dermatology Life Quality Index” or “DLQI” or “Dermatology Quality of Life Index” or “DQLI.” Citation tracking of the eligible studies was carried out by hand searching reference lists. Google Scholar was also searched (last on September 15, 2019) with the full names of the questionnaire versions identified during the study, and the first 100 hits for each instrument were screened for inclusion. No restrictions for language were applied. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline was followed for reporting this systematic review.¹⁶

Study Selection, Inclusion, and Exclusion Criteria

Studies were included in this review if used a modified questionnaire or scoring to DLQI in any disease (dermatological or other) in any patient population (children or adults). Assessing any measurement property of the modified questionnaire was not an entry requirement. Studies were excluded if (1) they were published as a dissertation, review, editorial, guideline, or conference abstract; (2) reported on the original DLQI or its cross-cultural adaptation in any language, and (3) reported on the original or a modified version of the Children’s Dermatology Life Quality Index (CDLQI) or Family Dermatology Life Quality Index.

Inclusion and exclusion criteria were applied by 2 reviewers (F.R. and A.S.) independently to titles and abstracts retrieved with searches to identify relevant studies. Potentially eligible full-texts were also screened independently by the 2 reviewers. Any disagreements about inclusion were resolved by consensus with a third reviewer (V.B.).

Data Extraction

Characteristics of the study population (patient number, age, and sex distribution), the disease (diagnosis, disease duration, and disease severity) and instrument administration (study design, clinical settings, number of centers, country, and language version of the used questionnaire) were extracted into Microsoft Excel 2016 spreadsheet. The following questionnaire characteristics were extracted in each study: questionnaire or scoring

modification performed, number of items, score range of the items and total scores recall period and target population (adults or children). DLQI modifications were categorized into the following nonmutually exclusive groups:

1. Scoring modifications. Any modifications that change how the response levels are scored or total DLQI score is calculated. This includes alternative scorings to the original DLQI as well as modifications that apply to any modified DLQI questionnaire. Note that all response scale modifications automatically imply a change in scoring, with the exception of removing or adding “not relevant” response options to the questionnaire.
2. Item modifications (bolt-on, bolt-off, bolt-on and off). Bolt-ons are additional questionnaire item(s) appended to the original questionnaire. Bolt-offs are DLQI items that are dropped. Bolt-on and offs represent the combination of bolt-ons and bolt-offs, whereby new items are added to and certain items are removed from the DLQI at the same time.
3. Recall period modifications. Changes that shorten or lengthen the recall period of DLQI.
4. Changes made in existing items. Modifications that change the wording of an existing item but not the entire item.
5. Response scale modifications. Changes in response scale of the items.
6. Body part, disease or symptom specifications. “Skin” is replaced by another word or phrase referring to a body part, disease, or symptom throughout the entire questionnaire or in certain items.
7. Illustrations. Changes that add pictorial illustrations to either the questions or response scale of the DLQI.
8. Changes made to the target population of the questionnaire. Modifications that change the target population of the DLQI to children aged < 16 years.

Assessment of the Methodologic Quality of the Included Studies

We rated the methodologic quality for each questionnaire in each included study separately using the COnsensus-based Standards for the Selection of Health Measurement INstruments (COSMIN) Risk of Bias checklist.¹⁷ The checklist includes 9 aspects of validity, reliability, and responsiveness. Each aspect consists of 5 to 18 items to be assessed. These items are scored in a standardized way on a 4-point scale (ie, “poor,” “fair,” “good,” or “excellent”).^{18,19} The overall rating of the quality of each study was determined using “the worst score counts” principle.

Evaluation of the Measurement Properties

The quality of measurement properties of all identified questionnaire modifications or scorings were evaluated according to the quality criteria adapted based on Terwee et al²⁰ and Prinsen et al²¹ (Appendix 1 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>). These criteria apply to the following properties: internal consistency, test–retest reliability, measurement error, content validity, structural validity, construct validity, criterion validity, cross-cultural validity and measurement invariance, responsiveness, floor and ceiling effects, and interpretability. All properties represented by one item that were rated as positive (+), intermediate (?), negative (–), or no information available (0). Both methodologic and quality assessment were done by 2 reviewers (F.R. and V.B.) separately and reached consensus through discussion.

Results

Inclusion of Relevant Studies

The electronic database search yielded 2104 records, 1663 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. In addition, 26 eligible articles were identified by tracking the reference lists of included articles and by searching Google Scholar. Thus, 81 articles reporting on 77 studies were included in this systematic review (Fig. 1). The 77 studies contained information on overall 59 questionnaire or scoring modifications of the DLQI. To make a clear distinction, “studies,” “articles,” and “modifications” are hereafter denoted as N, n, and k, respectively. Citations for each study are provided in Tables 1 to 4 and Appendices 2 to 10 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>.

Characteristics of the Included Studies

The characteristics of the study populations are presented in Appendix 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>. Sample sizes of the included studies varied widely, ranging from 1 to 9845 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 1). 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%).

Most study designs were cross-sectional studies (N = 35, 45%), noncontrolled 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 multicenter (N = 24, 31%; Appendix 3 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>).

Figure 1. Study flow diagram.

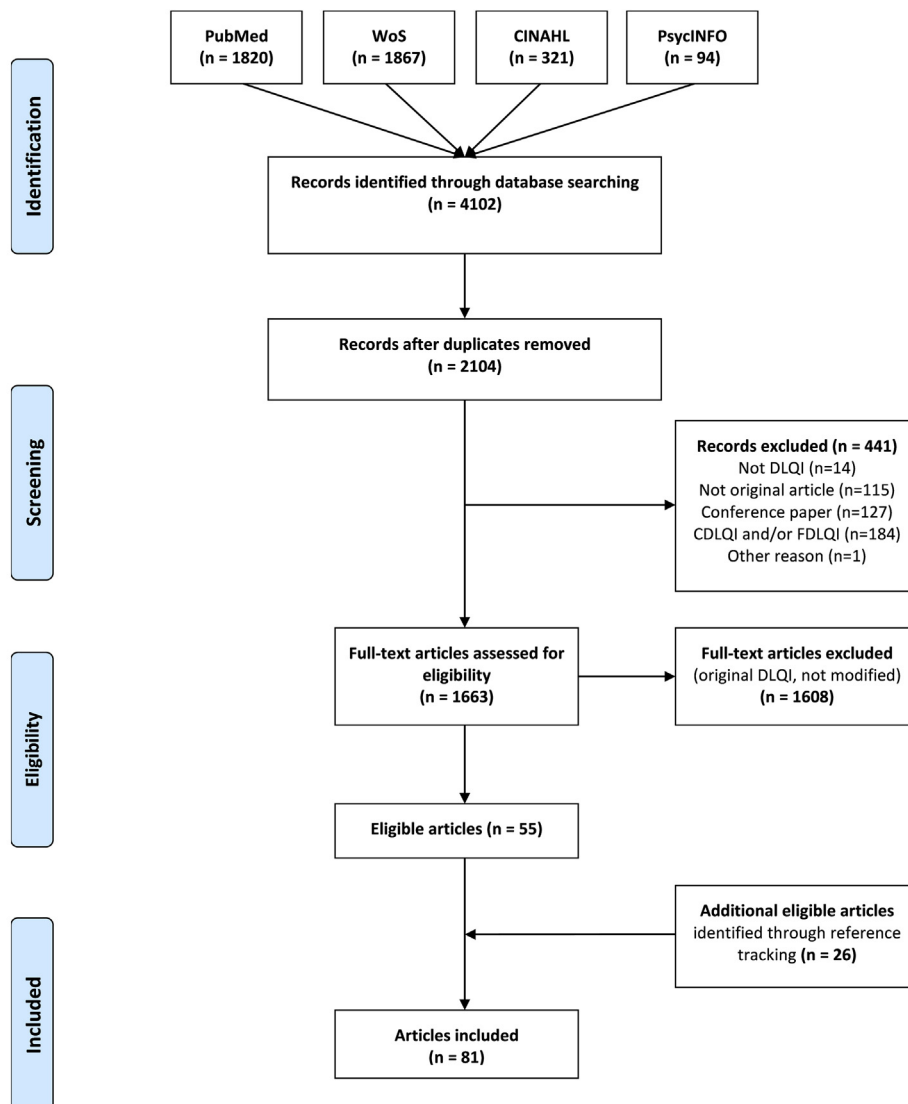


Table 1. Diagnoses/symptoms in which DLQI modifications were used.

	Studies (N)*	%	Patient number†	%	Modifications (k)	%	References
Acne	6	8	3721	15	5	8	22,29,30,33,83,101
Alopecia	5	6	496	2	5	8	24,45,54,80,102
Asteatotic eczema	1	1	5	<1	1	2	103
Atopic dermatitis	4	5	335	1	3	5	22,27,29,104
Bromhidrosis	5	6	494	2	2	3	48,105-108
Burn	1	1	49	<1	1	2	109
Contact dermatitis	4	5	1481	6	4	7	29,46,81,110
Cutaneous larva migrans	1	1	91	<1	2	3	94,95
Darier's disease	1	1	1	<1	1	2	111
Dermatitis (unspecified)	2	3	1294	5	2	3	22,29
Discoid lupus	1	1	7	<1	1	2	29
Eczema (unspecified)	2	3	1287	5	2	3	22,83
Filarial lymphedema	2	3	118	<1	2	3	31,112
Folliculitis	1	1	1	<1	1	2	83
Hand eczema	2	3	2319	9	1	2	23,113
Hidradenitis suppurativa	3	4	264	1	2	3	83,114,115
Hirsutism	6	8	293	1	3	5	39,116-120
Hyperhidrosis	4	5	207	1	2	3	37,50,83,121
Leg ulcers	1	1	17	<1	1	2	29
Lipodystrophia	1	1	84	<1	1	2	122
Melasma	1	1	8	<1	1	2	29
Morphea	1	1	101	<1	1	2	72
Nodular prurigo	1	1	6	<1	1	2	29
Obesity	1	1	79	<1	1	2	115
Pachyonychia congenita	1	1	76	<1	1	2	25
Pemphigus	2	3	115	<1	1	2	29,72
Photoaging	1	1	35	<1	1	2	123
Photodermatoses	3	4	949	4	3	5	43,79,82
Pigment disorder (unspecified)	1	1	2	<1	1	2	83
Port-wine stains	1	1	197	1	1	2	32
Pruritus	4	5	196	1	3	5	27,103,124,125
Psoriasis	16	21	5188	20	15	25	22,24,27-29,49,69,72,74,83-87,115,126-128
Rosacea	1	1	2	<1	1	2	83
Sarcoidosis	1	1	1	<1	1	2	83
Scabies	2	3	217	1	4	7	53,93
Scleroderma	1	1	1	<1	1	2	83
Seborrheic dermatitis	2	3	198	1	2	3	41,103
Sialorrhoea	2	3	13	<1	2	3	51,62
Skin toxicity after chemotherapy	3	4	547	2	3	5	40,61,129
Skin tumor (unspecified)	1	1	4	<1	1	2	83
Tinea capitis	1	1	10	<1	1	2	29
Tungiasis	1	1	50	<1	1	2	52
Urticaria	4	5	843	3	4	7	22,27,29,130
Vaginal candidiasis	2	3	303	1	2	3	131,132
Vascular malformation	1	1	20	<1	1	2	28
Vitiligo	3	4	283	1	3	5	32,38,133

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Table 1. Continued

	Studies (N)*	%	Patient number [†]	%	Modifications (k)	%	References
Warts	3	4	312	1	2	3	26,29,47
Other (unspecified)	6	8	2934	12	5	8	22,29,42,44,83,103
Healthy controls	3	4	255	1	3	5	25,29,95
Total [‡]	77		25 509		59		

DLQI indicates Dermatology Life Quality Index.

*The articles by Kim et al (2014,⁸⁵ 2015,⁸⁶ and 2015⁸⁷) used the same dataset and therefore considered one study. The articles by Barbieri and Gelfand (2019⁷⁴ and 2019⁷³) used the same dataset and therefore considered one study. The article by Schuster et al (2011⁹⁴) and Shimogowara et al (2013⁹⁵) used the same dataset and therefore considered one study.

[†]The patient populations of the Rencz et al (2018⁶⁹ and 2019⁷²) studies overlapped.

[‡]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 and symptoms.

Table 2. Categorization of DLQI modifications.

	Studies (N)	%	Modifications (k)	%	References
Scoring modifications	20	26	16	27	
Alternative scoring for the original questionnaire*	8	10	4	7	25,69,72-74,114,124,125,127
Other changes in scoring	12	16	12	20	22-24,31,38,46,51,61,113,115,130,133
Item modifications	28	36	28	48	
Bolt-on	4	5	4	7	29,103,118,126
Bolt-on and off*	14	20	17	29	25,26,38,46,47,51-53,93-95,110,115,120,133
Bolt-off	10	13	7	12	22,23,27,28,61,102,109,113,122,130
Recall period modifications	19	25	11	19	
Before the Botox treatment	2	3	1	2	50,111
Before the surgical treatment	2	3	1	2	48,106
Generally	2	3	1	2	26,47
Last month	1	1	1	2	112
Last 2 mo	1	1	1	2	33
Last 6 mo	1	1	1	2	46
Last year*	9	12	3	5	43,45,79-87
Over your lifetime with psoriasis*	1	1	1	2	85-87
Nowadays compared with before the phototherapy	1	1	1	2	133
Changes in existing items	28	36	20	34	
Change in one item	16	21	11	19	26,32,33,37,47,48,50,104-108,111,121,122,128
Change in more items	12	16	9	15	22,24,25,42,49,51-54,93,115,120
Response scale modifications	10	13	9	15	
Change related to the "not relevant" response option	6	8	4	7	26,29,47-49,51
Frequency scale	1	1	2	3	115
Rating scale	1	1	1	2	46
Other modifications	2	3	2	3	38,133
Disease/symptom/body part specifications [†]	30	39	25	42	
Disease specification*	11	14	10	17	25,26,30,33,47,52,54,85-87,112,115,131
Symptom specification	14	18	9	15	25,27,28,39,40,45,51,101,109,116,117,119,122,132
Body part specification	7	9	7	12	25,31,41,49,102,120,129
Illustrations	2	3	2	3	
Illustrated questions	1	1	1	2	44

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Table 2. Continued

	Studies (N)	%	Modifications (k)	%	References
Illustrated response options	1	1	1	2	52
Changes in the target population	4	5	4	7	
Children*	4	5	4	7	52,53,93-95
Total [‡]	77		59		

DLQI indicates Dermatology Life Quality Index.

*The articles by Kim et al (2014,⁸⁵ 2015,⁸⁶ and 2015⁸⁷) used the same dataset and therefore considered one study. The articles by Barbieri and Gelfand (2019⁷⁴ and 2019⁷³) used the same dataset and therefore considered one study. The articles by Schuster et al 2011⁹⁴ and Shimogowara et al (2013⁹⁵) used the same dataset and therefore considered one study.

[†]The article by Abbas et al (2015²⁵) used 3 different disease, symptom and body part specifications; therefore, the total number of disease, symptom, and body part specifications is 25 that have been used in overall 30 studies.

[‡]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.

Modified DLQI questionnaires or scorings were used in 23 different languages, with English being the most common (N = 23, 30%; [Appendix 4](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>). 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 5](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>).

Modified DLQI Questionnaires and Scorings

The entire collection of these questionnaire or scoring modifications is available in [Appendix 6](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>. Overall, 7 (9%) studies used more than one questionnaire modification. The majority of the 59 modifications were item modifications (k = 28, 48%) or disease, symptom, and body part specifications (k = 25, 42%; [Table 2](https://doi.org/10.1016/j.jval.2021.02.006)). Among the item modifications, there were 4 (7%) bolt-ons, 7 (12%) bolt-offs, and 17 (29%) bolt-on and bolt-offs. The number of items in DLQI modifications ranged between 3 and 20 ([Appendix 7](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>). The majority of bolt-on items concerned social life (k = 9) or mental health (k = 8; [Table 3](https://doi.org/10.1016/j.jval.2021.02.006)). Overall, 25 different disease, symptom, and body part specifications were identified, only one of which, “acne” was used in more than one modification ([Appendix 8](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>).

Overall, 15 (27%) different scoring modifications were identified, 4 (7%) of which were alternative scorings to the original DLQI questionnaire. Recall period was changed in 11 (19%) questionnaires to 9 different time frames, the most frequent of which was the past year (k = 3). Change in existing items occurred in 20 (34%) questionnaires. The most common wording changes in existing DLQI items were replacing “self-conscious” in item 2 with “ashamed” (k = 5), and removing the word “social” from “social and leisure time” in item 5 (k = 4; [Table 4](https://doi.org/10.1016/j.jval.2021.02.006)). Other modification types included response scale changes (k = 9, 15%), changes made to the target population (ie, children; k = 4, 7%) and pictorial illustrations (k = 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 scoring (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).

Methodologic Quality of Studies (COSMIN Criteria)

Overall, 29 (36%) of the included 81 articles presented information on the measurement properties of DLQI modifications according to the COSMIN checklist ([Appendix 9](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>). Overall, 25 (31%) publications applied classical test theory methods to evaluate measurement properties, 3 used item response theory,²²⁻²⁴ and one used both.²⁵ The overall methodologic quality of the articles was generally weak. There were only 3 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 = 5, 6%). 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.

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 modifications according to the Terwee criteria (n = 29, 36% without floor and ceiling effects and interpretability). Internal consistency was rated as positive for 4 questionnaires and intermediate for 9 others ([Appendix 10](https://doi.org/10.1016/j.jval.2021.02.006) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.02.006>). Cronbach's α and person separation index for these modified questionnaires ranged from 0.67 to 0.87²⁵⁻³³ and from 0.68 to 0.87, respectively.^{22-24,30} Evidence on reliability was available for 3 articles, 1 was rated as positive, while 2 of them were intermediate. Content validity was assessed for 5 articles (3 positive and 2 intermediate). There was positive evidence for structural validity in 2 publications, intermediate in 2 publications, and negative in 2 others. Construct validity was assessed for 22 articles (9 positive, 7 intermediate, and 6 negative). Good criterion validity with the original DLQI was described for 6 publications. 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, 7 of which were rated as positive, 14 as intermediate, and 2 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.

Table 3. DLQI bolt-on items.

Bolt-on items*	Studies (N)	% Modifications (k)	%	References	
Daily activities	7	39	6	29	
Disease making the living area messy or smelly	1	6	1	5	51
Lost time due to skin disease/ time spent to apply treatment or make-up to camouflage lesions	5	28	4	19	26,47,120,126,133
Playing	1	6	1	5	93
Disease-specific symptoms	2	11	1	5	
Bleeding from warts	2	11	1	5	26,47
Pain due to warts	2	11	1	5	26,47
Functioning	6	33	6	29	
Coughing/choking	1	6	1	5	51
Sleeping*	4	22	4	19	25,46,52,94,95
Speaking	1	6	1	5	51
Walking	1	6	1	5	52
General health	2	11	2	10	
Civil rights equivalent to that of a healthy citizen's	1	6	1	5	38
General rating of health	1	6	1	5	133
General rating of health compared with before the phototherapy	1	6	1	5	133
Influence on life	1	6	1	5	133
Mental health	8	44	8	38	
Anxiety	1	6	1	5	29
Being annoyed/irritable	1	6	1	5	46
Being frustrated	3	17	2	10	26,46,47
Being overwhelmed by the skin problem	1	6	1	5	38
Depression/inferiority complex	3	17	3	14	29,46,93
Effect on spirituality	1	6	1	5	38
Feeling uncomfortable	1	6	1	5	46
Getting upset	1	6	2	10	115
Insecurity/negative feelings	1	6	1	5	133
Worrying about infecting others	1	6	1	5	46
Social life	9	50	9	43	
Being teased*	3	17	3	14	53,93-95
Fear of negative appraisal by others	2	11	1	5	26,47
Feeling stared at by people in the neighborhood	1	6	1	5	133
Getting married	1	6	1	5	38
Interactions	1	6	2	10	115
Performing prayers publicly	1	6	1	5	38
Physical health and emotional problems inhibiting social activities with friends, family and others	1	6	1	5	133
Playing a role in finding new friends/relationship	1	6	1	5	133
Social exclusion	1	6	1	5	52
Therapy-related	4	22	3	14	
Alcohol/medication use	1	6	1	5	25
Frustrated with current treatment	2	11	1	5	26,47
Frustrated with past treatment	2	11	1	5	26,47
Herbal medicine therapy	1	6	1	5	103
Work and financial problems	5	26	4	19	
Disease interferes with daily work	2	11	2	10	25,46
Financial problems/costs of disease/costs of treatment	4	22	3	14	26,46,47,126
Using hands at work	1	6	1	5	46

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Table 3. Continued

Bolt-on items*	Studies (N)	% Modifications (k)	%	References	
Worrying about being fired	1	6	1	5	46
Other (unspecified)	1	5	1	5	118
Total	18		21		

DLQI indicates Dermatology Life Quality Index.

*The articles by Schuster et al (2011⁹⁴) and Shimogowara et al (2013⁹⁵) used the same dataset and therefore considered one study.

Discussion

This systematic review identified 81 eligible articles that described 59 questionnaire modifications and alternative scorings of the DLQI. These modifications have been administered in >40 different skin conditions covering almost the entire spectrum of dermatology. The results indicate that approximately 2% to 4% of all published DLQI studies used modified DLQI questionnaires.

Most HRQoL questionnaires, including the DLQI, are copyrighted to ensure the developers' rights to their work (ie, reproducing and distributing it, preparing derivative works) as well as to retain the integrity of validated and authorized version of the original questionnaire.³⁴⁻³⁶ As HRQoL measures are often used as endpoints in clinical trials, for health-related decisions (eg, choice of treatment), reimbursement decisions and labelling claims by regulatory bodies, such as the US Food and Drug Administration and the European Medicines Agency, maintaining quality standards is paramount. Users therefore are not allowed to change the content, wording or format of the questionnaire (eg, instructions, questions, and their order, response options, or recall period). Any modifications require a formal approval from the copyright holders, otherwise it is considered a copyright infringement.³⁶ The only exceptions are alternative scoring methods that use the original questionnaire.

Out of the 55 modifications that would theoretically require permission from the copyright holders (ie, not alternative scorings), we identified 8 (14.5%) modifications for which the authors explicitly stated to have obtained permission to alter the DLQI.^{25,29,37-42} Furthermore, Professor Andrew Finlay, developer of the DLQI is a co-author in further 4 (7.3%) modifications; thus, these were carried out with his consent.^{30,43-45} For the rest of the modifications ($k = 43$, 78%), the authors did not declare if they had a permission to modify the DLQI. For 11 (20%) modifications, the authors published a full reproduction of the modified questionnaire^{38,44,46-54}; however, only 2 of these indicated having received approval for reproduction from the copyright holders.^{38,44}

Studies reporting on cross-cultural adaptations of the original DLQI in any language were excluded from our review. In many non-Western countries, for example, the word "partner" in item 8 of the DLQI has been replaced with "spouse,"⁵⁵⁻⁵⁷ or in Spanish, the word "garden" in item 3 was replaced with "terrace."⁵⁸ Furthermore, in many languages (eg, Dutch, German, French, Italian, and Spanish) the recall period of the questionnaire is expressed in days ("7 days") compared with the original questionnaire that uses "last week." Given that the DLQI is used in more than 110 languages worldwide, very likely many similar subtle differences in wording may be present across the different language versions. These alterations are different from those summarized in our review, as these are typically authorized by the copyright holders and aim to ensure the conceptual equivalence between the source language and the target language as well as

the cultural relevance of the questionnaire for the target population. We identified a total of 25 DLQI modifications that replaced "skin" with a body part (eg, face), disease (eg, psoriasis) or symptom (eg, pruritus). These may be considered very minor modifications that are unlikely to result in the questionnaire being answered differently by most patients. Nevertheless, in principle, in patients with more than one dermatological condition, that is not uncommon, these modifications may narrow down the breadth of problems captured by the DLQI.

Drawing upon an existing, validated questionnaire, such as the DLQI, may simplify the process of developing a new questionnaire.⁵⁹ However, HRQoL questionnaires lose their validity, comparability of scores and reliability if any word is changed.⁶⁰ Thus, every questionnaire or scoring modification is required to be revalidated, no matter whether the entire content or only one word is altered. Notwithstanding, it seems that researchers often misunderstand this practice and assume that there is no revalidation requirement for questionnaire modifications. This is reflected in the large number of studies in which no psychometric properties were described at all (64% according to the COSMIN checklist).

The overall methodologic quality of the studies reported in the included articles was heterogeneous, but mostly appraised as weak. For certain studies, it was unclear precisely what modifications were made to the DLQI.^{61,62} The number of psychometric properties addressed per questionnaire in each study was limited. Thus, many data in the literature are lacking regarding the psychometric properties of the DLQI modifications. There is a wider body of literature on psychometric evaluation of modifications for generic HRQoL measures. Examples include methods used to identify bolt-on items for the EQ-5D using principal component analysis, confirmatory factor analysis or pairwise choices,⁶³⁻⁶⁵ identification of the least fitting items through item response theory for the Assessment of Quality of Life-8 (AQOL-8),⁶⁶ increasing the number of response levels for the EQ-5D⁸ and tests on measurement properties of a recall period change for the SF-36.⁶⁷ However, the majority of DLQI modification studies lag behind these studies in terms of methodologic quality.

Positive evidence on measurement properties from more than one study was available for only the DLQI-R scoring modification. The DLQI-R adjusts the total score of the questionnaire for the number of "not relevant" responses indicated by patients.⁶⁸⁻⁷¹ Three cross-sectional studies and a clinical trial used the DLQI-R in patients with psoriasis, pemphigus, and morphea.^{69,72-74} The DLQI-R showed an improved informativity, responsiveness to change, convergent validity with Psoriasis Area and Severity Index (PASI) and the generic health status measure, EQ-5D-3L, an excellent criterion validity against the original DLQI and no floor or ceiling effects. In addition, recent findings, published after the close of the literature search for this systematic review, support its validity in patients with psoriasis, hidradenitis suppurativa, and

Table 4. The most common changes in existing DLQI items.

DLQI item	Original wording	Wording changes	Studies (N)	% Modifications (k)	%	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."	7	27	2	11	37,50,105,107,108,111,121
		"Itchy, sore, painful or stinging" was removed.	1	4	1	6	25
		"Stinging" was changed to "burning."	1	4	1	6	49
		"Stinging" was changed to "irritation or oils on your scalp."	1	4	1	6	54
		"If you have ingrown hair" was added to the end of the question.	1	4	1	6	120
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	4	1	6	49
		"Frustration" was added.	1	4	1	6	54
		"Self-conscious" was changed to "ashamed".	3	12	5	28	52,53,93
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 with "attending college or work."	1	4	1	6	33
		The word "garden" was removed.	1	4	1	6	120
Item 4	Over the last week, how much has your skin influenced the clothes you wear?	"Hairstyle" was added to the question.	1	4	1	6	32
		"Clothing" was replaced with "hairstyle," and an extra sentence was added: "Do you need to wear a hat, wig, or special hair type to cover the thinner area?"	1	4	1	6	54
		"Make-up" was added to the question.	1	4	1	6	51
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	4	1	6	53
		The word "social" was removed.	3	12	4	22	52,53,115
Item 6	Over the last week, how much has your skin made it difficult for you to do any sport?	"Hobbies" was added.	1	4	1	6	54
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	12	3	17	53,93,128
		The word "work" was removed or "working or studying" was changed to "school work."	3	12	3	17	52,53,93
		The 2 separate questions were merged into one: "How much has your skin been a problem at work or studying?"	1	4	1	6	48
		The question was rephrased as "curtailed working or going out."	1	4	1	6	51

continued on next page

Table 4. Continued

DLQI item	Original wording	Wording changes	Studies (N)	%	Modifications (k)	%	References
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	4	1	6	51
		"Partner or any of your close friends or relatives" was changed to "relationships."	1	4	2	11	115
		"Partner or any of your close friends or relatives" was changed to "friendships."	3	12	3	17	52,53,93
		"Partner or any of your close friends or relatives" was changed to "social contacts."	2	8	2	11	53,93
Item 9	Over the last week, how much has your skin caused any sexual difficulties?	The question was rephrased as "interfere with personal relationships."	2	8	1	6	26,47
		"Sexual difficulties" was replaced by "problems in close personal relationships."	1	4	1	6	104
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	4	1	6	120
		"For example, by making your home messy, or by taking up time" was removed.	1	4	1	6	48,106
		"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	4	1	6	25
		"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	4	1	6	49
		The question was rephrased as "caused living area to be smelly and messy."	1	4	1	6	51
		"Treatment" was changed to "attempts to solve problems due to body changes."	1	4	1	6	122
		The items were rephrased into neutral frames, that is, not to lead a respondent to consider this as a negative phenomenon.	1	4	1	6	42
Total			26		18		

Note. Table does not item splits performed in Rasch analyses. DLQI indicates Dermatology Life Quality Index.

vitiligo.⁷⁵⁻⁷⁷ It also has been reported that the DLQI score bands are valid for the DLQI-R.⁷⁸ The adoption of the DLQI-R scoring in psoriasis treatment and reimbursement guidelines might hold the potential to improve the access to systemic treatments for patients who cannot comply with the DLQI benchmark criteria because one or more questionnaire items are not relevant to them.⁶⁹

We have identified 9 different recall period modifications of the DLQI. All but one of these modifications extended the 1-week

recall period of the original DLQI. Of these, LY-DLQI was the most common by having been used in 7 independent studies,^{43,79-84} and another 2 studies (4 publications)^{45,85-87} applied a 1-year recall period along with other modifications made. The LY-DLQI allows to capture the long-term HRQoL impact of skin diseases as well as to compare scores with those of the original DLQI. The longer recall period may be adequate for conditions in which changes in health status and symptoms are typically gradual, such

as in certain types of hair loss or if a disease occurs intermittently, such as in case of many photodermatoses. Nevertheless, the literature suggests that longer recall periods may be more susceptible to recall bias.⁸⁸⁻⁹⁰ Future validation is warranted to judge the usefulness of the LY-DLQI, particularly in alopecias and photodermatoses.

Since 1995, DLQI has an official, validated version for children, the CDLQI.^{91,92} Yet we identified 5 questionnaires that modified the adult DLQI to capture the HRQoL impact of skin disease on children. These modifications were applied in patients with cutaneous larva migrans, scabies, and tungiasis.^{52,53,93-95} Improving the awareness of the existence of child-specific HRQoL instruments, such as CDLQI, Teenager's Quality of Life, and Skindex-Teen is recommended.^{96,97}

Similarly, to other medical specialties, in dermatology, HRQoL can be assessed by using both disease-specific and generic measures. In addition, dermatology-specific measures, including the DLQI and the Skindex instrument family also are frequently used.⁹⁸ The rationale for the existence of these instruments arises from the common patient-reported symptoms in many skin diseases. However, 2 studies reported differential item functioning for the DLQI between patients with different diagnoses implying that the DLQI scores should not be compared across different patient populations.^{22,24} Furthermore, some argued that the DLQI is not able to capture the full range of HRQoL in certain conditions^{99,100} as also testified by the many bolt-on items identified in this review. For example, sleep disturbance or mental problems may contribute to the HRQoL impairment in many skin diseases that remains unexplored by using the DLQI. Notwithstanding, several studies showed evidence of favorable measurement properties of the DLQI in several different dermatological conditions that supports its legitimacy.⁹⁶

Given the widespread use of the DLQI in clinical practice, clinical trials, registries, and as a benchmark in treatment and reimbursement guidelines,⁴⁻⁷ this systematic review offers practical implications for clinicians, guideline developers, regulatory bodies, the industry, and decision makers in healthcare. One of the most important determinants of the success of DLQI is that it represents a uniform approach in assessing HRQoL of patients with >40 different diagnoses. The methodologic standardization ensures the comparability across all DLQI studies carried out in any dermatological condition, and modifications may detract from these advantages of the original questionnaire. Additionally, poorly designed and not validated questionnaires may compromise study outcomes and may give ground to "gaming" in medical product-labeling and reimbursement claims. We suggest 2 possible strategies to improve the usefulness of modified DLQI questionnaires. Firstly, higher methodologic standards should be introduced for future studies aiming to modify the DLQI questionnaire. Secondly, instead of designing additional DLQI modifications, researchers may be encouraged to further refine and validate the existing modifications, especially where initial validation produced positive evidence on measurement properties. The collection provided in this review is intended to facilitate this endeavor by aiding the selection of instruments for further validation.

A limitation of this systematic review is that we used a search strategy specifically targeting the DLQI. The use of this precise filter appeared to be a reasonable choice, and a sensitive filter (eg, all quality of life studies in dermatology) would have provided too many hits for full-text screening. Thus, our review might have missed a few studies with modified DLQI questionnaire versions that did not mention DLQI in their abstracts or among their keywords. To fill in potential data gaps, a reference tracking and a complementary search were performed using Google Scholar that

identified 26 additional studies. Another limitation is the applicability of the COSMIN Risk of Bias^{17,19,21} that is widely used to select the best available outcome measures for clinical studies but seems less useful for assessing the methodological quality of studies reporting on questionnaire modifications that are typically experimental in nature. Developing guidelines and checklists to assess the quality of patient-reported outcome measure modifications (eg, bolt-on, recall period modifications, and alternative scorings) is warranted.

Conclusion

In conclusion, this systematic review provides a collection of existing questionnaire and scoring modifications of the DLQI. Our findings indicate an incomplete psychometric overview of these DLQI modifications. The paucity of validation data does not necessarily imply poor measurement properties; however, the use of most DLQI modifications is not currently supported by solid evidence. The 2 most promising modifications for further validation are the DLQI-R scoring and the DLQI-LY questionnaire.

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