



# ACNE-Q®

## A User's Guide for Researchers and Clinicians

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# Table of Contents

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<b>1. What is the ACNE-Q?</b>	<b>2</b>
<b>2. How was the ACNE-Q Developed and Validated?</b>	<b>2</b>
<b>3. ACNE-Q Scales</b>	<b>6</b>
<b>4. Administration of the ACNE-Q</b>	<b>7</b>
<b>5. Scoring the ACNE-Q</b>	<b>7</b>
<b>6. Conditions of Use</b>	<b>8</b>
<b>7. Frequently Asked Questions</b>	<b>9</b>
<b>8. Acknowledgements</b>	<b>11</b>
<b>9. Publications Related to ACNE-Q Development and Validation</b>	<b>11</b>

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## 1. What is the ACNE-Q?

While an important outcome in clinical trials of treatments for acne and acne scarring is psychosocial distress, appearance is also important to patients. However, measuring appearance of acne and acne scarring is largely overlooked in existing acne-specific patient-reported outcome measures (PROMs). Therefore, ACNE-Q represents the first rigorously developed acne-specific PROM to provide a set of scales for patients to report how their skin, acne (facial, back, and chest), and acne scars look. These concepts are important to include in clinical trials of treatments to improve or clear acne, to prevent and improve acne scarring, or to prevent future outbreaks. Appearance is highly subjective and therefore requires self-report. The ACNE-Q was field-tested in children and adults aged 12 years of age and older.

## 2. How was the ACNE-Q Developed and Validated?

The ACNE-Q represents a new generation of PROMs developed using a modern psychometric approach called Rasch Measurement Theory (RMT). In RMT, scales that compose a PROM are each designed to measure and score a unidimensional construct. In scale development, data that meet the requirement of the Rasch model provide interval-level measurement. When a scale has high content validity and is targeted to measure a concept as experienced by a sample, accurate tracking of clinical change can be achieved. In addition to research, ACNE-Q scales can be used with individual patients to inform clinical care.

We followed internationally recommended guidelines for PROM development to create the ACNE-Q. Figure 1 shows the multiphase mixed methods approach used by our team to develop PROMs. Briefly, in phase 1, content for the ACNE-Q was developed from interviews with 21 adolescent and young adult patients with acne (13 females, 8 males). Qualitative analysis led to the identification of 3 top-level domains: appearance concerns, acne symptoms, and psychosocial concerns. These domains were important to participants with all types and severities of acne and acne scars. Figure 2 shows the ACNE-Q conceptual framework. The data were used to develop an item pool from which 7 scales were designed (see Table 2). To refine the scales, we performed cognitive debriefing interviews with 10 participants (6 females, 4 males) 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, and the USA) to provide feedback.

The refined version of the ACNE-Q was field-tested in an international study. Recruitment took place in dermatology clinics in Canada and the USA. A total of 256 participants provided 303 assessments. Table 1 shows participant characteristics. RMT analysis reduced the total number of items from 105 to 73. All items had ordered thresholds and good item fit. The data fit the Rasch model with nonsignificant Chi-square p-values for the

five appearance scales, with some misfit for the symptoms and appearance-related distress scales. Reliability was high, with Person Separation Index values and Cronbach alpha values  $> 0.90$  for the appearance scales,  $\geq 0.87$  for the appearance-related distress scale, and  $\geq 0.75$  for the symptoms scale. Worse scores on appearance scales correlated with worse symptom scores and more appearance-related distress.

**Table 1: Characteristics (Number, %) of field-test participants**

		<b>N</b>	<b>%</b>
<b>Age in years</b>	12-19	104	40.6
	20-29	98	38.3
	30-52	52	20.3
	Missing	2	0.8
<b>Gender</b>	Female	182	71.1
	Male	74	28.9
<b>Country</b>	Canada	59	23.0
	United States	197	77.0
<b>Racial/Ethnic Group</b>	White	102	39.8
	Other and mixed	102	39.8
	Missing	52	20.3
<b>Highest Education</b>	In elementary school	16	6.3
	In high school	61	23.8
	Finished high school	16	6.3
	In college or university	54	21.1
	Finished college or university	109	42.6
<b>Condition</b>	Acne	75	29.3
	Acne scars	5	2.0
	Acne and scars	176	68.8
<b>Location</b>	Face	164	64.1
	Back	75	29.3
	Chest	50	19.5

**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.)

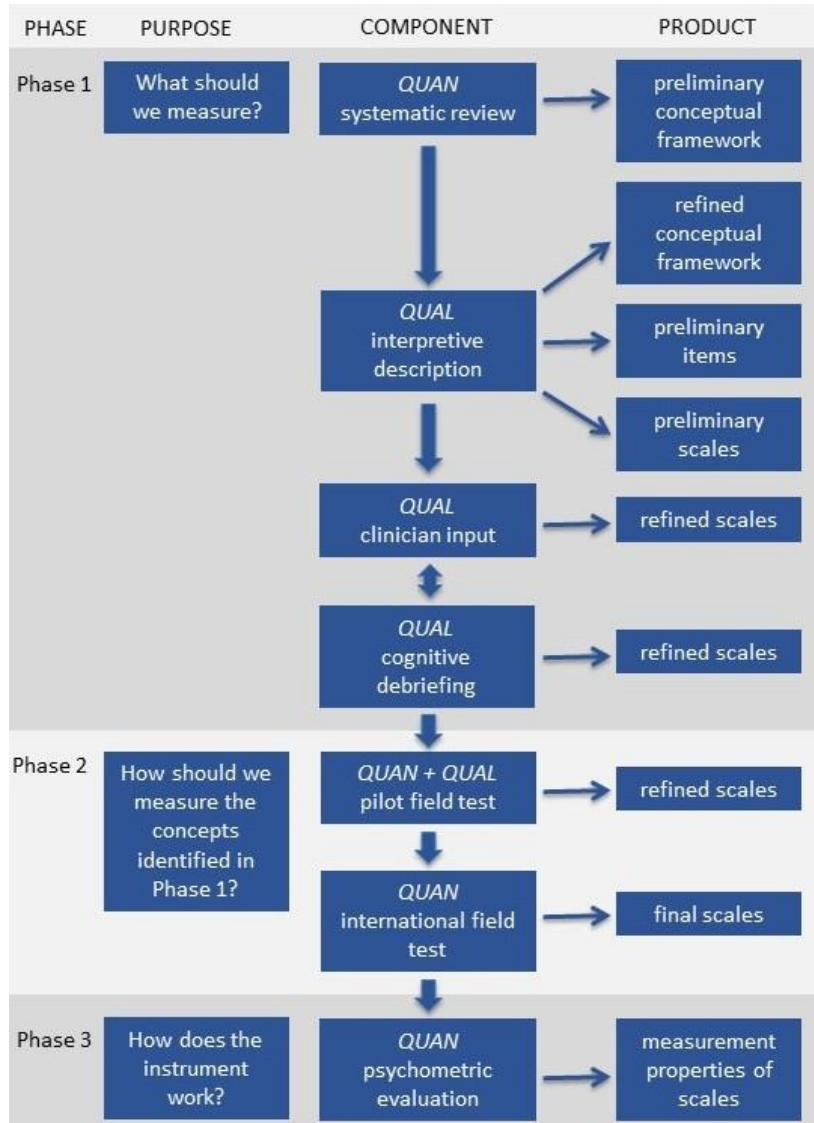
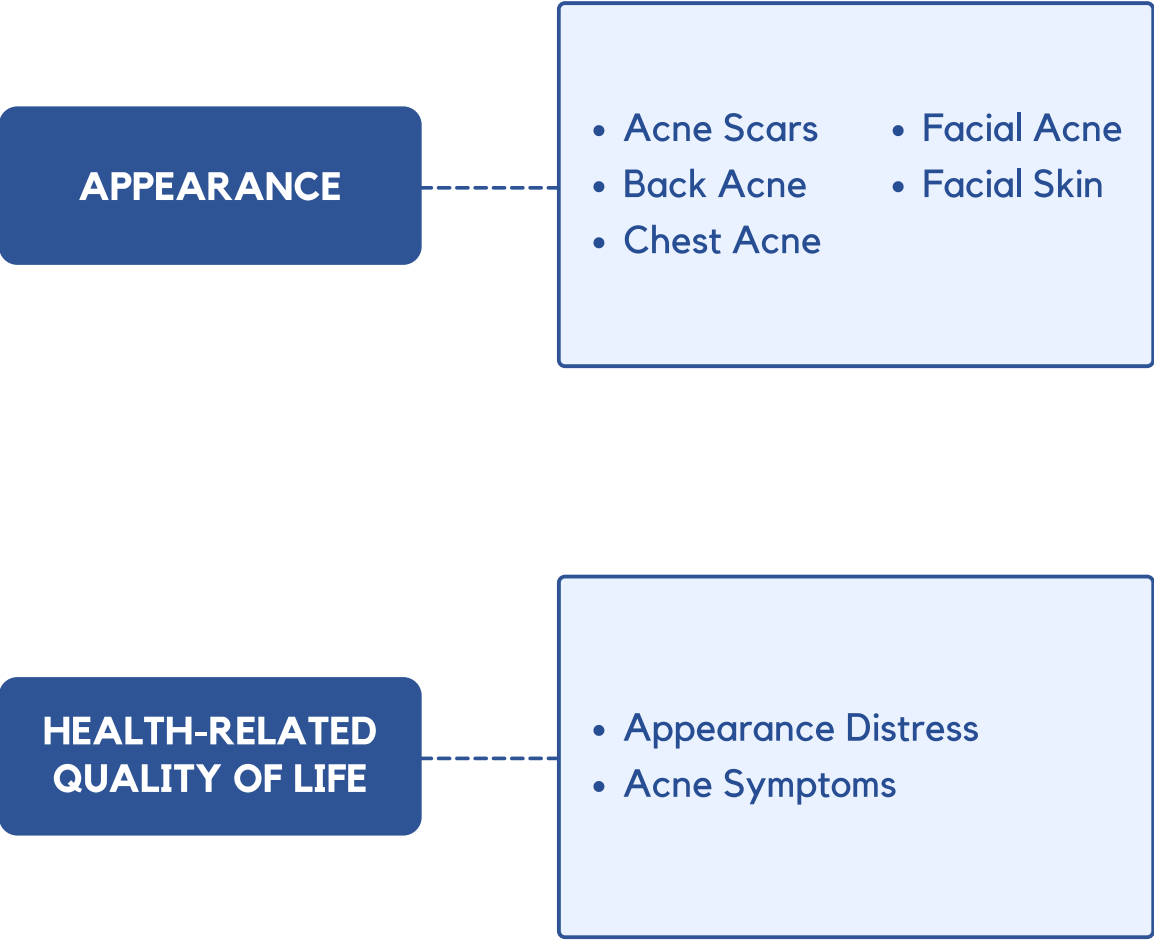


Figure 2: ACNE-Q conceptual framework



### 3. ACNE-Q Scales

Table 2 shows the ACNE-Q scales, including number of items, response options, recall period, and Flesch-Kincaid (FK) grade reading level. Below the table is a brief description of the content of each scale.

**Table 2: Description of ACNE-Q scales**

Name of scale	Items	Response options	Recall	FK
Acne Scars	10	not at all→bothered very much	now	1.7
Facial Acne	15	not at all→bothered very much	now	2.0
Chest Acne	10	not at all→bothered very much	now	1.1
Back Acne	10	not at all→bothered very much	now	1.1
Facial Skin	12	like not at all → very much	now	1.0
Acne Symptoms	6	not at all→bothered very much	now	2.7
Appearance-related Distress	10	never→always	1 week	3.6

**Acne Scars:** This 10-item scale measures how bothered (not at all, a little bit, quite a bit, very much) someone is by the appearance of their 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 certain scenarios, such as up close, in photos, or under a bright light.

**Facial Acne:** This 15-item scale measures how bothered (not at all, a little bit, quite a bit, very much) someone is by the appearance of their facial acne. Items ask about their acne in terms color, 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 10-item scale measures how bothered (not at all, a little bit, quite a bit, very much) someone is by the appearance of their chest acne. Items ask about chest acne in terms of amount, color, bumpiness, and how the acne looks up close, far away, or in a mirror.

**Back Acne:** This 10-item scale measures how bothered (not at all, a little bit, quite a bit, very much) someone is by the appearance of their back acne. Items ask about acne in terms of amount, color, 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 12-item scale measures how much (not at all, a little bit, quite a bit, very 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-colored, 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 6-item 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 10-item 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 was designed to be completed by patients on their own (self-report). Each scale is independently functioning, which means that only scales relevant to the clinical situation or research question need be completed. Brief instructions and the timeframe for reporting are provided at the start of each scale. ACNE-Q was field-tested using two modes of data collection, i.e., online data collection Research Electronic Data Capture System (REDCap) and paper-and-pencil. You may use the paper and pencil format or create an online version for ease of administration in non-profit academic research (e.g., REDCap) and in clinical care (e.g., hospital EMR such as Epic). If you plan to have an ePRO company capture and manage ACNE-Q data collection, the ePRO company may need a license. If you have had ACNE-Q scales converted into an electronic format and require an e-conversion review and certificate, please email [qportfolioteam@gmail.com](mailto:qportfolioteam@gmail.com).

#### 5. Scoring the ACNE-Q

There is no overall or total ACNE-Q score. Instead, the ACNE-Q is composed of independently functioning scales that are scored separately. To score the ACNE-Q scales, the raw scores for the set of items in a scale are added together to produce a total raw score. Scores for ACNE-Q scales range from 0 to 100. For 6 of the 7 scales (exception Appearance-Related Distress), higher scores represent a better outcome.

To ensure that higher scores represent a better outcome for these scales, the raw scores for the Acne Scar, Facial Acne, Chest Acne, Back Acne, and Symptoms scales need to be scored as follows: “Not at all” = 4; “A little” = 3; “Quite a bit” = 2; “Very much” = 1. The raw data for the Facial Skin scale should be scored as follows: “Not at all” = 1; “A little” =



2; “Quite a bit” = 3; “Very much” = 4. For the Appearance-Related Distress scale, higher scores indicate more distress. As such, the raw data should be scored as follows: “Never” = 1; “Sometimes” = 2; “Often” = 3; “Always” = 4.

If missing data is less than 50% of the scale’s items, the within person mean for the completed items can be imputed for the missing items prior to computing a total raw score. For example, if there is a 10-item scale and someone has not responded to all the items, but has responded to  $\geq 5$  items, all other items for that person can be imputed with a within-person mean (rounded to the nearest integer), and a summed score can be calculated. Alternatively, for a 10-item scale, if someone has responded to  $\leq 4$  items, the summed score for this person cannot be computed and is classified as missing data. Importantly, the Conversion Tables are only valid with complete data (i.e., when a person has  $\geq 50\%$  completed responses). Once a total raw score for the scale is computed, the Conversion Table can be used to convert the raw score into a score that ranges from 0 (worst) to 100 (best). The conversion, which linearizes the scores, is based on the findings from the Rasch analysis. The Conversion Tables for changing raw scores into 0 to 100 scores are available after a license agreement is signed.

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- You will not modify, adapt, or create another derivative work from the ACNE-Q
- You will not sell, sublicense, rent, loan, or transfer the ACNE-Q to anyone
- You will not reproduce any ACNE-Q scales in publications or other materials
- You will not translate the ACNE-Q without permission from our team

For questions regarding study design and optimal use of ACNE-Q scales, contact:

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## 7. Frequently Asked Questions

### *Do I have to use all of the ACNE-Q scales?*

Each scale functions independently, therefore patients can be asked to complete one 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 or add or change any items or response options of the ACNE-Q?*

You cannot delete or 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 prohibited under copyright laws. Also, making any changes to ACNE-Q scales would invalidate its psychometric properties.

### *Can I reproduce ACNE-Q scales in a publication or other public document (e.g., PhD thesis)?*

According to the licensing agreement, you cannot reproduce the content of ACNE-Q scales verbatim in a publication. However, it is possible to show shortened versions of items. The short forms of items that can be used in a publication are shown in Table 3 below. The short forms are from the psychometric publication that describes the ACNE-Q field-test study [1].

### ***Can I translate ACNE-Q scales into a new language?***

Yes, with permission, you can translate the ACNE-Q into different languages. Before starting a translation, check our translations list on [www.qportfolio.org](http://www.qportfolio.org) 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 obtain permission from our team, sign a translation licensing agreement, and receive information on the method you need to follow. Email us at [qportfolioteam@gmail.com](mailto:qportfolioteam@gmail.com) for more information. 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.

### ***Does it cost money to use the ACNE-Q?***

Use of ACNE-Q scales is free to non-profit users, including use by hospitals in patient care. For-profit users should contact McMaster University for information about fees ([milo@mcmaster.ca](mailto:milo@mcmaster.ca)).

**Table 3: Shortened items for ACNE-Q scales to use in a publication**

<b>ACNE SCARS</b>	photos	coverage	bright lights
far away	amount	bumpy	up close
healed so far	color	mirror	<b>SYMPTOMS</b>
size	bright lights	size	itchy
photos	mirror	color	hurts
amount	noticeable	amount	irritated
skin color	up close	up close	swollen
bright light	<b>CHEST ACNE</b>	noticeable	fluid
mirror	coverage	people seeing	uncomfortable
noticeable	far away	<b>FACIAL SKIN</b>	<b>APPEARANCE DISTRESS</b>
up close	size	clean	self-conscious
<b>FACIAL ACNE</b>	bumpy	healthy	dislike
far away	amount	sunlight	unhappy
wakeup	color	photos	avoid photo
raised up	up close	end of day	social media
bumpy	mirror	mirror	upset stare
coverage	noticeable	smooth	cover up
profile	people seeing	compared with others	avoid mirrors
end of day	<b>BACK ACNE</b>	clear	meeting people
size	far away	even-colored	avoid going out

## **8. Acknowledgements**

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## **9. Publications Related to ACNE-Q Development and Validation**

1. Klassen AF, Lipner S, O'Malley M, Longmire NM, Cano SJ, Breitkopf T, Rae C, Zhang YL, Pusic AL. Development of a New Patient-Reported Outcome Measure to Evaluate Treatments for Acne and Acne Scarring: The ACNE-Q. *Br J Dermatol*. 2019 Dec; 181(6):1207-1205. doi: 10.1111/bjd.18005.
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.