Patient reported outcomes in chronic skin diseases: eHealth applications for clinical practice
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Chapter 4

CONSUMER QUALITY INDEX
CHRONIC SKIN DISEASES (CQI-CSD)
a new instrument to measure quality of care from the patients’ perspective
ABSTRACT

Background: Assessing quality of care from the patients' perspective is considered to be highly relevant. As a standardized instrument in dermatology was lacking, we developed a patient experience questionnaire regarding chronic skin disease care: the Consumer Quality Index Chronic Skin Disease (CQI-CSD).

Objectives: 1) To evaluate the dimensional structure of the CQI-CSD, 2) to assess its ability to distinguish between hospitals according to patients' experiences with quality of care, 3) to explore patients' experiences with dermatological care and priorities for quality improvement according to patients, and 4) to optimize the questionnaire based on psychometric results and stakeholders' input.

Methods: In a cross-sectional study 5647 adult patients who received dermatological care in the past 12 months in 20 hospitals were randomly selected and invited to fill out the questionnaire.

Results: Overall 1160 of 989 eligible respondents (29.0% response rate, 30-87 per hospital) were included for analyses. The CQI-CSD comprised seven scales with high internal consistency (Cronbach's α = 0.74-0.92). The instrument's discriminative power was limited. Patients were positive about the care provided by nurses and doctors, but the provision of information by health care providers, accessibility of care and patient involvement could be improved. We optimized the CQI-CSD, resulting in a revised questionnaire containing 65 items.

Conclusions: In conclusion, the CQI-CSD is a useful instrument to measure patient experiences with dermatological care.
INTRODUCTION

Chronic skin diseases, such as psoriasis, atopic dermatitis, and hidradenitis suppurativa, have a negative impact on patients' physical, psychological and social functioning, and well-being\textsuperscript{1-4}, termed health-related quality of life (HRQoL)\textsuperscript{5}. Dermatological treatment may result in temporary symptom suppression, but chronic skin diseases cannot be cured. Therefore, patients with a chronic skin disease require prolonged use of dermatological care.

Needless to say, high quality of dermatological care is of paramount importance. To achieve high quality, patient-centred care is increasingly advocated\textsuperscript{6}. In addition to indicators based on expert consensus and clinical measures, patient satisfaction is considered a relevant indicator to measure quality of care from patients' perspective\textsuperscript{7}. Concerning psoriasis, surveys in the U.S.A.\textsuperscript{8} and Europe\textsuperscript{9} have suggested that patients are dissatisfied with the management of their psoriasis, despite (inter)national treatment guidelines. Dissatisfaction can lead to poor adherence and consequently suboptimal health outcomes\textsuperscript{10,11}, whereas higher satisfaction can improve HRQoL\textsuperscript{12}.

Nowadays, questions about patients' actual experiences are preferred to questions about satisfaction, as the answers to these questions are less influenced by subjective expectation and provide a more discriminating measure of a hospital's performance\textsuperscript{13}. Information on patient experiences can be used by different stakeholders and for multiple purposes\textsuperscript{14}. For instance, health care providers can use this information to measure their provided healthcare and initiate improvement projects. In a system of regulated competition, transparency of health care enables patients to make a well-informed choice between health care providers. Insurance companies can use the information in their negotiations with health care providers\textsuperscript{15}.

A standardized instrument to measure patients' experience with dermatological care is currently lacking. In the Netherlands, the standard for the measurement of patient experiences in healthcare is the Consumer Quality Index (CQI)\textsuperscript{15}. A CQI may consider a general level (CQI Healthcare and Insurances), a sector in health care (CQI Physiotherapy), a specific disease (CQI Diabetes) or a specific treatment (CQI Hip and Knee Replacement). A CQI consists of two questionnaires: one to assess patient experiences with respect to relevant quality aspects (CQI Experience) and one to measure the importance that patients attach to these aspects (CQI Importance). We developed an new experience and importance questionnaire: CQI Chronic Skin Disease (CQI-CSD). This new instrument is intended to provide reliable information about patient experiences with dermatological care and to reveal differences between hospitals based on patient experiences.

The aims of this cross-sectional study were 1) to evaluate the dimensional structure of the CQI-CSD, 2) to assess its ability to distinguish between hospitals according to patients' experiences with quality of care, 3) to explore patient experiences with dermatological care and priorities for quality improvement according to patients, and 4) to optimize the questionnaire based on psychometric results and input of stakeholders.
MATERIALS & METHODS

Measurements

Questionnaire development

In concordance with CQI protocols, the CQI-CSD was constructed in cooperation with various stakeholders: dermatologists, nurses, skin therapists, psychologists specialised in dermatology, representatives of patient organizations and health insurance companies. The CQI methodology is based on classical test theory. To identify relevant quality aspects, we first conducted a literature search and examined existing questionnaires and previous focus group interviews with patients with psoriasis (n=9), lichen planus (n=10) and lichen sclerosus (n=9). Next we organised two further focus group discussions with 13 patients (four male and nine female, mean age 45 year, with various chronic skin diseases). Two researchers independently performed qualitative analyses on the transcribed audiotapes of the discussions. Statements reflecting quality aspects were identified. In cooperation with stakeholders, we constructed pilot versions of the CQI-CSD: CQI-CSD Experience and CQI-CSD Importance. To check whether questions were clear and concise, and response options were adequate, the focus group participants completed and commented on both questionnaires. Further developmental details are described elsewhere.

Consumer Quality Index Chronic Skin Disease Experience

The pilot version of the CQI-CSD Experience (Appendix I) consisted of 74 items of which 53 items referred to patients’ experiences with and evaluations of dermatological care. Forty-six items were formulated as ‘experience’ items (yes/no or never/sometimes/usually/always), two as ‘problem’ items (not a problem/a small problem/a big problem) and five as ‘global rating’ items (0-10 or definitely not/probably not/probably/definitely). The remaining 21 items consisted of five skip items to screen eligibility of respondents to answer specific items, 15 items on patients’ background characteristics, and one item on questionnaire improvement. The questionnaire comprised the following sections: health care provided by general practitioner, accessibility of hospital, waiting times, hospital facilities, information about care process, health care provided by physician, health care provided by nurses, cooperation of health care providers, information provision by health care providers, patient participation, safety, global rating of hospital, skin complaints, and about the respondent.

Consumer Quality Index Chronic Skin Disease Importance

For each experience/problem item in the CQI-CSD Experience, a corresponding Importance item was formulated. Quality aspects represented more than once, such as conduct of dermatologist and nurse, were converted into one item, for example, ‘How important is it to you that health care providers treat you with respect?’ (1, not important at all to 4, extremely important). The CQI-CSD Importance consisted of 48 items.

Subjects and data collection

Three health insurance companies randomly selected 5647 patients from 20 hospitals for whom costs of dermatological care were claimed between September 2011 and
Measuring quality of care from the patient’s perspective

September 2012, according to previously identified declaration codes. These codes differentiate between diagnostic groups, but cannot distinguish between chronic and acute skin diseases. Inclusion criteria were: 1) one or more chronic skin disease diagnosis (self-reported), 2) health care received for this diagnosis during the past 12 months, and 3) age ≥ 18 years. We purposely included 20 hospitals with the highest patient volumes meeting our inclusion criteria, covering both academic and peripheral hospitals in various regions of the Netherlands. We aimed to invite approximately 300 patients per hospital, based on the CQI-specific recommendation to invite at least 200 patients per hospital for sufficient discriminative power14, and our expectation that a proportion of patients would not meet our inclusion criteria (no chronic skin disease) due to our sampling strategy.

In September 2012, invitations to complete the CQI-CSD Experience online were sent to the selected patients by postal mail on behalf of the health care insurer. Following the protocol of Dillman17, reminders were sent after 1 week to all patients and in the fifth and seventh week to nonrespondents. The second reminder included a paper version of the questionnaire and a prepaid return envelope.

We randomly invited one out of four patients to complete the CQI-CSD Importance online, immediately after they completed the CQI-CSD Experience online. We aimed to attain at least 150 completed CQI-CSD Importance questionnaires, as this number was assumed to provide sufficient information on importance at an aggregated level, and we did not expect meaningful differences in importance scores across hospitals.

The study was conducted according to the Declaration of Helsinki Principles of 1983. The study was exempted for ethical approval, as research by means of once-only surveys that are not intrusive for patients is not subject to the Dutch Medical Research Involving Human Subjects Act.

Statistical analyses
Analyses were performed in SPSS 19.0 (IBM, Armonk, NY, U.S.A.) and MLwiN 2.0218. Analyses were performed at a significance level of 0.05. For each analysis, we included patients with complete data on the particular variables involved. We performed $\chi^2$-tests to examine whether respondents differed from nonrespondents in sex, age or diagnosis.

Consumer Quality Index Chronic Skin Disease Experience: dimensional structure
We performed principal-component analyses with oblique rotation, given the expected correlation between factors, after checking whether the following criteria were met: Kaiser-Meyer-Olkin measure of sampling adequacy >0.60, and Bartlett’s test of sphericity. These criteria were not met when analysing all items simultaneously. Therefore, we performed analyses for each questionnaire section separately. The number of factors was determined by Kaiser’s criterion (eigen value)19 and scree plots. Factor loadings of items had to be ≥0.3 for items to belong to a factor20.

To evaluate the internal consistency of each scale, we calculated Cronbach’s $\alpha$ and accepted $\alpha$ ≥0.60 according to Cohen’s criteria21. To obtain insight into the multidimensionality of the questionnaire, we calculated interscale correlations. Pearson correlations of <0.70 indicate that the constructed factors can be seen as measuring separate constructs22.
To examine the discriminative power of the questionnaire, we performed multilevel analyses that take into account the correlation of the experiences of patients who are treated in the same hospital. We used the iterative generalized least squares method\cite{23,24} and calculated intraclass correlation coefficients (ICCs) to examine whether response patterns of patients within hospitals were correlated. A higher ICC means that more of the variance in patient experiences can be attributed to differences between hospitals.

When comparing hospitals, differences in respondent characteristics (age, sex, diagnosis, self-reported health status and education), so called case-mix adjusters\cite{26}, were taken into account. These characteristics may influence responses in their own right, and an uneven distribution of these characteristics in hospitals can unfairly influence hospitals’ comparisons.

To explore patient experiences with dermatological care, we calculated the mean scores of the scales and global rating items. To explore priorities for quality improvement according to patients, we calculated ‘quality improvement’ scores for each separate item\cite{27-29}. Quality improvement scores were computed by multiplying the quality aspects' mean importance score by the valid percentages of patients reporting a negative experience (never/sometimes, no/a little or a small problem /a big problem) and dividing this score by 100. Quality improvement scores could vary between 0 and 4, with higher scores suggesting more urgency for improvement.

Items were considered for removal if they decreased internal consistency of the relevant scale, belonged to the 10 least important quality aspects according to patients, had a proportion of ≥10% missing data, and/or had a significant high interitem correlation (Pearson’s $r \geq 0.80$, $p<0.001$). Stakeholders discussed whether items should be included in the revised version. The opinion of stakeholders was leading in deciding which items to maintain.

Overall 1658 of the 5647 selected patients were not eligible because they did not have a chronic skin disease (n=1354), they had not received care for their skin disease in the past 12 months (n=277), the invitation was returned undeliverable (n=21) or it was returned because the patient was deceased (n=6). Of the remaining 3989 patients, 704 declined to participate, 646 completed fewer than five questions, and 1453 did not respond. Subsequently, 26 patients were excluded because they had not completed the questionnaire themselves. Therefore, 1160 patients (29.1% response rate, 30 - 87 patients per hospital) remained for further analyses. In total 166 of 175 (94.9%) completed importance questionnaires were valid for analyses.
Table 1
Background characteristics of respondents and non-respondents to the CQI-CSD Experience

<table>
<thead>
<tr>
<th></th>
<th>Respondents (n=1160)</th>
<th>Non-respondents (n=4487)</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41.5</td>
<td>39.7</td>
<td>0.014</td>
</tr>
<tr>
<td>Female</td>
<td>58.5</td>
<td>60.3</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 to 34</td>
<td>10.5</td>
<td>18.3</td>
<td>0.13*</td>
</tr>
<tr>
<td>35 to 54</td>
<td>19.7</td>
<td>25.0</td>
<td></td>
</tr>
<tr>
<td>55 to 64</td>
<td>20.7</td>
<td>14.2</td>
<td></td>
</tr>
<tr>
<td>65 to 74</td>
<td>24.9</td>
<td>17.9</td>
<td></td>
</tr>
<tr>
<td>≥75</td>
<td>24.2</td>
<td>24.5</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acneiform dermatoses</td>
<td>5.9</td>
<td>9.0</td>
<td>0.15*</td>
</tr>
<tr>
<td>Allergological problem</td>
<td>2.4</td>
<td>4.1</td>
<td></td>
</tr>
<tr>
<td>Eczema</td>
<td>27.2</td>
<td>27.5</td>
<td></td>
</tr>
<tr>
<td>Hair- and nail disorders</td>
<td>2.5</td>
<td>5.5</td>
<td></td>
</tr>
<tr>
<td>Inflammatory dermatoses</td>
<td>5.8</td>
<td>6.1</td>
<td></td>
</tr>
<tr>
<td>Pigment disorders</td>
<td>1.1</td>
<td>3.3</td>
<td></td>
</tr>
<tr>
<td>Premalignant dermatoses</td>
<td>37.4</td>
<td>30.3</td>
<td></td>
</tr>
<tr>
<td>Psoriasiform dermatoses</td>
<td>13.2</td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>Leg ulcers</td>
<td>4.6</td>
<td>7.3</td>
<td></td>
</tr>
<tr>
<td>Educational status (n=1080)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education or primary education only</td>
<td>12.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower or senior secondary education</td>
<td>44.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary vocational education</td>
<td>19.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher secondary education or higher</td>
<td>23.1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1 continues on the next page
Chapter 4

Table 1, continued

<table>
<thead>
<tr>
<th>Global perceived health (n=1125)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good / Excellent</td>
</tr>
<tr>
<td>Good</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Poor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis established (n=1122)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year ago</td>
</tr>
<tr>
<td>1-5 years ago</td>
</tr>
<tr>
<td>5-15 years ago</td>
</tr>
<tr>
<td>&gt; 15 years ago</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healthcare professionals contacted in past 12 months regarding chronic skin disease*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatologist</td>
</tr>
<tr>
<td>General Practitioner (GP)</td>
</tr>
<tr>
<td>Nurse</td>
</tr>
<tr>
<td>Other health care professional</td>
</tr>
<tr>
<td>Assistant to GP</td>
</tr>
<tr>
<td>Skin therapist</td>
</tr>
</tbody>
</table>

*: p<0.001; * multiple answers allowed.

The respondents’ background characteristics (Table 1) were comparable with those of the nonrespondents for sex, but not for age or diagnosis.

Consumer Quality Index Chronic Skin Disease Experience: dimensional structure

Thirty of 53 items of the experience questionnaire could be divided into seven scales, with high internal consistency (Cronbach’s α 0.74 - 0.92). These were 1) Information about the care process, 2) Health care provided by physicians, 3) Health care provided by nurses, 4) Cooperation of healthcare providers, 5) Information provision by healthcare providers, 6) Patient participation, and 7) Safety. The remaining 23 items did not fit into any of these scales statistically and/or by content. Inter scale correlations ranged from 0.37 to 0.69, indicating that the constructed scales measure separate aspects of dermatological care (Table 2).

Consumer Quality Index Chronic Skin Disease Experience: discriminative power

Multilevel analyses were performed on the seven constructed scales and 16 separate
items. Seven remaining items were excluded from analyses due to high nonresponse and/or low importance scores. A model correcting for age, education, self-reported health status and sex, fitted the data best (Table 3). Likelihood ratio analyses revealed that the instrument was able to discriminate between the performance of hospitals on the scale 'cooperation of healthcare providers' and four items (waiting time in waiting area, information about waiting time, facilities in waiting area and cleanliness of hospital). Using this scale and these items, between two and seven hospitals scored significantly lower, and three to seven hospitals scored significantly higher than the other included hospitals.

**Exploration of patient experiences and priorities for quality improvement**

Patients reported the most positive experiences on the scales 'health care provided by nurses' and 'cooperation of healthcare providers' (Table 2). The global ratings of the physician (n=954, mean 8.2 ± 1.5), nurse (n=421, mean 8.0 ± 1.4) and hospital (n=1109, mean 8.0 ± 1.4) were all high. Almost all patients would definitely/probably recommend the hospital to friends and family (n=1108, 95.5%) and would themselves definitely/probably choose this hospital again (n=1104, 95.2%).

According to the 10 highest 'quality improvement' scores (Table 4), major topics for quality improvement concerned information provision (e.g. information on patient associations, side-effects, waiting time), accessibility (e.g. through email, in case of emergency), and patient involvement (e.g. taking into account patients’ expectations, shared decision making).

**Optimizing the Consumer Quality Index Chronic Skin Disease**

Based on the item characteristics, 16 items were considered for removal from the questionnaire because they met one or more of the following criteria: decreased internal consistency of the relevant scale (12 items), belonged to the 10 lowest quality improvement scores (nine items), having ≥10% missing data (four items), and resembled another question (two items). In consultation with stakeholders, it was agreed to maintain six items, to remove six items, and to rephrase four items. Additionally, stakeholders suggested four other items to remove, two items to rephrase and one item about self-management to add. This resulted in a revised version of the CQI-CSD Experience questionnaire containing 65 items (Appendix II).

**DISCUSSION**

Our results indicate that the CQI-CSD consists of seven independent, internally consistent scales. However, the instrument's discriminative power is limited. Patients were positive about the care provided by nurses and doctors, but the information provision by healthcare providers, accessibility of care and patient involvement could be improved. Based on these results, we revised the questionnaire into the 65-item version.

The limited discriminative power of the CQI-CSD is not unique. Previous studies on other CQI instruments also reported limited discriminative power. Differences between hospitals were found mainly in hospital facilities and not in aspects concerning
<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
<th>Example Item</th>
<th>Patient Experience</th>
<th>Dimensional Structure</th>
<th>Inter-scale correlations</th>
<th>Internal consistency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Information about care process</td>
<td>4</td>
<td>Did the staff told you beforehand what a treatment or examination entailed?</td>
<td>3.07</td>
<td>1050.46</td>
<td>0.67</td>
<td>0.44</td>
</tr>
<tr>
<td>2. Health care provided by physician</td>
<td>4</td>
<td>Did the physician listen carefully to you?</td>
<td>3.51</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
<tr>
<td>3. Health care provided by nurse</td>
<td>4</td>
<td>Did the nurse have enough time for you?</td>
<td>3.57</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
<tr>
<td>4. Cooperation of healthcare providers</td>
<td>4</td>
<td>Did the staff within this healthcare facility cooperate well with each other?</td>
<td>3.57</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
<tr>
<td>5. Information provision by healthcare providers</td>
<td>4</td>
<td>Did you get clear answers to your questions from the health care providers?</td>
<td>3.57</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
<tr>
<td>6. Patient participation of healthcare providers</td>
<td>4</td>
<td>Were you involved in the decision about (follow-up) treatment?</td>
<td>3.57</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
<tr>
<td>7. Safety</td>
<td>4</td>
<td>Was it ascertained that you were the right person?</td>
<td>3.51</td>
<td>928.09</td>
<td>0.85</td>
<td>0.59</td>
</tr>
</tbody>
</table>

Note: SD = standard deviation. Range: 1-4, with higher scores indicating more positive experiences. Cronbach's alpha: * p<.05
### Table 3
Multilevel analyses of the CQI-CSD Experience

<table>
<thead>
<tr>
<th>Scale</th>
<th>Model*</th>
<th>n</th>
<th>ICC</th>
<th>P-value (χ² likelihood ratio test)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scales:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S1. Information about care process</td>
<td></td>
<td>989</td>
<td>0.09</td>
<td>0.44</td>
</tr>
<tr>
<td>S2. Health care by physician</td>
<td></td>
<td>902</td>
<td>0.46</td>
<td>0.23</td>
</tr>
<tr>
<td>S3. Health care by nurse</td>
<td></td>
<td>406</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td><strong>S4. Cooperation of healthcare providers</strong></td>
<td></td>
<td>299</td>
<td>8.76</td>
<td>0.00</td>
</tr>
<tr>
<td>S5. Information provision of healthcare providers</td>
<td></td>
<td>1048</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td>S6. Patient participation</td>
<td></td>
<td>1032</td>
<td>0.48</td>
<td>0.22</td>
</tr>
<tr>
<td>S7. Safety</td>
<td></td>
<td>884</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td><strong>Quality aspects (separate items):</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Reaching hospital by phone is a problem</td>
<td></td>
<td>859</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td>9. Waiting time until consultation is a problem</td>
<td></td>
<td>1053</td>
<td>0.02</td>
<td>0.46</td>
</tr>
<tr>
<td>10. Waiting time in waiting area</td>
<td></td>
<td>1016</td>
<td>5.11</td>
<td>0.00</td>
</tr>
<tr>
<td>11. Information about waiting time</td>
<td></td>
<td>884</td>
<td>34.79</td>
<td>0.00</td>
</tr>
<tr>
<td>12. Facilities in waiting area</td>
<td></td>
<td>996</td>
<td>7.99</td>
<td>0.00</td>
</tr>
<tr>
<td>13. Cleanliness hospital</td>
<td></td>
<td>1056</td>
<td>2.11</td>
<td>0.00</td>
</tr>
<tr>
<td>14. Privacy hospital</td>
<td></td>
<td>1027</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td>40. Nurse's attention for consequences of disease</td>
<td></td>
<td>394</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td>45. Conflicting information of health care providers</td>
<td></td>
<td>301</td>
<td>0.00</td>
<td>0.50</td>
</tr>
<tr>
<td>58. Recommend hospital to friends/family</td>
<td></td>
<td>0.25</td>
<td>0.32</td>
<td></td>
</tr>
<tr>
<td>59. Would choose again for this hospital</td>
<td></td>
<td>0.42</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>62. Skin complaints decreased past 12 months</td>
<td></td>
<td>0.24</td>
<td>0.36</td>
<td></td>
</tr>
<tr>
<td>63. Negative consequences of skin disease past 12 months</td>
<td></td>
<td>0.59</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td><strong>Global ratings:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Physician</td>
<td></td>
<td>904</td>
<td>0.14</td>
<td>0.40</td>
</tr>
<tr>
<td>41. Nurse</td>
<td></td>
<td>405</td>
<td>0.05</td>
<td>0.50</td>
</tr>
<tr>
<td>60. Healthcare organization</td>
<td></td>
<td>1056</td>
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*correcting for age, education, global perceived health, and sex. Significant (p <0.05) in bold
doctor-patient contact \(^{34-36}\), as was the case in our study. Lack of discriminative power may be explained in several ways. Firstly, quality of care might be equally high in all hospitals. Secondly, patients’ experiences with doctor-patient contact between healthcare providers within a hospital might differ as much as or even more than between hospitals, leading to comparable scores at the hospital level \(^{37}\). Thirdly, the wording of questions might have been too generic and/or the available response formats might not have been sensitive enough to detect differences between hospitals. Finally, for statistical reasons it can be questioned whether differences can be detected in as few as 20 hospitals\(^{14}\). However, as approximately 25% of all Dutch hospitals were included, covering both academic and peripheral hospitals in various regions, we feel our data are representative for all Dutch hospitals.

As in previous studies, information provision and patient involvement were identified as priorities for improving the quality of dermatological care. Printed information could aid in information transfer and in enhancing patients’ satisfaction and outcome\(^7\). Also, dermatologists’ interpersonal skills - in particular the dermatologists’ ability to answer a patient’s questions, to give explanations about the skin problem and to demonstrate concern for the patient’s health - have been associated with patient satisfaction and may be improved\(^{38}\). For instance, in our study the majority of patients stated that their provider did not ask them about their expectations. Involving patients in their care may lead to increased patient satisfaction, more treatment adherence, improved recovery and better health outcomes \(^{6,36,39,40}\).

Our study has several limitations. Firstly, we invited many patients who did not belong to our target group (chronic skin disease), as we selected patients through registration of health insurers based on declaration codes, which are categorized into diagnostic groups. For future studies we suggest that patients should be selected by the hospitals themselves, based on specific diagnoses. Secondly, the response rate of 29% is low. Unfortunately, we have no information on reasons for nonresponse. Respondents were older than nonrespondents and differed in diagnoses, setting limits to the generalizability of our results with respect to patient experiences and priorities for quality improvement. Moreover, this limited representativeness may have affected the psychometric results.

The invitations to participate were sent on behalf of insurance companies. Although the patient association and hospital were both mentioned in the invitational letter, their involvement might not have been clear to patients. Patients may be more willing to respond when senders are more familiar or when the doctor invites them\(^{41}\). However, another study concluded that varying senders had no effect on response rates\(^{42}\). Other ways to increase response rates should be examined for future studies. Completion of the revised 65-item questionnaire may be time-consuming. Nevertheless, previously differences in CQI questionnaire length did not result in differences in response rates\(^{43}\). However, questionnaire length could be a barrier for routine measurement. Further research to shorten the questionnaire is therefore recommended. A final limitation is that we were not able to examine the CQI-CSD’s test-retest reliability, an important topic for future research.

Our study also has several strengths. Firstly, the instrument was developed according to a strict methodology, consisting of both qualitative and quantitative methods,
involving various stakeholders and a substantial number of hospitals and patients. Secondly, patients with a broad range of diagnoses were included. Thirdly, we were able to develop the first standardized instrument to measure the quality of care for chronic skin diseases from the patients’ perspective. The instrument may be internationally used after cross-cultural adaptation and a forward-backward translation procedure. The inclusion of items that are also part of other CQIs enables comparisons across specialties or hospital departments, and the included dermatology-specific items differentiate the instrument from others.

In conclusion, the CQI-CSD provides useful information about patient experiences with dermatological care on several quality aspects. The questionnaire may be used by healthcare providers to measure the healthcare provided in their hospital, to identify priorities for quality improvement, and to make comparisons among hospitals with respect to cooperation of healthcare providers, waiting time and facilities of care.

ACKNOWLEDGEMENT
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CONFLICT OF INTEREST
The authors state no conflict of interest.
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APPENDICES

Appendix I
Pilot version CQI Chronic Skin Disease (translated one-way only by the authors, for the purpose of this manuscript).

1. In the past 12 months, have you received treatment for a chronic skin disease at [health care facility]?
   □ No  à this questionnaire does not apply to you. Would you please be so kind as to return the questionnaire in the enclosed envelope? No postage stamp is required.
   □ Yes, I have been treated for: (multiple answers allowed)
     □ Acne, or an acne-related condition (e.g. rosacea, hidradenitis suppurativa)
     □ Eczema
     □ Allergy/allergies
     □ A hair condition (e.g. alopecia, excessive hair growth) or nail disorder
     □ Skin cancer (non-melanoma), or a precursor of skin cancer
     □ Lichen planus
     □ Lichen sclerosus
     □ Lymphedema
     □ A pigment disorder (e.g. vitiligo)
     □ Psoriasis or a psoriasis-related condition (e.g. Andrews-Barber disease)
     □ Open leg (leg ulcers)
     □ Another chronic skin condition: [open]

2. How long have you had this chronic skin condition? (In case you have multiple chronic skin conditions, please answer the questions in this questionnaire with regard to the chronic skin condition causing you the most trouble at the moment.)
   □ Less than a year
   □ Between 1 and 5 years
   □ Between 5 and 10 years
   □ Between 10 and 15 years
   □ More than 15 years
   □ I don’t know

3. Which health care provider(s) have you seen with regard to your chronic skin condition(s) in the past 12 months? (multiple answers allowed)
   □ General practitioner
   □ Dermatologist (doctor specialized in skin diseases)
   □ Nurse
   □ Skin therapist
   □ Doctor’s Assistant
   □ Another health care provider: [open]

HEALTH CARE PROVIDED BY GENERAL PRACTITIONER (GP)
Questions 4 to 6 concern your experiences with the GP in the last 12 months. If you have seen more than one GP, please answer the questions for the GP whom you have seen most frequently in the past 12 months.

4. In the past 12 months, have you seen your GP with regard to your chronic skin condition?
   □ No  à proceed to question 7
   □ Yes

5. Did your GP provide you with sufficient information about different treatment options for your chronic skin condition?
   □ No
   □ Yes
   □ I don’t know/remember

6. Did your GP refer you to the health care facility as quickly as you would have liked?
   □ No
   □ Yes
   □ Not applicable: I have not been referred by the GP

ACCESSIBILITY OF THE HEALTHCARE FACILITY
Questions 7 to 9 concern your experience with the accessibility of the healthcare facility during your last visit.
Measuring quality of care from the patient’s perspective

7. Has it been a problem to reach the healthcare facility by phone during the daytime between 9:00 and 17:00 o’clock?
   □ A big problem
   □ A small problem
   □ Not a problem
   □ Not applicable: I have not called the health care facility

8. Was it possible to ask the staff questions by e-mail (e-consultation)?
   □ No
   □ Yes
   □ I don’t know

9. Has the time between making the appointment and the appointment itself been a problem for you?
   □ A big problem
   □ A small problem
   □ Not a problem

WAITING TIME
Questions 10 and 11 concern your experiences with the waiting time during your last visit to the health care facility.

10. How long did you have to wait additionally, after the scheduled time of your appointment?
    □ Less than 15 minutes
    □ Between 15-30 minutes
    □ Between 30-60 minutes
    □ More than 60 minutes
    □ I don’t remember

11. In the waiting area, was there an indicator showing the waiting time?
    □ No
    □ Yes
    □ Not applicable: I did not have to wait
    □ I don’t know/remember

FACILITIES
Questions 12 to 15 concern your experiences with the facilities of the health care facility during your last visit.

12. Were there adequate facilities in the waiting area? (e.g. magazines, something to drink, toys, leaflets)
    □ No, not at all
    □ A little
    □ Largely
    □ Yes, totally
    □ I don’t know/remember
    □ Not applicable: I have not used the waiting area

13. Was the healthcare facility clean?
    □ No, not at all
    □ A little
    □ Largely
    □ Yes, totally

14. Was your privacy sufficiently respected at this health care facility (e.g. at the counter, when changing clothes, during visiting hours, dealing with confidential data)?
    □ No, not at all
    □ A little
    □ Largely
    □ Yes, totally à proceed to question 16
    □ I don’t know/remember à proceed to question 16

15. In what way did the health care facility not offer sufficient privacy? (multiple answers allowed)
    □ Open listening at the counter
    □ When (un)dressing
    □ During treatment or examination
    □ Other employees walking in or out during consultations, treatment or examination
    □ Open listening to conversations during treatment
    □ The handling of confidential data
    □ Otherwise: [open]

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INFORMATION ABOUT PROCESS OF CARE

Questions 16 to 22 concern the information about the care you received from your health care providers (e.g. doctors, assistants, nurses, skin therapists) in the last 12 months.

16. Did the staff explain what your condition entailed?
   - Never
   - Sometimes
   - Usually
   - Always
   - Not applicable: this was discussed at a previous occasion

17. Did the staff discuss various (follow-up) treatment options with you?
   - No
   - Yes
   - Not applicable: there is only one possible treatment for my condition

18. Did the staff tell you beforehand what a treatment or examination entailed?
   - Never
   - Sometimes
   - Usually
   - Always
   - I don’t know/remember
   - Not applicable: this was discussed at a previous occasion

19. Did the staff explain how you had to use your medication?
   - Never
   - Sometimes
   - Usually
   - Always
   - I don’t know/remember
   - Not applicable: I don’t have medication

20. Did the staff ask in advance about your expectations of the (follow-up) treatment?
   - Never
   - Sometimes
   - Usually

21. Did the staff tell in advance what results you could expect from the (follow-up) treatment or examination?
   - Never
   - Sometimes
   - Usually
   - Always
   - I don’t know/remember

22. Did the staff provide you with information about fees of the treatment(s) and possible contributions on your part?
   - Never
   - Sometimes
   - Usually
   - Always
   - I don’t know/remember
   - Not applicable: this was discussed at a previous occasion

HEALTH CARE PROVIDED BY PHYSICIAN

Questions 23 to 32 concern your experiences with the care you received from your physician in the last 12 months.

23. During the past 12 months, have you been in contact with a physician from the health care facility?
   - No – proceed to question 33
   - Yes

24. Did you have faith in the expertise of the physician?
   - Never
   - Sometimes
   - Usually
   - Always

25. In your opinion, was the physician well-informed about the latest developments regarding your skin condition?
   - Never
   - Sometimes
   - Usually
   - Always
Measuring quality of care from the patient’s perspective

26. Did the physician explain things in an understandable way?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: the doctor did not explain anything

27. Did the physician listen to you attentively?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

28. Did the physician have enough time for you?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

29. Did the physician take you seriously?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

30. Did the physician treat you respectfully?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

31. Did the physician pay attention to the consequences of your skin disease for your daily life? (e.g. your sleep, your mood, functioning at work and at home)
   □ Never
   □ Sometimes
   □ Usually

32. What rating would you give for the physician? A 0 means very poor. A 10 means excellent.
   □ 0 Very poor physician
   □ 1
   □ 2
   □ 3
   □ 4
   □ 5
   □ 6
   □ 7
   □ 8
   □ 9
   □ 10 Excellent physician

HEALTH CARE PROVIDED BY NURSE

Questions 33 to 41 are about the care provided by your nurse in the past 12 months.

33. During the past 12 months, have you been in contact with a nurse?
   □ No à proceed to question 42
   □ Yes

34. Did you have faith in the expertise of the nurse?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

35. Did the nurse explain things in an understandable way?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: the nurse did not explain anything

36. Did the nurse listen to you attentively?
   □ Never
Chapter 4

37. Did the nurse have enough time for you?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

38. Did the nurse take you seriously?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

39. Did the nurse treat you respectfully?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

40. Did the nurse pay attention to the consequences of your skin disease for your daily life? (e.g. your sleep, your mood, functioning at work and at home)
   □ Never
   □ Sometimes
   □ Usually
   □ Always

41. What rating would you give for the nurse? A 0 means very poor. A 10 means excellent.
   □ 0 Very poor nurse
   □ 1
   □ 2
   □ 3
   □ 4
   □ 5
   □ 6
   □ 7
   □ 8
   □ 9
   □ 10 Excellent nurse

COOPERATION OF HEALTH CARE PROVIDERS
Questions 42 to 46 concern your experiences with the cooperation between different health care providers within the health care facility (e.g. physicians, nurses, assistants, skin therapists) in the past 12 months. This does not concern the collaboration with the GP.

42. In the last 12 months, did you receive care from more than one health care provider in the [health facility] for your chronic skin condition?
   □ No à proceed to question 47
   □ Yes

43. Did your health care providers have all your data at hand?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

44. Did the staff within this healthcare facility cooperate well with each other?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

45. Did the various health care providers in the healthcare facility give you conflicting information?
   □ Always
   □ Usually
   □ Sometimes
   □ Never

46. Did the referral to other health care providers run smoothly?
   □ No, not at all
   □ A little
   □ Largely
   □ Yes, totally
   □ Not applicable: I have not been referred
Measuring quality of care from the patient’s perspective

INFORMATION FROM YOUR HEALTH CARE PROVIDERS
Questions 47 to 50 concern your experiences with the information and education you received in the last 12 months from your health care providers (e.g. physicians, assistants, nurses, skin therapists).

47. Did you have the opportunity to ask the health care providers all your questions?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

48. Did you get clear answers to your questions from the health care providers?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

49. Did the health care providers tell you who you could turn to with (acute) problems, questions and side effects and in what way to contact this person (e.g. telephone number or email address)?
   □ No
   □ Yes
   □ Not applicable: this was discussed at a previous occasion

50. Did the health care providers tell you about patient associations, the Dutch National Skin Foundation or Skin Patients Netherlands?
   □ No
   □ Yes
   □ Not applicable: this was discussed at a previous occasion

PATIENT PARTICIPATION
Questions 51 to 53 concern your participation in your health care during the past 12 months.

51. Were you able to take part in decisions about the (follow-up) treatment(s) you received?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

52. Did the health care providers take your personal wishes, feelings and circumstances into account?
   □ Never
   □ Sometimes
   □ Usually
   □ Always

53. Were your nearest and dearest able to take part in the discussions about your care and treatment?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ I don't know/remember
   □ Not applicable: no one else was present during the conversation

SAFETY
Questions 54 to 57 concern your experience with the safety of the health care facility during the past 12 months.

54. Prior to medical examinations, was it ascertained that you were the right person?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: I did not undergo medical examination

55. At the beginning of the treatment, was it ascertained that you were the right person?
   □ Never
   □ Sometimes
56. Were the health care providers aware of other medications you are taking (including medications for other diseases)?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: I don’t use other medication

57. Did the health care providers ask about to the occurrence of side effects?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: I don’t have medication

GLOBAL RATING
Questions 58 to 60 concern your overall rating of the outpatient clinic, department or facility you visited for your skin condition(s).

58. Would you recommend this healthcare facility to your friends and family?
   □ Definitely not
   □ Probably not
   □ Probably
   □ Definitely

59. Would you again choose this health care facility?
   □ Definitely not
   □ Probably not
   □ Probably
   □ Definitely

60. What rating would you give this health care facility? A 0 means very poor. A 10 means excellent.
   □ 0 Very poor healthcare facility
   □ 1
   □ 2
   □ 3
   □ 4
   □ 5
   □ 6
   □ 7
   □ 8
   □ 9
   □ 10 Excellent healthcare facility

YOUR SKIN PROBLEMS
Questions 61 to 63 concern your skin problems.

61. Have you had your skin problems for more than 12 months?
   □ No à proceed to question 64
   □ Yes

62. To what extent have your skin problems been reduced compared to 12 months ago?
   □ Strongly worsened
   □ Somewhat worsened
   □ Unchanged
   □ Somewhat reduced
   □ Strongly reduced

63. In the last 12 months, to what extent did your skin condition have negative consequences in your daily life? (e.g. your sleep, your mood, functioning at work and at home)
   □ Never
   □ Sometimes
   □ Usually
   □ Always

ABOUT YOU
The following questions are about you (the person who fills in the questionnaire). This information will enable us to gain an understanding of the experiences of different sections of the population.

64. How would you describe your general health?
   □ Excellent
   □ Very good
   □ Good
   □ Moderate
65. **How old are you?**
- 18 t to 24 years
- 25 t to 34 years
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 to 74 years
- 75 years or older

66. **Are you male or female?**
- Male
- Female

67. **What is the highest level of education you have completed?**
- No education (primary education not completed)
- Primary education (primary school, special primary school)
- Lower secondary vocational education or pre-vocational education
- Junior general secondary education
- Senior secondary vocational education or apprenticeship education
- Senior general secondary education or pre-university education
- Higher professional education
- University education
- Other level: [open]

68. **Where were you born?**
- Netherlands
- Indonesia / Dutch East Indies
- Suriname
- Morocco
- Turkey
- Germany
- (former) Dutch Antilles
- Aruba
- Other: [open]

69. **Where was your father born?**
- Netherlands
- Indonesia / Dutch East Indies
- Suriname
- Morocco

70. **Where was your mother born?**
- Netherlands
- Indonesia / Dutch East Indies
- Suriname
- Morocco
- Turkey
- Germany
- (former) Dutch Antilles
- Aruba
- Other: [open]

71. **What language do you speak most at home?**
- Dutch
- Fries
- Dutch dialect
- Indonesian
- Sranan (Surinam)
- Moroccan Arabic
- Turkish
- German
- Papiamento (Netherlands Antilles)
- Other: [open]

72. **Did anyone help you to fill in this questionnaire?**
- No à proceed to question 74
- Yes

73. **How did this person help you? (multiple answers allowed)**
- Read out the questions
- Filled in my answers
- Answered the questions instead of me
- Translated the questions into my language
- Helped in some other way: [open]
74. We are keen to go on improving the questionnaire, so we should like to know what you think of it. Do you think there is anything missing from the questionnaire? Or do you have any comments or tips? You can write them below.

THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE. Please return the completed questionnaire using the enclosed reply envelope. No stamp is needed.
Appendix II
Revised version CQI Chronic Skin Disease
(translated one-way only by the authors, for the purpose of this manuscript).

1. In the past 12 months, have you received treatment for a chronic skin disease at [health care facility]?
   □ No  this questionnaire does not apply to you. Would you please be so kind as to return the questionnaire in the enclosed envelope? No postage stamp is required.
   □ Yes, I have been treated for: (multiple answers allowed)
     □ Acne, or an acne-related condition (e.g. rosacea, hidradenitis suppurativa)
     □ Eczema
     □ Allergy/allergies
     □ A hair condition (e.g. alopecia, excessive hair growth) or nail disorder
     □ Skin cancer (non-melanoma), or a precursor of skin cancer
     □ Lichen planus
     □ Lichen sclerosus
     □ Lymphedema
     □ A pigment disorder (e.g. vitiligo)
     □ Psoriasis or a psoriasis-related condition (e.g. Andrews-Barber disease)
     □ Open leg (leg ulcers)
     □ Another chronic skin condition: [open]

2. Which health care provider(s) have you seen with regard to your chronic skin condition(s) in the past 12 months? (multiple answers allowed)
   □ General practitioner
   □ Dermatologist (doctor specialized in skin diseases)
   □ Nurse
   □ Skin therapist
   □ Doctor's Assistant
   □ Another health care provider: [open]

3. In the past 12 months, have you seen your GP with regard to your chronic skin condition?
   □ No à proceed to question 6
   □ Yes

4. Did your GP provide you with sufficient information about different treatment options for your chronic skin condition?
   □ No
   □ Yes
   □ I don't know/remember

5. Did your GP refer you to the health care facility as quickly as you would have liked?
   □ No
   □ Yes
   □ Not applicable: I have not been referred by the GP

6. Has it been a problem to reach the healthcare facility by phone during the daytime between 9:00 and 17:00 o'clock?
   □ A big problem
   □ A small problem
   □ Not a problem
   □ Not applicable: I have not called the health care facility

HEALTH CARE PROVIDED BY GENERAL PRACTITIONER (GP)
Questions 3 t o 5 concern your experiences with the GP in the last 12 months. If you have seen more than one GP, please answer the questions for the GP whom you have seen most frequently in the past 12 months.

ACCESSIBILITY OF THE HEALTHCARE FACILITY
Questions 6 to 8 concern your experience with the accessibility of the healthcare facility during your last visit.
7. Was it possible to ask the health care providers questions by e-mail (e-consultation)?
   - No
   - Yes
   - I don’t know

8. Has the time between making the appointment and the appointment itself been a problem for you?
   - A big problem
   - A small problem
   - Not a problem

**WAITING TIME**
Questions 9 and 10 concern your experiences with the waiting time during your last visit to the health care facility.

9. How long did you have to wait additionally, after the scheduled time of your appointment?
   - Less than 15 minutes
   - Between 15-30 minutes
   - Between 30-60 minutes
   - More than 60 minutes
   - I don’t remember

10. Were you informed about the waiting time?
    - No
    - Yes
    - Not applicable: I did not have to wait
    - I don’t know/remember

**FACILITIES**
Questions 11 and 12 concern your experiences with the facilities of the health care facility during your last visit.

11. Was the healthcare facility clean?
    - No, not at all
    - A little
    - Largely
    - Yes, totally

12. Was your privacy sufficiently respected at this health care facility (e.g. at the counter, when changing clothes, during visiting hours)?
    - No, not at all
    - A little
    - Largely
    - Yes, totally
    - I don’t know/remember

**INFORMATION ABOUT THE PROCESS OF CARE**
Questions 13 to 18 concern the information about the care you received from your health care providers (e.g. physicians, assistants, nurses, skin therapists) in the last 12 months.

13. Did the health care providers explain what your condition entailed?
    - Never
    - Sometimes
    - Usually
    - Always
    - Not applicable: this was discussed at a previous occasion

14. Did the health care providers discuss various (follow-up) treatment options with you?
    - No
    - Yes
    - Not applicable: there is only one possible treatment for my condition

15. Did the staff tell you beforehand what a treatment or examination entailed?
    - Never
    - Sometimes
    - Usually
    - Always
    - I don’t know/remember
    - Not applicable: this was discussed at a previous occasion

16. Did the health care providers explain how you had to take your medication?
    - Never
    - Sometimes
    - Usually
    - Always
    - I don’t know/remember
    - Not applicable: I don’t have medication
17. Did the health care providers tell in advance what results you could expect from the (follow-up) treatment or examination?
□ Never
□ Sometimes
□ Usually
□ Always
□ I don’t know/remember

18. Did the health care providers provide you with information about fees of the treatment(s) and possible contributions on your part?
□ Never
□ Sometimes
□ Usually
□ Always
□ I don’t know/remember
□ Not applicable: this was discussed at a previous occasion

19. During the past 12 months, have you been in contact with a physician from the health care facility?
□ No à proceed to question 26
□ Yes

20. Did the physician explain things in an understandable way?
□ Never
□ Sometimes
□ Usually
□ Always
□ Not applicable: the doctor did not explain anything

21. Did the physician listen to you attentively?
□ Never
□ Sometimes
□ Usually
□ Always

22. Did the physician have enough time for you?
□ Never
□ Sometimes
□ Usually
□ Always

23. Did the physician take you seriously?
□ Never
□ Sometimes
□ Usually
□ Always

24. Did the physician pay attention to the consequences of your skin disease for your daily life? (e.g. your sleep, your mood, functioning at work and at home)
□ Never
□ Sometimes
□ Usually
□ Always

□ 0 Very poor physician
□ 1
□ 2
□ 3
□ 4
□ 5
□ 6
□ 7
□ 8
□ 9
□ 10 Excellent physician

HEALTH CARE PROVIDED BY NURSES
Questions 26 to 32 concern the care provided by your nurse in the past 12 months.

26. During the past 12 months, have you been in contact with a nurse?
□ No à proceed to question 33
□ Yes

27. Did the nurse explain things in an understandable way?
□ Never
□ Sometimes
□ Usually
□ Always
□ Not applicable: the nurse did not explain anything

28. Did the nurse listen to you attentively?
□ Never
□ Sometimes
□ Usually
□ Always

29. Did the nurse have enough time for you?
□ Never
□ Sometimes
□ Usually
□ Always

30. Did the nurse take you seriously?
□ Never
□ Sometimes
□ Usually
□ Always

31. Did the nurse pay attention to the consequences of your skin disease for your daily life? (e.g. your sleep, your mood, functioning at work and at home)
□ Never
□ Sometimes
□ Usually
□ Always

32. What rating would you give for the nurse? A 0 means very poor. A 10 means excellent.
□ 0 Very poor nurse
□ 1
□ 2
□ 3
□ 4
□ 5
□ 6
□ 7
□ 8
□ 9
□ 10 Excellent nurse

COOPERATION OF HEALTH CARE PROVIDERS

Questions 33 to 37 concern your experiences with the cooperation between different health care providers within the health care facility (e.g. physician, nurses, assistants, skin therapists) in the past 12 months. This does not concern the collaboration with the GP.

33. In the last 12 months, did you receive care from more than one health care provider in the [health facility] for your chronic skin condition?
□ No à proceed to question 38
□ Yes

34. Did your health care providers have all your data at hand?
□ Never
□ Sometimes
□ Usually
□ Always

35. Did the health care providers within this healthcare facility cooperate well?
□ Never
□ Sometimes
□ Usually
□ Always

36. Did the various health care providers in the healthcare facility give you conflicting information?
□ Always
□ Usually
□ Sometimes
□ Never

37. Did the referral to other health care providers run smoothly?
□ No, not at all
□ A little
Measuring quality of care from the patient’s perspective

□ Largely
□ Yes, totally
□ Not applicable: I have not been referred

INFORMATION FROM YOUR HEALTH CARE PROVIDERS
Questions 38 to 42 concern your experiences with the information and education you received in the last 12 months from your health care providers (e.g. physician, assistants, nurses, skin therapists).

38. Did you have the opportunity to ask the health care providers all your questions?
□ Never
□ Sometimes
□ Usually
□ Always

39. Did you get clear answers to your questions from the health care providers?
□ Never
□ Sometimes
□ Usually
□ Always

40. Did a health care provider tell you who you turn to with (acute) problems, questions and side effects?
□ No
□ Yes
□ Not applicable: this was discussed at a previous occasion

41. Did the health care providers tell you about patient associations or peer groups?
□ No
□ Yes
□ Not applicable: this was discussed at a previous occasion

42. Did the health care providers give you advice on how to cope with your skin condition in daily life?
□ No
□ Yes

PATIENT PARTICIPATION
Questions 43 to 45 concern your participation in your health care during the past 12 months.

43. Were you able to take part in decisions about the (follow-up) treatment(s) you received?
□ Never
□ Sometimes
□ Usually
□ Always

44. Did the health care providers take your personal wishes, feelings and circumstances into account?
□ Never
□ Sometimes
□ Usually
□ Always

45. Were your nearest and dearest able to take part in the discussion about your care and treatment?
□ Never
□ Sometimes
□ Usually
□ Always
□ I don’t know/remember
□ Not applicable: no one else was present during the conversation

SAFETY
Questions 46 to 49 concern your experience with the safety of the health care facility during the past 12 months.

46. Prior to medical examinations, was it ascertained that you were the right person?
□ Never
□ Sometimes
□ Usually
□ Always
□ Not applicable: I did not undergo medical examination

47. At the beginning of the treatment, was it ascertained that you were the right person?
□ Never
□ Sometimes
Chapter 4

48. Were the health care providers aware of other medications you are taking (including medications for other diseases)?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: I don’t use other medication

49. Did the health care providers ask about the occurrence of side effects?
   □ Never
   □ Sometimes
   □ Usually
   □ Always
   □ Not applicable: I don’t have medication

GLOBAL RATING
Questions 50 and 51 are about your overall rating of the outpatient clinic, department or facility you visited for your skin condition(s).

50. Would you recommend this healthcare facility to your friends and family?
   □ Definitely not
   □ Probably not
   □ Probably
   □ Definitely

SKIN PROBLEMS
Questions 52 to 54 concern your skin problems.

52. Have you had your skin problems for more than 12 months?
   □ No à proceed to question 55
   □ Yes

53. To what extent have your skin problems been reduced compared to 12 months ago?
   □ Strongly worsened
   □ Somewhat worsened
   □ Unchanged
   □ Somewhat reduced
   □ Strongly reduced

54. In the last 12 months, to what extent did your skin condition have negative consequences for your daily life? (e.g. your sleep, your mood, functioning at work and at home)
   □ Never
   □ Sometimes
   □ Usually
   □ Always

ABOUT YOU
The following questions are about you (the person who fills in the questionnaire). This information will enable us to gain an understanding of the experiences of different sections of the population.

55. How would you describe your general health?
   □ Excellent
   □ Very good
   □ Good
   □ Moderate
   □ Poor

56. How old are you?
   □ 18 t to 24 years
   □ 25 t to 34 years
   □ 35 to 44 years
   □ 45 to 54 years
   □ 55 to 64 years
   □ 65 to 74 years
   □ 75 years or older
57. Are you male or female?
   □ Male
   □ Female

58. What is the highest level of education you have completed?
   □ No education (primary education not completed)
   □ Primary education (primary school, special primary school)
   □ Lower secondary vocational education or pre-vocational education
   □ Junior general secondary education
   □ Senior secondary vocational education or apprenticeship education
   □ Senior general secondary education or pre-university education
   □ Higher professional education
   □ University education
   □ Other level: [open]

59. Where were you born?
   □ Netherlands
   □ Indonesia / Dutch East Indies
   □ Suriname
   □ Morocco
   □ Turkey
   □ Germany
   □ (former) Dutch Antilles
   □ Aruba
   □ Other: [open]

60. Where was your father born?
   □ Netherlands
   □ Indonesia / Dutch East Indies
   □ Suriname
   □ Morocco
   □ Turkey
   □ Germany
   □ (former) Dutch Antilles
   □ Aruba
   □ Other: [open]

61. Where was your mother born?
   □ Netherlands
   □ Indonesia / Dutch East Indies
   □ Suriname
   □ Morocco
   □ Turkey

62. What language do you speak most at home?
   □ Dutch
   □ Fries
   □ Dutch dialect
   □ Indonesian
   □ Sranan (Surinam)
   □ Moroccan Arabic
   □ Turkish
   □ German
   □ Papiamento (Netherlands Antilles)
   □ Other: [open]

63. Did anyone help you to fill in this questionnaire?
   □ No à proceed to question 74
   □ Yes

64. How did this person help you? (multiple answers allowed)
   □ Read out the questions
   □ Filled in my answers
   □ Answered the questions instead of me
   □ Translated the questions into my language
   □ Helped in some other way: [open]

65. We are keen to go on improving the questionnaire, so we should like to know what you think of it. Do you think there is anything missing from the questionnaire? Or do you have any comments or tips? You can write them below.
   [open]

THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE

Please return the completed questionnaire using the enclosed reply envelope. No stamp is needed.