

# FACE-Q | Skin Cancer<sup>©</sup>

*A Guide for Researchers and Clinicians*

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***USER'S GUIDE***

***VERSION 1.0***

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## **1. What is the FACE-Q Skin Cancer©?**

The FACE-Q Skin Cancer© is a patient-reported outcome (PRO) measure that can be used to evaluate healthcare experience and outcomes after facial skin cancer procedures from the patient's perspective. The FACE-Q Skin Cancer© can be used to measure outcomes that matter to patients having any type of facial skin surgery.

The FACE-Q Skin Cancer© measures 3 domains: Appearance, Health-Related Quality of Life (HRQOL) and Patient Experience of Care. These domains form the basis of the FACE-Q Skin Cancer© conceptual framework. Each domain includes multiple scales. Only the subset of scales most relevant to a specific research objective or clinical patient population need be administered.

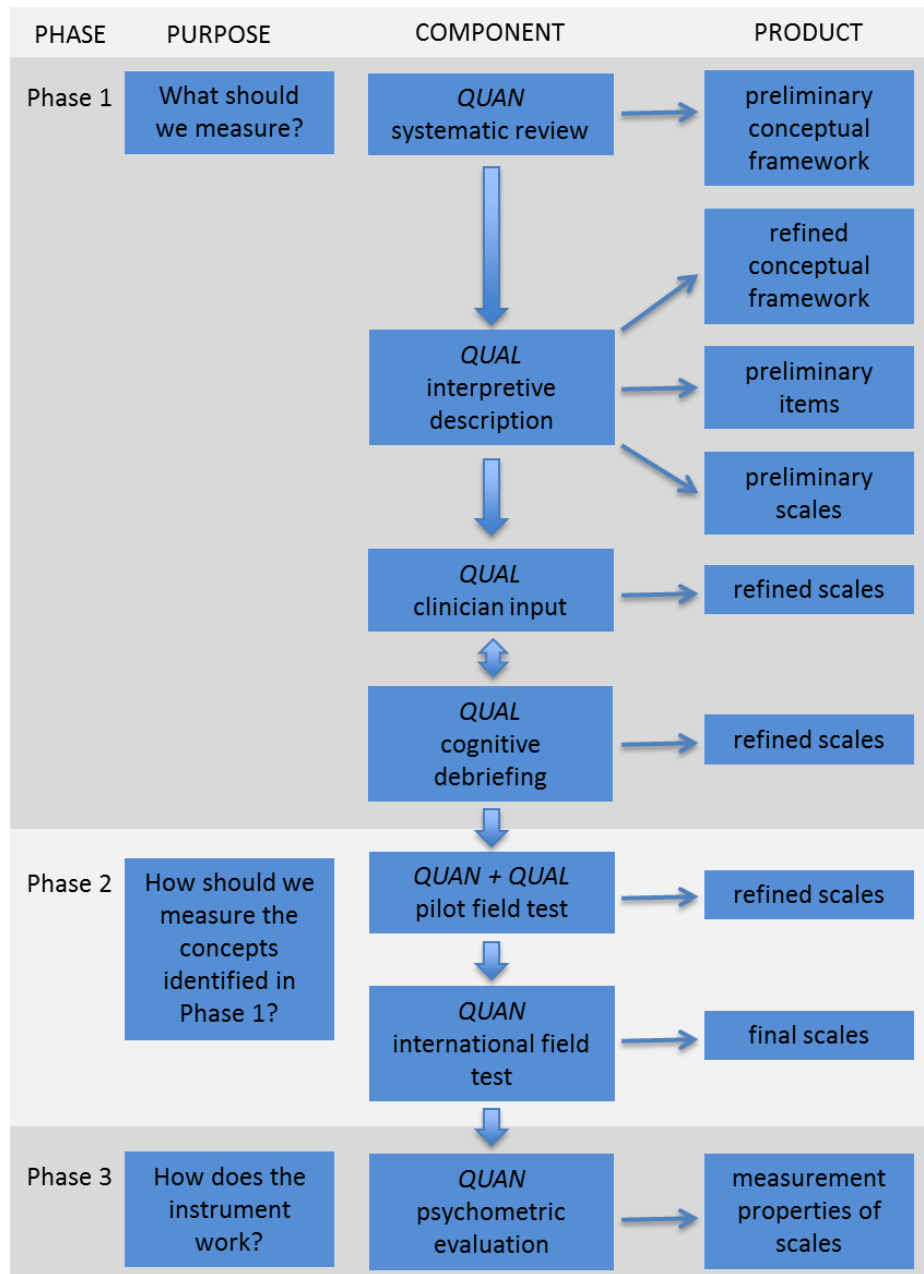
## **2. How was the FACE-Q Skin Cancer© Developed?**

Figure 1 shows the multiphase mixed methods approach used by our team to develop PRO measures. The FACE-Q Skin Cancer© conceptual framework was developed from extensive qualitative research with skin cancer patients (15 initial interviews and 5 cognitive interviews), close examination of the research literature and engagement of 10 clinical experts. We followed internationally recommended guidelines for patient-reported outcome instrument development to ensure the FACE-Q Skin Cancer© meets requirements of regulatory bodies.

The FACE-Q Skin Cancer© represents a new generation PRO measure that was developed using a modern psychometric approach called Rasch Measurement Theory (RMT). In RMT, scales that compose a PRO measure are each designed to measure and score a unidimensional construct (no total score). 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.

Each FACE-Q Skin Cancer© scale (Table 1) is composed of a series of items (or questions) that evaluate a concept of interest. There are 7 independently functioning scales measuring three domains: HRQOL (n=4); appearance (n = 2) and experience of care (n=1).

**Figure 1:** Multiphase mixed methods approach for developing the PRO measure (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. *BMJ Open*. 2017;7(1):015467.)



### 3. FACE-Q Skin Cancer© Scales

The table below shows the FACE-Q Skin Cancer© scales, including number of items, response options, time frame and grade reading level. Below the table is a brief description of each scale.

Name of Scale	Items	Response Options	Recall period	FK grade
<b>Appearance Scales</b>				
Facial Appearance	9	dissatisfied/satisfied	past week	0.0
Scars	8	bothered / not at all bothered	past week	1.4
<b>HRQOL Scales</b>				
Cancer worry	10	disagree/agree	past week	6.1
Appearance/Face distress	8	disagree/agree	past week	3.2
<b>Checklists</b>				
Sun Protective Behavior	5	never/always	n/a	3.3
Adverse Effects	10	not at all / extremely bothered	Past week	9.9
<b>Patient Experience Scales</b>				
Information: Appearance	6	dissatisfied/satisfied	n/a	0.6

FK = Flesch-Kincaid grade level.

#### Appearance Scales

**Satisfaction with Facial Appearance:** This 9-item scale measures the appearance of the entire face with items that ask about symmetry and shape, as well as how the face looks in photos, in the mirror and up close.

**Appraisal of Scars:** This 8-item scale measures the appearance of scars with items that ask about features such as color, length and location.

#### HRQOL Scales

**Cancer worry:** This 10-item scale measures cancer worry. Respondents are asked to indicate how often they worry the skin cancer may come back, spread to other parts of the body and how much it interferes with their relationships.

**Appearance - related psychosocial distress:** This 8-item scale measures how facial appearance affects the respondent by asking them to indicate how much they agree/disagree with feeling depressed, anxious or unhappy when others look at them.

#### Checklists

**Sun Protection Behavior:** This 5-item checklist assesses sun protection behavior. When spending time outdoors, the respondent indicates how often sun screen, a hat or clothing is used.

**Adverse Effects:** This 10-item checklist asks about problems you may be experiencing due to your recent skin cancer treatment such as pain, numbness, itching or swelling.

## **Patient Experience of Care Scale**

**Satisfaction with Information: Appearance:** This 6-item scale measures satisfaction with information provided by the medical team with items concerning how your appearance would change and how scars would change over time.

### **4. Administration of the FACE-Q Skin Cancer©**

The FACE-Q Skin Cancer© scales are self-administered. Each scale takes only a few minutes to complete. Patients are given instructions in an introductory paragraph at the beginning of the questionnaire. The FACE-Q Skin Cancer© is available in paper and pencil format or REDCap for electronic data collection. It is important to note that patients do not need to complete all of the available FACE-Q Skin Cancer© 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.

### **5. Scoring the FACE-Q Skin Cancer©**

There is no overall or total FACE-Q Skin Cancer© score, only scores for each independent scale. FACE-Q Skin Cancer© scales are easy to score. The raw scores for items that make up a scale are added to provide a total score. The total score is converted to a score from 0 to 100. Higher scores for all scales, with two exceptions, reflects a better outcome. 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).

### **6. Conditions of Use of the FACE-Q Skin Cancer©**

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Use of the FACE-Q Skin Cancer© questionnaire requires completion of a User's agreement. The use of the FACE-Q Skin Cancer© and its modules in non-profit academic research and in clinical care is free of charge. The use of the FACE-Q Skin Cancer© by "for-profit" organizations is subject to a licensing fee per module per protocol.

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

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## **7. Frequently Asked Questions**

### ***Do I need to sign a license to use the FACE-Q Skin Cancer©?***

Yes, you must sign a licence agreement for any use of the questionnaires, whether it is commercial or academic. The questionnaires are protected by copyright and are the exclusive property of the universities where they were developed.

### ***Does it cost money to use the FACE-Q Skin Cancer©?***

Use of FACE-Q Skin Cancer© scales is free to non-profit users. For-profit users need to pay a licensing fee through Memorial Sloan Kettering Cancer Centres (see conditions of use above).

### ***Do I have to use all the FACE-Q Skin Cancer© scales?***

Each scale functions independently, therefore patients can be asked to complete some or all FACE-Q Skin Cancer© scales. It is not necessary for a patient to complete all of the scales as there is no overall or total FACE-Q Skin Cancer© 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 FACE-Q Skin Cancer©?***

You cannot make any changes to the wording of any items or response options of the FACE-Q Skin Cancer©. 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 FACE-Q Skin Cancer© scales. The second reason is that by deleting or adding items, it would then not be possible to score the FACE-Q Skin Cancer© and you would not be able to compare findings with those of other FACE-Q Skin Cancer© studies. Finally, adding or deleting items is prohibited under copyright laws.

### ***Can I translate the FACE-Q Skin Cancer© into a new language?***

Yes, you can translate the FACE-Q Skin Cancer© into different languages. Check our website and with our team first to make sure there is not already a translation in the language you need. You will need to sign a licensing agreement. Please note that the developers of the FACE-Q Skin Cancer© own the copyright of all translations of the FACE-Q Skin Cancer©.

### ***Are there specific time points when patients complete the scales?***

A researcher or clinician can decide the time points he/she would like to administer the scales.

***Is there an electronic version I can use?***

A template file of the FACE-Q Skin Cancer© for administration via the Research Electronic Data Capture (REDCap) portal is available. Please contact the authors for more information.

**8. FACE-Q Skin Cancer© Publications**

1. Lee EH, Klassen AF, Cano SJ, Pusic AL. Development and psychometric evaluation of the FACE-Q Skin Cancer Scales and Checklists for Dermatologic Procedures. JAAD. In press.
2. Lee EH, Klassen AF, Lawson JL, Cano SJ, Scott AM, Pusic AL. Patient experiences and outcomes following facial skin cancer surgery: A qualitative study. Australas J Dermatol. 2016 Aug;57(3):e100-4.
3. Lee EH, Klassen AF, Nehal KS, Cano SJ, Waters J, Pusic AL. A systematic review of patient-reported outcome instruments of nonmelanoma skin cancer in the dermatologic population. J Am Acad Dermatol. 2013 Aug;69(2):e59-67.