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DLQI-R scoring improves the discriminatory power of the Dermatology Life Quality Index in patients with psoriasis, pemphigus and morphea

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Summary

Background The Dermatology Life Quality Index (DLQI) rates 'not relevant' responses (NRRs) as the item on the questionnaire having no impact on the patients' lives at all. The DLQI-Relevant (DLQI-R) is a recently developed scoring that adjusts the total score of the questionnaire for the number of NRRs indicated by a patient.

Objectives To compare the discriminatory power of the original and DLQI-R scoring approaches in terms of absolute and relative informativity.

Methods Cross-sectional data from 637 patients with morphea, pemphigus and psoriasis were used for the analyses. To assess absolute and relative informativity, Shannon's index and Shannon's evenness index were calculated for the 10 items on the questionnaire and for DLQI and DLQI-R total scores.

Results Mean DLQI and DLQI-R scores of patients were 6·13 vs. 6·91. In the subset of patients with NRRs (n = 261, 41%), absolute informativity was higher with the DLQI-R scoring for all eight items with NRR options in all three conditions. The DLQI-R exhibited a better relative informativity in 8, 8 and 6 items in pemphigus, morphea and psoriasis, respectively. The DLQI-R led to an improvement in average item-level informativity in all DLQI score bands up to 20 points. Regarding total scores, the DLQI-R produced both a higher absolute and relative informativity in all three conditions.

Conclusions In patients with morphea, pemphigus and psoriasis, DLQI-R scoring improves the discriminatory power of the questionnaire by benefiting from the additional information in NRRs. DLQI-R scoring may be useful both in clinical practice and research. A scoring chart has been developed to aid physicians with scoring.

What's already known about this topic?

- The original scoring of the Dermatology Life Quality Index (DLQI) rates 'not relevant' responses as the item of the questionnaire having no impact on the patients' lives at all.
- DLQI-Relevant (DLQI-R) is a new scoring developed in 2018 that adjusts the total score of the questionnaire for the number of 'not relevant' responses indicated by patients.
- The discriminatory power of the DLQI-R compared with the DLQI has not yet been investigated.

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What does this study add?

- In patients with psoriasis, pemphigus and morphea, DLQI-R scoring improves the discriminatory power of the questionnaire by benefiting from the additional information in 'not relevant' responses.

What are the clinical implications of this work?

- DLQI-R scoring may help to more accurately quantify patients' health-related quality of life both in clinical practice and research.
- A scoring chart has been developed to aid physicians with scoring.

The Dermatology Life Quality Index (DLQI) is the most commonly applied questionnaire to measure health-related quality of life (HRQoL) in dermatology.[1] Since its development in the early 1990s, it has been used in over 40 different skin conditions worldwide.[2,3] It is recognized as being useful in various health service settings including primary care, day-case treatment, outpatient consultations, inpatient care and teledermatology.[4,5] Moreover, the DLQI is the most frequently used HRQoL measure in dermatological clinical trials.[6,7]

In eight out of the 10 items of the DLQI, patients may answer that the item does not apply to their life ['not relevant' response (NRR)]. The original scoring of the DLQI suggests rating NRRs as the item having no impact on the patient's HRQoL at all. In 2018–2019, three large independent studies from the U.S.A. and Europe raised concerns about scoring NRRs on the DLQI.[8–10] To address the issue, a new scoring, the DLQI-Relevant (DLQI-R) has been developed that adjusts the total DLQI score of patients for the number of NRRs.[11] The DLQI-R showed good validity and responsiveness to change in patients with psoriasis.[11–14] However, a U.S. study did not recommend the use of the DLQI-R and called for additional refinement and validation.[12] In addition to validity and responsiveness, other important measurement properties of the DLQI-R scoring, such as discriminatory power, need to be confirmed to encourage its use in clinical practice and research.

Discriminatory power is often measured by the form of informativity indicating whether an instrument can define the full range of potential health states, and whether it is sensitive over this range.[15,16] As the original scoring of DLQI does not differentiate between responses that are marked 'not at all' and 'not relevant', valuable information may be discarded about patients when using the original DLQI scoring instead of DLQI-R that may result in a decrease in the discriminatory power of the questionnaire. This study therefore aims to compare the informativity of the DLQI and DLQI-R scoring methods with regard to the 10 items of the questionnaire as well as the total scores in three conditions (morphea, pemphigus and psoriasis).

Patients and methods

Patient populations

A large dataset containing DLQI data from four earlier cross-sectional surveys in three diagnoses (morphea, pemphigus and psoriasis) were used for the analyses.[17–24] All these surveys were carried out between 2012 and 2017 at four university dermatology clinics in Hungary. Only patients with no missing DLQI total scores were eligible to be included in this comparative analysis.

Dermatology Life Quality Index scoring methods

Both DLQI and DLQI-R total scores were calculated for each patient. According to the DLQI scoring, four distinct scores can be attached to all items of the questionnaire regardless of the number of response options in that item: 'not at all' or 'not relevant', 0; 'a little', 1; 'a lot', 2; and 'very much', 3 (Table 1).[1] This scoring method makes no difference between 'not at all' and 'not relevant' responses. The DLQI total score is calculated by summing the score of the 10 items. The total score is expressed on a scale ranging between 0 and 30, where a higher score represents a greater impairment in HRQoL.

The DLQI-R scoring formula distinguishes between the 'not at all' and 'not relevant' responses for items 3 to 10 of the questionnaire.[11] For each patient, the DLQI-R score is estimated as a product of the original DLQI score and the rate of the total number of items to the relevant items of the questionnaire. Compared with the 31 possible distinct scores with the original scoring, the DLQI-R scoring may result in 97 unique scores that may take on not only integers but decimal numbers.

Assessing discriminatory power

Shannon's indices

Reliability, validity and responsiveness are three key qualities for HRQoL measures.[25] An underlying property of these three concepts is the discriminatory power that indicates the capacity

Table 1 Characteristics of the Dermatology Life Quality Index (DLQI) and DLQI-Relevant (DLQI-R) scoring methods

	DLQI[a] (Finlay and Khan 1994)[1]	DLQI-R[a] (Rencz *et al.* 2018)[11]
Classification system		
Number of response options considered for scoring		
Item 1 (sore, itchy, painful)	4	4
Item 2 (embarrassment)	4	4
Item 3 (shopping /home)	4	5
Item 4 (clothes)	4	5
Item 5 (social activities)	4	5
Item 6 (sport)	4	5
Item 7 (working/studying)	4	5
Item 8 (interpersonal problems)	4	5
Item 9 (sexual difficulties)	4	5
Item 10 (treatment difficulties)	4	5
Total number of health states defined	1 048 576	6 250 000
Scoring		
Scoring formula	$DLQI = \sum_{i=1}^{10} dlqi_i$	$DLQI\text{-}R = DLQI \times \frac{10}{10-NRR}$
Score range	0–30	0–30
Number of possible scores	31	97
Arithmetic characteristics of the scores	integers	integers or decimals

$dlqi_i$, the score on the ith item of the questionnaire; NRR, number of 'not relevant' responses. [a]Both DLQI and DLQI-R scorings are based on the same DLQI questionnaire, they merely differ in how the scores are estimated from responses.

of the instrument to distinguish between different levels of HRQoL.[16] A good discriminatory power is essential to differentiate between groups of patients, for example, when distinguishing between mild and moderate-to-severe disease, determining whom to treat or judging therapeutic response. Discriminatory power of health classification systems can be expressed in terms of absolute and relative informativity. HRQoL instruments function best when they are not only able to capture the maximum amount of information about the patients (absolute informativity), but also their response options are evenly used by the patients (relative informativity).

In this article, we follow a methodology to assess informativity using Shannon's indices proposed by Janssen *et al.*[16,26] Firstly, Shannon's indices were applied to assess the item-level informativity of the DLQI and DLQI-R. Secondly, the Shannon's indices were calculated for the DLQI and DLQI-R total scores. Since the DLQI-R scoring only alters the total score of patients who indicated at least one NRR, the 'true' difference between the two scoring methods can be detected in this group of patients and is expected to be smaller in the total sample. Thus, all calculations were first carried out for the subset of patients with NRRs and then for the total sample involving patients with and without NRRs.

To assess absolute informativity of the two different DLQI scorings, the Shannon's index (H′) was computed as follows:

$$H' = -\sum_{i=1}^{C} p_i \log_2 p_i,$$

where C denotes the number of possible categories (e.g. responses) in an item of the DLQI, and $p_i = \frac{n_i}{N}$ the proportion of observations in the ith category (i = 1, …, C) where n_i is the observed number of responses in category i and N is the total sample size. The higher the H′ index, the more information is captured by the item. The H′ is a function of the number of categories and their evenness.[16]

To measure relative informativity [i.e. to test how a system performs compared with its potential maximum (H'_{max})] a Shannon's evenness index (J′) was calculated: $J' = \frac{H'}{H'_{max}}$, where $H'_{max} = \log_2 C$.

In contrast to H′, the J′ is independent from the number of categories. J′ values range between 0 and 1, where 1 refers to a perfectly even distribution.[16]

Shannon's indices for Dermatology Life Quality Index items

To calculate Shannon's indices for DLQI items, C represents the number of response options per each item. For the original DLQI scoring, as both 'not relevant' and 'not at all' responses are scored as '0', C = 4 for all items. In contrast, using the DLQI-R score, C = 4 for items 1 and 2 that have no NRR options, but C = 5 for all other items that distinguish between 'not at all' and 'not relevant' responses. H'_{max} values are equal to $\log_2 4 = 2$ for all DLQI items and for the first two items of DLQI-R. For items 3–10 on the DLQI-R H'_{max} can be computed as $\log_2 5 = 2{\cdot}32$. Suppose, for example, that item 6 (sport) is scored by 10 patients as follows: NRR (n = 3), not at all (n = 1), a little (n = 2), a lot (n = 3) and very much (n = 1). Shannon's index (H′) and Shannon's evenness index (J′) for the item sport in DLQI would be calculated as follows:

$$H'_{DLQI_6} = -\left(\left(\frac{3+1}{10}\log_2\frac{3+1}{10}\right)+\left(\frac{2}{10}\log_2\frac{2}{10}\right)+\left(\frac{3}{10}\log_2\frac{3}{10}\right)+\left(\frac{1}{10}\log_2\frac{1}{10}\right)\right) = 1{\cdot}846 \quad \text{and} \quad J'_{DLQI_6} = \frac{H'_{DLQI_6}}{H'_{max}} = \frac{1{\cdot}846}{2} = 0{\cdot}923.$$

Likewise, for DLQI-R the Shannon's indices may be calculated as follows:

$$H'_{DLQI-R_6} = -\left(\left(\frac{3}{10}\log_2\frac{3}{10}\right)+\left(\frac{1}{10}\log_2\frac{1}{10}\right)+\left(\frac{2}{10}\log_2\frac{2}{10}\right)+\left(\frac{3}{10}\log_2\frac{3}{10}\right)+\left(\frac{1}{10}\log_2\frac{1}{10}\right)\right) = 2{\cdot}171 \quad \text{and} \quad J'_{DLQI-R_6} = \frac{H'_{DLQI-R_6}}{H'_{max}} = \frac{2{\cdot}171}{2{\cdot}322} = 0{\cdot}935.$$

The differences in informativity between the DLQI-R and DLQI were expressed as ratios of Shannon's indices for each item of the questionnaire in each condition. The DLQI-R was considered superior in terms of informativity if it showed a ratio of $\frac{H'_{DLQI-R}}{H'_{DLQI}} > 1$ along with $\frac{J'_{DLQI-R}}{J'_{DLQI}} \geq 1$.

Average Shannon's indices for Dermatology Life Quality Index items per score bands

To compare the informativity of the DLQI and DLQI-R in patients with different severity levels, we classified DLQI scores in the pooled dataset based on the banding system developed by Hongbo *et al.*[27] These bands describe the overall impact of skin disease on HRQoL: 0,' no effect'; 2–5, 'small effect'; 6–10, 'moderate effect'; 11–20, 'very large effect'; 21–30, 'extremely large effect'. The average H′ and J′ index values of the 10 items of the DLQI and DLQI-R were compared for each score band.

Shannon's indices for Dermatology Life Quality Index (DLQI) and DLQI-Relevant total score

To estimate Shannon's indices for the DLQI and DLQI-R total scores, the numbers of categories (C) were equal to the possible number of total scores in the questionnaire. As suggested by earlier research,[26] we rounded the DLQI-R scores to the nearest integers so that the DLQI and DLQI-R have an identical number of possible total scores (i.e. 31). Thus, H'_{max} values were $\log_2 31 = 4{\cdot}95$ for both the DLQI and DLQI-R. All analyses were performed by using Excel 2016 (Microsoft, Redmond, WA, U.S.A.).

Results

Study populations

The dataset contained DLQI responses from 637 patients [morphea (n = 101), pemphigus (n = 108) and psoriasis (n = 428)]. Age of respondents ranged from 18 to 93 years, with means across studies ranging from 49·2 (psoriasis) to 57·1 (pemphigus) (Table 2). The lowest rate of women was observed in psoriasis (35·0%) and the highest in morphea (84·2%).

Distribution of responses on the 10 items of the DLQI are presented in Table S1 (see Supporting Information). Mean DLQI scores in the three patient populations varied from 3·99 (morphea) to 6·78 (psoriasis). The mean DLQI-R scores in the population were slightly higher compared with the DLQI varying from mean 4·54 (morphea) to 7·44 (psoriasis). Overall, 36 (8·4%), 4 (4·0%) and 20 (18·5%) of psoriasis, morphea and pemphigus patients, respectively, moved to a different descriptor band using the DLQI-R score. The proportion of patients with NRRs was the lowest in morphea (36·6%) and the highest in pemphigus (53·7%).

Item-level informativity

In the subset of patients with NRRs, absolute informativity (H′) of the DLQI was the highest in psoriasis (range 0·61–1·99), followed by pemphigus (range 0·29–1·87) and the lowest for morphea (range 0·48–1·70). For all three conditions, in items 3–10 (i.e. items with NRR options), the DLQI-R exhibited higher H′ values: psoriasis (range 1·25–2·07), pemphigus (0·65–2·06) and morphea (1·28–1·97), respectively (Table S2; see Supporting Information). A very large improvement in H′ was observed in items 6, 7, 9 and 10 for morphea, and in items 6 and 9 for psoriasis and pemphigus (Fig. 1).

Range of relative informativity (J′) indices per DLQI items varied considerably across conditions: morphea (0·24–0·85), pemphigus (0·15–0·94) and psoriasis (0·30–0·99). Corresponding values for the DLQI-R were better: 0·55–0·85, 0·28–0·94 and 0·54–0·99. Considering the eight items of the questionnaire with NRRs, by using the DLQI-R, J′ remained improved for eight of eight items in morphea and pemphigus and for six of eight items in psoriasis (items 3, 5, 6, 7, 8 and 9) (Fig. 1). In all three conditions, the greatest improvement in H′ and J′ values was achieved in items 6 (sport) and 9 (sexual difficulties).

As expected, the improvement in absolute and relative informativity achieved with the DLQI-R was lower in the pooled dataset because of the identical DLQI and DLQI-R scores in patients indicating no NRRs (Table S2; see Supporting Information).

Average item-level informativity by Dermatology Life Quality Index score bands

In patients with NRRs (n = 261), H′ and J′ values showed a gradual rise from 0 to 10 points, reached a peak in the 11–20 band, then declined in the band of 21–30 points (Fig. 2). Compared with the DLQI, the DLQI-R led to an improvement in H′ for all bands. J′ index values for DLQI-R were identical or higher in all bands with the exception of the most severe one (DLQI 21–30). A very similar trend was visible for the

Table 2 Characteristics of the patient populations

	Morphea	Pemphigus	Psoriasis	Pooled dataset
All patients, n	101	108	428	637
Age, years: mean ± SD	56·8 ± 14·8	57·1 ± 14·8	49·2 ± 14·3	51·8 ± 14·9
Women, %	84·2	63·9	35	57
Biological therapy, %	N/A	0	43·7	29·4
DLQI, mean ± SD	3·99 ± 4·79	5·56 ± 6·98	6·78 ± 7·38	6·13 ± 7·03
DLQI-R, mean ± SD	4·54 ± 5·77	7·03 ± 8·40	7·44 ± 7·98	6·91 ± 7·81
Patients with NRRs, n (%)	37 (36·6)	58 (53·7)	166 (38·8)	261 (41·0)
1 NRR, %	13·9	13·9	19·6	17·7
2 NRRs, %	10·9	11·1	11·4	11·3
3 NRRs, %	4	10·2	5·1	5·8
4 NRRs, %	5	8·3	1·6	3·3
5 NRRs, %	1	3·7	0·2	0·9
6 NRRs, %	2	1·9	0·5	0·9
7 NRRs, %	0	0·9	0	0·2
8 NRRs, %	0	3·7	0·2	0·8
Age, years: mean ± SD	61·4 ± 14·5	60·5 ± 15·6	55·7 ± 14·3	57·6 ± 14·8
Women, %	91·9	65·5	44	55·2
Biological therapy, %	N/A	0	37·3	23
DLQI, mean ± SD	4·62 ± 5·55	5·64 ± 5·86	7·23 ± 6·29	6·51 ± 6·15
DLQI-R, mean ± SD	6·13 ± 7·48	8·36 ± 8·45	8·94 ± 7·75	8·41 ± 7·90

DLQI, Dermatology Life Quality Index; DLQI-R, DLQI-Relevant; N/A, not applicable; NRR, 'not relevant' response.

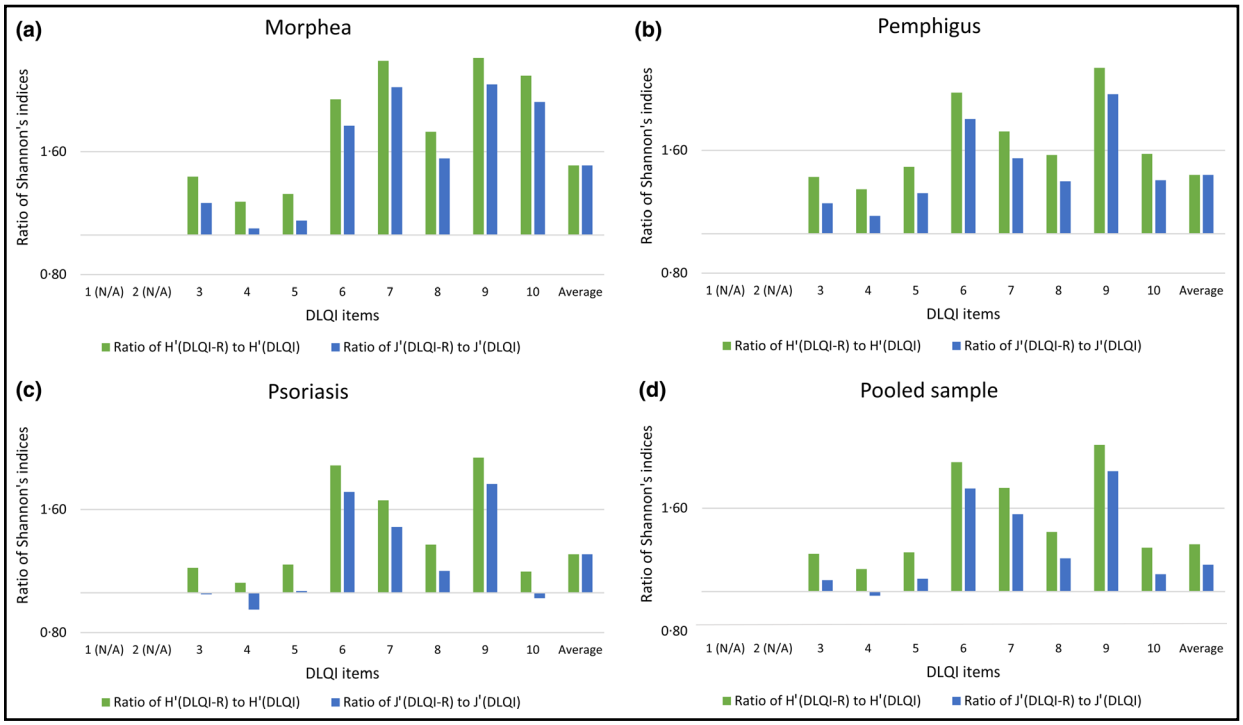


Fig 1. Ratios of Shannon's indices ($H'_{DLQI\text{-}R}$ to H'_{DLQI} or $J'_{DLQI\text{-}R}$ to J'_{DLQI}) per items on the questionnaire in patients with NRRs (n = 261, $\log_2$-based scale). DLQI items: 1, sore, itchy, painful; 2, embarrassment; 3, shopping/home; 4, clothes; 5, social activities; 6, sport; 7, working/studying; 8, interpersonal problem; 9, sexual difficulties; 10, treatment difficulties. Note that there are no differences between Shannon's indices (H' and J') on the DLQI and DLQI-R for items 1 and 2 on the questionnaire as these two items have no NRR option. The DLQI-R is considered superior in terms of informativity if it demonstrates a H' ratio of > 1 along with a J' ratio of ≥ 1. DLQI, Dermatology Life Quality Index; DLQI-R, DLQI-Relevant; N/A, not applicable; NRR, 'not relevant' response.

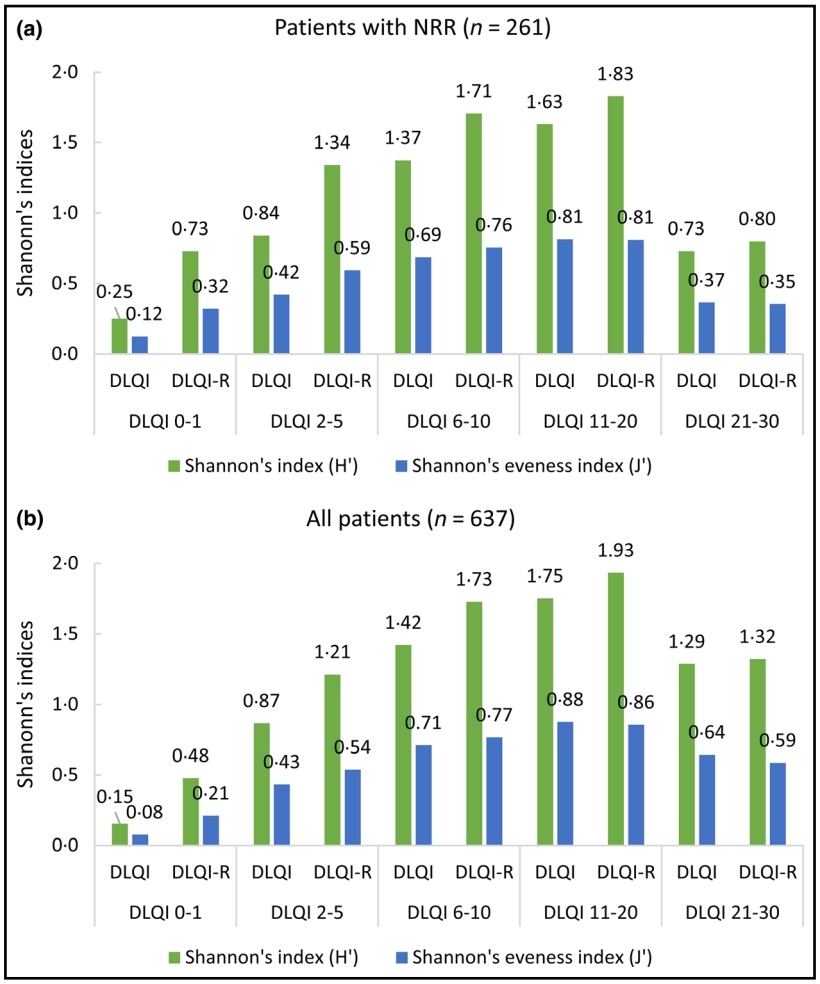


Fig 2. Average Shannon's indices of the 10 items per DLQI score band in the pooled dataset. (a) The distribution of patients with NRRs (n = 261) according to DLQI defined score bands was as follows: DLQI 0–1: n = 77 (29·5%); DLQI 2–5: n = 60 (23·0%); DLQI 6–10: n = 55 (21·1%); DLQI 11–20: n = 65 (24·9%) and DLQI 21–30: n = 4 (1·5%). (b) The distribution of patients (n = 637) according to DLQI defined score bands was as follows: DLQI 0–1: n = 241 (37·8%); DLQI 2–5: n = 146 (22·9%); DLQI 6–10: n = 99 (15·5%); DLQI 11–20: n = 120 (18·8%) and DLQI 21–30: n = 31 (4·9%). H'_{max} index values were 2 for the DLQI and the first two items of DLQI-R, and 2·32 for items 3–10 of DLQI-R in all score bands. DLQI, Dermatology Life Quality Index; DLQI-R, DLQI-Relevant; NRR, 'not relevant' response.

total sample including patients with and without NRRs (n = 637); however, J′ indices started to fall from the band DLQI 11–20.

Informativity of Dermatology Life Quality Index (DLQI) and DLQI-Relevant total scores

In the subset of patients with NRRs, the DLQI-R scoring led to a higher absolute informativity and also a higher relative informativity establishing a better distributional evenness (Table 3). Considering all patients irrespective of NRRs, both absolute and relative informativity were higher for the DLQI-R in all three conditions.

Discussion

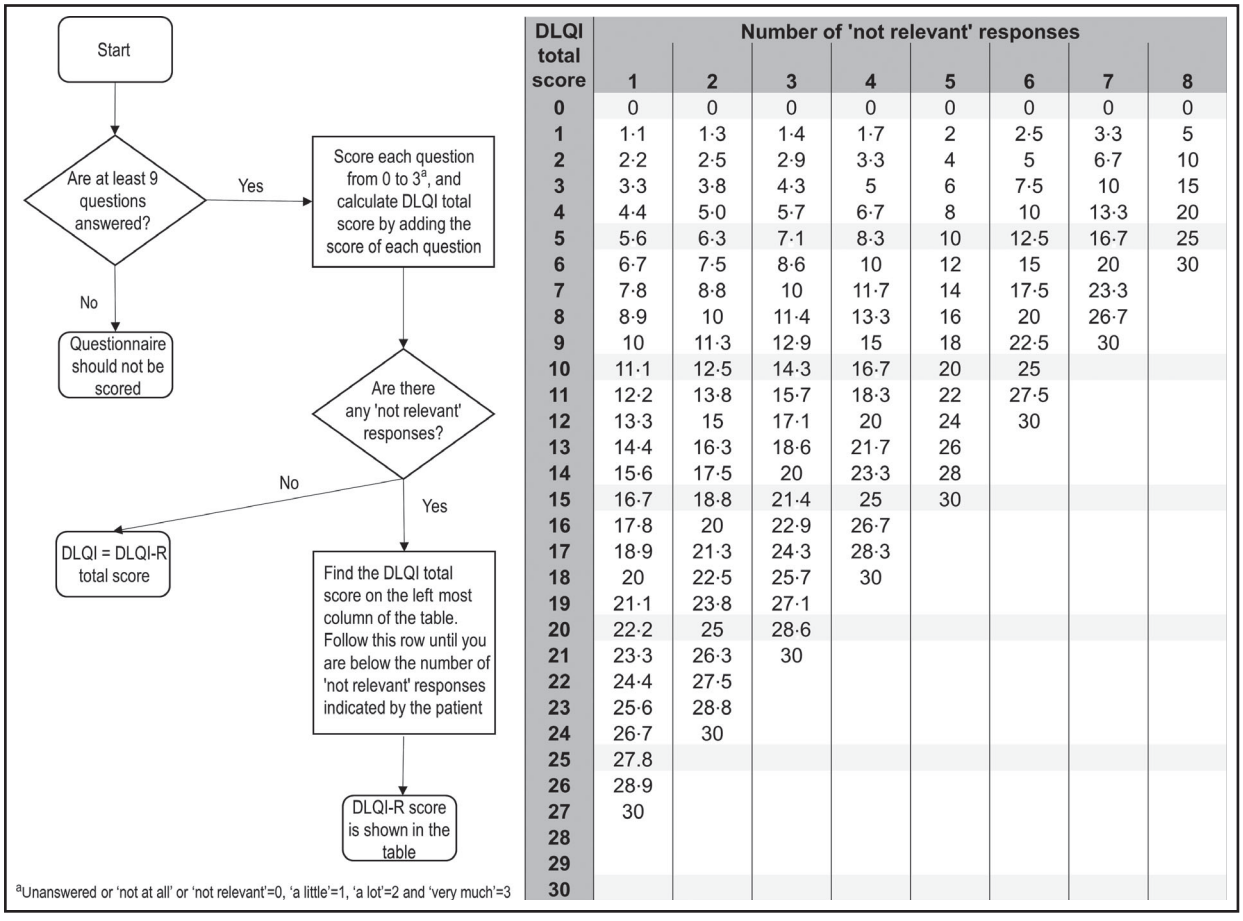
In this study, we compared the discriminatory power of the DLQI and DLQI-R scorings in terms of informativity in patients with morphea, pemphigus and psoriasis. The DLQI-R scoring improved the discriminatory power of the questionnaire by benefiting from the additional information in items marked as 'not relevant'. In the discussion, we provide an overview of the potential clinical relevance of our findings, including the magnitude of the problem with NRRs, the benefits, drawbacks and practical implications of applying the DLQI-R scoring.

Recently, a number of concerns have been expressed about NRRs on the DLQI.[8–10,13] In three independent studies the frequency of NRRs was increased among those with more severe disease, suggesting that the DLQI may underestimate disease severity in patients with psoriasis who responded NRR to one or more items.[8–10] To investigate the magnitude of the problem all three studies reported the number of patients affected by NRRs. In Germany, 48% out of 1243 patients, in the U.S.A. 23% of 1724 patients and in Hungary 38·8% of 428

Table 3 Absolute and relative informativity of Dermatology Life Quality Index (DLQI) and DLQI-Relevant (DLQI-R) total scores

	Patients with NRRs			All patients		
Condition, scoring	Number of scores used (%)	H′[a]	J′	Number of scores used (%)	H′[a]	J′
Morphea						
DLQI	14 (45)	3·32	0·67	17 (55)	3·42	0·69
DLQI-R[b]	16 (52)	3·55	0·72	19 (61)	3·52	0·71
Pemphigus						
DLQI	18 (58)	3·64	0·73	22 (71)	3·52	0·71
DLQI-R[b]	25 (81)	4·06	0·82	26 (84)	3·72	0·75
Psoriasis						
DLQI	23 (74)	4·15	0·84	29 (94)	4·07	0·82
DLQI-R[b]	27 (87)	4·36	0·88	31 (100)	4·15	0·84
Pooled dataset						
DLQI	24 (77)	4·07	0·82	29 (94)	3·97	0·80
DLQI-R[b]	31 (100)	4·38	0·88	31 (100)	4·09	0·82

NRR, 'not relevant' response; H′, Shannon's index; J′, Shannon's evenness index. [a]H'_{max} = 4·95 for both the DLQI and DLQI-R; [b]DLQI-R scores are rounded to the nearest integers to have an identical number of possible scores as the DLQI (i.e. 31).



DLQI total score	Number of 'not relevant' responses							
	1	2	3	4	5	6	7	8
0	0	0	0	0	0	0	0	0
1	1·1	1·3	1·4	1·7	2	2·5	3·3	5
2	2·2	2·5	2·9	3·3	4	5	6·7	10
3	3·3	3·8	4·3	5	6	7·5	10	15
4	4·4	5·0	5·7	6·7	8	10	13·3	20
5	5·6	6·3	7·1	8·3	10	12·5	16·7	25
6	6·7	7·5	8·6	10	12	15	20	30
7	7·8	8·8	10	11·7	14	17·5	23·3	
8	8·9	10	11·4	13·3	16	20	26·7	
9	10	11·3	12·9	15	18	22·5	30	
10	11·1	12·5	14·3	16·7	20	25		
11	12·2	13·8	15·7	18·3	22	27·5		
12	13·3	15	17·1	20	24	30		
13	14·4	16·3	18·6	21·7	26			
14	15·6	17·5	20	23·3	28			
15	16·7	18·8	21·4	25	30			
16	17·8	20	22·9	26·7				
17	18·9	21·3	24·3	28·3				
18	20	22·5	25·7	30				
19	21·1	23·8	27·1					
20	22·2	25	28·6					
21	23·3	26·3	30					
22	24·4	27·5						
23	25·6	28·8						
24	26·7	30						
25	27.8							
26	28·9							
27	30							
28								
29								
30								

Fig 3. Scoring chart for DLQI-R. DLQI, Dermatology Life Quality Index; DLQI-R, DLQI-Relevant.

patients included at least one NRR.[8–10] In the present study, the proportion of patients with NRRs varied between 36·6% and 53·7%. These findings from a total of six patient populations in three different chronic skin conditions underscore the clinical importance of the problem with NRRs.

There is increasing evidence about the potential benefits of using the DLQI-R scoring. Firstly, as the DLQI-R is a method of scoring the original DLQI, not a new or a revised version of the DLQI, the integrity of the questionnaire remains intact.

Secondly, DLQI-R showed improved measurement properties, including validity,[11,12] responsiveness[14] and discriminatory power in comparison with the DLQI. Its convergent validity with widely acknowledged generic HRQoL measures, the EuroQol 5-Dimension 3-Level (EQ-5D-3L) and EuroQol visual analogue scale (EQ VAS), was found to be statistically significantly better.[11,12] A 12-week clinical trial demonstrated that in patients with psoriasis who marked one or more NRRs, the DLQI-R was more responsive compared with the DLQI.[14] The favourable measurement properties of the DLQI-R may be equally useful in clinical trials as in daily clinical practice. In particular, applying the DLQI-R may be considered in the following clinical situations: diagnosing moderate-to-severe disease, deciding on the need for admission to a hospital ward, initiating systemic treatments and monitoring the response to treatment.[4,28–30]

Thirdly, DLQI-R may help to improve the access to systemic treatments for patients with psoriasis who cannot comply with the DLQI > 10 criterion in treatment guidelines because certain items of the questionnaire are not relevant to them.[11] In a previous study, switching to the DLQI-R allowed 3·3 percentage points more patients with moderate-to-severe psoriasis to achieve the 'Psoriasis Area and Severity Index > 10 and DLQI > 10' threshold set out by treatment guidelines.[11] Other authors, however, argued that instead of changing the scoring of DLQI, rather the criteria of the 'Rule of Tens' need to be interpreted in a less absolute way.[31]

With regard to the limitations of the DLQI-R, calculating a DLQI-R score may prolong the consultation and seem burdensome in a time-pressured clinical environment. On the other hand, the formula of the DLQI-R cannot be considered very complicated, and the estimated calculation time is less than a minute. From a practical perspective, developing scoring aids is a reasonable solution to facilitating the pen-and-paper administration. The Oswestry Disability Index (ODI)[32] – the most commonly applied instrument to measure disability related to low back pain – has a very similar scoring system to the DLQI-R. Building on a previously published and successfully applied scoring aid for the ODI,[33] we developed a possible scoring chart for DLQI-R (Fig. 3). In the long run, a more effective solution would be migrating to an electronic format with a built-in option for the DLQI-R scoring formula. An electronic version of the DLQI has been available since 2017.[34,35] The paperless era of medicine is getting closer and closer bringing forth the daily use of patient-reported outcome measures in an electronic format. In such an environment, the seemingly complicated formula of the DLQI-R may no longer will be an issue.

Our study has a few limitations. Shannon's indices are specific for these three patient populations under study and may not be generalizable to other patient populations. The sample sizes of the two rare diseases, namely pemphigus and morphea populations are relatively small; however, both of our datasets are among the largest HRQoL studies in these diagnoses in Europe.[17,18] The limited sample size of the study did not allow us to compare directly the item-level informativity for each DLQI total score category between zero and 30 points. Furthermore, the DLQI and DLQI-R scores are identical in patients with no NRRs not allowing any comparisons between the two scoring approaches. As a result of this inherent property of the DLQI-R scoring, the difference between the DLQI and DLQI-R will always be smaller at a population level compared with what can be observed in the subgroup of patients who marked NRRs.

The following possible future research areas are identified. Firstly, there is currently little experience with using the DLQI-R. We encourage physicians to try out the DLQI-R scoring chart and encourage researchers with access to existing DLQI data to experiment with the DLQI-R scoring and publish the results. Secondly, although the better measurement properties of the DLQI-R in psoriasis seem to be established,[11,12,14] further studies testing the performance of DLQI-R in other dermatological conditions are needed. Thirdly, the performance and the benefits of the DLQI and DLQI-R in the routine clinical environment are yet to be investigated. Fourthly, finding ways to integrate the DLQI-R scoring formula in the electronic version of the DLQI would be beneficial. Fifthly, exploring how patients interpret the NRRs and whether they are able to differentiate between the terms 'not relevant' and 'not at all' deserve further study.[36,37] Finally, the established banding system[27] and the 'Rule of Tens'[38] are among the greatest advantages of the DLQI that allow the clinical interpretation of scores. Future studies are required to test whether the Hongbo's banding system can be applied to DLQI-R and, if so, under what rules.[27] It also needs to be defined when the change in DLQI-R becomes 'significant' to a patient (i.e. minimal clinically important difference).[31] This would be an essential step to get the DLQI-R scoring accepted by professional societies and treatment guidelines.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Table S1 Distribution of responses on the 10 items of the Dermatology Life Quality Index (DLQI) questionnaire in three patient populations.

Table S2 Shannon's (H′) and Shannon's evenness (J′) indices per items of the Dermatology Life Quality Index (DLQI) and DLQI-Relevant in three patient populations.