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Systematic review: Use of the Dermatology Life Quality Index (DLQI) in National and Regional Registries and Guidelines V.1

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We use this protocol and it's working

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Keywords: Dermatology Life Quality Index , DLQI, National and Regional Registries, Guidelines, dlqi use in skin disease guideline, use of the dermatology life quality index, dermatology life quality index, skin disease guideline, patient measurement instrument in dermatology, regional dermatology organisation, dlqi data from routine clinical practice, dermatology, impact of skin condition, skin condition, use of the dlqi, application in additional national guideline, dlqi use, national guideline, additional national guideline, use in guideline, evidence of the dlqi, regional guideline, pro measure in clinical trial, systematic review, guideline, dlqi, disease registry, collecting dlqi data, qol in routine practice, clinical trial, clinical decision making, routine clinical practice, used patient measurement instrument, routine treatment, guidelines rationale, clinical decision taking, reimbursement guideline

Abstract

Rationale: Since its publication in 1994, the DLQI has become the most widely used patient measurement instrument in dermatology to measure the impact of skin conditions on a patient's QoL in routine practice to inform clinical decision taking and as a PRO measure in clinical trials. A study in 2020 (Singh RK, Finlay AY. DLQI use in skin disease guidelines and registries worldwide. JEADV 2020 Dec; 34(12): e822-e824) identified that it was embedded in national guidelines and disease registries in >45 countries. That survey was likely incomplete and was not a systematic review. There is accumulating evidence of the DLQI's application in additional national guidelines, registries and reimbursement guidelines.

Working Objectives. This study will systematically review the use of the DLQI in guidelines and registries. Firstly, it will extract data from academic publications describing registries collecting DLQI data from routine clinical practice, and describing national or regional guidelines that encourage or require the use of the DLQI in routine treatment and clinical decision making. Secondly it will survey country and regional dermatology organisations to determine the DLQI's use in guidelines and registries.



Header

- 1 **Review title:** Use of the Dermatology Life Quality Index (DLQI) in National and Regional Registries and Guidelines
- 2 Anticipated or actual start date. 05/12/2023
- 3 Anticipated completion date. 31/12/2024
- 4 Stage of review at time of this submission. The review has not yet started
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- 11 Funding sources/sponsors. Division of Infection and Immunity, Cardiff University School of Medicine, Cardiff, UK
- 12 Conflicts of interest. None
- 13 Collaborators. None

Main body

- 14 **Review question:** How widely is the DLQI used in clinical guidelines and registries throughout the world?

Operational definitions for this study: Patient registries have been defined as “an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves a predetermined scientific, clinical, or policy purpose(s) [Gliklich R, Dreyer N. Registries for Evaluating Patient Outcomes: A User’s Guide. Rockville, MD: Agency for Healthcare Research and Quality; 2010. AHRQ Publication No. 10-EHC049]. A patient registry is a collection—for one or more purposes—of standardized information about a group of patients who share a condition or experience.

Terms such as clinical registries, clinical data registries, disease registries, and outcomes registries are also used to describe the same data collection method.

Clinical practice guidelines (or simply “clinical guidelines”) are recommendations on how to diagnose and treat a medical condition. They are meant to help ensure that patients receive appropriate treatment and care. Guidelines summarize the current medical knowledge, weigh the benefits and harms of diagnostic procedures and treatments, and give specific recommendations based on this information. [<https://www.ncbi.nlm.nih.gov/books/NBK390308/>]. Clinical guidelines may also assess whether treatments and ways of managing a condition are good value for money for the healthcare provider, providing advice for policy and reimbursement decisions.

Rationale: Since its publication in 1994, the DLQI has become the most widely used patient measurement tool in dermatology. It is used to measure the impact of skin conditions on a patient's quality of life in routine practice to inform clinical decision taking and as a patient reported outcome measure in clinical trials. A study in 2020

(reference. Singh Finlay) identified that it was embedded in national guidelines and disease registries in >45 countries. That survey was likely incomplete and was not a systematic review. There is accumulating evidence of the DLQI's application in additional national guidelines, registries and reimbursement guidelines.

Reference: Singh RK, Finlay AY. DLQI use in skin disease guidelines and registries worldwide. *JEADV* 2020 Dec; 34(12): e822-e824.

Working Objectives. This study will systematically review the use of the DLQI in guidelines and registries. Firstly, it will extract data from academic publications describing registries collecting DLQI data from routine clinical practice, and describing national or regional guidelines that encourage or require the use of the DLQI in routine treatment and clinical decision making. Secondly it will survey country and regional dermatology organisations to determine the DLQI's use in guidelines and registries.

15 **Searches**

1. Systematic review of published academic literature (using MEDLINE (Ovid), EMBASE (Ovid), and Scopus databases) describing registries collecting DLQI data from routine clinical practice, and guidelines that inform the use of DLQI in routine clinical decision making.
2. Systematically contact dermatological societies globally to survey countries/regions using the DLQI in national/regional guidelines and in registries. We will use the International League of Dermatology Societies (ILDS) Member Directory of organisations (open access on their website) to provide contact points (email addresses) for the survey.
 - a. Ethics committee approval is not required for this study. It has been confirmed by the Cardiff University School of Medicine Research Ethics Committee that ethical approval is not required for this survey. as the survey is obtaining information from organisations, not from or about individuals.
 - b. Organisations will be emailed a request for information, with reply by email. Respondents' email identities will be kept anonymous.
 - c. There will be monthly follow-up emails to non-responders for up to three months.

16 **Condition or domain being studied.** Any disease

17 **Participants/population.**

Inclusion criteria: Articles describing registries or guidelines for the treatment of adults (≥ 16 years old) with any skin diseases, of any gender, ethnicity, any settings or countries. Publications may report creation, collecting or adding data to, or use of

registries or the creation or use of clinical guidelines using the DLQI. Children are excluded because the DLQI has not been validated for those aged under 16 years of age.

18 **Intervention(s), exposure(s).** No intervention.

19 **Comparator(s)/control.** N/A

20 **Types of study to be included:** For the systematic review of published academic literature:
Included: Publications where the study registry data comes from routine clinical practice settings
Excluded: Publications where the study registry data was collected from controlled clinical trials e.g. RCT, where interventions follow a trial protocol, and cannot be therefore considered routine clinical practice.

21 **Context.**
Any healthcare setting performing routine clinical practice in dermatology.
Any country/region having clinical guidelines using the DLQI or registries collecting DLQI data.

22 **Main outcome(s). Matching Searches above**

From the ILDS survey:

- Responding ILDS organisation
- Country/region
- Registry name and disease(s)
- Guideline(s) using the DLQI and disease(s)

From literature review:

- Country/region
- Registry name, disease(s), drug(s), date of registry formation, number of sites contributing, no. of patients data collect from (to date)
- Guideline(s) name, disease(s), drug(s), issuing body, date guideline implemented, scope of the guideline, impact on reimbursement
- URL links to registry(s) or guideline(s)

23 **Data extraction (selection and coding):**

Literature review: Searches from MEDLINE (Ovid), EMBASE (Ovid), and Scopus databases will be merged into an EndNote database and duplicated removed.

Selection of studies: Two authors (JJ and JV) will independently select studies from the Endnote database, based on inclusion/exclusion criteria from the titles/abstracts of the studies, also using full texts if necessary. Reasons for exclusion of studies will be recorded, and counts for inclusions/exclusions will be recorded in a PRISMA 2020 flowchart.

Data extraction and management: The authors will extract data (based on the main outcomes of the review specified in Section 24 above) from full texts of studies that meet the inclusion criteria, to a REDCap database, a secure web application for building and managing online surveys and databases that will also code data. Missing data will be noted in the data templates and study investigators will contact authors for unreported data/additional details if deemed sufficiently important. A third author (FA) will resolve any disagreements in study selection or data extraction.

- 24 **Risk of bias (quality) assessment.** As the included studies do not contain clinical/patient data but are factual "reporting", risk of bias assessment is not relevant.
- 25 **Strategy for data synthesis.** Extracted data in a REDCap database will be exported and analysed with Microsoft Excel/SPSS to produce aggregated and summary data tables for publication.
- 26 **Analysis of subgroups or subsets,** No subgroups or subsets are relevant