



CLEFT-Q©

A User's Guide for Researchers and Clinicians

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1. What is the CLEFT-Q?

The CLEFT-Q is a rigorously developed patient-reported outcome measure (PROM) that can be used internationally to collect and compare evidence-based outcomes data from patients aged 8 to 29 years with cleft lip and/or palate (CL/P). The CLEFT-Q is composed of 12 independently functioning scales and 1 checklist. The use of a modular approach means that only the subset of scales/checklist most relevant to a specific research objective or clinical patient population needs to be administered.

2. How was the CLEFT-Q Developed and Validated?

The CLEFT-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 their use in research studies, CLEFT-Q scales can be used with individual patients to inform clinical care.

We followed internationally recommended guidelines for PROM development to create the CLEFT-Q. Figure 1 shows the multiphase mixed-methods approach we use to develop Q-Portfolio instruments [1]. A detailed description of the protocol has been published: <https://bmjopen.bmj.com/content/10/3/e032332>.

The qualitative phase involved interviews with 138 patients from Canada, England, India, Kenya, the Philippines, and the USA [2]. The findings from the interviews were used to develop a conceptual framework comprised of the following 3 domains: appearance, health-related quality of life (HRQOL), and facial function. Figure 2 shows the CLEFT-Q conceptual framework. Cognitive interviews with 69 patients from Canada, India, Ireland, the Philippines, the Netherlands, and the USA, along with feedback from 44 international CL/P experts provided input used to refine the scales and to establish their content validity [3]. To establish their content validity, we used cognitive interviews with 69 patients from Canada, India, Ireland, the Philippines, the Netherlands, and the USA, along with feedback from 44 international CL/P experts [3].

To facilitate the involvement of multiple non-English speaking countries, the scales were translated and culturally adapted into Dutch, Hindi, Spanish, Swedish, and Turkish following ISPOR international guidelines [4-5]. The quantitative phase involved the collection of data from 2434 patients with CL/P at 30 hospitals in 12 countries. Table 1 shows the sample characteristics. RMT analysis led to the refinement of an Eating/Drinking checklist and 12 scales that evidenced reliability and validity [6]. Normative values for the CLEFT-Q were computed for age, gender, and cleft type [6].

Figure 1: The multiphase mixed methods approach for developing the CLEFT-Q (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.)

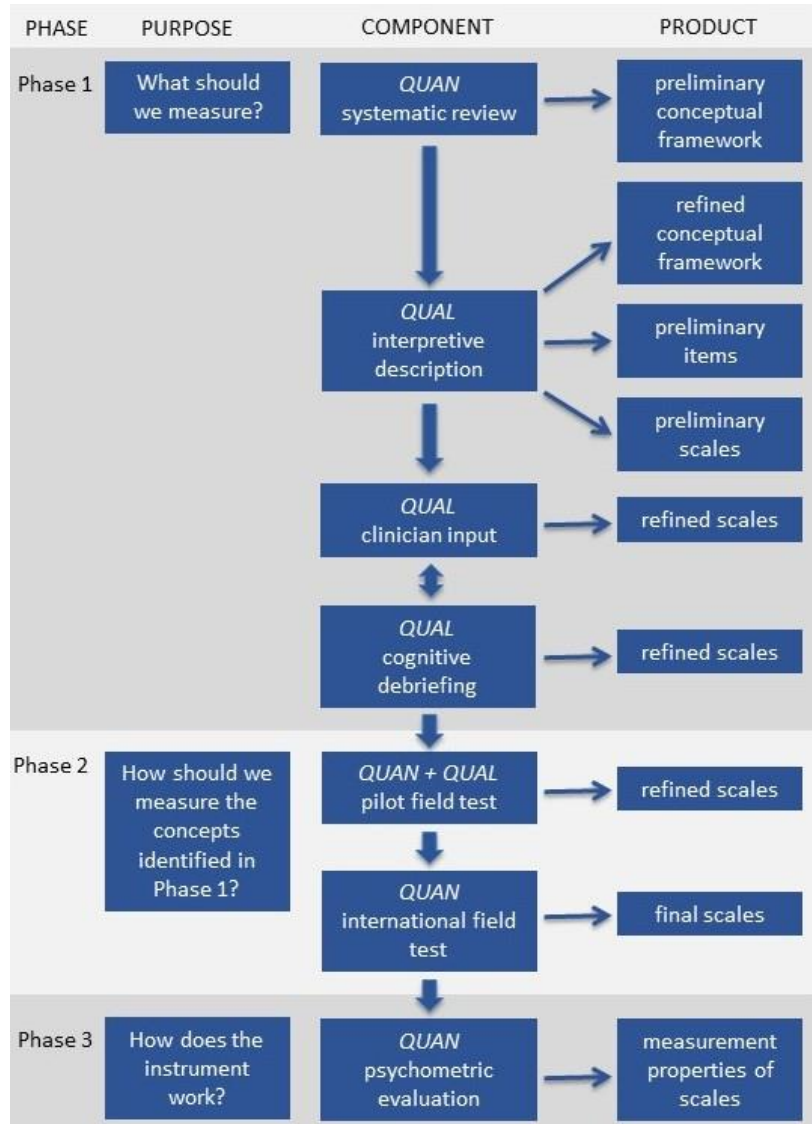


Figure 2: CLEFT-Q conceptual framework

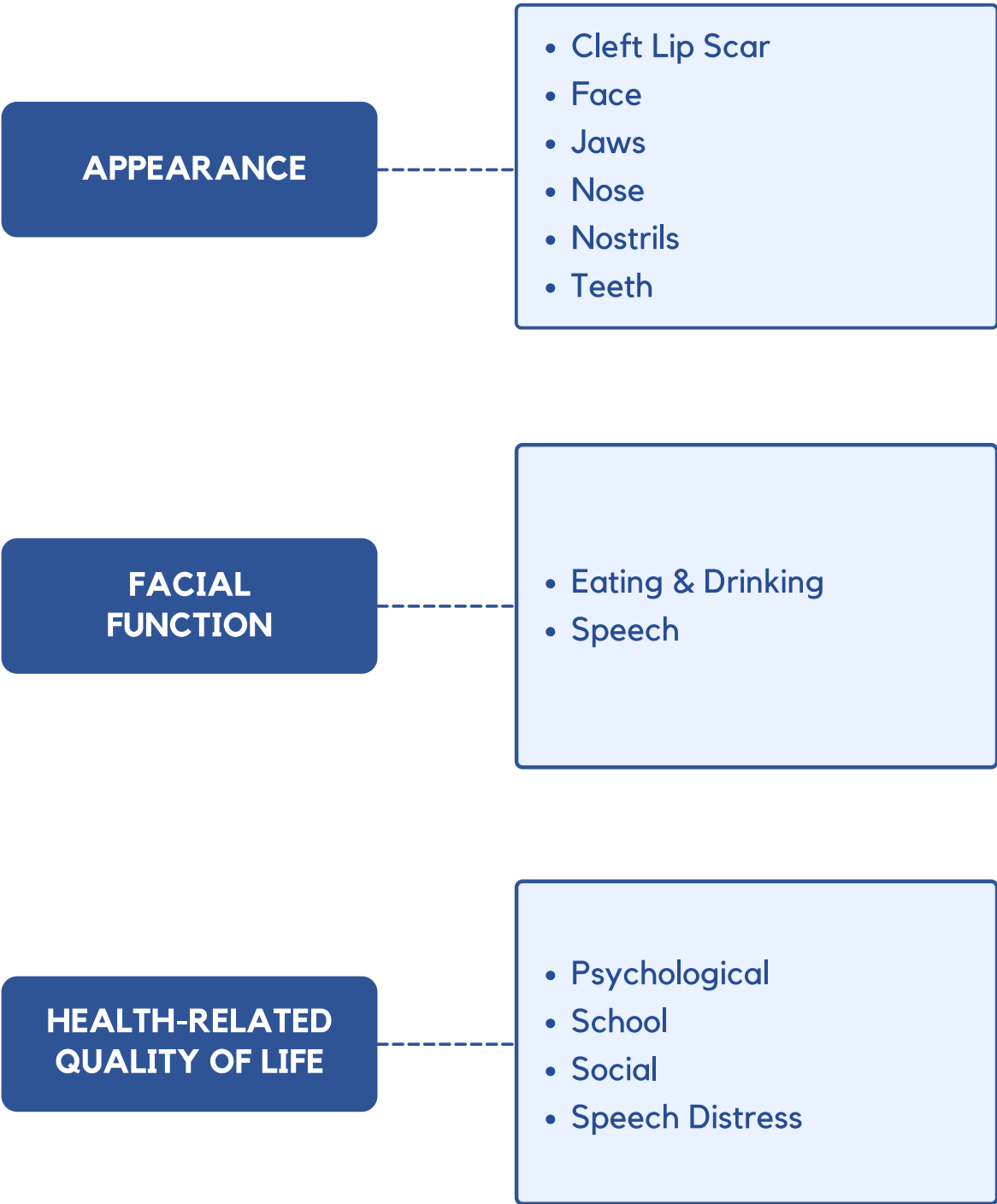


Table 1: Characteristics (Number, %) of field-test participants

		N	%
Country	Australia	25	1.0
	Canada	624	25.6
	Chile	89	3.7
	Columbia	210	8.6
	England	339	14.0
	India	232	9.5
	Ireland	100	4.1
	Netherlands	206	8.5
	Spain	93	3.8
	Sweden	100	4.1
	Turkey	54	2.2
	United States	362	14.9
Language	English	1450	59.6
	Dutch	206	8.5
	Hindi	232	9.5
	Spanish	392	16.1
	Swedish	100	4.1
	Turkey	54	2.2
Age	8-9	426	17.5
	10-11	411	16.9
	12-13	372	15.3
	14-15	385	15.8
	16-17	293	12.0
	18-20	300	12.3
	≥21	246	10.1
	Missing	1	0.1
Gender	Male	1351	55.5
	Female	1081	44.4
	Missing	2	0.1
Cleft type	Cleft lip and palate	1399	57.5
	Cleft palate	568	23.3
	Cleft lip	263	10.8
	Cleft lip and alveolus	204	8.4
Current speech problem	No	1271	52.2
	Mild	808	33.2
	Moderate	270	11.1
	Severe	32	1.3

3. CLEFT-Q and FACE-Q® | Craniofacial

After developing the CLEFT-Q [1-9], to address noncleft craniofacial conditions, we interviewed 84 patients aged 8 to 29 years with 28 different congenital and acquired conditions (e.g., microtia, facial paralysis, craniosynostosis, craniofacial microsomia) [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 qualitative study 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.

In the FACE-Q | Craniofacial phase 2 study, 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. RMT analysis was used to examine reliability and validity of the scales. The findings are reported in 2 publications [12-13].

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 negligible impact on scale scoring. In the combined sample of 4743 patients with cleft and noncleft conditions, RMT analysis led to the retention of the original content for 10 CLEFT-Q scales, modification of the Teeth scale, and the addition of an Eating/Drinking scale.

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, and Smile), 2 function scales (Breathing, Facial), and an Appearance Distress scale [13].

4. CLEFT-Q Scales

Table 2 shows the CLEFT-Q scales/checklists including number of items, the age of participants included in the validation study, cleft type, response options, recall period, scoring, and Flesh-Kincaid (FK) grade reading level. Below the table is a brief description of the content of each scale.

Table 2: Description of CLEFT-Q scales

Scale	Items	Age	Cleft type	Response options	Recall	Scoring	FK
Appearance							
Cleft Lip Scar	7	8-29	CLP CLA CL	not at all → very much	now	0-100	0.3
Face	9	8-29	Any	not at all → very much	now	0-100	0.7
Jaws	7	12-29	Any	not at all → very much	now	0-100	0.3
Lips	9	8-29	Any	not at all → very much	now	0-100	0.1
Nose	12	8-29	Any	not at all → very much	now	0-100	0.8
Nostrils	6	8-29	Any	not at all → very much	now	0-100	1.2
Teeth	8	8-29	Any	not at all → very much	now	0-100	0.6
Facial Function							
Eating/ Drinking	9	8-29	Any	always → never	1 week	checklist	1.2
Speech Function	12	8-29	CLP CP CLA	always → never	1 week	0-100	2.9
Health-Related Quality of Life							
Psychological	10	8-29	Any	always → never	1 week	0-100	2.2
School	10	8-18	Any	always → never	1 week	0-100	1.9
Social	10	8-29	Any	always → never	1 week	0-100	1.8
Speech Distress	10	8-29	CLP CP CLA	always → never	1 week	0-100	2.5

CLP = cleft lip and palate; CLA = cleft lip and alveolus; CL = cleft lip only; CP = cleft palate only; All diagnoses = CL, CLP, CLA, CP.

APPEARANCE

Cleft Lip Scar: This 7-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their cleft lip scar looks. Items ask about the appearance of the cleft scar in terms of shape, width, color, and size, as well as how the cleft scar looks when smiling, in photos, and in the mirror.

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.

Jaws: This 7-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their jaws look. Items ask about the shape and size of the jaws, how the jaws look in photos, and from the side.

Lips: This 9-item scale measures how much (not at all, a little, 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 the lips look when smiling and up close.

Nose: This 12-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their nose looks. Items ask about the size, shape, and length of the nose, as well as how the patient's nose looks in photos, from the side, and when smiling.

Nostrils: This 6-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their nostrils look. Items ask about the size, shape, and width of the nostrils.

Teeth: This 8-item scale measures how much (not at all, a little, quite a bit, very much) someone likes how their teeth look. Items ask about spacing, how straight the teeth look, as well as how the teeth look when smiling and up close.

FACIAL FUNCTION

Eating/Drinking: This 9-item checklist measures how often (never, sometimes, often, always) in the past week someone has problems with eating and drinking. Items ask about food or liquid nasal regurgitation, avoidance of certain foods, having to eat slowly, and difficulty biting certain foods.

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

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.

5. Administration of the CLEFT-Q

The CLEFT-Q is 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 to be completed. Patients can thus be asked to complete a subset of scales relevant to their situation. Brief instructions and the timeframe for reporting are provided at the start of each scale. The CLEFT-Q was 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 CLEFT-Q data collection, the ePRO company may need a license. If you have had CLEFT-Q scales converted into an electronic format and require an e-conversion review and certificate, please email qportfolioteam@gmail.com.

6. Scoring the CLEFT-Q

There is no overall or total CLEFT-Q score. Instead, the CLEFT-Q is composed of independently functioning scales and a checklist (see Table 2).

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 $\geq 50\%$ 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. Higher scores for CLEFT-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 the checklist, the raw scores for the items in a checklist can be used to identify problems experienced by a patient or a sample. The checklist does not have a Rasch Conversion Table 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 is no Conversion Table based on Rasch analysis, the checklist can provide clinically important information about eating/drinking problems.

7. Conditions of Use

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PLEASE NOTE

When you sign a CLEFT-Q license, you agree to the following terms:

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

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

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8. Frequently Asked Questions

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

A number of CLEFT-Q and FACE-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 CLEFT-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 CLEFT-Q scales?

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

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

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

According to the licensing agreement, you cannot reproduce the content of CLEFT-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 describing the CLEFT-Q field-test study [6].

Can I translate CLEFT-Q scales into a new language?

Yes, with permission, you can translate the CLEFT-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 methods you need to follow. Email us at qportfolioteam@gmail.com for more information. Please note that the developers of the CLEFT-Q own the copyright of all translations of the CLEFT-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 CLEFT-Q?

Use of CLEFT-Q scales is free for non-profit users. For-profit users should contact McMaster University for information about fees (milo@mcmaster.ca).

9. Acknowledgements

Development of the CLEFT-Q has involved more than 2000 children and young adults with cleft lip and/or palate, 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 CLEFT-Q study has been generously funded by the following grants:

Phase I: Qualitative

Wong KW, Klassen A, Forrest C. CLEFT-Q: Development of a Patient-Reported Outcome Measure for Cleft Lip and Palate. Canadian Society of Plastic Surgeons Outcomes/Clinical study Research Grant, July 2012 – June 2013.

Wong KW, Klassen A, Forrest C. CLEFT-Q: Development of a Patient-Reported Outcome Measure for Cleft Lip and Palate. Physician Services Incorporated Foundation Resident Grant, July 2010 – June 2011.

Phase II and Phase III: Field-Test and Psychometric Study

Klassen A, Wong K, Forrest C, Pusic A. An International Study to Develop a Patient-Reported Outcome Instrument for Cleft-Lip and/or Palate Patients: The CLEFT-Q. Canadian Institutes of Health Research (FRN 130515), July 2013 – August 2018.

Table 3: Shortened items for CLEFT-Q scales/checklist to use in a publication

CLEFT SCAR	mirror	SOCIAL
color	shape	friends accept
smile	tip	fun friends
width	profile	people listen
size	match	treat same
photo	NOSTRILS	like being with
shape	smile	confident out
mirror	mirror	fit in
FACE	size	make friends
look best	width	same others
go out	photo	people look
shape	shape	SPEECH DISTRESS
photos	TEETH	go out
match	size	make friends
smile	close together	teased
laugh	smile	frustrated
profile	profile	embarrassed
up close	straight	avoid
JAWS	show	nervous
size	up close	worry
shape	meet	repeat
mirror	PSYCHOLOGICAL	understood
photo	happy with life	EATING/DRINKING
closed	enjoy life	food falls
smile	feel happy	straw
profile	feel okay	certain foods
LIPS	believe in self	hard to chew
smile	proud of self	stuck in hole
size	like self	up nose
photo	feel confident	trouble biting
laugh	feel great	small bites
mirror	good look	eat slowly
closed	SCHOOL	SPEECH
shape	seeing friends	family
full	teachers	friends
up close	accepted	read aloud
NOSE	liked	some sentences
length	happy	avoid
smile	nice to me	phone
middle	listen to me	new people
size	safe	try hard
photo	make friends	repeat
straight	join activities	speak slow
width		concentrate
		some words

10. Publications Related to CLEFT-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.
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8. Harrison C, Geerards D, Offenhof M, Klassen AF, Riff KW, Swan MC, Pusic AL, Sidey-Gibbons CJ. Computerised adaptive testing accurately predicts CLEFT-Q scores by selecting fewer, more patient-focused questions. *J Plast Reconstr Aesthet Surg*. 2019 Nov; 72(11):1810-24.
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10. Longmire NM, Wong Riff KWY, Bhoomika P, O'Hara J, Goodacre TEE, Forrest C, Klassen AF. Development of a new module of the FACE-Q for children and young adults with diverse conditions associated with visible and/or functional facial differences. *Facial Plast Surg*. 2017 Oct;33(5):499-508.

11. Kamran R, Longmire NM, Rae C, Riff KWW, Forrest CR, O'Hara J, Bulstrode N, Klassen AF. Concepts Important to Patients With Facial Differences: A Qualitative Study Informing a New Module of the FACE-Q for Children and Young Adults. *Cleft Palate Craniofac J*. 2021 Aug;58(8):1020-1031.
12. Klassen AF, Rae C, Wong Riff KW, Bulstrode N, Denadai R, Goldstein J, Hol ML, Murray DJ, Bracken S, Courtemanche DJ, O'Hara J, Butler D, Tassi A, Malic CC, Ganske IM, Phua YS, Marucci DD, Johnson D, Swan MC, Breuning EE, Goodacre TE, Pusic AL, Cano S. FACE-Q Craniofacial Module: Part 1 validation of CLEFT-Q scales for use in children and young adults with facial conditions. *J Plast Reconstr Aesthet Surg*. 2021 Jun 10:S1748-6815(21)00292-8.
13. Klassen AF, Rae C, Riff W, Denadai R, Murray DJ, Bracken S, Courtemanche DJ, Bulstrode N, O'Hara J, Butler D, Goldstein J, Tassi A, Hol ML, Johnson D, Ganske IM, Kölby L, Benitez S, Breuning EE, Malic CC, Allen GC, Pusic AL, Cano S. FACE-Q craniofacial module: Part 2 Psychometric properties of newly developed scales for children and young adults with facial conditions. *J Plast Reconstr Aesthet Surg*. 2021 Mar 25:S1748-6815(21)00098-X.