FACE-Q® | PARALYSIS

A User's Guide for Researchers and Clinicians

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1. What is the FACE-Q | Paralysis?

The FACE-Q Paralysis is a rigorously developed patient-reported outcome measure (PROM) that can be used to collect and compare evidence-based outcomes data from children and adults aged 8 years and older with facial nerve paralysis. This condition can affect facial appearance and function, such as speech, vision, smiling, eating, and drinking. Facial nerve paralysis can be congenital or acquired and may have a considerable impact on health-related quality of life (HRQOL). The paralysis module includes the subset of scales/checklists from the FACE-Q Craniofacial that measures appearance (Eyes, Face, Forehead, Lips, Smile), function (Breathing, Eating, Eyes, Facial, Speech), HRQOL (Appearance Distress, Psychological, Social, School, Speech Distress), and adverse effects (Eyes, Face).

2. How was the FACE-Q | Craniofacial Developed and Validated?

FACE-Q Craniofacial represents a new generation PROM 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 their use in research studies, FACE-Q Craniofacial scales can be used with individual patients to inform clinical care.

We followed internationally recommended guidelines for PROM development to create FACE-Q Craniofacial. Figure 1 shows the multiphase mixed-methods approach used by our team [1]. After developing the CLEFT-Q© [2-9], to address noncleft craniofacial conditions, we interviewed 84 patients aged 8 to 29 years with 28 different congenital and acquired conditions that included facial paralysis [10-11]. This qualitative study provided evidence to support the use of the original content from the CLEFT-Q with patients with noncleft craniofacial conditions. The research also identified the need for additional scales to measure constructs not covered by the CLEFT-Q. Our team used the qualitative data to design new scales measuring additional aspects of appearance, facial function, and HRQOL. Table 1 shows the full set of the FACE-Q Craniofacial scales.

In phase 2, field-test data were collected in multiple countries between December 2016 and December 2019. The full field-test sample included 2233 patients aged 8 to 29 years with a broad range of conditions associated with a visible and/or functional facial difference, including 90 participants with facial paralysis. RMT analysis was used to examine reliability and validity of the scales. The findings are reported in two publications [12-13].

Table 1: FACE-Q | Craniofacial

Appearance		Function	HRQOL	Adverse Effects
Birthmark	Head Shape	Breathing	Appearance Distress	Ears
Cheeks	Jaws	Eating/Drinking	Psychological	Eyes
Chin	Lips	Eyes	Social	Face
Ears	Nose	Face	School	
Eyes	Nostrils	Speech	Speech Distress	
Face	Teeth			
Forehead	Smile			

In the first publication, Differential Item Functioning (DIF) was conducted to determine if the *original* CLEFT-Q scales function the same in cleft and noncleft facial conditions [12]. DIF was found to have a negligible impact on scale scoring. In the combined sample of 4743 participants, RMT analysis led to retention of original content for 10 CLEFT-Q scales, modification of the Teeth scale, and the addition of an Eating/Drinking scale that replaced the CLEFT-Q Eating/Drinking checklist.

In the second publication, the RMT analysis for the *new* FACE-Q Craniofacial scales not covered by the CLEFT-Q provided evidence for the reliability and validity of 7 appearance scales (Birthmark, Cheeks, Chin, Eyes, Forehead, Head Shape, Smile), 2 function scales (Breathing, Facial), and an Appearance Distress Scale [13].

3. How was the FACE-Q | Paralysis Module Validated?

In qualitative research to develop the FACE-Q Craniofacial, interviews with 11 children with facial nerve palsy were conducted as part of the larger qualitative study of 84 children and young adults with a broad range of facial conditions [10-11]. Our team also interviewed 14 adults with facial nerve paralysis to identify their concerns. Elsewhere we described a range of outcomes related to facial function (e.g., open/close eye, smile, eat/drink, speech), appearance (e.g., how eyes, face, smile look), psychological function (e.g., feel self-conscious, embarrassed, upset, sad), and social function (e.g., people look, comment, judge) [14]. To establish content validity for adult facial paralysis, we combined phase 1 qualitative data from 11 children from the FACE-Q qualitative study with that of the 14 adults to identify concepts and common themes across age. The adult sample included 5 males and 9 females with a mean age of 57.6 (range 36 to 78 years). The pediatric sample included 6 females and 5 males with a mean age of 12.9 (range 8 to 17 years). The qualitative sample of 25 patients provided 2052 codes related to 4 top-level outcome domains: appearance, physical, psychological, and social function. Figure 2 shows the FACE-Q Paralysis conceptual framework. Many of the concerns expressed by participants were found to be common across age.

To examine the psychometric properties of the FACE-Q Craniofacial scales/checklists in patients with facial paralysis aged 8 years and older, we examined data from 235 patients [15]. Table 2 shows participant characteristics. The sample included 90 (38.3%) children and young adults from the FACE-Q Craniofacial field-test sample and 145 additional adults. RMT analysis was used to examine the psychometric performance of 13 FACE-Q Craniofacial scales. All 122 items had ordered thresholds and good item fit to the Rasch model. For 12 scales, Person Separation Index values were >0.79 and Cronbach alpha values were >0.82. Eye Function, along with Eye and Face Adverse Effects were scored as checklists. The remaining scales' reliability values were >0.71.

The qualitative and RMT findings provided evidence of reliability and validity for 13 FACE-Q Craniofacial scales in children and adults with facial paralysis [15]. The School scale is also relevant to patients aged 8 to 18 years with facial nerve paralysis. The psychometric findings for that scale, which included 90 children with facial nerve paralysis in the field-test sample, were published separately [12].

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.)

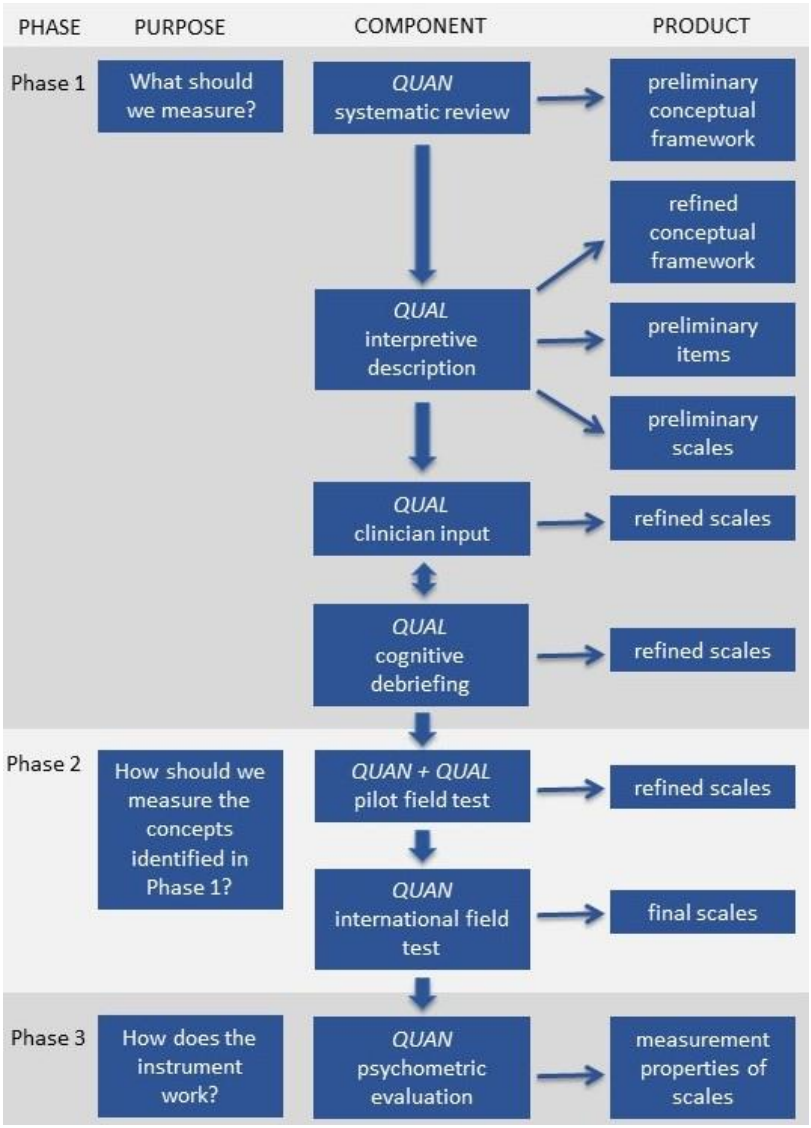

Figure 2: FACE-Q Paralysis Conceptual Framework

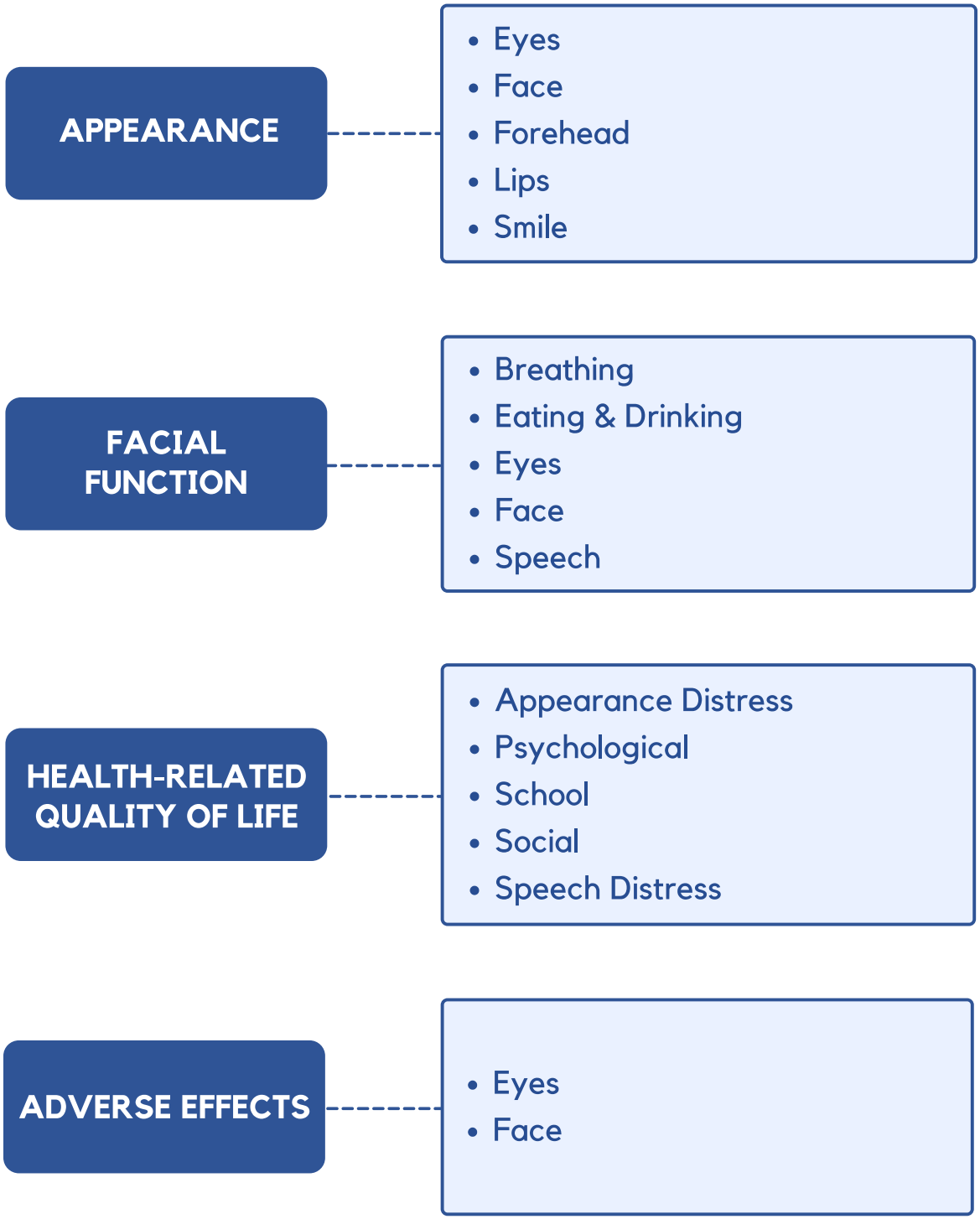

Table 2: Characteristics (Number, %) for 235 participants with facial paralysis

		N	%
Age in years	8-17	44	18.7
	18-29	46	19.6
	30-49	64	27.2
	≥50	78	33.2
	Missing	3	1.3
Gender	Male	69	29.4
	Female	165	70.2
	Missing	1	0.4
Country	Australia	8	3.4
	Brazil	4	1.7
	Canada	93	39.6
	Chile	7	3.0
	France	4	1.7
	Ireland	13	5.5
	Netherlands	11	4.7
	United Kingdom	27	11.5
	United States	63	26.8
	Other	5	2.1
Language	English	209	88.9
	Dutch	11	4.7
	French	4	1.7
	Portuguese	4	1.7
	Spanish	7	3.0
Recruitment	Clinic	168	71.5
	Social media	67	28.5

Note: Table 2 is reproduced from Klassen AF, Rae C, Gallo L, Norris JH, Bogart K, Johnson D, Van Laeken N, Baltzer HL, Murray DJ, Hol MLF, O T, Wong Riff KWY, Cano SJ, Pusic AL. Psychometric Validation of the FACE-Q Craniofacial Module for Facial Nerve Paralysis. Facial Plast Surg Aesthet Med. 2021 Apr 7.

4. FACE-Q | Paralysis Scales

Table 3 shows the FACE-Q scales/checklists, including number of items, age of the participants included in the validation study, response options, recall period, scoring, and Flesch-Kincaid (FK) grade reading level. Below the table is a brief description of the content of each scale.

Table 3: Description of the FACE-Q scales and checklists in the Paralysis module

Name of scale	Items	Age	Response options	Recall	Scoring	FK
Appearance						
Eyes	9	8+	not at all → very much	now	0-100	2.8
Face	9	8+	not at all → very much	now	0-100	0.7
Forehead	10	8+	not at all → very much	now	0-100	3.2)
Lips	9	8+	not at all → very much	now	0-100	0.1
Smile	9	8+	not at all → very much	now	0-100	0.9
Function						
Breathing	7	8+	always →never	1 week	0-100	0.1
Eating/Drinking	9	8+	always →never	1 week	0-100	1.5
Eyes	7	8+	not at all → very much	1 week	checklist	5.5
Face	10	8+	cannot do → can do	1 week	0-100	3.6
Speech	12	8+	always → never	1 week	0-100	2.9
Health-related Quality of Life						
Appearance Distress	8	8+	always → never	1 week	0-100	3.2
Psychological	10	8+	always → never	1 week	0-100	2.2
School	10	8-18	always → never	1 week	0-100	1.9
Social	10	8+	always → never	1 week	0-100	1.8
Speech Distress	10	8+	always → never	1 week	0-100	2.5
Adverse Effects						
Eyes	7	8+	not at all → very much	1 week	Checklist	2.0
Face	10	8+	not at all → very much	1 week	Checklist	1.4

APPEARANCE

Eyes: This 9-item scale measures how much (not at all, a little bit, quite a bit, very much) someone likes how their eyes and eyelids look. Items ask about the shape and size of the eyes, how the eyes look in photos, as well as how open and even the eyelids look.

Face: This 9-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their face looks. Items ask about how the face looks in photos, from the side, as well as the shape of the face and how the face looks up close.

Forehead: This 10-item scale measures how much (not at all, a little bit, quite a bit, very much) someone likes how their forehead and eyebrows look. Items ask about the position of the eyebrows, the height and shape of the forehead, as well as how it looks from the side and when the hair is wet or pulled back.

Lips: This 9-item scale measures how much (not at all, a little bit, quite a bit, very much) someone likes how their lips look. Items ask about the shape, size, and fullness of the lips, as well as how their lips look when they smile and up close.

Smile: This 9-item scale measures how much (not at all, a little bit, quite a bit, very much) someone likes how their smile looks. Items ask about their smile in terms of how it looks in the mirror, in photos, how big (wide) their smile looks, and how even it looks.

FACIAL FUNCTION

Breathing: This 7-item scale measures how hard it is to breathe in terms of frequency (always, sometimes, never) and in the past week. Items ask about breathing through the nose and mouth, as well as during exercise, sleep, and when eating.

Eating/Drinking: This 9-item scale asks about problems with eating and drinking in terms of frequency (always, sometimes, never) and in the past week. Items ask about avoiding certain foods, eating slowly, as well as trouble biting and chewing some foods.

Eyes: This 7-point checklist measures problems with eye function in terms of severity (not at all, a little, quite a bit, very much) and in the past week. Items ask about blinking, opening and closing the eyelids all the way, as well as keeping the eyes closed during sleep and vision problems.

Facial: This 10-item scale measures problems with facial movements (cannot do, have some trouble doing, can do) and in the past week. Items ask about having trouble with smiling, eating/drinking, blowing, frowning, and speaking.

Speech: This 12-item scale measures how often (never, sometimes, always) in the past week someone has trouble speaking. Items ask about reading out loud, trouble with specific words or sentences, and the need to use strategies such as speaking slowly or needing to concentrate to speak well.

HEALTH-RELATED QUALITY OF LIFE

Appearance Distress: This 8-item scale measures psychosocial distress caused by appearance in terms of frequency (always, sometimes, never) and in the past week. Items ask about social issues (going out, meeting people, covering up) and psychological issues (feeling unhappy or self-conscious about appearance).

Psychological: This 10-item scale measures psychological function in terms of frequency (never, sometimes, often, always) and in the past week. Items are positively worded and ask about self-esteem (e.g., I like myself), body image (e.g., I feel good about how I look), and confidence.

School: This 10-item scale measures social function at school in terms of frequency (never, sometimes, often, always) and in the past week. Items are positively worded and ask about seeing friends at school, feeling safe (not bullied), fitting in, and liking school.

Social: This 10-item scale measures social function in terms of frequency (never, sometimes, often, always) and in the past week. Items are positively worded and ask about having fun with friends, feeling accepted by friends, fitting in, and feeling the same as other people.

Speech Distress: This 10-item scale measures how someone feels about speaking in terms of frequency (always, sometimes, never) and in the past week. Items ask about nervousness, frustration, teasing, embarrassment, and the ability to be understood.

ADVERSE EFFECTS

Eyes: This 7-item checklist measures how eyes feel in terms of severity (not at all, a little bit, quite a bit, very much) and in the past week. Items ask if their eyes feel itchy, sore, dry, and if they twitch or water too much.

Face: This 10-item checklist measures how the face feels in terms of severity (not at all, a little bit, quite a bit, very much) and in the past week. Items ask if the face feels sore, tingly, sensitive, itchy, numb, tight, or firm.

5. Administration of the FACE-Q | Paralysis

The FACE-Q is designed to be completed by patients aged 8 years and older on their own (self-report). Each scale is independently functioning, which means that only scales relevant to the particular research or clinical situation need be completed. Brief instructions are provided at the start of each scale. FACE-Q scales were field-tested using online data collection, i.e., Research Electronic Data Capture System (REDCap), as well as 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 FACE-Q data collection, the ePRO company may need a license. If you have had or plan to have an ePRO company convert FACE-Q scales into an electronic format, e-conversion review and certification is required, please email qportfolioteam@gmail.com.

6. Scoring the FACE-Q | Paralysis

There is no overall or total FACE-Q score. Instead, the FACE-Q is composed of independently functioning scales and checklists that are scored separately. Table 3 identifies the scales and checklists.

To score a scale, the raw scores for the set of items in a scale are added together to produce a total raw score. 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 ≥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 ≤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 ≥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. Higher scores for FACE-Q scales reflect a better outcome. The Conversion Tables for changing raw scores into 0 to 100 scores are available after a licensing agreement is signed.

To score a checklist, the raw scores for the items in a checklist can be used to identify problems experienced by a patient or a sample. Checklists do not have Rasch Conversion Tables because the set of items did not work together statistically (i.e., the item set did not map out a clinical hierarchy for the concept of interest). Even though there are no Conversion Tables based on Rasch analysis for the 3 checklists, they can provide clinically important information, such as monitoring for post-operative complications.

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- **You will not reproduce any FACE-Q scales in publications or other materials**
- **You will not translate the FACE-Q without permission from our team**

For questions regarding study design and optimal use of FACE-Q scales, please contact either:

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8. Frequently Asked Questions

Which FACE-Q | Craniofacial scales are in the International Consortium for Health Outcome Measurement (ICHOM) standard sets?

A number of FACE-Q and CLEFT-Q scales are included in the pediatric ICHOM standard sets for cleft lip and/or palate, craniofacial microsomia, and facial paralysis. More information about these ICHOM standard sets is available on the ICHOM website:

https://www.ichom.org/standard-sets/

To use the FACE-Q as part of an ICHOM standard set, you must sign a licensing agreement. To obtain a license, please use the following link:

https://research.mcmaster.ca/industry-investors/technologies-available-for-licensing/request-for-license/

Do I have to use all of the FACE-Q | Paralysis scales?

Each scale functions independently; therefore, patients can be asked to complete one or all of the FACE-Q scales. It is not necessary for a patient to complete all of the scales as there is no overall or total FACE-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 FACE-Q | Paralysis?

You cannot delete or add or change the wording of any items or response options of the FACE-Q**.** Any modification to the content of the FACE-Q is prohibited under copyright laws. Also, making any changes to FACE-Q scales would invalidate their psychometric properties.

Can I reproduce FACE-Q | Paralysis scales in a publication or other public document (e.g., PhD thesis)?

According to the license agreement, you cannot reproduce the content of FACE-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 4 below. They are from the psychometric publications describing the FACE-Q field-test study [12-13].

Can I translate FACE-Q | Paralysis into a new language?

Yes, with permission, you can translate the FACE-Q into different languages. Before starting a translation, check our translations list on 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 for more information. Please note that the developers of the FACE-Q own the copyright of all translations of the FACE-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 FACE-Q | Paralysis?

Use of FACE-Q scales is free to non-profit users, including use by hospitals. For-profit users should contact McMaster University for information about fees: milo@mcmaster.ca.

Table 4: Shortened items for FACE-Q scales/checklists to use in a publication

EYES	even	people look	raise eyebrows
suit	straight	**SPEECH DISTRESS**	speak clearly
size	photo	go out	smile fully
photos	teeth	make friends	**SPEECH**
smile	other people	teased	family
even	**APPEAR DISTRESS**	frustrated	friends
shape	going out	embarrassed	read aloud
match	mirror	avoid	some sentences
lids open	cover up	nervous	avoid
lids even	meet people	worry	phone
FACE	unhappy	repeat	new people
look best	dislike	understood	try hard
go out	people stare	**BREATHING**	repeat
shape	self-conscious	eat	speak slow
photos	**PSYCHOLOGICAL**	mouth	concentrate
match	happy with life	one side	some words
smile	enjoy life	sleep	**AE EYES**
laugh	feel happy	exercise	twitch
profile	feel okay	nose	sore
up close	believe in self	snore	itchy
FOREHEAD	proud of self	**EATING/DRINKING**	whites
position eyebrows	like self	food falls	feels
hairline	feel confident	liquid spills	water
match	feel great	straw	dry
shape	good look	open mouth	**AE FACE**
profile	**SCHOOL**	avoid foods	bruised
height	seeing friends	trouble biting	sore
frown	teachers	chew	tingly
smooth	accepted	small bits	sensitive
wet hair	liked	eat slow	itchy
lift eyebrows	happy	**EYES**	numb
LIPS	nice to me	unexpectedly	puffy
smile	listen to me	open	uncomfortable
size	safe	blink	tight
photo	make friends	see	
laugh	join activities	close	
mirror	**SOCIAL**	sleep	
closed	friends accept	one better	
shape	fun friends	**FACIAL**	
full	people listen	smile spontaneously	
up close	treat same	eat/drink	
SMILE	like being with	open/close mouth	
expresses	confident out	blow	
mirror	fit in	face moves	
wide	make friends	frown	
shape	same others	open/close eyes	

9. Acknowledgements

Development of the FACE-Q has involved more than 2000 children and young adults with craniofacial conditions, along with the collaboration of numerous health care professionals and researchers around the world. We are truly grateful for their dedication and help with our research. The FACE-Q study has been generously funded by the following grants:

Phase I: Qualitative

Klassen A, Wong K, Forrest C, Davidge K, Borschell G, Zuker R, Giglia L, Pusic A. Development of the FACE-Q Kids PRO Instrument. The Plastic Surgery Foundation, May 2015 – April 2016.

Phase II: International Field-Test

Klassen A, Wong K, Forrest C, Pusic A. An International Study to Develop a Patient-Reported Outcome Instrument for Conditions Associated with a Facial Difference: FACE-Q Kids, Canadian Institutes of Health Research (FRN 148779), July 2016 – June 2018.

10. Publications Related to FACE-Q Development and Validation

1. Wong Riff KW, Tsangaris E, Goodacre T, Forrest CR, Pusic AL, Cano SJ, Klassen AF. 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 Jan 11;7(1):e015467.

2. Wong Riff KWY, Tsangaris E, Goodacre TEE, Forrest CR, Lawson J, Pusic AL, Klassen AF. What Matters to Patients with Cleft Lip and/or Palate: An International Qualitative Study Informing the Development of the CLEFT-Q. Cleft Palate Craniofac J. 2018 Mar;55(3):442-50.

3. Tsangaris E, Wong Riff KWY, Goodacre T, Forrest CR, Dreise M, Sykes J, de Chalain T, Harman K, O'Mahony A, Pusic AL, Thabane L, Thoma A, Klassen AF. Establishing content validity of the CLEFT-Q: A new patient-reported outcome measure for cleft lip and/or palate. Plast Reconstr Surg Glob Open. 2017 Apr 25;5(4):1305.

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