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Original Article

Systematic review of the use of the Dermatology Life Quality Index in routine clinical practice: evidence from 287 articles across 56 countries

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Abstract

Background Although quality of life instruments are widely used in research, it is challenging to find evidence of their use in routine clinical use. The most widely used measure for skin disease burden is the Dermatology Life Quality Index (DLQI), and its scores have validated clinical meaning.

Objectives To identify evidence of the use of the DLQI in routine clinical practice and explore the nature of its use.

Methods The study followed PRISMA guidelines, and the protocol was registered with PROSPERO. MEDLINE (Ovid), Embase, Scopus and CINAHL (EBSCO) databases were systematically searched for articles describing studies using the DLQI in routine clinical practice. Studies were excluded if participants were aged < 16 years and if there were predetermined treatment interventions, as in a clinical trial. Information was extracted on publications' authors' opinions on the use of the DLQI in their routine practice.

Results In total, 2178 publications were screened and 287 articles met the inclusion criteria, reporting on 112 diseases and describing 66 434 patients from 56 countries, using the DLQI in at least 29 languages. Of the studies, 121 (42.2%) were reported as retrospective and 63 (22.0%) as observational. Fifty-two (18.1%) stated DLQI data were retrieved from patient records, 29 (10.1%) as 'real life', 39 (13.6%) reported 'real-world data' and 47 (16.4%) used consecutive patient recruitment. In total, 264 (92.0%) studies were conducted in a single country; 96 (33.4%) were multicentred studies, whereas 171 (59.6%) were conducted at a single site. There were 93 (32.4%) that were conducted in hospitals, 66 (23.0%) specified outpatient clinics, 38 (13.2%) tertiary care, 33 (11.5%) clinics, 4 (1.4%) in the community, 18 (6.3%) in other settings and 35 (12.2%) were unspecified. The most common diseases in the study settings were psoriasis (106 studies, 36.9%), atopic dermatitis (32, 11.1%), urticaria (24, 8.4%), hidradenitis suppurativa (22, 7.7%) and vitiligo (17, 5.9%). Thirty studies (10.5%) used Hongbo *et al.*'s (*J Invest Dermatol* 2005; **125**:659–64) DLQI score banding.

Conclusions The DLQI was widely used in routine care locations internationally, informing clinical decisions and monitoring of treatment. The DLQI was embedded into some clinics' continuing routine practice.

What is already known about this topic?

- Although the Dermatology Life Quality Index (DLQI) is the most widely used measure for skin disease burden in clinical trials and research, there is little evidence of its use in routine clinical use.

What does this study add?

- This study shows evidence of international use of the DLQI in routine settings, informing clinical decisions and aiding in monitoring of treatment.
- The DLQI was embedded into some clinics' continuing routine practice.
- It gives some insights into healthcare workers' and patients' experiences with the DLQI in routine settings and treatments in a large number of countries and dermatological diseases.

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The original article describing the Dermatology Life Quality Index (DLQI) stated, 'There is a need for a simple, compact, uniform measure, applicable to patients with any skin disease, for use as an assessment tool in routine daily clinical practice'.[1] There is a vast literature confirming the embedding of the DLQI in clinical research,[2–4] but this study's purpose was to collate the evidence of the use of the DLQI for that primary stated clinical purpose.

A systematic review of 22 randomized controlled trials (RCTs)[5] compared the additional use of patient-reported outcome measures (PROMs) to standard clinical care. Overall, the review found studies reported a positive effect or gave justification for the use of a PROM. Many potential benefits of routine use of patient-reported outcomes (PROs) in routine clinical dermatology practice have been described by a European Academy of Dermatology and Venereology task force on the quality of life,[6] including improving patients' ability to discuss issues with the clinician.[7] Secrest and Chren[8] discussed incorporating PROs as a key indicator for clinical care, and emphasized the need to identify normal ranges for dermatology-specific PROs.

The DLQI[1] is the most widely used dermatology PROM in routine practice and clinical trials[9,10] because of the simplicity of reporting a single meaningful summary score, its ease of completion in 2 min, comparability between studies and over time as there is only a single version of the tool, and wide language accessibility.[11] It is embedded in national guidelines and disease registries in > 45 countries[12] and available in 138 translations.[13] However, users of the DLQI need structured access to evidence concerning its use. Our previous four systematic reviews of 454 RCTs using the DLQI in 69 diseases and 43 countries[3] as the primary outcome in RCTs,[4] as the benchmark comparator in the validation of 101 new quality of life (QoL) measures[2] and of DLQI validation data across 207 publications[14] have highlighted the extensive use of the DLQI internationally and across many diseases and languages.

In a study of the practical reality of using the DLQI in a routine dermatology clinic,[15] 417 patients attended and 268 questionnaires (64.3%) were completed. The DLQI information in this study was used by clinicians in 64 consultations: in 37 (14% of 268), it influenced the clinicians' treatment decision making. However, there has been no review published, to the best of our knowledge, of DLQI use in routine practice. The aim of this systematic review was therefore to collate evidence about the use of the DLQI in routine clinical practice settings.

Materials and methods

For this study, 'routine practice' describes the use of the DLQI within a routine patient–clinician interaction and included assignment of patients to a particular therapeutic strategy decided by the treating physician, not carried out as an interventional study and not decided in advance by a trial protocol. The therapeutic decision fell within current practice and was clearly separated from any decision to include the patient in a study. This specifically excludes randomized trials where treatment intervention is determined by a study protocol, not by the care team. We also included therapeutic outcome monitoring studies.

Routine clinical practice occurs in a broad range of healthcare settings, including hospitals, mental health facilities, rehabilitation centres, general practice centres, polyclinics and other outpatient clinics. These settings may offer either physical or mental healthcare and may provide care in both outpatient and inpatient environments.

Within the context of clinical practice, PROMs are used for individual patient management. PROMs are systematically administered to patients to routinely monitor PROs in a standardized manner. The PROM results may be used during patient–clinician interactions to inform consultations/appointments, support patient–clinician communication, guide treatment planning and aid decision making.

Additionally, we defined 'retrospective' as a study based on existing data recorded for reasons other than research or without an a priori research question. Even this definition is problematic, because the data may be collected primarily for clinical decision making but with some expectation of future analysis.

A formal evidence-grading process (for example, GRADE, i.e. imprecision, inconsistency, indirectness, risk of bias estimation of size of intervention, publication bias) was not applied, as it was not deemed appropriate or informative to this largely descriptive review.

Data sources

This study follows 2020 PRISMA guidelines for reporting systematic reviews and checklist.[16] The study protocol and detailed search strategy were published on PROSPERO Prospective Register of Systematic Reviews[17] (CRD42022304734). MEDLINE (Ovid), Embase, SCOPUS and CINAHL (EBSCO) online databases from 1 January 1994 (DLQI creation) to 2 June 2023 were searched and results were corroborated independently by two authors (J.R.J., A.T.). Search terms included 'DLQI' and 'dermatology life quality index'. Database specific 'article type/study type' keywords, language keywords (English) and age selection keywords were also used to search the required types of study to be included, for example, MeSH terms for RCT. Duplicates were excluded. Full search scripts are provided in Table S1 (see Supporting Information).

Search strategy/selection

Table 1 gives the eligibility criteria for included studies. Search results were imported into EndNote20® to keep track of references.[18] Two authors (J.R.J., A.T.) independently compared study titles and abstracts retrieved by searches against the inclusion and exclusion criteria and examined full study texts potentially meeting the criteria but whose abstracts lacked sufficient information. Rejected studies were recorded with reasoning. A third author (F.M.A.) resolved and recorded any study selection disagreements. A PRISMA flowchart gives search counts for inclusions and exclusions and reasons for study exclusions[16] (Figure 1).

Outcome measures extracted

Information was extracted on publications' authors' opinions on the use of the DLQI in their routine practice. Other detailed information recorded included the countries, number of study sites and study settings, number of patients

Table 1 Eligibility criteria for study selection

Variables	Inclusion	Exclusion
Patients	• Adults ≥ 16 years, any gender, ethnicity, settings, countries • Any inflammatory and noninflammatory dermatological conditions	• People < 16 years
Methods	• Full papers in peer-reviewed journals • Published between January 1994 and June 2023 • Treatment given (described in the study) should be the standard care provided to patients in that setting, which has been implemented into the routine practice of the setting, with its use being at the discretion of the clinician. May include any drug, therapeutic intervention, alternative or traditional medicines, educational or lifestyle interventions	• Not in English language • 'Grey' literature, including dissertations, conference abstracts, reports, editorials, letters to editors, commentaries, protocols, reviews, conference proceedings and dissertations • Any study with an intervention determined by a trial/study protocol
Setting	• DLQI used in routine practice	• No DLQI data given or setting is not routine care, for example, randomized controlled trial

DLQI, Dermatology Life Quality Index.

who completed the DLQI, mean/median age, disease(s) studied, treatment(s), treatment duration, study design and study period, if the study was retrospective, observational, real-world data or real life, used consecutive recruitment and whether DLQI data were retrieved from patient records. Additionally, data were recorded on the frequency and period of the DLQI data collection, mean/median DLQI scores, and DLQI outcomes, including any evidence of statistically significant and/or clinically significant changes.

Data extraction and synthesis

For data extraction, guidance of the Cochrane Handbook for Systematic Reviews of Interventions was followed.[19] A REDCap database[20–22] (a secure web application for building/managing online surveys and databases) was created based on the Cochrane Handbook Version 5.1.0[23] and the updated guidance[19] recommendations. The authors J.R.J. and A.T. independently extracted data from the included publications to parallel REDCap database tables, and an adjudicator (J.V.) resolved any disagreements in data extraction. Missing data were noted in the data templates, but none were sufficiently important to contact the original authors.

The DLQI was designed and validated for use in people aged 16 years and older.[24] But after searching the online databases, 79 studies were excluded because the participants were < 16 years of age. Most of these studies utilized the Children's DLQI (CDLQI):[25] their inclusion from our initial search strategy did not include a method to sift these out.

There can be an impact on a study's validity, reliability and relevancy by recruitment diversity bias.[26–28] Owing in part to genetic ancestry,[29] marginalized populations can have different outcomes, and thus recruiting for diversity is essential to elucidate any sociodemographic factors that may have an impact on the study and results should be stratified by race/ethnicity if relevant to the study.[30] This aspect is currently rarely addressed in systematic reviews. To raise awareness of this issue, an appraisal of the representation of minoritized ethnic groups in the studies was conducted using Naicker's Critically Appraising for Antiracism Tool.[31]

Results

In total, 2668 studies were provided by online database searching. There were 490 duplicates, and the remainder,

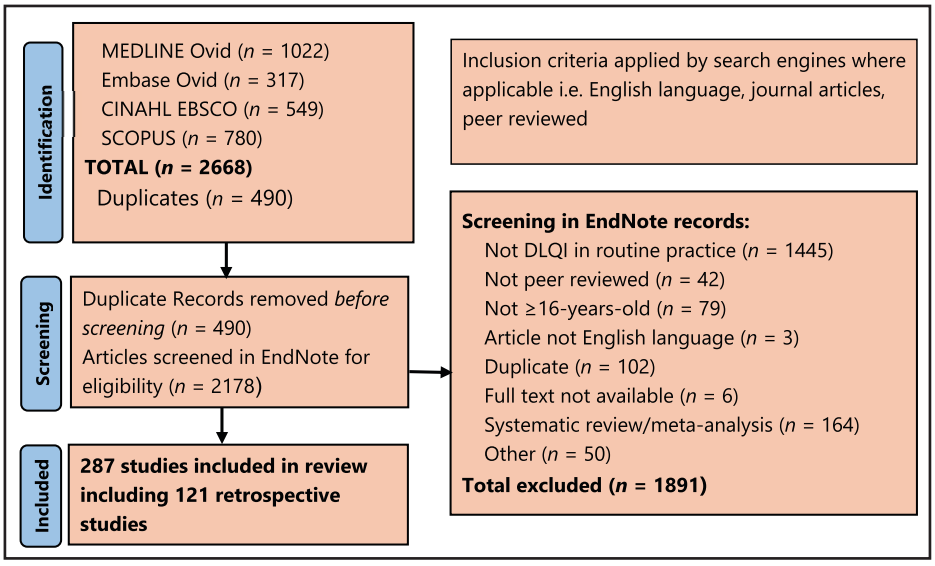

Figure 1 PRISMA flowchart showing identification, screening and inclusion of articles. DLQI, Dermatology Life Quality Index.

Table 2 The diseases most frequently studied in the papers reviewed[a] (*N*=287 studies)

Disease	*n* (%)
Psoriasis	106 (36.9)
Atopic dermatitis	32 (11.1)
Urticaria	24 (8.4)
Hidradenitis suppurativa	22 (7.7)
Vitiligo	17 (5.9)
Eczema/hand eczema	17 (5.9)
Acne	15 (5.2)
Alopecia	10 (3.5)
'Any skin disease'	8 (2.8)
Prurigo nodularis	8 (2.8)
Pruritus	8 (2.8)

[a]Some publications studied more than one disease.

2178 were assessed from the articles' full text, of which 287 described research on 66 434 patients meeting the inclusion eligibility criteria (Table 1). Publications describing the use of DLQI in routine practice have been increasing in number since 2010 (Figure S1; see Supporting Information).

Study sites and settings

Studies were conducted in 56 different countries and in at least 29 different languages. There were 264 studies (92.0%) that were conducted in a single country. In total, 96 (33.4%) were specified as multicentred studies, with 171 (59.6%) conducted at a single site and 20 (7.0%) not specified. Of the 287 studies, 93 (32.4%) were conducted in hospitals, 66 (23.0%) specified outpatient clinics, 38 (13.2%) tertiary care, 33 (11.5%) clinics, 4 (1.4%) the community, 18 (6.3%) other settings and 35 (12.2%) unspecified.

The review found that 121 (42.2%) of the studies were reported as retrospective; the rest were collecting DLQI data for a specific purpose within a routine clinical setting that was then reported within the included study. Sixty-three (22.0%) studies were reported as observational. In 52 (18.1%) they stated DLQI data were retrieved from patient records, 29 (10.1%) as 'real life', 39 (13.6%) reported 'real-world data' and 47 (16.4%) used consecutive patient recruitment.

In total, 249 (86.8%) studies used the DLQI for the reported study's purpose and 38 (13.2%) indicated they were using the DLQI routinely without regard to the study. Patients from minority ethnic groups were only reported in the demographic data in 34 (11.8%) of studies; in 251 (87.5%) of studies this information was not reported and 2 studies stated patients from minority ethnic groups were not recruited.

For all studies included, patient disease, demographics and study details based on keywords are given in Table S2 (see Supporting Information).

Disease profile

There were at least 112 different diseases or conditions reported. The most common diseases in the study settings were psoriasis (106 studies, 36.9%), atopic dermatitis (32, 11.1%), urticaria (24, 8.4%), hidradenitis suppurativa (22, 7.7%) and vitiligo (17, 5.9%) (Table 2).

Treatments

The routine treatments used within the study setting were captured from the published data. These are shown in Supplementary Table S3 (see Supporting Information), along with the diseases presented, treatment duration, comments on the study design and the study period. We also captured the use of biologics. These comprised dupilumab (*n*=21 studies), secukinumab (*n*=15 studies), ustekinumab (*n*=14 studies), adalimumab (*n*=13 studies), guselkumab (*n*=9 studies), omalizumab (*n*=9 studies), etanercept (*n*=8 studies), infliximab (*n*=6 studies), ixekizumab (*n*=5 studies), brodalumab (*n*=4 studies), tildrakizumab (*n*=4 studies), golimumab (*n*=3 studies), efalizumab (*n*=2 studies), rituximab (*n*=2 studies), risankizumab (*n*=1 study) and tralokinumab (*n*=1 study).

Dermatology Life Quality Index scores and other patient-reported outcome/quality of life measures

Data on DLQI scores reported are presented in Table S4 (see Supporting Information), including the frequency that DLQI was collected, the collection period, details of the DLQI, mean and median DLQI scores, and DLQI outcomes. Any opinions about the use of the DLQI in their setting were also captured. Very few studies reported the medium used for DLQI data collection, such as paper, tablet, phone or computer, in the setting, remote online or postal, so these data have not been presented.

Thirty studies (10.5%) used Hongbo *et al.*'s DLQI score banding, where DLQI scores 0–1=no effect on patient's life; scores 2–5=small effect on patient's life; scores 6–10=moderate effect on patient's life; scores 11–20=very large effect on patient's life; and scores 21–30=extremely large effect on patient's life.[32] There were 127 studies (44.3%) that used other PRO/QoL and severity scale measures in addition to the DLQI. Table S5 (see Supporting Information) presents these PRO/QoL and severity scale measures collected by the studies and the associated diseases.

Some author comments and opinions, and experiences of healthcare workers with the use of the DLQI in their routine practice setting, are given in Table 3.

Retrospective studies

We determined 121 (42.2%) of the included studies reported themselves as retrospective studies, based on this keyword. As a proportion, 40.5% of retrospective studies (49/121) stated DLQI data were retrieved from patient records, compared with only 1.8% for nonretrospective studies (3/166). We found that 23 of 121 (19.0%) retrospective studies, compared with 6 of 166 (3.6%) nonretrospective, were reported as 'real life' studies, and 33 of 121 (27.3%), compared with 6 of 166 (3.6%), were reported as 'real-world data'. However, only 10 of 121 (8.3%) retrospective studies compared with 37 of 166 (22.3%) nonretrospective studies used consecutive patient recruitment, and 39 of 121 (32.2%) retrospective studies compared with 24 of 166 (14.5%) nonretrospective studies reported themselves as 'observational studies'. Interestingly, only 3 out of 121 retrospective studies used Hongbo *et al.*'s score banding[32] (2.5%) compared with 30/166 (18.1%) for nonretrospective studies.

Table 3 Selected comments and opinions of authors of articles

Reference	Authors' comments and opinions
Adisen (2015)[43]	Results indicated that 'inpatient therapy may improve QoL of patients with dermatological diseases and that clinicians should consider assessment of DLQI to determine the therapy option for a patient'.
Ayyalaraju (2003)[44]	'If QoL measures were used routinely as one aspect of recording skin disease status, high scores indicating severe disability would provide an additional alert to a physician over the need for intervention.'
Bardazzi (2020)[51]	Routinely recorded patient compliance to therapy and administered DLQI questions to their patients, 'so we were able to verify their scores retrospectively from the hospital records. This score permit us to evaluate with a number the adherence to the therapy'.
Berg (2011)[52]	'The choice of DLQI for evaluating QoL in these acne patients may be discussed. However, DLQI was chosen though there are more acne-specific instruments available. This choice is based on the fact that DLQI is easy to use, has previously been shown to measure impact of acne on QoL and the results can be used for comparison of other skin diseases.' '…in this study it was again demonstrated that DLQI can be used to evaluate treatment effects in acne.'
Cakmak (2023)[53]	'The DLQI is routinely administered to patients when they attend the allergy clinic for an omalizumab injection every 4 weeks.'
Chaptini (2016)[54]	This was a retrospective longitudinal study. 'A strength of this study is that the DLQI was used to assess QoL for all patients, which, as described previously is a highly validated measure of QoL.'
Dalgard (2020)[55]	'The use of validated patient-reported outcome measures, such as the DLQI and the HADS, to guide clinical decisions, to assess improvement and to evaluate the effectiveness of the clinical service is appropriate, meaningful and feasible.'
Davies (2008)[56]	'Concerning patients' views of the appropriateness of discussion of their HRQoL in their consultation, the mean ± SD score of patients who had QoL discussion was 4.9 ± 1.2, which was similar to that of patients who did not have HRQoL discussion (4.5 ± 1.5).'
Dilnawaz (2013)[57]	'PASI and DLQI combined can thus be quite helpful and can have an impact on the overall care and the treatment plan.' They noted that 'There is a very high success rate of accurate completion of the DLQI. However, sometimes subjects do make mistakes'.
Dilworth (2015)[47]	'We recommend that PASI and DLQI should be recorded routinely in all new and return patients.' 'Performing PASI and DLQI assessments in clinic was beneficial. For new patients these were used as an aid to guide treatment. Patients with mild psoriasis were offered topical treatments and/or phototherapy while patients with severe disease were considered for systemic agents or admission. Patients in clinic are often seen by different doctors at their return appointments. Carrying out PASI and DLQI assessments offers a more standardised method of monitoring patients, reducing inter-observer variability. Enhanced nursing resources, both as specialist nurses to counsel patients as well as outpatient nursing staff to aid with performing the quantitative measurements, and to hand out questionnaires in advance of the consultation, would all aid in a more holistic consultation.'
Hagg (2015)[58]	'The strength of DLQI is the validity of the questions reflecting the reality of the patients' experience of living with the skin disease. However, DLQI is a self-reported measurement which may be affected by a number of unmeasured factors, and the comparability between individuals can be questioned. However, as both the patients' suffering and the societal costs are better expressed by the DLQI than by the PASI10, it is important to emphasize the importance of combining the DLQI with the PASI in the decision process when considering a biological therapy.'
Hahn (2001)[45]	'The DLQI is an easily administered instrument with a rapid method to measure QOL in various skin conditions. It is especially valuable because it can be readily used in a busy clinic. This index seems to capture data of greatest relevance to the dermatology population. The scoring system is straightforward. Our studies further show the reliability and validity of the index in a cross-cultural setting.' 'We find that the DLQI is a useful instrument for obtaining information about the impact of dermatologic disease on a person's QOL. The instrument is efficient to use and the form is easy to complete.' 'In general, patients seemed to be able to fill out the DLQI with minimal difficulty.'
Harlow (2000)[46]	'The DLQI was easy to use in general practice. It was acceptable to the patients, who found it quick and easy to complete: all but one of the patients completed the entire questionnaire correctly. Scoring was also quick and simple.'
Kinahan (2009)[59]	'The DLQI is an excellent clinical tool to measure how much the patient's treatment-induced skin problem has affected their skin in the past week. It measures broad categories that can affect the patient's QOL such as effects of actual dermatologic symptoms (itching, scratching) feelings related to the skin issues (embarrassment or self-consciousness), effects on daily activities, leisure activities, work, school and personal relationships. In retrospect, it was not the ideal tool to measure these same effects in a long-term survivor population because many of the dermatologic issues have resolved.'
Li (2022)[60]	'The DLQI was a valid and reliable scale for assessing the influence of skin problems on QoL.'
Mastorino (2022)[61]	'The use of questionnaires such as DLQI and POEM in clinical practice is advisable and adequate for assessing the impact of itching on atopic dermatitis.'
Mayba (2017)[62]	'Seeing as this review was conducted in a very active dermatology practice, it was not feasible to measure indices such as body surface area (BSA), Psoriasis Area and Severity Index (PASI), and Dermatology Life Quality Index (DLQI) for each patient at every patient visit.'
Mazzotti (2003)[63]	'For this purpose, a short self-evaluation instrument such as the DLQI is an asset in every busy dermatological clinic.' 'This study suggests that the DLQI performs well in Italian patients with psoriasis, in addition to those populations previously studied; the instrument is short and easy to administer to large numbers of patients even in busy dermatological clinics. A valid and reliable quality-of-life measure such as the DLQI has significant potential to aid both clinical and policy decisions in dermatology.'
Meeuwis (2011)[64]	'Ideally, the physician takes the initiative to ask about QoL and sexuality. Optionally, a very short disease-specific questionnaire such as the DLQI, which is practical and of clinical value when used in a busy clinical setting may be used.'

(*Continued*)

Table 3 (*Continued*)

Reference	Authors' comments and opinions
Nayak (2018)[65]	'As psoriasis is a chronic disease with periods of exacerbation and remission, DLQI can act as a reference score, which can be useful in determining the change in QoL before, during, and after treatment due to significant psychological and physical risk in psoriasis.' 'This study showed that psoriasis affects DLQI and that the impairment of QoL is directly proportional to the severity of psoriasis measured by PASI. The lowering in DLQI following decrease in PASI denotes the psychosocial wellbeing of the patient following remission or treatment.'
Newton (1997)[66]	'In the present study, the most specific patient measure, the DLQI, was also the most responsive to change, as expected.' 'The DLQI has some drawbacks in its present form but probably represents a good compromise between the generic and specific. It can be used in any dermatological group and yet it can be responsive to change in one group.'
Poon (1999)[67]	'As a relatively simple and quick questionnaire, it should also be suitable in the clinic setting as an adjunct to clinical observations. This would make it an important adjunctive assessment tool in chronic urticaria where examination in the clinic often does not bear correlation with disease severity and morbidity.'
Reinholz (2015)[68]	'The DLQI provides a promising adjunct for quantifying the QoL in patients suffering from keloids, atrophic- and self-harm scars and may constitute an interesting additional tool for monitoring the progress of scar treatments.' 'Thus, the DLQI allowed us to assess valuable information that we would have missed without its use and that would have been hard to come by using other methods. Not only does this demonstrate the DLQI's effectiveness as a diagnostic tool, it also shows how the use of a single questionnaire might lead to overlooking important information thus establishing the importance of a multi-level diagnostic approach.' 'Since a significant association between pathological scarring and varied intensities of influence on QoL could be established through this study, the general use of the DLQI or other QoL measures during scar treatment seems warranted.'
Russo (2023)[69]	'Our goal is to emphasize the importance of combining both EASI, DLQI, and SNRS and PNRS not only in decision making when choosing therapy in-clinical practice, but also in the follow-up of these patients.'
Salek (2007)[15]	'The information was used more frequently if the patient was suffering from an inflammatory condition. The DLQI information was drawn on in 57 consultations (32.9%) with patients suffering from inflammatory conditions. In comparison, QoL information was used by the clinicians in only 7 consultations (8.1%) with patients suffering from non-inflammatory.' 'Specialist nurses used the DLQI more than any other group in their treatment decision-making. GPs with a special interest in dermatology used the DLQI information during 25 consultations (43.1%) and this influenced their treatment decision-taking in 21 (36.2%), more than the other groups ($p < 0.01$).'
Shah (2006)[70]	'The results show that by using simple to administer questionnaires, we can quickly and easily assess QoL of older people. The DLQI is a rapidly applied questionnaire that gives a good indication of dermatology QoL in older people.' 'We would recommend using the DLQI and HADS for a quick and easy assessment of patients within the setting of busy dermatology clinics.'
Sojevic Timotijevic (2013)[71]	'…analyzing not only the total scores of the questionnaires, but also the EQ-5D dimensions and DLQI and PDI subscales and their relationships with other variables (e.g. sociodemographic and clinical characteristics) allowed identification of psoriatic patients at risk of a higher QoL impairment and in particular specific problems that may affect their QoL.'
Sondermann (2021)[72]	'Using the DLQI alone, clinically important levels of depression, anxiety and addictive behaviour may be missed. Patients more severely affected by psoriasis and patients with a significantly impaired dermatology-related QoL should be paid particular attention regarding assessment of psychiatric conditions.'
Szepietowski (2009)[73]	'We demonstrated that DLQI can be successfully used for the assessment of QoL in large populational studies. This instrument is easy and quick to complete and can also be employed in QoL evaluation among older patients with skin diseases.'
Tang (2013)[74]	'Attending dermatologists or physicians should be encouraged to assess patients' QoL because management decisions are partly guided by the impact of psoriasis on this important parameter. The DLQI and SF-12v2 are two practical QoL assessment tools.'

DLQI, Dermatology Life Quality Index; EASI, Eczema Area and Severity Index; HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; PASI, Psoriasis Area and Severity Index; PDI, Psoriasis Disability Index; POEM, Patient-Oriented Eczema Measure; PRNS, pruritus numerical scale; QoL, quality of life; SF-12v2, 12-item Short Form, version 2; SNRS, sleep numerical rating scale.

Information provided

The authors of the 287 included studies categorized them as addressing QoL in 141 (49.1%) studies, efficacy in 84 (29.3%), safety in 50 (17.4%), impact of disease in 36 (12.5%), drug survival in 12 (4.2%), treatment outcomes in 11 (3.8%), depression in 9 (3.1%), tolerance in 9 (3.1%), anxiety in 6 (2.1%), disease burden in 6 (2.1%), cost, financial burden or socioeconomic impact in 5 (1.7%) and stigma and self-esteem in 5 (1.7%). Other descriptors included sexual, dosage, sleep and coping: some studies occur in multiple categories. Although every study used the DLQI, some did not explicitly mention they were studying QoL.

Discussion

This review showed prospective DLQI use in clinical care routine settings. We excluded RCTs as they are not routine care, and we previously systematically reviewed DLQI use in that context.[3] Finding evidence of routine clinical use of a measure is challenging, as routine use is rarely reported. Our key approach was to identify articles describing where DLQI information had been collected routinely and then retrospectively assessed.

DLQI data taken from patient records, consecutive recruitment (not necessarily all patients but maybe a subset, for example, with one dermatological disease), or collection

of DLQI data over a long time period (unless the disease studied necessitated this) may be indicators of routine use. However, none provide definite evidence of routine use. We therefore considered 'routine use' only where DLQI data had already been collected and was used retrospectively for the published study.

Of the included studies, 121 (42.2%) stated they were retrospective, i.e. they analysed data previously collected before the study. The rest (prospectively) collected DLQI data for a specific purpose within a routine setting. Retrospective studies were 10 times more likely than nonretrospective ones to state DLQI data were retrieved from patient records and three times more likely to state using 'real life' studies or 'real-world' data, suggesting studies were of DLQI routine use in a routine clinical setting. However, a declaration of 'consecutive patient recruitment' or studies reporting themselves as 'observational studies' does not necessarily imply 'routine use', particularly where 'consecutive' may in some cases mean the next patient was selected when convenient, for example, a nurse was available to administer the questionnaire, rather than strictly consecutive arrivals.

Where a study aims to capture aspects of treatment (such as QoL, efficacy or tolerance) within a specific clinical setting, this is a local aim for which the outcome would not be relevant to a different setting. This is different from the goal of an RCT, where broader representation of patients from different settings is desirable, where sufficient patient numbers to power the trial are needed and the trial is designed to mitigate differences between study settings. However, only 59.6% of studies were conducted at a single site, with 33.4% multicentred studies (7.0% did not specify). These were often conducted across linked settings within a broader healthcare network.

The value of PROMs in routine clinical practice has been discussed since 2004.[33] Many studies have considered which characteristics of PROMs are important for use in clinical practice[34] and investigated the impact of routine collection of PROMs on patients, providers and health organizations in different settings,[35] their impact on health outcomes[36] and implementation factors.[37]

The importance of involving patients and the public in the development and evaluation of healthcare service delivery is increasingly recognized.[38] PROMs are instruments developed to ensure valid and reliable measurement of outcomes, such as QoL measures, or functional status associated with the healthcare received. PROMs can provide a better understanding of the impact of an intervention and/or service on a patient.[38]

Studies were conducted in 56 different countries, and the DLQI was used in at least 29 different languages, indicating the impact of the DLQI internationally in routine practice. This may be because of its wide acceptance,[3] simplicity of reporting a single score that is meaningful,[32] ease of completion,[39] knowledge about the minimum clinically important score difference[40,41] to aid score interpretation, stability and familiarity over time owing to there being only a single version of the tool, and being embedded in national guidelines and disease registries in > 45 countries[42] with availability in 138 translations.[13]

Results indicated inpatient therapy may improve the QoL of patients with dermatological diseases and clinicians should consider assessment using the DLQI to inform therapy decisions.[43] If QoL measures are used routinely, extreme scores indicating severe disability provide an additional alert over the need for intervention.[44]

Several publications provide detailed analysis of DLQI use in routine clinical practice (see Table 3). Hahn *et al*.[45] investigated DLQI use in a Midwestern US urban clinic and collected feedback from the healthcare team and patients. Harlow *et al*.[46] examined use of the DLQI in primary care settings and recorded responses about ease of use and patient acceptability in general practice. Dilworth *et al*.[47] performed an audit of DLQI use in routine practice in consultant-led and specialist nurse-led dermatology clinics and reported some barriers and benefits.

A strength of this review is the large number of relevant articles identified. However, a limitation was the decision to include only English-language articles. Only 11.8% of studies reported the ethnicity of participants, with the recruitment strategy unclear in 88.2%. Usually, it was unclear whether the recruitment ethnic mix was representative of the populations studied. Only six (2.1%) of the study reports justified or appropriately explained results stratified by race/ethnicity. Differences in study outcomes for minoritized ethnic groups were appropriately addressed and interpreted in only 15 (5.2%) of studies. It is important to publish data on participants' ethnicity, as many dermatological conditions are affected by race/ethnicity and skin colour.[48–50]

Inevitably many healthcare settings using the DLQI routinely have not been identified, as we could only find those described in articles reporting specific studies. However, this review does produce a snapshot of how and where the DLQI is being implemented, routinely in the case of retrospective studies, or to achieve specific goals or collect data in a routine setting in others. It would be of interest to carry out a broader systematic review to assess from published reports how many practitioners used any PROs (including the DLQI) in their routine clinical practice. The best direct way to measure how common DLQI use is in routine practice would be to identify a random sample of physicians' offices around the globe and ask for the completion of a questionnaire concerning the use of the DLQI. However, our study reports published evidence of use, whereas a questionnaire survey would provide descriptive, rather than evidence-based, data.

The final paragraph of the original 1994 article describing the DLQI stated, 'We hope that the use of the DLQI in the routine clinical assessment of patients with skin disease may make the patient–physician interaction more patient-centred by highlighting the psychosocial influences on the individual patient's well-being, as well as providing a useful practical measure for regular use'.[1] This systematic review provides evidence that some of these hopes have been met.

In conclusion, this study has revealed evidence of extensive use of the DLQI in routine settings from a series of studies including > 66 000 patients from across 56 countries and in 112 different diseases. Some articles describe the DLQI being embedded into continuous routine practice. This study provides evidence of a successful translational journey of a QoL measure from research to supporting clinical practice.

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Conflicts of interest

A.Y.F. is joint copyright owner of the DLQI. Cardiff University receives royalties from some use of the DLQI: A.Y.F. receives a proportion of these under standard university policy. J.R.I. receives an authorship honorarium from UpToDate and received a stipend as immediate past-Editor-in-Chief of the *British Journal of Dermatology*. He is a consultant for AbbVie, Boehringer Ingelheim, Cantargia, ChemoCentryx, Citryll, Elasmogen, Engitix, Incyte, Indero, Insmed, Kymera Therapeutics, MoonLake, Novartis, Sanofi, UCB Pharma, UNION Therapeutics and Viela Bio. He is co-copyright holder of the Hidradenitis Suppurativa Quality of Life score, Investigator Global Assessment, and Patient Global Assessment instruments for HS. His department receives income from royalties from the DLQI and related instruments. S.S. has received an unrestricted educational grant from GSK, is a consultant for Novo Nordisk and produces educational materials for AbbVie. J.V. participated in an advisory board for Amgen, has received payment or honoraria from L'Oreal and support from UCB Pharma for attending meetings. F.M.A. has received honoraria from AbbVie, Janssen, LEO pharmaceuticals, Lilly pharmaceuticals, L'Oreal, Novartis and UCB. The department for F.M.A. and J.R.J. receives income from royalties from the DLQI and related instruments. A.T. declares no conflicts of interest.

Data availability

The data underlying this article will be shared upon reasonable request to the corresponding author.

Ethics statement

Not applicable.

Patient consent

Not applicable.

Supporting Information

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

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