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## REVIEW ARTICLE

# Quality of life measurement in acne. Position Paper of the European Academy of Dermatology and Venereology Task Forces on Quality of Life and Patient Oriented Outcomes and Acne, Rosacea and Hidradenitis Suppurativa

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## Abstract

Acne causes profound negative psychological and social effects on the quality of life (QoL) of patients. The European Dermatology Forum S3-Guideline for the Treatment of Acne recommended adopting a QoL measure as an integral part of acne management. Because of constantly growing interest in health-related QoL assessment in acne and because of the high impact of acne on patients' lives, the European Academy of Dermatology and Venereology Task Force on QoL and Patient Oriented Outcomes and the Task Force on Acne, Rosacea and Hidradenitis Suppurativa have documented the QoL instruments that have been used in acne patients, with information on validation, purposes of their usage, description of common limitations and mistakes in their usage and overall recommendations.

**Keywords:** dermatology, acne, quality of life, measurement.

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## Conflicts of interest

CCZ has received honorariums from Bayer Healthcare, Bioskin, Jenapharm and PPM for lectures or participation at advisory boards. The departments of CCZ have received compensation from Dr. Reddy's and Galderma Laboratories, for participation at clinical studies. GBJ has received consulting fees from Abbvie, AstraZeneca, MSD, LEO pharma, Novartis, Pfizer, InflaRx and UCB; lecture fees from Abbvie, Galderma and Roche; grant support from AbbvieNovartis and LEO Pharma; equipment on loan from Michelson Diagnostics. GBJ is a joint

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### Introduction

Acne is a common dermatological diagnosis accounting for 22–32% of dermatology patients and is one of the most common reasons for visiting a physician (1.1%)<sup>1</sup> with an estimated prevalence of 650 million people affected.<sup>2</sup> A systematic analysis for the Global Burden of Disease study indicated that acne was the 8th most prevalent disease globally in 2010.<sup>3</sup> Acne is considered a chronic disease owing to its prolonged course, pattern of recurrence and relapse, and manifestations such as acute outbreaks or slow onset. Moreover, the disease causes profound negative psychological and social effects on the quality of life (QoL) of patients.<sup>4</sup> Most people experience acne during adolescence, with >95% of teenage boys and 85% of teenage girls affected.<sup>5</sup> Of these young people, 20–40% have moderate-to-severe acne and as many as 50% continue to suffer from acne in adulthood. Familial predisposition and especially maternal acne are significantly associated with a more severe course.<sup>5</sup> Acne patients are managed primarily by dermatologists (93%) but also by general practitioners (6.3%) and paediatricians (0.6%).<sup>6</sup> In 2004, the direct annual costs of acne treatment in the USA had climbed to over 2.2 billion US dollars.<sup>7</sup>

Patients with clinical acne require medical therapy, either because of the severity or duration of their disease. Recent scientific advances have contributed to a better understanding of the pathogenesis of acne and to optimizing the therapeutic approach.<sup>8–12</sup> Health-related QoL (HRQoL) assessment in patients with acne is recommended by several national guidelines.<sup>13</sup> The European Dermatology Forum S3-Guideline for the Treatment of Acne recommended adopting a QoL measure as an integral part of acne management.<sup>14</sup>

HRQoL assessment in acne patients is often used in clinical trials as an outcome measure, but there are also many reasons to measure HRQoL in clinical practice.<sup>15</sup> To facilitate the integration of thinking about QoL into routine clinical practice, the new word 'QUIMP', meaning quality of life impairment, was recently proposed.<sup>16</sup>

Because of growing interest in the assessment of HRQoL in acne and the major impact of acne on patients' lives, the European Academy of Dermatology and Venereology (EADV) Task Forces (TFs) on QoL and Patient Oriented Outcomes (PO) and

Acne, Rosacea and Hidradenitis Suppurativa (ARHS) have documented the QoL instruments that have been used in acne patients, with information on validation, purposes of their usage, description of common limitations and mistakes in their usage and overall recommendations of the TFs.

This information should assist dermatologists and researchers in choosing appropriate QoL instruments, avoid common mistakes and facilitate the use of validated QoL instruments in their research and clinical work.

### Methods

Members of the EADV TFs on QoL/PO and ARHS were invited to participate. A literature search was performed using the PubMed database, which was searched from 1980 to November 2016 using the key words combination: 'acne' and 'quality of life'. All publications written in English or those having English abstracts were considered. All those who volunteered were allocated a section of the identified articles to review.

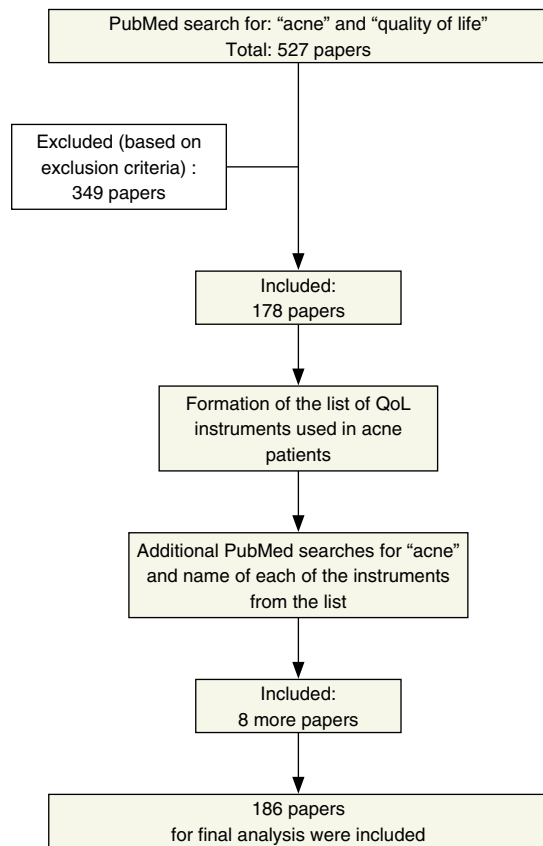
Exclusion criteria:

- Review articles, guidelines, protocols;
- Studies without HRQoL assessment;
- Measurement of HRQoL in conditions other than acne;
- Studies where HRQoL was measured in patients with conditions other than acne but some of whom may also have acne;
- Studies where HRQoL was studied in acne and other diseases but results on acne were not presented and/or discussed separately;
- Studies on postacne scars and postacne hyperpigmentation.

All publications were independently assessed by two co-authors. The assessments were compared and discrepancies discussed and resolved. The remaining publications were analysed in detail, and the QoL instruments used in acne were listed. Additional PubMed searches were carried out for 'acne' and the name of each of the measures from this list.

### Results

Thirteen members of the EADV TFs took part in the literature review. Figure 1 shows the literature search procedure. Validated HRQoL instruments that were used in acne studies are described in Table 1. Figure 2 shows how frequently these instruments were used.



**Figure 1** Literature search procedure.

Pärna *et al.*<sup>17</sup> used the RAND-36 instrument: this has identical content to the SF-36 but has a slightly different scoring system. Acne patients were included in the creation and initial validation of the 11-item Turkish quality of life (TQL) instrument.<sup>18</sup> The Children's Life Quality Index (CLQI), a 12-item generic proxy instrument has been used to compare children with skin disease with children with other chronic diseases.<sup>19</sup> Two German instruments were also used to assess HRQoL in acne patients.<sup>20,21</sup>

Truchuelo *et al.*<sup>22</sup> reported the use of the 9-item Social Quality-of-Life (SOQOL) scale, citing Krejci-Manwaring *et al.*<sup>23</sup> However, Krejci-Manwaring *et al.*<sup>23</sup> do not give information on the 9-item instrument. Nair and Nair appear to have combined the DLQI and CADI under the title Total Acne Quality of Life (TAQOL).<sup>24</sup> Five 'study-specific' untitled questionnaires with QoL elements were also used in acne patients.<sup>25–29</sup>

There are several reports of acne studies in which QoL instruments were used outside their validated age limits. For example, Skindex-29, an instrument for adults, was used in children from 12 years old,<sup>30</sup> and the DLQI, designed for use in those over 16 years old, was used in children aged 15,<sup>31,32</sup> 14,<sup>33,34</sup> 13<sup>35</sup> and 12 years old.<sup>36</sup>

The titles of some QoL instruments have been inaccurately presented.<sup>37,38</sup> Some authors did not provide references for the QoL instruments that they have used.<sup>30,39</sup>

Most of the publications identified were clinical trials, epidemiologic studies and studies on creation and/or validation of QoL instruments. However, there were also publications on educational work in acne patients,<sup>40–42</sup> compliance and adherence to treatment,<sup>36,43,44</sup> correlation of QoL with acne severity measures,<sup>45,46</sup> psychological problems,<sup>17,21,37,47–56</sup> gender differences,<sup>57,58</sup> racial differences,<sup>59</sup> comparison of generic and disease-specific QoL instruments,<sup>60,61</sup> and comparison of QoL impairment in patients with acne and other diseases.<sup>19,49,62–66</sup>

### Clinical trials

The different interventions assessed, for which the greatest number of studies have been identified, were those concerning isotretinoin<sup>31,48,50,67–76</sup> and benzoyl peroxide.<sup>30,77–85</sup>

### Epidemiological studies

A study from France showed that QUIMP in women with acne, assessed by the DLQI, was significantly different from women without acne.<sup>86</sup> Another French study reported that patients' daily lives were affected in nearly half of acne patients (48%).<sup>87</sup> A study from Iraq found significant association between age and QoL impairment in 510 acne patients.<sup>88</sup> Acne influenced QoL 'moderately' to 'very much', in 51.8% of patients in a study from Iran.<sup>89</sup> On the other hand, 478 Serbian pupils with self-reported acne reported low HRQoL impairment.<sup>90</sup>

### Educational work in acne patients

Mean DLQI<sup>40,41</sup> and CADI<sup>40</sup> scores improved after 12 weeks of text messages<sup>40</sup> and multiple-choice questions.<sup>41</sup> Internet-based acne education using automated counselling was not superior to standard website education in improving acne severity and QoL.<sup>42</sup>

### Compliance and adherence to treatment

In patients with acne, being female, married, employed and not paying for prescriptions were characteristics associated with increased medication adherence and better HRQoL.<sup>36</sup> Young females with high Skindex-29 scale scores and males with low Skindex scores are especially prone to non-adherence.<sup>43</sup> Better adherence was related to lower Skindex-29 scale scores at the end of their study.<sup>43</sup> Zaghoul *et al.* found significant negative correlation between DLQI scores and medication adherence.<sup>36</sup> Tan *et al.* reported that adherence increases with greater levels of impact on acne-specific QoL assessed by the Acne-QoL questionnaire.<sup>44</sup>

### Correlation of QoL with acne severity measures

In the majority of studies that addressed the issue, HRQoL correlated with acne severity.<sup>23,91,92</sup> Hanisah *et al.* found that only students with severe acne, assessed with the global acne grading

**Table 1** Details of HRQoL instruments that were used in articles reviewed

Titles of HRQoL instruments	Information on the structure of the instrument	Information on validation	Use in acne (references)
<b>World Health Organization Quality of Life (WHOQOL)-26</b>	<ul style="list-style-type: none"> <li>• 26 items</li> <li>• One item from each of the WHOQOL-100 24 facets plus two benchmark items for overall QoL and general health. The facets are subsumed into four domains: Physical health, Psychological, Social relations and Environment.</li> <li>• Five-point Likert scale</li> <li>• Scores from domains are transformed into a scale from 0 to 100.</li> </ul>	<ul style="list-style-type: none"> <li>• internal consistency</li> <li>• discriminant validity</li> <li>• construct validity</li> </ul>	67,68,106,107
<b>Dermatology Life Quality Index (DLQI)</b>	<ul style="list-style-type: none"> <li>• 10 items</li> <li>• Six headings: Symptoms and feelings, Daily activities, Leisure, Work and School, Personal relationships, Treatment</li> <li>• Responses are on a four-point Likert scale</li> <li>• Is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The higher the score, the more QoL is impaired</li> <li>• Validated score band descriptors have been described. For general inflammatory skin conditions a change in DLQI score of at least four points is considered clinically important</li> </ul>	<ul style="list-style-type: none"> <li>• test-retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> <li>• responsiveness</li> <li>• interpretability</li> </ul>	17,31–37,40,41, 45,47–51,57, 60–63,69,70,86, 89,98,102,106, 108–132
<b>Skindex (61 items)</b>	<ul style="list-style-type: none"> <li>• 61 items</li> <li>• Eight scales (cognitive, social, physical discomfort, physical limitation, depression, fear, embarrassment and anger)</li> <li>• Item responses are standardized from 0 (no effect) to 100 (effect always experienced)</li> <li>• A patient's scale score was the average of his or her responses to items in a given scale</li> </ul>	<ul style="list-style-type: none"> <li>• Reproducibility</li> <li>• Construct validity</li> <li>• Content validity</li> <li>• Internal consistency</li> </ul>	133
<b>Skindex-29</b>	<ul style="list-style-type: none"> <li>• 29 items</li> <li>• Seven items address the Symptoms domain, ten items the Emotional domain and twelve items the Functioning domain</li> <li>• Responses are on a five-point Likert scale</li> <li>• All responses are transformed to a linear scale of 100, varying from 0 (no effect) to 100 (effect experienced all the time). Skindex scores are reported as three scale scores, corresponding to the three domains; a scale score is the average of a patient's responses to items in a given domain</li> </ul>	<ul style="list-style-type: none"> <li>• test-retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> <li>• content validity</li> <li>• responsiveness</li> <li>• interpretability</li> </ul>	30,43,46,62,64, 65,77,78,120, 134–139
<b>Skindex-16</b>	<ul style="list-style-type: none"> <li>• 16 items</li> <li>• Consists of the items that had the best performance characteristics in the longer instrument, as well as additional items that are not in Skindex-29. There are three domains: symptoms (four items), emotions (seven items) and functioning (five items)</li> <li>• Responses are on a seven-point Likert</li> <li>• All responses are transformed to a linear scale of 100, varying from 0 (no effect) to 100 (effect experienced all the time). Skindex scores are reported as three scale scores, corresponding to the three domains; a scale score is the average of a patient's responses to items in a given domain</li> </ul>	<ul style="list-style-type: none"> <li>• test-retest reliability</li> <li>• internal consistency</li> <li>• content validity</li> <li>• construct validity</li> <li>• responsiveness</li> </ul>	23,52,97,140–144

Table 1 *Continued*

Titles of HRQoL instruments	Information on the structure of the instrument	Information on validation	Use in acne (references)
<b>Acne Disability Index (ADI)</b> <sup>145</sup>	<ul style="list-style-type: none"> <li>• 10 items</li> <li>• Questions about feelings, relationships, social and sporting activities</li> <li>• Responses are on a linear analogue scale for each item</li> <li>• Score is calculated by summing the scores for each item</li> </ul>	<ul style="list-style-type: none"> <li>• Test–retest reliability</li> <li>• Correlation coefficient for overall ADI score high</li> <li>• Overall score correlated with overall UKSIP score</li> <li>• Individual category score correlations high ADI and UKSIP</li> <li>• Internal consistency</li> </ul>	20,53,146,147
<b>Cardiff Acne Disability Index (CADi)</b> <sup>146,148</sup>	<ul style="list-style-type: none"> <li>• Five items</li> <li>• Questions about feelings, social life and relationships, skin exposure, overall severity</li> <li>• Responses on a four point scale for each question</li> <li>• Calculated by summing the score of each question (0–3), resulting in a maximum score of 15 and a minimum of 0</li> </ul>	<ul style="list-style-type: none"> <li>• Responsiveness to change</li> <li>• Correlation with clinical severity of acne and with UKSIP and CDLQI</li> <li>• Test–retest</li> <li>• Correlation coefficient for overall CADi score high</li> <li>• Internal consistency</li> <li>• Chinese, Serbian, Portuguese, Ukrainian, Persian and French validation: good reliability and internal consistency, good concurrent validity with DLQI/CDLQI</li> </ul>	32,40,50,54,58,71,79,87–90,93–96,99,107,115,118,128,130,146,149–166
<b>Acne-specific quality of life questionnaire (Acne-QoL)</b>	<ul style="list-style-type: none"> <li>• 19 items</li> <li>• Four domains: self-perception, role-social, role-emotional, acne symptoms</li> <li>• Seven-point rating scale ranging from 0 = ‘extremely’ or ‘extensive’ to 6 = ‘not at all’ or ‘none’</li> <li>• Summing all items within a domain</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> <li>• responsiveness</li> <li>• interpretability</li> </ul>	44,59,72,80–82,100,101,139,152,167–179
<b>Acne-Q4 (four-item index of the Acne-QoL)</b>	<ul style="list-style-type: none"> <li>• Shortened form of the Acne-QoL</li> <li>• Four items</li> <li>• One item from each domain of Acne-QoL</li> <li>• Seven-point rating scale ranging from 0 = ‘extremely’ or ‘extensive’ to 6 = ‘not at all’ or ‘none’</li> <li>• Total index score: summing four items</li> </ul>	<ul style="list-style-type: none"> <li>• Construct validity</li> </ul>	180–182
<b>Acne Quality of Life Scale (AQOL)</b>	<ul style="list-style-type: none"> <li>• nine items</li> <li>• four-point rating scale: 0 = not at all, 1 = mildly, 2 = moderately, 3 = very markedly</li> <li>• Mean of nine items</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> </ul>	38,39,45,51,83,84,183–189
<b>Acne Quality of Life Index (Acne-QOLI)</b>	<ul style="list-style-type: none"> <li>• 21 items</li> <li>• Three dimensions: social functioning, psychological functioning and emotional functioning</li> <li>• Seven-point scale anchored with 1 = ‘Not at all’, 4 = ‘Some’ and 7 = ‘Extremely’</li> <li>• Total score: summing all items</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> <li>• content validity</li> </ul>	23,190,191
<b>Short Form 36 Item Health Survey (SF-36)</b>	<ul style="list-style-type: none"> <li>• 36-item</li> <li>• Eight dimensions: Physical functioning, Social functioning, Role limitations (physical problems), Role limitations (emotional problems), Mental health, Vitality, Pain and General health perception</li> <li>• Three or six point scales</li> <li>• Scores are then coded, summed and transformed to a scale of 0 to 100 (worst and best health, respectively)</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> </ul>	48,60,61,63,66,73,74,122,124,126,170,183,192–194

Table 1 Continued

Titles of HRQoL instruments	Information on the structure of the instrument	Information on validation	Use in acne (references)
<b>Short Form 12-Item Health Survey (SF-12)</b>	<ul style="list-style-type: none"> <li>• 12 items</li> <li>• Shorter form of the SF-36. Physical Functioning, Role Physical, Role Emotional and Mental Health are estimated with two items, while Bodily Pain, General Health, Vitality and Social Functioning are estimated by one item</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> </ul>	55,137
<b>Children's Dermatology Life Quality Index (CDLQI)</b>	<ul style="list-style-type: none"> <li>• Children (4–16 years)</li> <li>• 10 items</li> <li>• Questions are about symptoms, feelings, leisure time, school and holidays, relationships, sleep and treatment impact</li> <li>• Responses are on a four-point Likert scale</li> <li>• Is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The higher the score, the more QoL is impaired. Can also be expressed as a percentage of the maximum possible score of 30</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> <li>• convergent validity</li> <li>• sensitivity to change</li> </ul>	19,37,42,50,85,90, 91,126,128,150, 153,156,195,196
<b>Global QoL</b>	<ul style="list-style-type: none"> <li>• eight items/domains: self-esteem, mood, relationship with peers, relationships with family, work/studies, lover relationships, money matters, health</li> <li>• Responses are on a seven-point Likert scale</li> <li>• The lower the score, the more QoL is impaired</li> </ul>	<ul style="list-style-type: none"> <li>• internal consistency</li> <li>• construct validity</li> </ul>	23,52
<b>Sheehan Disability Scale<sup>197</sup></b>	<ul style="list-style-type: none"> <li>• Five items (two optional)</li> <li>• Three domains: work/school</li> <li>• social life</li> <li>• family life</li> <li>• 11 point visual analog scale</li> <li>• The numerical ratings of 0–10 may be translated into percentage</li> <li>• The higher the score, the more QoL is impaired</li> </ul>	<ul style="list-style-type: none"> <li>• reliability</li> <li>• responsiveness</li> <li>• internal consistency</li> <li>• construct validity</li> </ul>	75,198
<b>Assessment of the Psychological and Social Effects of Acne (APSEA)</b>	<ul style="list-style-type: none"> <li>• 15 items</li> <li>• Nine items scored on continuous linear visual analogue scale (0–10)</li> <li>• Six items scored by ticking boxes (each box was allocated a score of 0, 3, 6 or 9)</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> </ul>	76,92,199
<b>Pediatric Quality of Life Inventory Child version (PedsQL-C)</b>	<ul style="list-style-type: none"> <li>• Child self-report (5–18 years)</li> <li>• 23 items</li> <li>• four domains: Physical functioning; Emotional functioning, Social functioning and School functioning</li> <li>• Five-point Likert scale for children</li> <li>• Items are reverse scored and linearly transformed to a 0–100 scale. Higher scores indicate a better quality of life</li> </ul>	<ul style="list-style-type: none"> <li>• reliability</li> <li>• validity</li> <li>• sensitivity to change</li> </ul>	56
<b>United Kingdom Sickness Impact Profile (UKSIP)<sup>200</sup></b>	<ul style="list-style-type: none"> <li>• 136-item</li> <li>• Twelve domains: body care and movement, mobility, ambulation, emotional behaviour, social interaction, alertness behaviour, communication, sleep and rest, home management, work, recreation and pastime and eating. In addition to this, patients are also asked to give an 'overall health' assessment, from a range of 'very good' to 'very poor'</li> <li>• Scores can be easily expressed as a percentage, either for each area separately or as an overall score</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• intrarate reliability</li> <li>• criterion validity (predictive/concurrent)</li> <li>• construct validity (convergent/discriminant)</li> </ul>	146

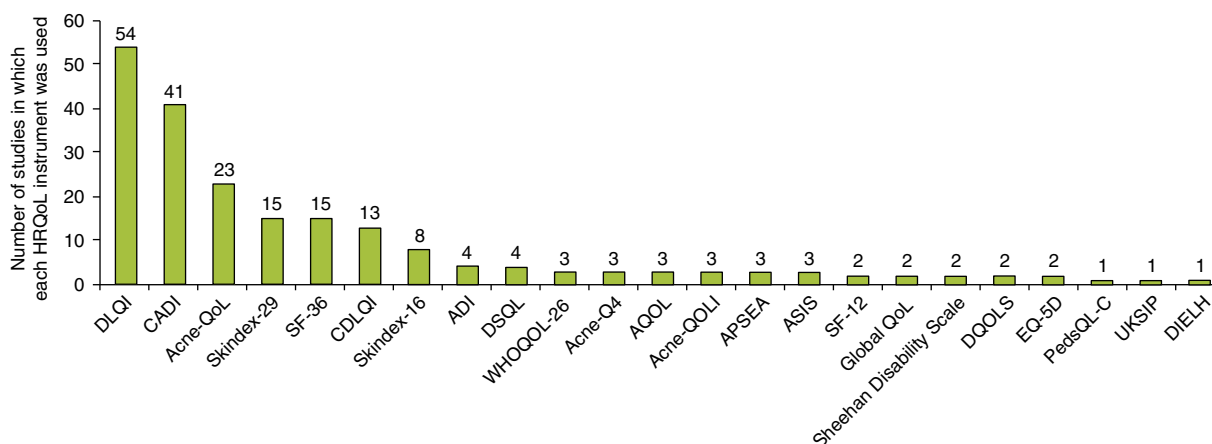
Table 1 *Continued*

Titles of HRQoL instruments	Information on the structure of the instrument	Information on validation	Use in acne (references)
<b>Patient-generated dermatology quality of life scales (DQOLS)</b>	<ul style="list-style-type: none"> <li>• 29 items (17 psychosocial items and 12 activities items)</li> <li>• four psychosocial subscales (embarrassment, despair, irritableness, distress) and four activities subscales (everyday, summer, social, sexual)</li> <li>• Five-point Likert scale</li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• construct validity</li> </ul>	126,201
<b>Dermatology-Specific Quality of Life (DSQL)</b>	<ul style="list-style-type: none"> <li>• 53 items</li> <li>• five subscales: <ul style="list-style-type: none"> <li>• Physical impact</li> <li>• Activities of daily living</li> <li>• Work difficulties</li> <li>• Social functioning</li> <li>• Self-perception</li> </ul> </li> </ul>		139,202–204
<b>EuroQoL 5-Dimension (EQ-5D)</b>	<ul style="list-style-type: none"> <li>• Two parts: EQ-5D descriptive system and EQ visual analogue scale (EQ-VAS). The descriptive system is made up of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression</li> <li>• Each dimension has three levels: no problems, some problems and severe problems. Each response is codified in a 1-digit number expressing the selected level, resulting in a 5-digit number describing respondent's health status. This codification describes 243 different health states, ranging from 11 111 (full health) to 33 333 (worst health). Numerals 1–3 have no arithmetic properties and should be used as an ordinal score. The EQ-VAS consists of a vertical, visual analogue scale where the respondent can assess his or her own health status. Its top point (100) is labelled 'Best imaginable health state' and its bottom point (0) is labelled 'Worst imaginable health state'</li> </ul>	<ul style="list-style-type: none"> <li>• convergent validity</li> <li>• absolute discriminatory power (Shannon index)</li> </ul>	61,62
<b>Deutsches Instrument zur Erfassung der Lebensqualität bei Hauterkrankungen [German instrument for the assessment of quality of life in skin diseases] (DIELH)</b>	<ul style="list-style-type: none"> <li>• 36 questions</li> <li>• seven domains</li> <li>• With a maximum score of 180</li> </ul>	<ul style="list-style-type: none"> <li>• internal consistency</li> <li>• convergent validity</li> <li>• discriminant validity</li> <li>• responsiveness</li> </ul>	205
<b>Acne Symptom and Impact Scale (ASIS)</b>	<ul style="list-style-type: none"> <li>• 17 items</li> <li>• two domains: <ul style="list-style-type: none"> <li>• symptoms (nine items)</li> <li>• psychosocial impact (eight items)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• test–retest reliability</li> <li>• internal consistency</li> <li>• Rasch analysis</li> </ul>	139,206,207

system (GAGS), had high CADI scores.<sup>93</sup> There was a positive correlation between overall scores on the Echelle de Cotation des Lésions d'Acné (ECLA) scale and CADI scales before and after treatment in one study<sup>94</sup> but no correlation in another study.<sup>58</sup> Some studies found no correlation between the impairment of QoL and the severity of acne.<sup>45,95,96</sup> The report of a case–control

study in university students stated that even though the AQOL and DLQI scores were significantly higher in acne patients compared to controls, the level of impairment of QoL was not associated with the severity of acne.<sup>45</sup> In addition, there was no correlation between CADI scores and GAGS in an acne study of female patients.<sup>96</sup>





**Figure 2** Number of studies in which each HRQoL instrument was used.

### Psychological problems

A high impairment of dermatologic QoL seems to be associated with an increased risk of having an anxiety disorder.<sup>51</sup> Anger was significantly related to both global QoL and skin-related QoL in the study by Rapp *et al.*<sup>52</sup> Bowe *et al.* showed that Body Image Disturbance Questionnaire scores correlated with Skindex-16 scores.<sup>97</sup> Significant correlation was found between Beck's depression inventory and APSEA.<sup>76</sup>

### Gender differences

In a population study of 1531 school pupils from Greece, the HRQoLs of girls and boys were equally affected in those with acne.<sup>91</sup> Similarly, no difference was reported in other studies.<sup>95,98</sup> In contrast, in several studies females were reported to experience a greater impact on QoL than males.<sup>57,88,92,99,100</sup> However in a study carried out in Egypt, the mean DLQI scores of male patients with acne were higher than those of female patients.<sup>34</sup>

### Racial and ethnic differences

Gorelick *et al.* explored the impact of racial background on the perceived HRQoL impact of acne,<sup>101</sup> categorising subjects into 'White', 'Black', 'Hispanic' and 'Asian'. 'White' and 'Black' subjects reported less negative impact of acne on QoL than 'Hispanic' and 'Asian/other subjects' measured by the Acne-QoL. 'Black' subjects reported significantly less negative impact in the self-perception domain compared with 'Asian/other subjects'. By racial/ethnic group, social functioning was less negatively impacted by acne in 'White' and 'Black' subjects than in 'Asian/other subjects'. There were no statistically significant differences in either the role-emotional or acne symptoms domains among racial/ethnic groups.<sup>101</sup> Callender *et al.* did not find significant differences in HRQoL between white/Caucasian and non-white/Caucasian women with acne.<sup>59</sup>

### Task Forces recommendations for use of HRQoL measures in acne

#### Process of selection

Questionnaires should be selected that are appropriate for the ages of the subjects studied. Questionnaires should only be used within their validated age limits.

When choosing questionnaires for use in research, investigators should ensure that they have been tested for scale structure, reliability, validity and responsiveness.<sup>208</sup>

#### Choice of measures

Use of validated acne-specific instruments in addition to generic and dermatology-specific questionnaires.

The Task Forces recommend the DLQI, CDLQI and Skindex-29 as dermatology-specific, the CADI and Acne-QoL as acne-specific and SF-36 as generic instruments.

#### Publication

Authors should always clearly state the names of any QoL instruments used, along with the original reference to its publication. Editors should ensure that published QoL data at least meets these minimum requirements.

#### Clinical use

The Task Forces encourage dermatologists to use HRQoL measurement in clinical practice, for many reasons<sup>15</sup> and to educate trainees about the benefits of their use.

**Figure 3** TFs recommendations for use of HRQoL measures in acne.

### Comparison of generic and disease-specific QoL instruments

Significant correlation in an acne population was reported between all domains of the SF-36 and the DLQI scores.<sup>60</sup> The dermatology-specific instrument, the DLQI, was demonstrated to be more responsive to change compared to the two generic measures, the SF-36 and EQ-5D.<sup>61</sup>

### Comparison of QoL impairment in patients with acne and other diseases

Patients with acne experienced functioning and emotional effects from their skin disease comparable with those experienced by patients with psoriasis, but had fewer symptoms.<sup>65</sup> Patients with severe acne reported levels of social, psychological and emotional problems that were as great as those reported by patients with chronic disabling asthma, epilepsy, diabetes, back pain or arthritis.<sup>63</sup> In a study from Brazil, patients with acne had the fourth highest QUIP, surpassed only by psoriasis, vitiligo and atopic dermatitis.<sup>102</sup> In children psoriasis and atopic dermatitis caused the greatest impairment of QoL, followed by urticaria and acne.<sup>19</sup>

### Discussion

In all studies reviewed, the measures used detected impairment of QoL caused by acne. Acne, especially when severe, may have an impact on the life of patients comparable to that caused by other dermatologic diseases, such as psoriasis, vitiligo, atopic dermatitis and urticaria<sup>19,65,102</sup> and non-dermatologic diseases, such as asthma, epilepsy, diabetes, back pain and arthritis.<sup>63</sup> In a study by Sampogna *et al.*,<sup>103</sup> the only skin diseases that had a greater psychosocial impact than acne were hyperhidrosis, hirsutism, ectoparasitic infections and bullous diseases.

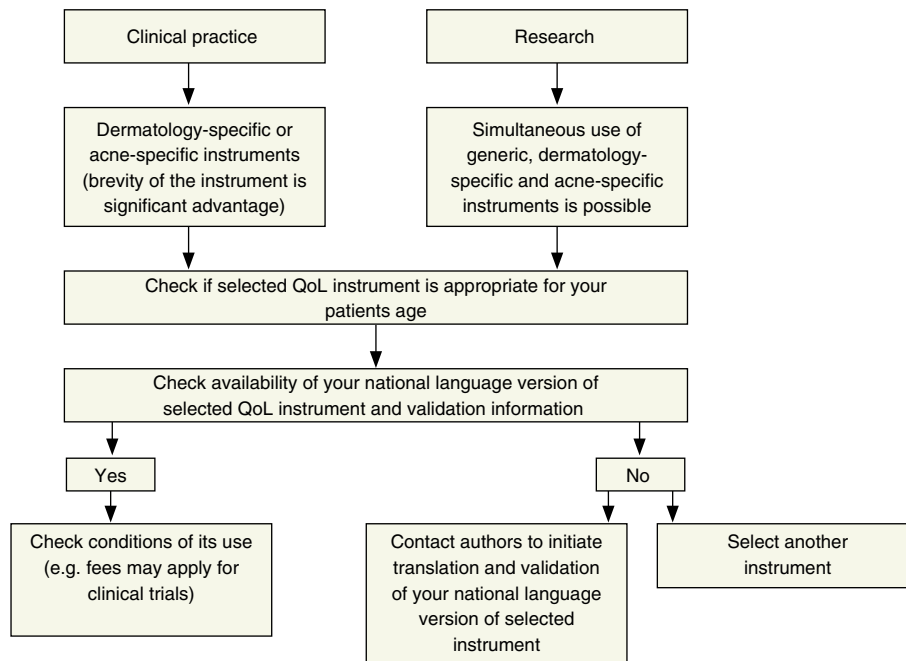
The DLQI, a dermatology-specific instrument, and the acne-specific instruments CADI and Acne-QoL were used much more

frequently than the generic SF-36 questionnaire. The dermatology-specific instruments CDLQI and Skindex-29 were also both used more than 10 times. This may reflect a higher interest amongst investigators in assessing dermatology- and acne-specific aspects of HRQoL impairment. Currently in routine clinical practice HRQoL assessment is still infrequent despite there being many potential benefits from such use.<sup>15</sup>

The dermatology-specific questionnaire the DLQI showed greater response sensitivity following successful treatment than the generic SF-36 and EQ-5D instruments.<sup>61</sup> Appropriate responses are especially important in clinical trials, the commonest reported context for QoL measurement in acne patients. The instruments most used in clinical trials are the DLQI and CADI.

The impairment of QoL in patients with acne has been reported in epidemiologic studies in various countries.<sup>86–89,91,95</sup> The impact on QoL correlates with acne severity in some but not all studies, underlying the need for the effective and timely management of acne even for patients with less severe acne.<sup>86,87,91</sup>

The major impact of acne on HRQoL documented in the reviewed studies emphasizes the need for educational programmes for acne patients about living with and treating acne.<sup>40,41</sup> An educational approach is currently much less developed than in atopic dermatitis or psoriasis. The creation and critical evaluation of high-quality educational programmes should be given priority by organizations that focus on acne,



**Figure 4** Flow chart to assist selection of appropriate HRQoL instrument.

researchers and clinicians. QoL assessment may be used in this context as an outcome measure and source of additional information from patients. Prediction of compliance and adherence to treatment in acne patients are another potential aspect of the use of HRQoL instruments. However, current evidence suggests that this is not an easy task.<sup>36,43,44</sup> When starting a new treatment, those patients with the most highly impaired HRQoL generally adhere better to the therapy. From a longer term perspective, those patients whose acne improved the most showed improvement in their HRQoL and had superior adherence to therapy.

Impaired QoL is also often associated with significant psychological problems in acne patients.<sup>51,52,76,97</sup> Gender differences may also play a role. Although acne affects female and male adolescents in about the same proportion, a higher impact on QoL in females compared to males has been shown in several studies.<sup>57,88,92,99,100</sup> No gender difference was found in other studies.<sup>91,95,98</sup> There is only one report<sup>34</sup> of male patients having a greater impact of acne on their QoL, probably influenced by regional peculiarities. It may be that racial and ethnic differences in QoL assessment by acne patients<sup>101</sup> are also based on difference in cultural attitudes.

As different studies examine different age ranges of subjects and use different HRQoL questionnaires, there is little standardization of results, emphasising the need for the development of agreed core outcome measures for use across all studies.

During this review, many examples were identified of inappropriate use or reporting of QoL measurement in acne. These included use of 'study-specific' unvalidated questionnaires that included elements of QoL, inaccurate presentation of titles of QoL instruments, absence of information on instruments and use of QoL instruments out of their validated age limits. Similar problems were also reported concerning QoL measurement in patients with atopic dermatitis.<sup>104</sup> Such activity reduces the scientific value of published results and may discredit HRQoL assessment. There is a need for educated input when researchers plan studies that include HRQoL assessment and a need for editors to set clear standards for the reporting of HRQoL data.

On the basis of this literature review and expert opinion our TFs recommend the DLQI, CDLQI and Skindex-29 as dermatology-specific, CADI and Acne-QoL as acne-specific and SF-36 as generic instruments for the assessment of HRQoL in acne. Experience of the use in acne of other instruments presented in this study is too limited. The brevity of the DLQI, CDLQI and CADI and Acne-QoL makes these instruments suitable for use in routine clinical practice. Acne-specific instruments may assess HRQoL in both children and young adults.<sup>105</sup> It is acknowledged that some of the recommended measures may not have ideal validation characteristics.

The recommendations of the TFs are given in Figs 3 and 4.

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