FACE-Q | Head and Neck Cancer©

A Guide for Researchers and Clinicians

USER'S GUIDE
VERSION 1.0
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1. What is the FACE-Q Head and Neck Cancer©?

The FACE-Q Head and Neck Cancer© is a patient-reported outcome (PRO) measure that measures healthcare experience and outcomes of treatment for head and neck cancer procedures from the patient's perspective. The FACE-Q Head and Neck Cancer© measures 4 domains: Appearance, Health-Related Quality of Life (HRQOL), Function and Patient Experience of Care. These domains form the basis of the FACE-Q Head and Neck 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 Head and Neck Cancer© Developed?

Figure 1 shows the multiphase mixed methods approach used by our team to develop PRO measures. The FACE-Q Head and Neck Cancer© conceptual framework was developed from extensive qualitative research with patients that have cancer that affects the head and neck region (26 interviews), close examination of the research literature and engagement of a panel of clinical experts. We followed internationally recommended guidelines for patient-reported outcome measure development to ensure the FACE-Q Head and Neck Cancer© meets requirements of regulatory bodies.

The FACE-Q Head and Neck Cancer© scales represent 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 Head and Neck Cancer© scale (Table 1) is composed of a series of items (or questions) that evaluate a concept of interest. There are 14 independently functioning scales measuring four domains: HRQOL (n=6), function (n=6), appearance (n=1) and experience of care (n=1).

Figure 1: Multiphase mixed methods approach taken by our team 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. BMJ Open. 2017;7(1):015467.)
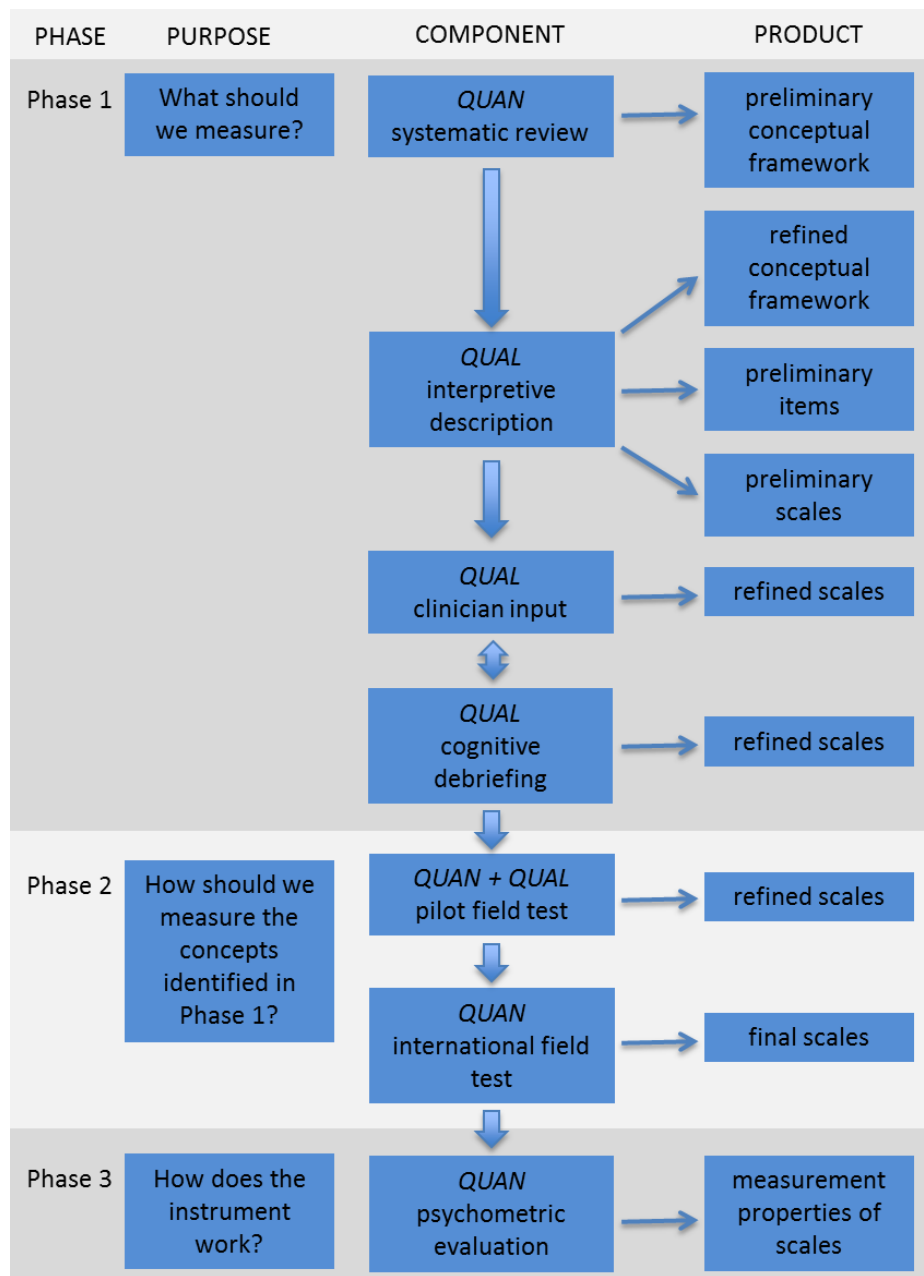
3. FACE-Q Head and Neck Cancer© Scales

Table 1 shows the FACE-Q Head and Neck Cancer© scales, including number of items, response options, time frame and grade reading level. Below Table 1 is a brief description of each scale.

Table 1: FACE-Q Head and Neck Cancer© scales including number of items, response options, time frame and grade reading level.

Name of Scale	Items	Response Options	Recall period	FK grade
Appearance Scale				
Appearance of face overall	10	agree/disagree	past week	2.2
Function Scales				
Eating and drinking	8	not at all / a lot bothered	past week	1.9
Oral competence	5	not at all / a lot bothered	past week	0.0
Salivation	8	not at all / a lot bothered	past week	1.9
Smiling	7	not at all / a lot bothered	past week	2.1
Speaking	7	not at all / a lot bothered	past week	5.6
Swallowing	8	not at all / a lot bothered	past week	2.3
HRQOL Scales				
Appearance/Face distress	6	agree/disagree	past week	3.2
Eating distress	7	none of the time/ all of the time	past week	4.5
Drooling distress	6	none of the time/ all of the time	past week	5.0
Smiling distress	5	none of the time/ all of the time	past week	3.1
Speaking distress	7	none of the time/ all of the time	past week	4.9
Cancer worry	8	none of the time/ all of the time	past week	5.7
Patient Experience of Care Scale				
Satisfaction with information	10	dissatisfied/satisfied	n/a	7.0

FK = Flesch-Kincaid grade level.

Appearance Scales

Appearance of Face Overall: This 10-item scale measures the appearance of the entire face with items that ask about proportion and size, as well as if the face looks unattractive, uneven or abnormal.

Function Scales

Eating and Drinking: This 8-item scale measures the ability to eat and drink with items that ask about chewing, drinking, taste and effort performing these activities.

Oral competence: This 5-item scales measures the ability to close the mouth and lips with items that ask about drooling and food falling out of the mouth when eating.

Salivation: This 8-item scale measures problems with saliva with items that ask about having a dry mouth, always having to drink liquids and trouble eating.

Smiling: This 7-item scale measures problems with smiling with items that ask about symmetry and movement.

Speaking: This 7-item scale measures problems with speaking with items that ask about difficulty making certain sounds, saying certain letters or words and having to repeat oneself.

Swallowing: This 8-item scale measures problems with swallowing with items that ask about choking, coughing and food getting stuck in the throat.

HRQOL Scales

Appearance/Face distress: This 6-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.

Eating distress: This 7-item scales measures how eating problems may affect the respondent by asking them to indicate how often they do not enjoy eating meals, feel self-conscious when eating or avoid eating in public.

Drooling distress: This 6-item scale measures how drooling affects the respondent by asking them to indicate how often they feel frustrated, embarrassed or avoid social situations.

Smiling distress: This 5-item scale measures how problems with smiling affect the respondent by asking them to indicate how often they feel self-conscious, embarrassed or avoid smiling.

Speaking distress: This 7-item scale measures how problems with speaking affect the respondent by asking them to indicate how often they feel socially isolated, feel embarrassed or avoid public speaking.

Cancer worry: This 8-item scale measures cancer worry. Respondents are asked to indicate how often they worry the cancer may come back, they will die from cancer and how much the cancer interferes with their daily activities.

Experience of Care Scale

Satisfaction with information: This 10-item scale measures satisfaction with information from the medical team and includes items concerning the options presented, surgical process, potential complications and recovery.

Scales in Development:
Vision Function
Vision Distress
Eye Tearing Distress
Rhinorrhoea Distress
Appearance Investment

4. Administration of the FACE-Q Head and Neck Cancer©

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

5. Scoring the FACE-Q Head and Neck Cancer©

There is no overall or total FACE-Q Head and Neck Cancer© score, only scores for each independent scale. FACE-Q Head and Neck 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 Head and Neck Cancer©

Memorial Sloan Kettering Cancer Center holds the copyright of the FACE-Q Head and Neck Cancer© and all its translations (past, on-going and future). To avoid any copyright infringement, a copyright notice shall be included on the original questionnaire and all its derivatives (including but not limited to translations) as

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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 Head and Neck 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 Head and Neck Cancer©?

Use of FACE-Q Head and Neck 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 Head and Neck Cancer© scales?

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

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

Can I translate the FACE-Q Head and Neck Cancer© into a new language?

Yes, you can translate the FACE-Q Head and Neck 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 Head and Neck Cancer© own the copyright of all translations of the FACE-Q Head and Neck 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 Head and Neck Cancer© for administration via the Research Electronic Data Capture (REDCap) portal is available. Please contact the authors for more information.

8. FACE-Q Head and Neck Cancer© Publications

1. Cracchiolo JR, Klassen AF, Young Afat D, Albornoz CR, Cano SJ, Patel S, Pusic AL, Matros E. Development and Psychometric Validation of the FACE-Q Head and Neck Oncology Module. Forthcoming

2. Cohen WA, Albornoz CR, Cordeiro PG, Cracchiolo J, Encarnacion E, Lee M, et al. Health-Related Quality of Life following Reconstruction for Common Head and Neck Surgical Defects. Plast Reconstr Surg. 2016;138(6):1312-20.

3. Albornoz CR, Pusic AL, Reavey P, Scott AM, Klassen AF, Cano SJ, et al. Measuring health-related quality of life outcomes in head and neck reconstruction. Clin Plast Surg. 2013;40(2):341-9.

4. Pusic A, Liu JC, Chen CM, Cano S, Davidge K, Klassen A, et al. A systematic review of patient-reported outcome measures in head and neck cancer surgery. Otolaryngol Head Neck Surg. 2007;136(4):525-35.