

ACNE-Q[©]

A Guide for Researchers and Clinicians

USER'S GUIDE

VERSION 1.0

SEPTEMBER 2018

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1. What is the ACNE-Q©?

The ACNE-Q© is a rigorously developed patient-reported outcome (PRO) measure that can be used to collect and compare evidence-based outcomes data from individuals. The ACNE-Q was field-tested in patients 12 years of age and older with facial, back and chest acne and/or acne scars.

2. How was the ACNE-Q© Developed?

Figure 1 shows the multiphase mixed methods approach used by our team to develop PRO measures. We followed internationally recommended guidelines for PRO measure development to ensure that the ACNE-Q© meets the requirements of regulatory bodies. We use a modern psychometric approach called Rasch measurement theory (RMT) analysis to develop PRO measures. This approach makes it possible to create scales where an individual is placed along the scale based on the probability that they answered the questions or items in a certain way. An RMT scale can be conceptualised as a ruler, with an ordered arrangement or hierarchy of items from a low to high 'amount' of the construct. RMT scales provide interval-level measurement as opposed to ordinal-level measurement, thus allowing for accurate tracking of change over time.

Content for the ACNE-Q© was developed from interviews with 21 adolescent and young adult patients with acne (13 female / 8 male). Qualitative analysis led to the identification of 3 top-level domains: appearance concerns, acne symptoms and social concerns. These domains were important to participants with all types and severities of acne and acne scars. The data were used to develop an item pool from which 7 scales were designed (see Table 1).

To refine the scales, we performed cognitive interviews with 10 participants aged 15 to 26 years. We also invited clinical experts (12 dermatologists, 3 plastic surgeons, 1 skin consultant) from 5 countries (Australia, Canada, France, Italy, USA) to provide feedback.

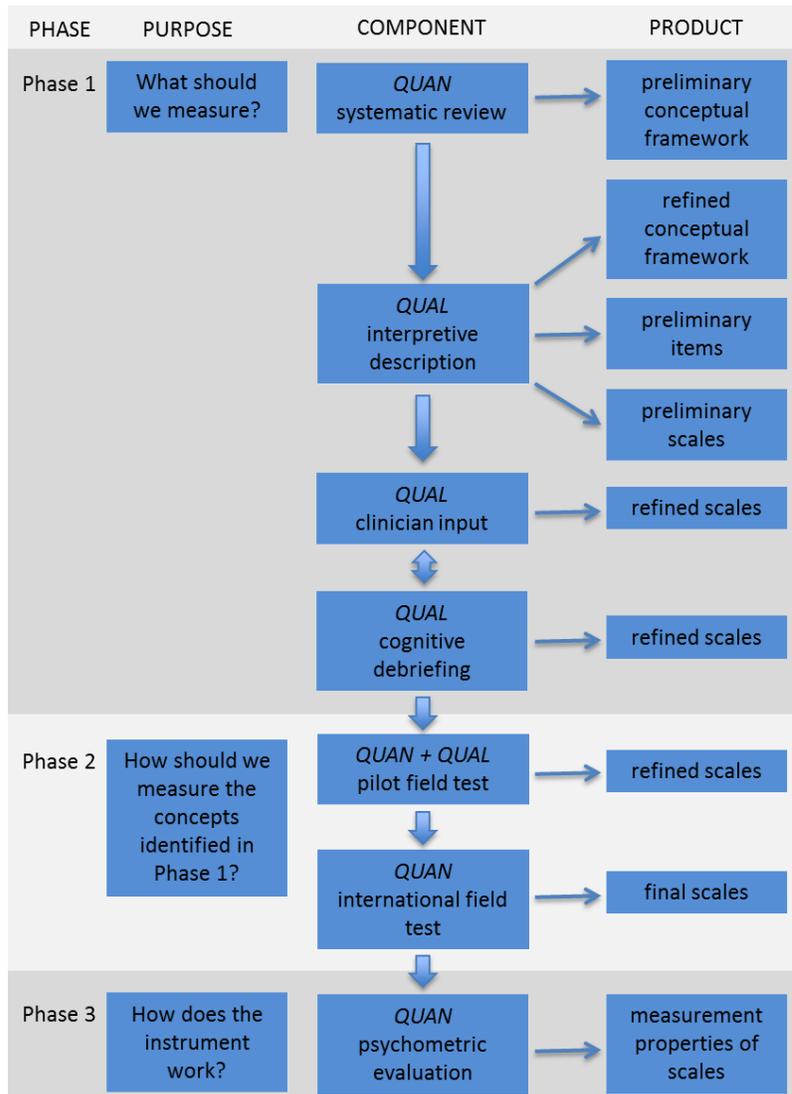
The refined version of the ACNE-Q© was field-tested in an international study with dermatology clinics in Canada and the USA. A total of 256 participants provided 303 assessments. The sample included more females than males. Age ranged from 12 to 52 years, with a mean of 23.1 years and standard deviation of 8.4 years. Most participants had both acne and acne scars.

3. ACNE-Q© Scales

Table 1: Description of the ACNE-Q© scales

Name of scale	Number of Items	Flesch-Kincaid grade reading level
Appearance of acne scars	10	1.7
Appearance of facial acne	15	2.0
Appearance of chest acne	10	1.1
Appearance of back acne	10	1.1
Appearance of skin	12	1.0
Acne symptoms	6	2.7
Appearance-related distress	10	3.6

Figure 1: The multiphase mixed methods approach our team follows to develop PRO measures (Reprinted from Riff KW, Tsangaris E, Goodacre T, et al. International multiphase mixed methods study protocol to develop a cross-cultural patient-reported outcome instrument for children and young adults with cleft lip and/or palate (CLEFT-Q). *BMJ Open* 2017;7(1):015467.)



Acne Scars: This scale measures how bothered someone is by the appearance of acne scars. This scale is not limited to facial acne scars and can be used with acne scars anywhere on the body. Individuals are instructed to answer thinking of how their scars look without make-up if they wear make-up to cover their scars. Items ask about scars in terms of their size, the way they have healed up so far, how noticeable they are, and how they look in scenarios, such as up close, in photos, or under a bright light.

Facial Acne: This scale measures how bothered someone is by the appearance of facial acne. People are instructed that if they wear make-up to cover their facial acne, they should answer thinking of how

they look without make-up. Items ask about their acne in terms colour, size of the pimples, amount of acne, how noticeable the acne is and how the acne looks in scenarios, such as at the end of the day, from the side (profile), or in a mirror.

Chest acne: This scale measures how bothered someone is by the appearance of their chest acne. Items ask about chest acne in terms of amount, colour, bumpiness, and how the acne looks up close, far away, or in a mirror.

Back acne: This scale measures how bothered someone is by the appearance of their back acne. Items ask about acne in terms of amount, colour, bumpiness and how the acne looks in various scenarios. Scenarios include how acne appears up close, far away, or in a mirror.

Facial skin: This scale measures how much someone likes the appearance of their skin. Individuals are instructed to answer thinking of how their skin looks without make-up if they wear make-up on their skin. Items ask about how clean, healthy, even-coloured and smooth their skin looks, as well as how their skin looks in various scenarios. Scenarios include how skin appears under a bright light, in photos, or at the end of the day.

Acne symptoms: This scale measures acne-related symptoms. Individuals are instructed to answer thinking of the area with acne that bothers them the most if they have acne in more than one place (e.g., face and chest). Items ask about pain, itchiness, irritation and blood/fluid coming from the acne.

Appearance-related distress: This scale includes a series of statements that measure how often someone behaves (e.g., cover up or hide, avoid having their photo taken, avoid going out) or feels a certain way about how they look (e.g., unhappy, self-conscious, upset).

4. Administration of the ACNE-Q©

The ACNE-Q© is designed to be completed independently by patients. It is important to note that patients do not need to complete all of the available ACNE-Q© scales in any given study or clinical encounter. Each scale is designed to function independently. Patients can thus be asked to complete a subset of scales relevant to their situation. Brief instructions are provided at the start of each scale. The ACNE-Q© field-test data were collected using paper-and-pencil as well as using an online data collection system (i.e., Research Electronic Data Capture System (REDCap)).

5. Response Options for the ACNE-Q©

Each ACNE-Q© scale provides 4 response options. The five appearance scales and the acne symptom scale use the following response options: 1 (Not at all), 2 (A little), 3 (Quite a bit), 4 (Very much). The appearance-related distress scale uses the following response options: 1 (Never), 2 (Sometimes), 3 (Often), 4 (Always).

6. Scoring the ACNE-Q©

There is no overall or total score for the ACNE-Q©, as each scale is scored independently. Each ACNE-Q© scale is converted into scores that range from 0-100. The scores are computed from the responses to the items by adding them together and converting the raw score to a scale from 0 to 100. Higher scores reflect a better outcome for the appearance and symptoms scales. Higher scores for the appearance-related distress scale indicates more distress. If missing data is less than 50% of the scale's

items, insert the mean of the completed items. Use the Conversion Tables available from the authors to convert the raw summed scale score into a score from 0 (worst) to 100 (best).

7. Conditions of Use of the ACNE-Q©

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Non-profit users can access the ACNE-Q using the following link:

<https://research.mcmaster.ca/industry-and-investors/technologies-available-for-licensing/questionnaire-request-form/>

For questions regarding fees to be paid by 'for-profit' organizations, please contact:

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8. Frequently Asked Questions

Do I need to sign a license to use the ACNE-Q©?

Yes, you must sign a licensing agreement for any use of the questionnaires, whether it is for commercial or academic purposes. The questionnaires are protected by copyright and are the exclusive property of McMaster University and Memorial Sloan Kettering Cancer Center.

Do I have to use all of the scales?

Patients can be asked to complete some or all of the ACNE-Q© scales. It is not necessary for a patient to complete all of the scales as there is no overall or total ACNE-Q© score. A researcher or clinician may therefore select a subset of scales depending on the particular purpose of the study or use.

Can I delete, add or change any items or response options of the ACNE-Q©?

You cannot delete, add or change the wording of any items or response options of the ACNE-Q©. Any modification to the content of the ACNE-Q© is not acceptable. There are three main reasons why deleting or adding items is not allowed. The first is that deleting or adding items would nullify the psychometric properties of ACNE-Q© scales. The second reason is that by deleting or adding items, it would then not be possible to score the ACNE-Q© and you would not be able to compare findings with those of other ACNE-Q© studies. Finally, adding or deleting items is prohibited under copyright laws.

Can I translate the ACNE-Q© into a new language?

Yes, you can translate the ACNE-Q© into different languages. Check with the licensing assistant at McMaster (milo@mcmaster.ca) to see if there is a translation in the language you need. If there is not a translation in the language you need, you will need to sign a licensing agreement. Please note that the developers of the ACNE-Q© own the copyright of all translations of the ACNE-Q©.

Are there specific time points when patients complete the scales?

A researcher or clinician can decide the time points they would like to administer the scales.

9. ACNE-Q© Publications

1. Klassen AF, Lipner S, O'Malley et al. Development of a New Patient-Reported Outcome Measure to Evaluate Treatments for Acne and Acne Scarring: The ACNE-Q. Br J Dermatol. 2019 Apr 12. doi: 10.1111/bjd.18005. [Epub ahead of print]
2. Longmire NM, Breitkopf T, Piplani B, Pusic AL, O'Malley M, Lipner S, Wong Riff K, Klassen AF. ACNE-Q is a New Patient Reported Outcome Instrument that Measures Appearance-Related Concerns. Qual Life Res 2017;26:136.