

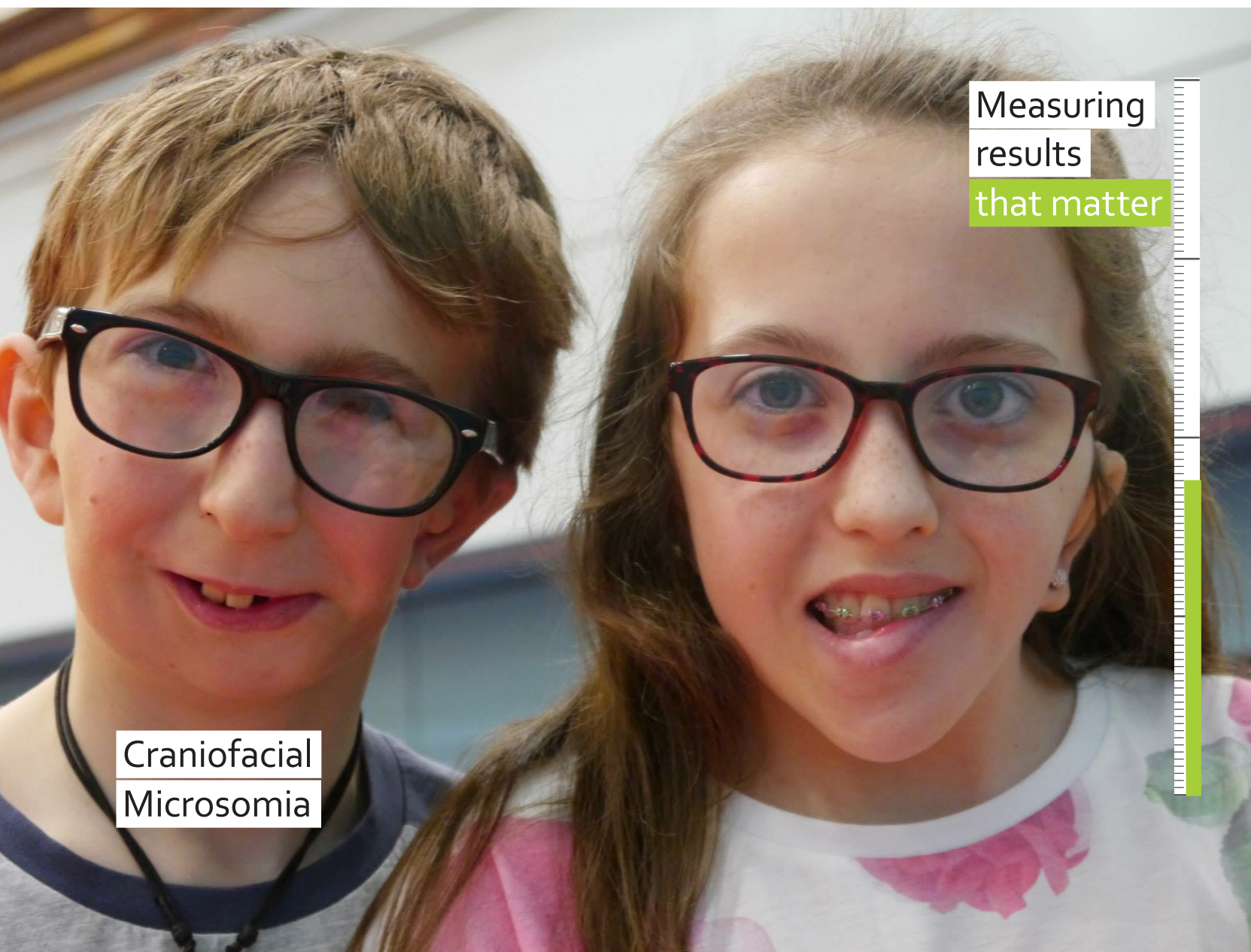


ICHOM

International Consortium for
Health Outcomes Measurement

CRANIOFACIAL MICROSOMIA DATA COLLECTION REFERENCE GUIDE

Version 1.0.4
Revised: April 18th, 2017



Measuring
results
that matter

Craniofacial
Microsomia



We are thrilled that you are interested in measuring outcomes for your patients with Craniofacial Microsomia according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. A comprehensive data dictionary, as well as scoring guides for patient-reported outcomes is included in the appendix.

Working Group Members for Craniofacial Microsomia

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Craniofacial Microsomia in partnership with ICHOM, under the leadership of Dr. Maarten Koudstaal and Dr. David Dunaway.

Australia Andrew Heggie	England Neil Bulstrode David Dunaway Justine O’Hara	Netherlands Linda Corel Maarten Koudstaal Sjoukje Loudon Petra Polulissen	South Africa Anil Madaree
Canada Christopher Forrest	France Thibaud Dumon	New Zealand Melissa Keesing Nicola Mills	United States Michael Cunningham Kristen Lowe Olivia Oppel Bonnie Padwa
China Hengyun Sun	India Anant Parameswaran	Scotland Emily Taylor	

Supporting Organizations

The Craniofacial Microsomia Standard Set is made possible only through the support of the following organizations.



Conditions and Treatment Approaches Covered for Craniofacial Microsomia

For Craniofacial Microsomia, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions*	<p>Patient population defined as: 2 major criteria or 1 major + 1 minor criteria or 3+ minor criteria</p> <p>Major criteria: Mandibular hypoplasia Microtia Orbital/facial bone hypoplasia Assymetric facial movement</p> <p>Minor criteria: Facial soft tissue deficiency Pre-auricular tags Macrostomia Clefting Epibulbar dermoids Hemivertabrae</p>
Treatment Approaches	<p>Plastic Surgery Maxillofacial Surgery Dentistry and Orthodontics Otolaryngology Ophthalmology Pediatrics Speech and Language Psychology/Psychiatry Nursing Feeding/Nutrition Audiology Social Care </p>

*Excluded diagnoses: Mandibulofacial dysostosis with microcephaly, Townes-Brocks Syndrome, Treacher Collins Syndrome, Auriculocondylar Syndrome, Bixler Syndrome, Branchiootorenal (BOR) Syndrome, CHARGE Syndrome, Miller Syndrome, Nager Syndrome, Oculoauriculofrontonasal Syndrome, Parry Rhomborg, Branchiooculofacial Syndromes (BOFS), isolated typical Tessier clefting (with no associated facial hypoplasia)

ICHOM Standard Set for Craniofacial Microsomia

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factors				
Patients with craniofacial microsomia	Gender	N/A	Age 2	Administrative data
	Age at first encounter with team			
	Race and ethnicity			
	Phenotype: Bilaterality	Tracked with PAT-CFM	All time points	Clinician-reported
	Phenotype: Severity			
	Phenotype: Asymmetry			
	Extracranial features	N/A	Age 2	
Syndrome/genetic diagnosis				
Family characteristics and community environment				
Patients with craniofacial microsomia	Parental education	N/A	Age 2	Administrative data
	Residence (post code)			
	Distance from treatment team			
	Loss of follow-up (peri-op)		2, 5, 8, 12, 22 years	
	Loss of follow-up (general)			
	Transferal of care			

Outcomes

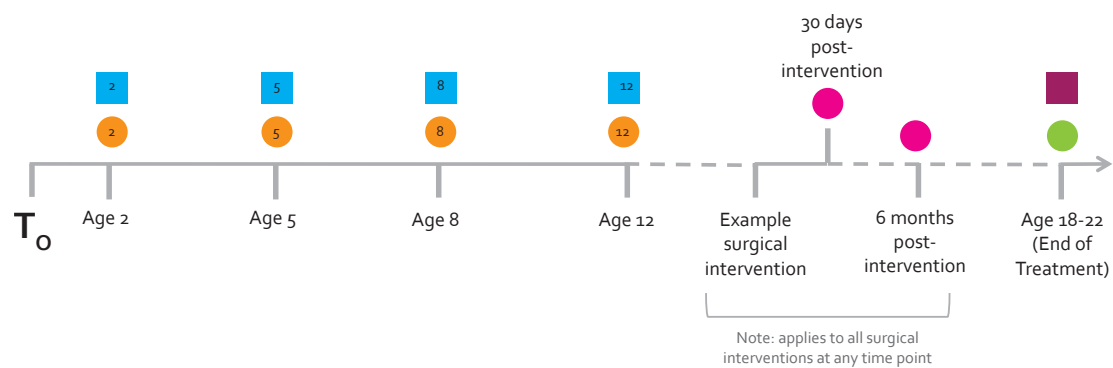
Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Psychosocial				
Patients with craniofacial microsomia	Psychometrics	Tracked with CleftQ	8, 12, 22 years	Patient/parent-reported
	Sociometrics	Psychological and Social Wellbeing		
	Behaviour/anxiety/depression/PTSD	Tracked with YP-CORE	12, 22 years	
		Tracked with HADS	22 years	
	Health-related quality of life	Tracked with CFEQ	12, 22 years	
	Family stress	Tracked with Distress Thermometer for Parents	2, 5, 8, 22 years	Parent-reported
Functional				
Patients with craniofacial microsomia	Airway/breathing	Tracked with Polysomnography	2 years	Clinician-reported
		Tracked with PSQ	5, 8, 12 years	Patient/parent-reported
		Yes/No Questions	2, 5, 8, 12, 22 years	
	Feeding/swallowing	Yes/No Questions	2, 5 years	
	Growth	Tracked with WHO/National growth chart	2, 5 years	Clinician-reported
	Hearing	Tracked with Audiogram	2, 5, 12, 22 years	Patient/parent-reported
		Yes/No Questions	2, 5, 8, 12, 22 years	
	Speech	Tracked with ICS	5 years	Clinician-reported
		Tracked with PCC	5, 8, 12, 22 years	
	Mastication and occlusion	Tracked with CleftQ Speech and Feeling about Speaking	8, 12, 22 years	Patient/parent-reported
		Tracked with CleftQ Eating and Drinking		
	Oral Health	Tracked with Cephalometrics	8, 22 years	Clinician-reported
		Tracked with DMFT	5, 12 years	
	Vision	Tracked with COHIP	12, 22 years	Patient/parent-reported
		Yes/No Questions	2, 5 years	

Appearance				
Patients with craniofacial microsomia	Facial form/profile	Tracked with PAT-CFM	5, 8, 12, 22 years	Clinician-reported
		Tracked with CleftQ Appearance	8, 12, 22 years	Patient/parent-reported
	Jaws	Tracked with PAT-CFM	5, 8, 12, 22 years	Clinician-reported
		Tracked with CleftQ Appearance	8, 12, 22 years	Patient/parent-reported
	Eyes	Tracked with PAT-CFM	5, 8, 12, 22 years	Clinician-reported
	Ears			Clinician-reported
	Smile/facial movement	Tracked with Ear HRQoL	8, 12, 22 years	Patient/parent-reported
		Tracked with PAT-CFM	5, 8, 12, 22 years	Clinician-reported
	Asymmetry	Tracked with CleftQ Appearance	8, 12, 22 years	Patient/parent-reported
		Tracked with PAT-CFM	12, 22 years	Clinician-reported

Burden of care				
Patients with craniofacial microsomia	Hospital appointments	NA	All between ages 2-22	Administrative data
	Hospital readmissions		Within 30d. All between ages 2-22.	
	Length of stay		All between ages 2-22	
	Activity limitations	Tracked with CFEQ	12, 22 years	Patient/parent-reported
	Complications	Adverse or unexpected event arising from intervention	30 days and 6 months post-operatively	Clinician-reported

Follow-Up Timeline and Sample Questionnaires

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.



- T_0 Entrance into outcome tracking system for CFM
- 2 2 Year Patient-Reported Form (link)
 - 2 2 Year Clinical Form (link)
 - 5 5 Year Patient-Reported Form (link)
 - 5 5 Year Clinical Form (link)
 - 8 8 Year Patient-Reported Form (link)
 - 8 8 Year Clinical Form (link)
 - Complications post-intervention (link)
 - 12 12 Year Patient-Reported Form (link)
 - 12 12 Year Clinical Form (link)
 - 18-22 Years Patient-Reported Form (link)
 - 18-22 Years Clinical Form (link)

Collecting Patient-, Parent-, and Clinician-Reported Outcome Measures

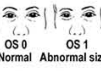
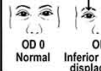


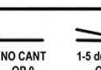
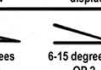
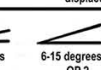
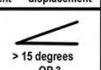
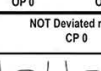
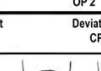
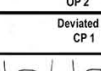
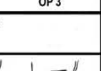
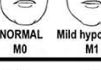
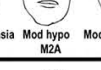
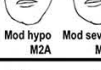
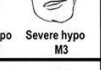
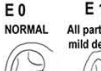
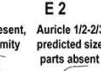
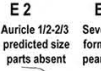
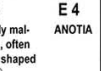

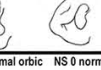

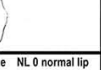




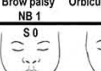



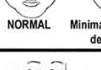
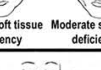
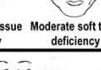



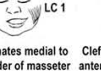

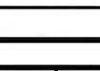
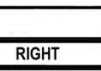
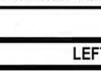
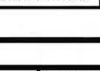
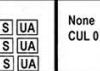
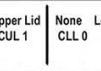
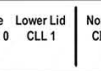
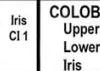
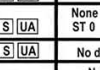
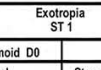
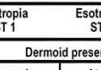
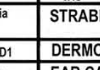
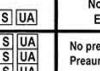
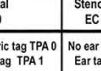
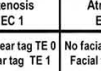

Survey Used	Licensing Information	Scoring Guide
Cleft Q - Patient/parent	The CLEFT-Q, authored by Drs Anne Klassen and Karen Wong, is the copyright of McMaster University (Copyright ©2015, McMaster University). The CLEFT-Q, provided under license from McMaster University may not be copied, distributed or used in any way without the prior written consent of McMaster University Contact the McMaster Industry Liason Office at: milo@mcmaster.ca for licensing details.	
Young Person - CORE - Patient/parent	The YP-CORE is free for all health care organizations, and a license is not needed.	
Hospital Anxiety and Depression Scale (HADS) - Patient	The HADS can be bought in paper format (British English) from GL Assessment or licensed from GL Assessment for research or study purposes via permissions@gl-assessment.co.uk , or from Mapi Research Trust for translations.	
Craniofacial Experiences Questionnaire (CFEQ) - Patient	The CFEQ is free for all health care organizations, and a license is not needed.	
Distress Thermometer - Parent	The Distress Thermometer is free for all health care organizations, and a license is not needed.	Scoring guides may be found on page 15
WHO Growth Charts - Clinician	The WHO Growth Charts are free for all health care organizations, and a license is not needed.	
Phenotypic Assessment Tool (PAT-CFM) - Clinician	The PAT-CFM is free for all health care organizations, and a license is not needed.	
Ear Health-Related Quality of Life (HRQoL) - Patient/parent	The Ear HRQoL is free for all health care organizations, and a license is not needed.	
COHIP Oral Symptoms Scale - Patient/parent	The COHIP is free for all health care organizations, and a license is not needed.	
Pediatric Sleep Questionnaire (PSQ) - Parent	The PSQ is free for all health care organizations, and a license is not needed.	
Intelligibility in Context Scale (ICS) - Parent/parent	The ICS is free for all health care organizations, and a license is not needed. It may be found at http://www.csu.edu.au/research/multilingual-speech/ics	
PCC - Clinician	The PCC is free for all health care organizations, and a license is not needed.	

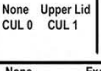
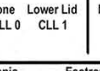
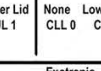
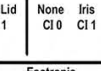
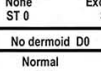
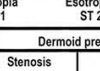
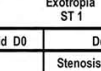

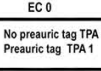
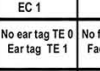
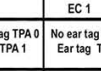
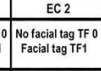
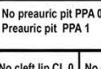
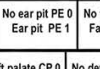
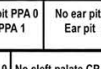
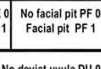
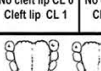
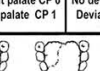
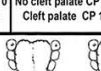
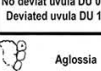
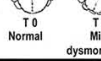
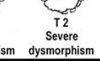

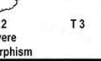
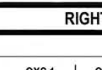
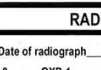
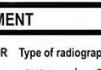
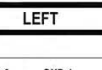
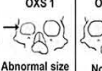
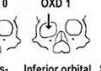
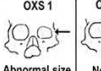
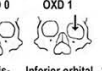
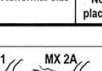
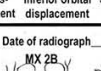
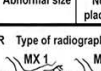
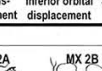



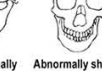
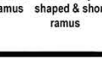
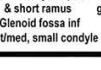
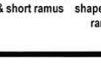
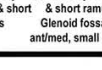
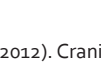

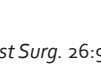
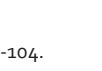
















The Phenotypic Assessment Tool-Craniofacial Microsomnia (PAT-CFM)

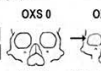
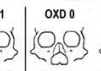
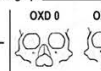
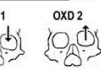
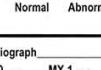
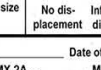
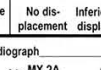
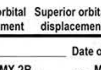




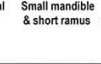
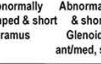
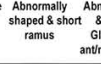
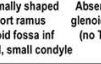
UA = unable to complete rating. Mark this box for any features you are unable to categorize. Also choose S (s/p surgery) and/or AT (atypical), if relevant.
S = status post surgery. Mark this if you observe surgical scars or obtain a history of prior surgery on this feature. DK to mark this and make a category choice, for all features except "Ear" and "Lateral Cleft".
AT = atypical. Mark this box if the feature does not fit precisely in one of the available categories, and select the closest code, if possible

Date: / / Rater: Ratings on: 2D 3D PAT contact sheet PE

Name: MRN: OR Study ID:

		RIGHT		GLOBAL ASSESSMENT		LEFT			
ORBIT	O Size								
	O Disp								
OCCLUSAL PLANE	OP								
CHIN POINT	CH								
MANDIBLE	NO XRAY								
	M								
EAR	E								
	E								
NERVE	NB								
	NO								
SOFT TISSUE	S								
	S								
LATERAL CLEFT	LC								
	LC								

		RIGHT		DETAILED ASSESSMENT		LEFT			
COLOBOMA	Upper lid								
	Lower lid								
STRABISMUS	ST								
	ST								
DERMOID	D								
	D								
EAR CANAL	EC								
	EC								
TAGS	TPA								
	TF								
PITS	PPA								
	PF								
CLEFT	CL								
	CP								
TONGUE	T								
	T								

		RIGHT		RADIOGRAPHIC ASSESSMENT		LEFT			
ORBIT XRAY	OXS								
	OXD								
MANDIBLE XRAY	MX								
	MX								

NOTES:

From Birgfield, C et al, (2012). Craniofacial Microsomnia. *Semin Plast Surg.* 26:91-104.

Table 5. This OMENS form used for this study was adapted from prior studies to enhance usability and optimize complete data collection for clinical studies.

This form is focused specifically on the common facial features that are associated with CFM, and does not include extracranial features (e.g. anomalies of the cervical spine anomalies, heart, and kidneys) that can occur frequently in children with CFM. Therefore, this tool is not intended to provide comprehensive phenotypic classification in CFM, but instead it is focused on optimizing complete and reliable data collected for common facial features.

Adapted from

Vento, A. R., et al. The O.M.E.N.S. classification of hemifacial microsomia. *The Cleft palate-craniofacial journal*. 28, 68-76; discussion 77, (1991).

Horgan, J. E., et al. . OMENS-Plus: analysis of craniofacial and extracraniofacial anomalies in hemifacial microsomia. *The Cleft palate-craniofacial journal*: 32, 405-412, (1995).

Gougoutas AJ, Singh DJ, Low DW, Bartlett SP. Hemifacial microsomia: Clinical features and pictographic representations of the OMENS classification system. *Plast Reconstr Surg*. 2007;120:112e–120e.)

Prior publications regarding the use of the revised pictorial OMENS characterization form for facial features:

Birgfeld CB, et al. A phenotypic assessment tool for craniofacial microsomia. *Plast Reconstr Surg* 2011, 127(1):313-320.

Birgfeld CB, et al. Comparison of Two-Dimensional and Three-Dimensional Images for Phenotypic Assessment of Craniofacial Microsomia. *Cleft Palate Craniofac J* 2012.

Heike CL, et al. Photographic Protocol for Image Acquisition in Craniofacial Microsomia. *Head Face Med* 2011, 7(1):25.

The multi-view imaging protocol enables raters to use multiple images to assess facial features.

Orbit

Malformations of the orbit in CFM commonly include small size, and/or displacement. The appearance of the orbit may be impacted by multiple factors, such as challenges identifying the midline plane in a child with significant facial asymmetry. This rating scale does not distinguish between degree of variation in size or displacement, and some degree of orbital asymmetry is common in the general population.

Occlusal plane

Adequate classification requires use of a tongue blade; however, the appearance of the tongue blade angle in the photos may not accurately reflect the degree of maxillary asymmetry. The ultimate classification should be based on the rater's interpretation of the most appropriate angle.

S/p surgery: Often unable to identify on images alone

Unable to rate: Mark this category if the tongue blade is not used or not properly positioned and the rater is unable to reliably approximate the symmetry of the maxillae.

Mandible

Mandibular asymmetry is a hallmark of CFM and is classically attributable to hypoplasia of the ramus. Mandibular hypoplasia can be difficult to evaluate on two-dimensional images. Our protocol incorporates multiple views of the mandible to enhance the rater's ability to characterize the mandible. Mild mandibular asymmetry can be common in the general population.

S/p surgery: Mark "yes" if evidence to suggest prior mandibular surgery. OK to rate on current image, despite history of surgery

Unable to rate: if feature is not well-visualized

Ear

CFM is frequently associated with various grades of microtia with or without absence of the external auditory meatus. We have incorporated profile, oblique, and frontal views to allow for assessment of ear size, shape, and position. This system relies on assessment of morphology, and does not account for measurements. Must see all parts of the ear to rate. Some clinicians do not consider grade 1 as microtia.

S/p surgery: should be used for all instances in which the original appearance of the ear has been modified by surgery. This feature cannot be rated if the ear has been significantly altered surgically.

Unable to rate: applied to all ears in which features (such as the helix) are obscured by hair, or the feature has been significantly altered surgically

Nerve

Facial palsies can involve any or all branches of the facial nerve and may be unilateral or bilateral. The photographic protocol includes series of images designed to capture the participant in a neutral expression, and well as animation that requires function of each branch of the facial nerve. It can be challenging on images to distinguish between asymmetric movement related to nerve function, and asymmetry that occurs as a result of the underlying structural malformations. Movement does not have to be symmetric to be considered functional. Given the challenges identifying nerve function on a series of static images, we classify "present" if images suggest true paralysis.

S/p surgery: typically unable to determine based on images

Unable to rate: Low threshold for not rating if inadequate images of animation are obtained

Soft Tissue

Deficiency of the soft tissue is common in CFM. As described for the mandible, capturing soft tissue deficiency and the resultant facial asymmetry can be challenging using a 2D images. For this reason, we've included several views of the face to allow for assessment of soft tissue asymmetry.

S/p surgery: Any evidence of scarring that could indicate prior surgery affecting this feature; OK to rate feature with or without evidence of prior surgery

Unable to rate: if feature is not well-visualized

Lateral Cleft (Macrostomia)

S/p surgery: OK to rate degree based on the location of the scar

Unable to rate: inadequate information to complete the rating with confidence, based on poor image or scarring that is not clearly related to prior cleft repair

Coloboma

S/p surgery: often challenging to identify on images

Unable to rate: Inadequate information to complete the rating with confidence

Strabismus

Typically based on the identification of an asymmetric corneal light reflex

S/p surgery: Not applicable to ratings based on photos

Unable to rate: Can be difficult to assess on photos

Dermoid

Can be difficult to assess on photos, particularly if eyes are not fully open and/or the dermoids have been treated surgically. Artifact on images is also common and may interfere with an accurate assessment

S/p surgery: often challenging to identify on images

Unable to rate: Inadequate information to complete the rating with confidence

Ear Canal

Can be challenging to obtain an adequate view of the canal on photos. Raters cannot identify ear canal stenosis on photos

S/p surgery: Mark this category if evidence of surgical ear/canal reconstruction

Unable to rate: Mark this category if the rater is unable to determine with certainty the presurgical appearance of the canal

Tags and Pits

S/p surgery: Mark this category if the rater identifies scars suggesting prior ear or soft tissue surgery in the location of preauricular or facial tags. If the surgical scars are characteristic for preauricular or facial tag removal, OK to also mark "present" and "s/p" surgery for these features.

Unable to rate: if evidence of prior surgery and the rater cannot identify the presurgical state.

Cleft lip

S/p surgery: OK to rate degree based on the scar

Unable to rate: Inadequate information to complete the rating with confidence

Cleft palate. The photographic protocol does not include an intraoral view, currently based only on physical exam.

S/p surgery: OK to rate degree based on the appearance of the scar

Unable to rate: Inadequate information to complete the rating with confidence

Tongue

Unable to rate: Mark this category if the views are insufficient to confidently classify the morphology of the tongue

































































Radiographic features: We have not formally tested the reliability of radiographic illustrations for the orbits and mandible.

Please contact daniela.luquetti@seattlechildrens.org or carrie.heike@seattlechildrens.org for more detailed questions

Guidance on using the PAT-CFM to measure case-mix variables

Asymmetry

Scoring: Recording of anomalies right and left. Calculate the differential of each score for asymmetry.

	RIGHT	GLOBAL ASSESSMENT	LEFT	
ORBIT O Size <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT O Disp <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	ORBIT O Size <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT O Disp <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
Occlusal plane OP: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	Occlusal plane OP: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
Chin point CH: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	 		 	Chin point CH: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
MANDIBLE NO XRAY M: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	MANDIBLE NO XRAY M: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
EAR E: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	EAR E: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
NERVE NB: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NO: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NS: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NL: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	NERVE NB: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NO: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NS: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NL: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
SOFT TISSUE S: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	SOFT TISSUE S: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
LATERAL CLEFT LC: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	  		  	LATERAL CLEFT LC: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT

Asymmetry

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1

3

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1

































































1

0

7

Bilaterality

Scoring: A check-box to indicate presence or absence of disease on each side of face.

	RIGHT	GLOBAL ASSESSMENT	LEFT	
ORBIT O Size <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT O Disp <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	ORBIT O Size <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT O Disp <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
Occlusal plane OP: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	Occlusal plane OP: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
Chin point CH: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	 		 	Chin point CH: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
MANDIBLE NO XRAY M: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	MANDIBLE NO XRAY M: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
EAR E: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	    		    	EAR E: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
NERVE NB: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NO: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NS: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NL: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	NERVE NB: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NO: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NS: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT NL: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
SOFT TISSUE S: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	   		   	SOFT TISSUE S: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT
LATERAL CLEFT LC: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT	  		  	LATERAL CLEFT LC: <input type="checkbox"/> UA <input type="checkbox"/> S <input type="checkbox"/> AT



Severity

Scoring: Recording of anomalies right and left. Sum to most severe side for each facial domain, to a maximum of 23 in total for severity

Severity

1

2

3



































































1

1

2

0

10

	RIGHT	GLOBAL ASSESSMENT	LEFT
ORBIT O Size <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> O Disp <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 OS 0  OS 1  OD 0  OD 1  OD 2	 OS 0  OS 1  OD 0  OD 1  OD 2	ORBIT O Size <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> O Disp <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Occlusal plane OP: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 NO CANT  1-5 degrees  6-15 degrees  15 degrees	 NO CANT  1-5 degrees  6-15 degrees  15 degrees	Occlusal plane OP: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Chin point CH: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 NOT Deviated right  Deviated right	 NOT deviated left  Deviated left	Chin point CH: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
MANDIBLE NO XRAY M: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 NORMAL  Mild hypoplasia  Mod hypo  Mod sev hypo  Severe hypo	 NORMAL  Mild hypoplasia  Mod hypo  Mod sev hypo  Severe hypo	MANDIBLE NO XRAY M: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
E AR E: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 E 0  E 1  E 2  E 3  E 4	 E 0  E 1  E 2  E 3  E 4	E AR E: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
NERVE NB: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NO: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NS: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NL: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 NB 0 normal  NB 1  NB 2  NB 3  NB 4	 NB 0 normal  NB 1  NB 2  NB 3  NB 4	NERVE NB: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NO: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NS: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> NL: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
SOFT TISSUE S: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 S 0  S 1  S 2  S 3	 S 0  S 1  S 2  S 3	SOFT TISSUE S: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
LATERAL CLEFT LC: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	 LC 0  LC 1  LC 2	 LC 0  LC 1  LC 2	LATERAL CLEFT LC: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at implement@ichom.org, or visit <http://www.ichom.org/measure>.

Appendix

Scoring Instructions for the Cleft Q

Please do not rely on this Reference Guide for CLEFT-Q content. The scales and specific scoring conversion tables are provided under license from McMaster University. Please note the CLEFT-Q includes illustrations to help with scoring. Please contact the McMaster Industry Liaison Office at milo@mcmaster.ca for details.

Scoring Instructions for the COHIP Oral Symptoms Scale

Sum the scores to get a minimum of 0 and a maximum of 20.

Scoring Instructions for the Intelligibility in Context Scale (ICS)

Scoring

The ICS is designed to be scored by SLPs. The total score is the average of the items completed. Scoring the ICS involves adding up all of the ratings indicated by the parent and dividing that number by seven. This creates an overall mean (average) score for the measure.

It is important to ensure that all 7 items have been completed. If parents do not complete an item (e.g., parents may not complete item 6 if their child does not attend school/preschool), then calculate the average score out of the number of completed items.

Analysis

ICS scores indicate a child’s level of functional intelligibility, ranging from a score of 1.00 (low intelligibility) to a score of 5.00 (high intelligibility). If a child achieves an average score of 3.5, then it may be appropriate to indicate that the child is usually to sometimes understood.

Please note. Research is currently unavailable to determine the level/score at which a child’s intelligibility begins to impact children’s everyday communication.

Scoring Instructions for the PCC

Scoring

Scoring is the percent consonants out of a restricted number of target consonants. The PCC is designed to be scored by SLPs. The total score is the percentage of the items (target consonants) produced correctly. Scoring involves transcription/assessment of target consonant productions in a restricted single word list. The words should be elicited by naming pictures or by reading the words.

Analysis

PCC scores indicate the patient’s level of articulation proficiency.

Please note. Reference data should preferably be collected within a given language. Until then, preliminary normative scores for Swedish are recommended.

5 years:	12 years:	22 years:
Normal (-1 s.d.);	Normal (-1 s.d.)	Normal (-1 s.d.)
Not normal (<-1 s.d. = <91%)	Not normal (<-1 s.d. = <95%)	Not normal (<-1 s.d.) = (<98%)

Scoring Instructions for the PAT-CFM

For asymmetry

Scoring: Recording of anomalies right and left for each feature of the global assessment of the PAT CFM.

Calculate the difference between each score then sum for complete asymmetry. (All timepoints, appraising outcome).

For severity

Scoring: Recording of anomalies right and left for each feature of the global assessment of the PAT CFM. Sum the most severe side for each facial feature, to a maximum 19 in total for severity. (At initial assessment)

Example: Using the PAT-CFM to score asymmetry and severity -

Severity		GLOBAL ASSESSMENT										Asymmetry
		RIGHT					LEFT					
2	ORBIT	O0	O1	O2	O3	O4	O0	O1	O2	O3	O4	2
	S/P SURGERY UNABLE	NORMAL	Abnormal size	Inferior orbital displacement	Superior orbital displacement	Abnormal orbital size and position	NORMAL	Abnormal size	Inferior orbital displacement	Superior orbital displacement	Abnormal orbital size and position	
2	OCCLUSAL PLANE	OP0	OP1	OP2	OP3		OP0	OP1	OP2	OP3		1
	S/P SURGERY UNABLE	NO CANT	1-5 degrees	6-15 degrees	> 15 degrees		NO CANT	1-5 degrees	6-15 degrees	> 15 degrees		
3	MANDIBLE NO XRAY	M0	M1	M2A	M2B	M3	M0	M1	M2A	M2B	M3	2
	S/P SURGERY UNABLE	NORMAL	Mild asym	Moderate asym	Mod Severe asym	Severe asym	NORMAL	Mild asym	Moderate asym	Mod Severe asym	Severe asym	
1	EAR	E0	E1	E2	E3	E4	E0	E1	E2	E3	E4	0
	S/P SURGERY UNABLE	NORMAL	All parts present, mild deformity	Auricle 1/2-2/3 of predicted size, not all parts present	Severely malformed, often peanut shaped	ANOTIA	NORMAL	All parts present, mild deformity	Auricle 1/2-2/3 of predicted size, not all parts present	Severely malformed, often peanut shaped	ANOTIA	
1	NERVE	N0	N1	N2	N3	N4	N0	N1	N2	N3	N4	1
	S/P SURGERY UNABLE	ALL NORMAL	Normal brow unaltered	Orbital palsy Normal orbital unaltered	Smile palsy Normal smile unaltered	Lower lip palsy Normal lip unaltered	ALL NORMAL	Normal brow unaltered	Orbital palsy Normal orbital unaltered	Smile palsy Normal smile unaltered	Lower lip palsy Normal lip unaltered	
2	SOFT TISSUE	S0	S1	S2	S3		S0	S1	S2	S3		1
	S/P SURGERY UNABLE	NORMAL	Minimal soft tissue deficiency	Moderate soft tissue deficiency	Severe soft tissue deficiency		NORMAL	Minimal soft tissue deficiency	Moderate soft tissue deficiency	Severe soft tissue deficiency		
0	CLEFTING	C0	C1	C2			C0	C1	C2			0
	S/P SURGERY UNABLE	NO CLEFT	Cleft terminates medial to anterior border of masseter	Cleft terminates lateral to anterior border of masseter			NO CLEFT	Cleft terminates medial to anterior border of masseter	Cleft terminates lateral to anterior border of masseter			
NOTES:												
11		Fig. 1. Global Assessment of the modified pictorial OMENS-Plus classification system (page 1). (Adapted from Gougoutas AJ, Singh DJ, Low DW, Bartlett SP. Hemifacial microsomia: Clinical features and pictographic representations of the OMENS classification system. <i>Plast Reconstr Surg.</i> 2007;120:112e–120e.)										7

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Craniofacial Microsomia Standard Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **We are happy to provide an Excel version of this data dictionary for technical use.**

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

CASE-MIX VARIABLES

Variable ID:	N/A
Variable:	Patient ID
Definition:	Indicate the patient's medical record number
Supporting Definition:	This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	On all forms
Reporting Source:	Administrative data
Type:	Numerical
Response Options:	According to institution

Patient Characteristics

Variable ID:	FIRSTENC
Variable:	Age at first encounter with team
Definition:	Indicate the patient's age at first encounter with team
Supporting Definition:	Recorded in months at 24 months and younger. Recorded in years if older than 24 months
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Numerical value
Response Options:	Numerical value
Variable ID:	SEX
Variable:	Sex
Definition:	Indicate the patient's sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Single answer

Response Options:	1 = Male 2 = Female 999 = Undisclosed
Variable ID:	ETNIC
Variable:	Race/ethnicity
Definition:	Varies by country and should be determined by country (not for cross-country comparison)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	N/A
Variable ID:	PHENBIL
Variable:	Phenotype: Bilaterality
Definition:	Is the patient affected bilaterally?
Supporting Definition:	Tracked with PAT-CFM
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	PHENASYM
Variable:	Phenotype: Asymmetry
Definition:	Please calculate Asymmetry score?
Supporting Definition:	Tracked with PAT-CFM
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	All time points
Reporting Source:	Clinician-reported
Type:	Numerical value
Response Options:	Numerical value
Variable ID:	PHENSEV
Variable:	Phenotype: Severity
Definition:	Please calculate severity score:
Supporting Definition:	Tracked with PAT-CFM
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Clinician-reported
Type:	Numerical value
Response Options:	Numerical value
Variable ID:	PHENEXT
Variable:	Extracranial features
Definition:	Please indicate extracranial features per system:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Clinician-reported
Type:	Multiple answer
Response Options:	1 = Cardiac 2 = Renal 3 = Nervous system 4 = Digestive 5 = Skeletal 6 = Respiratory
Variable ID:	GENETICSYN

Variable:	Syndrome/genetic diagnosis
Definition:	Indicate if the patient has a genetically confirmed mutation, known to be associated with craniofacial microsomia?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

Variable ID:	GENETICDIAG
Variable:	Syndrome/genetic mutation
Definition:	Indicate which mutation:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	Free text

Family characteristics and community environment

Variable ID:	PAREducation
Variable:	Parent education
Definition:	Please indicate your highest level of schooling completed (level of schooling defined in each country as per ISCED [International Standard Classification of Education])
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = None 1 = Primary 2 = Secondary 3 = Tertiary
Variable ID:	RES
Variable:	Residence
Definition:	Geographic location where the patient resides, specified by country and country specific postal code.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Alphanumeric value
Response Options:	Alphanumeric entry
Variable ID:	DIST
Variable:	Distance from treatment team
Definition:	Specify the distance in km from treatment team
Supporting Definition:	Calculated from residence and hospital location
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2 years
Reporting Source:	Administrative data
Type:	Numerical value
Response Options:	Numerical value of distance in km
Variable ID:	LOSSFUPERI
Variable:	Lost to follow-up (perioperative)

Definition:	Indicate if there is a circumstance in which the patient has not presented for routine scheduled follow-up in the perioperative period ("no-show") despite 3 attempts
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	LOSSFUGEN
Variable:	Lost to follow-up (general)
Definition:	Indicate if the patient has missed three (3) routine scheduled appointments or more prior to being officially discharged from clinic
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	TOCIN
Variable:	Transferal of care into your institution
Definition:	Indicate if the patient has been transferred to your institution after care was begun elsewhere
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	TOCOUT
Variable:	Transferal of care out of your institution
Definition:	Indicate if the patient has been transferred out of your institution to receive care elsewhere and thus has ceased to have follow-up at your institution
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes

Outcomes

Psychometrics and Sociometrics

Variable ID:	CLEFTQSOCLIFE_Qo1
Variable:	Question 1 of Cleft-Q Social Function
Definition:	HOW IS YOUR SOCIAL LIFE? Answer each question by circling one number. Please answer thinking of the PAST WEEK. 1: My friends accept me.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo2
Variable:	Question 2 of Cleft-Q Social Function
Definition:	2: I have fun with friends.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo3
Variable:	Question 3 of Cleft-Q Social Function
Definition:	3: People listen to what I have to say.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo4
Variable:	Question 4 of Cleft-Q Social Function
Definition:	4: People treat me the same as everyone else.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always

Variable ID:	CLEFTQSOCLIFE_Qo5
Variable:	Question 5 of Cleft-Q Social Function
Definition:	5: I like being with other people.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo6
Variable:	Question 6 of Cleft-Q Social Function
Definition:	6: I feel confident when I go out (like to a party).
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo7
Variable:	Question 7 of Cleft-Q Social Function
Definition:	7: I feel like I fit in.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo8
Variable:	Question 8 of Cleft-Q Social Function
Definition:	8: It's easy for me to make friends.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Qo9
Variable:	Question 9 of Cleft-Q Social Function
Definition:	9: I feel the same as other people my age.
Supporting Definition:	N/A

Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSOCLIFE_Q10
Variable:	Question 10 of Cleft-Q Social Function
Definition:	10: It's okay when people look at my face.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Q01
Variable:	Question 1 of Cleft-Q School Function
Definition:	HOW IS YOUR SCHOOL LIFE? Answer each question by circling one number. Please answer thinking of the PAST WEEK (Note: if you were not in school this week, think about when you were last in school). 1: I like seeing my friends at school.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Q02
Variable:	Question 2 of Cleft-Q School Function
Definition:	2: My teachers treat me well.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Q03
Variable:	Question 3 of Cleft-Q School Function
Definition:	3: I feel accepted at school.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip

	and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo4
Variable:	Question 4 of Cleft-Q School Function
Definition:	4: Other students like me.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo5
Variable:	Question 5 of Cleft-Q School Function
Definition:	5: I am happy at school.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo6
Variable:	Question 6 of Cleft-Q School Function
Definition:	6: Other students are nice to me.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo7
Variable:	Question 7 of Cleft-Q School Function
Definition:	7: Other students listen to me when I talk.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer

Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo8
Variable:	Question 8 of Cleft-Q School Function
Definition:	8: I feel safe at school (not bullied).
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Qo9
Variable:	Question 9 of Cleft-Q School Function
Definition:	9: It's easy for me to make friends.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQSCHLIFE_Q10
Variable:	Question 10 of Cleft-Q School Function
Definition:	10: I get asked to join activities and games at school.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Qo1
Variable:	Question 1 of Cleft-Q Psychological Function
Definition:	HOW DO YOU FEEL? Answer each question by circling one number. Please answer thinking of the PAST WEEK. 1: I am happy with my life.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes

	3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q02
Variable:	Question 2 of Cleft-Q Psychological Function
Definition:	2: I enjoy life.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q03
Variable:	Question 3 of Cleft-Q Psychological Function
Definition:	3: I feel happy.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q04
Variable:	Question 4 of Cleft-Q Psychological Function
Definition:	4: I feel okay about myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q05
Variable:	Question 5 of Cleft-Q Psychological Function
Definition:	5: I believe in myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q06
Variable:	Question 6 of Cleft-Q Psychological Function

Definition:	6: I am proud of myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Qo7
Variable:	Question 7 of Cleft-Q Psychological Function
Definition:	7: I like myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Qo8
Variable:	Question 8 of Cleft-Q Psychological Function
Definition:	8: I feel confident.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Qo9
Variable:	Question 9 of Cleft-Q Psychological Function
Definition:	9: I feel great about myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Never 2 = Sometimes 3 = Often 4 = Always
Variable ID:	CLEFTQFEEL_Q10
Variable:	Question 10 of Cleft-Q Psychological Function
Definition:	10: I feel good about how I look.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip

Timing: 12 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Never
 2 = Sometimes
 3 = Often
 4 = Always

Health-related Quality of Life

Variable ID:	CFEQYASTR_Q1
Variable:	Question 1 of CFEQ_YA Stressor
Definition:	Here is a list of things which people with a craniofacial condition sometimes have to deal with. I am interested in what you have had to deal with. Please read each problem and think if this has happened to you in the last year. Tick the box that says how often it has happened. 1. Having difficulty being accepted as a friend by others my age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q2
Variable:	Question 2 of CFEQ_YA Stressor
Definition:	2. Not being invited to do things with others my age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q3
Variable:	Question 3 of CFEQ_YA Stressor
Definition:	3. Worrying that I will have trouble finding a boyfriend girlfriend
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q4
Variable:	Question 4 of CFEQ_YA Stressor
Definition:	4. Being asked questions by people about my craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported

Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q5
Variable:	Question 5 of CFEQ_YA Stressor
Definition:	5. Having people make comments about my craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q6
Variable:	Question 6 of CFEQ_YA Stressor
Definition:	6. Being stared at by people I don't know
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q7
Variable:	Question 7 of CFEQ_YA Stressor
Definition:	7. Being teased because of my craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q8
Variable:	Question 8 of CFEQ_YA Stressor
Definition:	8. Having problems with my school work
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q9
Variable:	Question 9 of CFEQ_YA Stressor
Definition:	9. Not being able to do things as well as others my age

Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q10
Variable:	Question 10 of CFEQ_YA Stressor
Definition:	10. People having trouble understanding what I say
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q11
Variable:	Question 11 of CFEQ_YA Stressor
Definition:	11. Having problems doing things like catching a ball or playing sport
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q12
Variable:	Question 12 of CFEQ_YA Stressor
Definition:	12. Having problems with pain
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q13
Variable:	Question 13 of CFEQ_YA Stressor
Definition:	13. Having problems with getting tired
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often

	3 = Always
Variable ID:	CFEQYASTR_Q14
Variable:	Question 14 of CFEQ_YA Stressor
Definition:	14. Having trouble finding a doctor or dentist to help with my treatment who is close to where I live
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q15
Variable:	Question 15 of CFEQ_YA Stressor
Definition:	15. Missing out on school because of being at the hospital or at appointments
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q16
Variable:	Question 16 of CFEQ_YA Stressor
Definition:	16. Not wanting to have treatment that my doctors want me to have
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q17
Variable:	Question 17 of CFEQ_YA Stressor
Definition:	17. Having an operation which I was worried or stressed about
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q18
Variable:	Question 18 of CFEQ_YA Stressor
Definition:	18. Not liking the way I look
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years

Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q19
Variable:	Question 19 of CFEQ_YA Stressor
Definition:	19. Thinking about why I have a craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYASTR_Q20
Variable:	Question 20 of CFEQ_YA Stressor
Definition:	20. Trying to wear my clothes or hair or holding my head so you can't notice my craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q1
Variable:	Question 1 of CFEQ_YA Positive
Definition:	Now here is a list of good things that sometimes happen to people with a craniofacial condition or qualities they can have. Please read each good thing, think if this has applied to you in the last year and tick the box that says how often it has happened. 1. Being able to do things that other people can't do because of the way my craniofacial condition has made my body
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q2
Variable:	Question 2 of CFEQ_YA Positive
Definition:	2. Being kinder to people than other young people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer

Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q3
Variable:	Question 3 of CFEQ_YA Positive
Definition:	3. Getting more out of life than other young people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q4
Variable:	Question 4 of CFEQ_YA Positive
Definition:	4. Being more independent than other young people my age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q5
Variable:	Question 5 of CFEQ_YA Positive
Definition:	5. Being more understanding of other people with a disability than others
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q6
Variable:	Question 6 of CFEQ_YA Positive
Definition:	6. Being nicer to people who are different in some way
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q7
Variable:	Question 7 of CFEQ_YA Positive
Definition:	7. Feeling closer to God than other young people
Supporting Definition:	N/A

Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q8
Variable:	Question 8 of CFEQ_YA Positive
Definition:	8. Getting help with my school work
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q9
Variable:	Question 9 of CFEQ_YA Positive
Definition:	9. Getting support from my doctors and other people in the hospital
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q10
Variable:	Question 10 of CFEQ_YA Positive
Definition:	10. Getting to meet famous or important people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q11
Variable:	Question 11 of CFEQ_YA Positive
Definition:	11. Getting to do special things for people with a disability (like camps or sports)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always

Variable ID:	CFEQYAPOS_Q12
Variable:	Question 12 of CFEQ_YA Positive
Definition:	12. Getting special presents or treats
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q13
Variable:	Question 13 of CFEQ_YA Positive
Definition:	13. Getting extra attention
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q14
Variable:	Question 14 of CFEQ_YA Positive
Definition:	14. My family getting closer because of my craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q15
Variable:	Question 15 of CFEQ_YA Positive
Definition:	15. Helping other people be more aware of people with disabilities
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q16
Variable:	Question 16 of CFEQ_YA Positive
Definition:	16. Helping other young people know how to relate to people who are different in some way
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported

Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q17
Variable:	Question 17 of CFEQ_YA Positive
Definition:	17. Making friends more easily than other young people do
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q18
Variable:	Question 18 of CFEQ_YA Positive
Definition:	18. Having more really strong friendships than others my age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQYAPOS_Q19
Variable:	Question 19 of CFEQ_YA Positive
Definition:	19. Feeling good 'cos I know that the doctors are keeping a close eye on me so if there is something wrong, it won't get missed
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q1
Variable:	Question 1 of CFEQ_Carer Stressor
Definition:	Here is a list of things which people with a craniofacial condition sometimes have to deal with. I am interested in what your son or daughter has had to deal with. Please read each problem and think if this has happened to them in the last year. Tick the box that says how often it has happened. 1. Having difficulty being accepted as a friend by others their age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes

	2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q2
Variable:	Question 2 of CFEQ_Carer Stressor
Definition:	2. Not being invited to do things with others their age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q3
Variable:	Question 3 of CFEQ_Carer Stressor
Definition:	3. Worrying that they will have trouble finding a boyfriend or girlfriend
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q4
Variable:	Question 4 of CFEQ_Carer Stressor
Definition:	4. Being asked questions by people about their craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q5
Variable:	Question 5 of CFEQ_Carer Stressor
Definition:	5. Having people make comments about their craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q6
Variable:	Question 6 of CFEQ_Carer Stressor
Definition:	6. Being stared at by people they don't know
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years

Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARSTR_Q7
Variable: Question 7 of CFEQ_Carer Stressor
Definition: 7. Being teased because of their craniofacial condition
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARSTR_Q8
Variable: Question 8 of CFEQ_Carer Stressor
Definition: 8. Having problems with their school work
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARSTR_Q9
Variable: Question 9 of CFEQ_Carer Stressor
Definition: 9. Not being able to do things as well as others their age
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARSTR_Q10
Variable: Question 10 of CFEQ_Carer Stressor
Definition: 10. People having trouble understanding what they say
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARSTR_Q11
Variable: Question 11 of CFEQ_Carer Stressor

Definition:	11. Having problems doing things like catching a ball or playing sport
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q12
Variable:	Question 12 of CFEQ_Carer Stressor
Definition:	12. Having problems with pain
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q13
Variable:	Question 13 of CFEQ_Carer Stressor
Definition:	13. Having problems with getting tired
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q14
Variable:	Question 14 of CFEQ_Carer Stressor
Definition:	14. Having trouble finding a doctor or dentist to help their treatment who is close to where you live
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q15
Variable:	Question 15 of CFEQ_Carer Stressor
Definition:	15. Missing out on school because of being at the hospital or at appointments
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never

	1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q16
Variable:	Question 16 of CFEQ_Carer Stressor
Definition:	16. Not wanting to have treatment that their doctors want them to have
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q17
Variable:	Question 17 of CFEQ_Carer Stressor
Definition:	17. Having an operation which they were worried or stressed about
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q18
Variable:	Question 18 of CFEQ_Carer Stressor
Definition:	18. Not liking the way they look
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q19
Variable:	Question 19 of CFEQ_Carer Stressor
Definition:	19. Thinking about why they have a craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARSTR_Q20
Variable:	Question 20 of CFEQ_Carer Stressor
Definition:	20. Trying to wear their clothes or hair or holding their head so you can't notice their craniofacial condition
Supporting Definition:	N/A

Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q1
Variable:	Questions 1 of CFEQ_Carer Positive
Definition:	Now here is a list of good things that sometimes happen to people with a craniofacial condition or qualities they can have. Please read each good thing, think if this has applied to you in the last year and tick the box that says how often it has happened. 1. Being able to do things that other people can't do because of the way the craniofacial condition has made their body
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q2
Variable:	Questions 2 of CFEQ_Carer Positive
Definition:	2. Being kinder to people than other young people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q3
Variable:	Questions 3 of CFEQ_Carer Positive
Definition:	3. Getting more out of life than other young people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q4
Variable:	Questions 4 of CFEQ_Carer Positive
Definition:	4. Being more independent than other young people their age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported

Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q5
Variable:	Questions 5 of CFEQ_Carer Positive
Definition:	5. Being more understanding of other people with a disability than others
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q6
Variable:	Questions 6 of CFEQ_Carer Positive
Definition:	6. Being nicer to people who are different in some way
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q7
Variable:	Questions 7 of CFEQ_Carer Positive
Definition:	7. Feeling closer to God than other young people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q8
Variable:	Questions 8 of CFEQ_Carer Positive
Definition:	8. Getting help with their school work
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q9
Variable:	Questions 9 of CFEQ_Carer Positive
Definition:	9. Getting support from their doctors and other people in the hospital

Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q10
Variable:	Questions 10 of CFEQ_Carer Positive
Definition:	10. Getting to meet famous or important people
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q11
Variable:	Questions 11 of CFEQ_Carer Positive
Definition:	11. Getting to do special things for people with a disability (like camps or sports)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q12
Variable:	Questions 12 of CFEQ_Carer Positive
Definition:	12. Getting special presents or treats
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q13
Variable:	Questions 13 of CFEQ_Carer Positive
Definition:	13. Getting extra attention
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often

	3 = Always
Variable ID:	CFEQCARPOS_Q14
Variable:	Questions 14 of CFEQ_Carer Positive
Definition:	14. Their family getting closer because of their craniofacial condition
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q15
Variable:	Questions 15 of CFEQ_Carer Positive
Definition:	15. Helping other people be more aware of people with disabilities
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q16
Variable:	Questions 16 of CFEQ_Carer Positive
Definition:	16. Helping other young people know how to relate to people who are different in some way
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q17
Variable:	Questions 17 of CFEQ_Carer Positive
Definition:	17. Making friends more easily than other young people do
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Sometimes 2 = Often 3 = Always
Variable ID:	CFEQCARPOS_Q18
Variable:	Questions 18 of CFEQ_Carer Positive
Definition:	18. Having more really strong friendships than others their age
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years

Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Variable ID: CFEQCARPOS_Q19
Variable: Questions 19 of CFEQ_Carer Positive
Definition: 19. Feeling good 'cos they know that the doctors are keeping a close eye on them so if there is something wrong, it won't get missed
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = Never
 1 = Sometimes
 2 = Often
 3 = Always

Family Stress

Variable ID: DT-P_Q01
Variable: Question 1 of Distress Thermometer for Parents
Definition: Please indicate on the thermometer which number best describes 0-10 how much distress you have been experiencing in the past week (including today) physically, emotionally, socially and practically in general.
Supporting Definition: N/A
Inclusion Criteria: Parents of patients with craniofacial microsomia
Timing: 2, 5, 8, 12 years
Reporting Source: Parent-reported
Type: Single answer
Response Options: 0 = no distress at all
 1 = 1
 2 = 2
 3 = 3
 4 = 4
 5 = 5
 6 = 6
 7 = 7
 8 = 8
 9 = 9
 10 = extreme distress

Variable ID: DT-P_Q02
Variable: Question 2 of Distress Thermometer for Parents
Definition: Please indicate by checking yes or no if any of the following has been a problem for you in the past week (including today). Be sure to check YES or NO for each item.
 Practical Problems
 1. Housing
Supporting Definition: N/A
Inclusion Criteria: Parents of patients with craniofacial microsomia
Timing: 2, 5, 8, 12 years
Reporting Source: Parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes

Variable ID: DT-P_Q03

Variable:	Question 3 of Distress Thermometer for Parents
Definition:	2. Work/study
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Qo4
Variable:	Question 4 of Distress Thermometer for Parents
Definition:	3. Finances/insurance
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Qo5
Variable:	Question 5 of Distress Thermometer for Parents
Definition:	4. Housekeeping
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Qo6
Variable:	Question 6 of Distress Thermometer for Parents
Definition:	5. Transport
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Qo7
Variable:	Question 7 of Distress Thermometer for Parents
Definition:	6. Child care/child supervision
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Qo8
Variable:	Question 8 of Distress Thermometer for Parents
Definition:	7. Leisure activities/relaxing
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported

Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q09
Variable:	Question 9 of Distress Thermometer for Parents
Definition:	Family/social problems 1. Dealing with (ex)partner
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q10
Variable:	Question 10 of Distress Thermometer for Parents
Definition:	2. Dealing with family
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q11
Variable:	Question 11 of Distress Thermometer for Parents
Definition:	3. Dealing with friends
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q12
Variable:	Question 12 of Distress Thermometer for Parents
Definition:	4. Interacting with your child(ren)
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q13
Variable:	Question 13 of Distress Thermometer for Parents
Definition:	Emotional Problems 1. Keeping emotions under control
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q14

Variable:	Question 14 of Distress Thermometer for Parents
Definition:	2. Self-confidence
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q15
Variable:	Question 15 of Distress Thermometer for Parents
Definition:	3. Fears
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q16
Variable:	Question 16 of Distress Thermometer for Parents
Definition:	4. Depression
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q17
Variable:	Question 17 of Distress Thermometer for Parents
Definition:	5. Feeling tense or nervous
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q18
Variable:	Question 18 of Distress Thermometer for Parents
Definition:	6. Loneliness
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q19
Variable:	Question 19 of Distress Thermometer for Parents
Definition:	7. Feelings of guilt
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported

Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q20
Variable:	Question 20 of Distress Thermometer for Parents
Definition:	8. Use of substances (e.g. use of alcohol, drugs, and/or medication)
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q21
Variable:	Question 21 of Distress Thermometer for Parents
Definition:	9. Intrusive/recurrent thoughts about a specific event
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q22
Variable:	Question 22 of Distress Thermometer for Parents
Definition:	Physical Problems 1. Eating
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q23
Variable:	Question 23 of Distress Thermometer for Parents
Definition:	2. Weight
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q24
Variable:	Question 24 of Distress Thermometer for Parents
Definition:	3. Sleep
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q25
Variable:	Question 25 of Distress Thermometer for Parents

Definition:	4. Fatigue
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q26
Variable:	Question 26 of Distress Thermometer for Parents
Definition:	5. Out of shape/condition
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q27
Variable:	Question 27 of Distress Thermometer for Parents
Definition:	6. Pain
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q28
Variable:	Question 28 of Distress Thermometer for Parents
Definition:	7. Sexuality
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q29
Variable:	Question 29 of Distress Thermometer for Parents
Definition:	Cognitive Problems 1. Concentration
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q30
Variable:	Question 30 of Distress Thermometer for Parents
Definition:	2. Memory
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported

Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q31
Variable:	Question 31 of Distress Thermometer for Parents
Definition:	Parenting your child that is (has been) receiving treatment in the (children's) hospital <2 years old child 1. Feeling connected with your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q32
Variable:	Question 32 of Distress Thermometer for Parents
Definition:	2. Caring for your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q33
Variable:	Question 33 of Distress Thermometer for Parents
Definition:	3. Feeding your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q34
Variable:	Question 34 of Distress Thermometer for Parents
Definition:	4. Development of your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q35
Variable:	Question 35 of Distress Thermometer for Parents
Definition:	5. Following advice about treatment/Giving your child his/her medication
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

Variable ID:	DT-P_Q36
Variable:	Question 36 of Distress Thermometer for Parents
Definition:	6. Your child's sleeping
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q37
Variable:	Question 37 of Distress Thermometer for Parents
Definition:	7. Behavior/crying of your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q38
Variable:	Question 38 of Distress Thermometer for Parents
Definition:	≥ 2 years old child 1. Dealing with your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q39
Variable:	Question 39 of Distress Thermometer for Parents
Definition:	2. Dealing with the feelings of your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q40
Variable:	Question 40 of Distress Thermometer for Parents
Definition:	3. Talking about the disease/consequences with child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q41
Variable:	Question 41 of Distress Thermometer for Parents
Definition:	4. Independence of your child
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia

Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q42
Variable:	Question 42 of Distress Thermometer for Parents
Definition:	5. Following advice about treatment/Giving your child his/her medication
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q43
Variable:	Question 43 of Distress Thermometer for Parents
Definition:	Additional questions 1a. Do you feel you receive enough support from people around you?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q44
Variable:	Question 44 of Distress Thermometer for Parents
Definition:	1b. (If yes) What kind of support do you receive?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = Practical 1 = Emotional 2 = Both 3 = Other
Variable ID:	DT-P_Q45
Variable:	Question 45 of Distress Thermometer for Parents
Definition:	2. Do people often react to your situation with a lack of understanding?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q46
Variable:	Question 46 of Distress Thermometer for Parents
Definition:	3. Do you have a (chronic) disease?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer

Response Options:	0 = No 1 = Yes
Variable ID:	DT-P_Q47
Variable:	Question 47 of Distress Thermometer for Parents
Definition:	4. How do you get along with the medical staff?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = Very well 1 = Well 2 = Fair 3 = Poor
Variable ID:	DT-P_Q48
Variable:	Question 48 of Distress Thermometer for Parents
Definition:	5a. Would you like to talk to a professional about your situation?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = Yes 1 = Maybe 2 = No
Variable ID:	DT-P_Q49
Variable:	Question 49 of Distress Thermometer for Parents
Definition:	5b. Please explain:
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Free text
Response Options:	N/A
Variable ID:	DT-P_Q50
Variable:	Question 50 of Distress Thermometer for Parents
Definition:	6. Do you have any further comments/questions about this questionnaire or anything you would like to add about your responses?
Supporting Definition:	N/A
Inclusion Criteria:	Parents of patients with craniofacial microsomia
Timing:	2, 5, 8, 12 years
Reporting Source:	Parent-reported
Type:	Free text
Response Options:	N/A

Behavior/Anxiety/Depression/PTSD

Variable ID:	HADS_QA1
Variable:	Question A1 of HADS
Definition:	This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important. A1. I feel tense or 'wound up':
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years

Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Most of the time 1 = A lot of the time 2 = From time to time (occ.) 3 = Not at all
Variable ID:	HADS_QD1
Variable:	Question D1 of HADS
Definition:	D1. I still enjoy the things I used to enjoy:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Definitely as much 1 = Not quite as much 2 = Only a little 3 = Hardly at all
Variable ID:	HADS_QA2
Variable:	Question A2 of HADS
Definition:	A2. I get a sort of frightened feeling as if something awful is about to happen:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Very definitely and quite badly 1 = Yes, but not too badly 2 = A little, but it doesn't worry me 3 = Not at all
Variable ID:	HADS_QD2
Variable:	Question D2 of HADS
Definition:	D2. I can laugh and see the funny side of things:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = As much as I always could 1 = Not quite so much now 2 = Definitely not so much now 3 = Not at all
Variable ID:	HADS_QA3
Variable:	Question A3 of HADS
Definition:	A3. Worrying thoughts go through my mind:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = A great deal of the time 1 = A lot of the time 2 = From time to time, but not often 3 = Only occasionally
Variable ID:	HADS_QD3
Variable:	Question D3 of HADS

Definition:	D3. I feel cheerful:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Not often 2 = Sometimes 3 = Most of the time
Variable ID:	HADS_QA4
Variable:	Question A4 of HADS
Definition:	A4. I can sit at ease and feel relaxed:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Definitely 1 = Usually 2 = Not often 3 = Not at all
Variable ID:	HADS_QD4
Variable:	Question D4 of HADS
Definition:	D4. I feel as if I am slowed down:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Nearly all the time 1 = Very often 2 = Sometimes 3 = Not at all
Variable ID:	HADS_QA5
Variable:	Question A5 of HADS
Definition:	A5. I get a sort of frightened feeling like "butterflies" in the stomach:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Quite often 3 = Very often
Variable ID:	HADS_QD5
Variable:	Question D5 of HADS
Definition:	D5. I have lost interest in my appearance:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Definitely 1 = I don't take as much care as I should

	2 = I may not take quite as much care 3 = I take just as much care
Variable ID:	HADS_QA6
Variable:	Question A6 of HADS
Definition:	A6. I feel restless as I have to be on the move:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Very much indeed 1 = Quite a lot 2 = Not very much 3 = Not at all
Variable ID:	HADS_QD6
Variable:	Question D6 of HADS
Definition:	D6. I look forward with enjoyment to things:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = As much as I ever did 1 = Rather less than I used to 2 = Definitely less than I used to 3 = Hardly at all
Variable ID:	HADS_QA7
Variable:	Question A7 of HADS
Definition:	A7. I get sudden feelings of panic:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Very often indeed 1 = Quite often 2 = Not very often 3 = Not at all
Variable ID:	HADS_QD7
Variable:	Question D7 of HADS
Definition:	D7. I can enjoy a good book or radio/TV program:
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Often 1 = Sometimes 2 = Not often 3 = Very seldom
Variable ID:	YPCORE_Q1
Variable:	Question 1 of Young Person CORE
Definition:	Over the last week... 1. I've felt edgy or nervous
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia

Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q2
Variable:	Question 2 of Young Person CORE
Definition:	2. I haven't felt like talking to anyone
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q3
Variable:	Question 3 of Young Person CORE
Definition:	3. I've felt able to cope when things go wrong
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q4
Variable:	Question 4 of Young Person CORE
Definition:	4. I've thought of hurting myself
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q5
Variable:	Question 5 of Young Person CORE
Definition:	5. There's been someone I felt able to ask for help
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all

	1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q6
Variable:	Question 6 of Young Person CORE
Definition:	6. My thoughts and feelings distressed me
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q7
Variable:	Question 7 of Young Person CORE
Definition:	7. My problems have felt too much for me
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q8
Variable:	Question 8 of Young Person CORE
Definition:	8. It's been hard to go to sleep or stay asleep
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time
Variable ID:	YPCORE_Q9
Variable:	Question 9 of Young Person CORE
Definition:	9. I've felt unhappy
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time

Variable ID:	YPCORE_Q10
Variable:	Question 10 of Young Person CORE
Definition:	10. I've done all the things I wanted to
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Not at all 1 = Occasionally 2 = Sometimes 3 = Often 4 = Most or all of the time

Airway and Breathing

Variable ID:	PSQ_Q01
Variable:	Question 1 of Pediatric Sleep Questionnaire
Definition:	Please answer the following questions by checking the box under the yes, no, or don't know column to the right. When sleeping, does your child...
	1. ...snore more than half the time?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know

Variable ID:	PSQ_Q02
Variable:	Question 2 of Pediatric Sleep Questionnaire
Definition:	2. ...always snore?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know

Variable ID:	PSQ_Q03
Variable:	Question 3 of Pediatric Sleep Questionnaire
Definition:	3. ...snore loudly?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know

Variable ID:	PSQ_Q04
Variable:	Question 4 of Pediatric Sleep Questionnaire
Definition:	4. ...have 'heavy' or loud breathing?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia

Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Qo5
Variable: Question 5 of Pediatric Sleep Questionnaire
Definition: 5. ...have trouble breathing, or struggle to breathe?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Qo6
Variable: Question 6 of Pediatric Sleep Questionnaire
Definition: Have your ever...
 6. ...seen your child stop breathing during the night?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Qo7
Variable: Question 7 of Pediatric Sleep Questionnaire
Definition: Does your child?
 7. ...tend to breathe through the mouth during the day?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Qo8
Variable: Question 8 of Pediatric Sleep Questionnaire
Definition: 8. ...have a dry mouth on waking up in the morning?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Qo9
Variable: Question 9 of Pediatric Sleep Questionnaire
Definition: 9. ...occasionally wet the bed?
Supporting Definition: N/A

Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Q10
Variable: Question 10 of Pediatric Sleep Questionnaire
Definition: Does your child...
 10. ...wake up feeling unrefreshed in the morning?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Q11
Variable: Question 11 of Pediatric Sleep Questionnaire
Definition: 11. ...have a problem with sleepiness during the day?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Q12
Variable: Question 12 of Pediatric Sleep Questionnaire
Definition: 12. Has a teacher or other supervisor commented that your child appears sleepy during the day?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Q13
Variable: Question 13 of Pediatric Sleep Questionnaire
Definition: 13. Is it hard to wake your child up in the morning?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 8, 12 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 0 = No
 1 = Yes
 2 = Don't know

Variable ID: PSQ_Q14
Variable: Question 14 of Pediatric Sleep Questionnaire
Definition: 14. Does your child wake up with headaches in the morning?

Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q15
Variable:	Question 15 of Pediatric Sleep Questionnaire
Definition:	15. Did your child stop growing at a normal rate at any time since birth?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q16
Variable:	Question 16 of Pediatric Sleep Questionnaire
Definition:	16. Is your child overweight?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q17
Variable:	Question 17 of Pediatric Sleep Questionnaire
Definition:	This child often... 17. ...does not seem to listen when spoken to directly?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q18
Variable:	Question 18 of Pediatric Sleep Questionnaire
Definition:	18. Had difficulty organizing task and activities?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q19
Variable:	Question 19 of Pediatric Sleep Questionnaire
Definition:	19. ...is easily distracted by extraneous stimuli?

Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q20
Variable:	Question 20 of Pediatric Sleep Questionnaire
Definition:	This child often... 20. ...fidgets with hands or feet or squirms in seat?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q21
Variable:	Question 21 of Pediatric Sleep Questionnaire
Definition:	21. Is 'on the go' of often acts as if 'driven by a motor'?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	PSQ_Q22
Variable:	Question 22 of Pediatric Sleep Questionnaire
Definition:	22. ...interrupts or intrudes on others (e.g. butts into conversations or games)?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 2 = Don't know
Variable ID:	AIRBREATH_Q01
Variable:	Tracheostomy
Definition:	Does your child presently require a tracheostomy?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	AIRBREATH_Q02
Variable:	Prong
Definition:	Does your child presently require a prong (nasopharyngeal airway)?

Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	AIRBREATH_Q03
Variable:	Jaw surgery
Definition:	Has your child/have you required surgery on their/your jaw for their/your airway?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	AIRBREATH_Q04
Variable:	CPAP
Definition:	Does your child/do you require airway support when sleeping – CPAP?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	AIRBREATH_Q05
Variable:	Airway surgery
Definition:	Has the patient had surgery for the airway?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5, 8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Tonsillectomy 2 = Adenoidectomy 3 = Mandibular distraction

Feeding and Swallowing

Variable ID:	FEEDSWALL_Q01
Variable:	Nasogastric feeding tube
Definition:	Does your child presently require a nasogastric feeding tube?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	FEEDSWALL_Q02
Variable:	Surgically placed feeding tube
Definition:	Has your child required a surgically placed feeding tube?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years

Reporting Source:	
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	FEEDSWALL_Qo3
Variable:	Swallowing
Definition:	Does your child presently require their liquids/food to be thickened to be safe to swallow?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	FEEDSWALL_Qo4
Variable:	Aspiration
Definition:	Does the patient regularly aspirate their food/feeds?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

Hearing

Variable ID:	HEAROTOHEALTH_Qo1
Variable:	Hearing aid
Definition:	Does the patient need a hearing aid?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes, right 2 = Yes, left
Variable ID:	HEAROTOHEALTH_Qo2
Variable:	Otitis media
Definition:	How many times has your child had an ear infection (otitis media) in the last 12 months?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Patient/parent-reported
Type:	Numerical value; Integer (≥ 0)
Response Options:	Free text
Variable ID:	HEAROTOHEALTH_Qo3
Variable:	Ear tubes
Definition:	Has your child required "ear tubes" (myringotomy & tympanostomy tube procedure) to improve hearing?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5 years
Reporting Source:	Patient/parent-reported

Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	HEAROTOHEALTH_Qo4
Variable:	BAHA
Definition:	Has the patient had a surgically fitted BAHA?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 12 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes, right 2 = Yes, left
Variable ID:	HEAROTOHEALTH_Qo5
Variable:	Audiogram
Definition:	Audiogram (bone conduction and air conduction; right ear and left ear, with and without aiding)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Numerical value; dB
Response Options:	Free text

Vision

Variable ID:	VISION_Qo1
Variable:	Vision difficulty
Definition:	Does your child have difficulty with their vision?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	VISION_Qo2
Variable:	Ointment for eyes
Definition:	Does your child require ointment to protect their eyes?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	VISION_Qo3
Variable:	Eye surgery
Definition:	Has your child required surgery on their eyes?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	2, 5 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes

Speech

Variable ID:	CLEFTQSPEAK_Q01
Variable:	Question 1 of Cleft-Q Speech Distress
Definition:	HOW DO YOU FEEL ABOUT SPEAKING? Answer each question by circling one number. Please answer thinking of the PAST WEEK. 1: I avoid going out because of my speech (like to a party).
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Q02
Variable:	Question 2 of Cleft-Q Speech Distress
Definition:	2: My speech makes it hard for me to make new friends.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Q03
Variable:	Question 3 of Cleft-Q Speech Distress
Definition:	3: I get teased about my speech.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Q04
Variable:	Question 4 of Cleft-Q Speech Distress
Definition:	4: I get frustrated when I speak.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Q05
Variable:	Question 5 of Cleft-Q Speech Distress
Definition:	5: I feel embarrassed when I speak.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer

Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Qo6
Variable:	Question 6 of Cleft-Q Speech Distress
Definition:	6: I try to avoid speaking in front of people.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Qo7
Variable:	Question 7 of Cleft-Q Speech Distress
Definition:	7: I feel nervous when I speak.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Qo8
Variable:	Question 8 of Cleft-Q Speech Distress
Definition:	8: I worry that my speech is hard to understand.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Qo9
Variable:	Question 9 of Cleft-Q Speech Distress
Definition:	9: I get upset when I need to repeat myself.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEAK_Q10
Variable:	Question 10 of Cleft-Q Speech Distress
Definition:	10: I feel upset when I am not understood.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always

2 = Sometimes
3 = Never

Variable ID:	CLEFTQSPEECH_Qo1
Variable:	Question 1 of Cleft-Q Speech Function
Definition:	HOW IS YOUR SPEECH? Answer each question by circling one number Please answer thinking of the PAST WEEK. 1: It's hard for my family to understand my speech.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never

Variable ID:	CLEFTQSPEECH_Qo2
Variable:	Question 2 of Cleft-Q Speech Function
Definition:	2: It's hard for my friends to understand my speech.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never

Variable ID:	CLEFTQSPEECH_Qo3
Variable:	Question 3 of Cleft-Q Speech Function
Definition:	3: I have trouble reading out loud.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never

Variable ID:	CLEFTQSPEECH_Qo4
Variable:	Question 4 of Cleft-Q Speech Function
Definition:	4: I have trouble saying some sentences.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never

Variable ID:	CLEFTQSPEECH_Qo5
Variable:	Question 5 of Cleft-Q Speech Function
Definition:	5: I avoid using words that are hard for me to say.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer

Response Options: 1 = Always
2 = Sometimes
3 = Never

Variable ID: CLEFTQSPEECH_Qo6

Variable: Question 6 of Cleft-Q Speech Function

Definition: 6: It's hard for new people to understand my speech on the phone.

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate

Timing: 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Always
2 = Sometimes
3 = Never

Variable ID: CLEFTQSPEECH_Qo7

Variable: Question 7 of Cleft-Q Speech Function

Definition: 7: It's hard for new people to understand my speech.

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate

Timing: 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Always
2 = Sometimes
3 = Never

Variable ID: CLEFTQSPEECH_Qo8

Variable: Question 8 of Cleft-Q Speech Function

Definition: 8: I need to try hard to speak well.

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate

Timing: 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Always
2 = Sometimes
3 = Never

Variable ID: CLEFTQSPEECH_Qo9

Variable: Question 9 of Cleft-Q Speech Function

Definition: 9: I need to repeat what I say to be understood.

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate

Timing: 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Always
2 = Sometimes
3 = Never

Variable ID: CLEFTQSPEECH_Q10

Variable: Question 10 of Cleft-Q Speech Function

Definition: 10: I need to speak slowly to be understood.

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate

Timing: 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Always

	2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEECH_Q11
Variable:	Question 11 of Cleft-Q Speech Function
Definition:	11: I need to concentrate to speak well.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	CLEFTQSPEECH_Q12
Variable:	Question 12 of Cleft-Q Speech Function
Definition:	12: I have trouble saying some words.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Sometimes 3 = Never
Variable ID:	ICS_Q01
Variable:	Question 1 of Intelligibility in Context Scale
Definition:	1. Do you understand your child?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate
Timing:	5, 12 years
Reporting Source:	Parent-reported
Type:	Single answer
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Variable ID:	ICS_Q02
Variable:	Question 2 of Intelligibility in Context Scale
Definition:	2. Do immediate members of your family understand your child?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Variable ID:	ICS_Q03
Variable:	Question 3 of Intelligibility in Context Scale
Definition:	3. Do extended members of your family understand your child?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5 years

Reporting Source: Clinician-reported
Type: Single answer
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Usually
 5 = Always

Variable ID: ICS_Qo4
Variable: Question 4 of Intelligibility in Context Scale
Definition: 4. Do your child's friends understand your child?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Usually
 5 = Always

Variable ID: ICS_Qo5
Variable: Question 5 of Intelligibility in Context Scale
Definition: 5. Do other acquaintances understand your child?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Usually
 5 = Always

Variable ID: ICS_Qo6
Variable: Question 6 of Intelligibility in Context Scale
Definition: 6. Do your child's teachers understand your child?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 1 = Never
 2 = Rarely
 3 = Sometimes
 4 = Usually
 5 = Always

Variable ID: ICS_Qo7
Variable: Question 7 of Intelligibility in Context Scale
Definition: 7. Do strangers understand your child?
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: 1 = Never
 2 = Rarely

3 = Sometimes
4 = Usually
5 = Always

Variable ID:	PCC
Variable:	Percent consonants
Definition:	Indicate the percent consonants
Supporting Definition:	Speech assessment material can be found at https://clispi.org/node/15
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	5 years: Normal (-1 s.d.) Not normal (<-1 s.d. = <91%) 12 years: Normal (-1 s.d.) Not normal (<-1 s.d. = <95%) 22 years: Normal (-1 s.d.) Not normal (<-1 s.d. = <98%)

Mastication and Occlusion

Variable ID:	CLEFTQED_Q01
Variable:	Question 1 of Cleft-Q Eating and Drinking
Definition:	HOW IS YOUR EATING AND DRINKING? Answer each question by circling one number. Please answer thinking of the PAST WEEK. 1: Food falls out of my mouth when I eat.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Often 3 = Sometimes 4 = Never

Variable ID:	CLEFTQED_Q02
Variable:	Question 2 of Cleft-Q Eating and Drinking
Definition:	2: I have trouble drinking through a straw.
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Always 2 = Often 3 = Sometimes 4 = Never

Variable ID:	CLEFTQED_Q03
Variable:	Question 3 of Cleft-Q Eating and Drinking
Definition:	3: I have to avoid eating certain foods.
Supporting Definition:	N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo4
Variable: Question 4 of Cleft-Q Eating and Drinking
Definition: 4: Some types of food are hard for me to chew.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo5
Variable: Question 5 of Cleft-Q Eating and Drinking
Definition: 5: Food gets stuck in a hole in my mouth.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo6
Variable: Question 6 of Cleft-Q Eating and Drinking
Definition: 6: Food or drinks go up my nose.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo7
Variable: Question 7 of Cleft-Q Eating and Drinking
Definition: 7: I have trouble biting into some foods.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported

Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo8
Variable: Question 8 of Cleft-Q Eating and Drinking
Definition: 8: I have to take small bites when I eat.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Variable ID: CLEFTQED_Qo9
Variable: Question 9 of Cleft-Q Eating and Drinking
Definition: 9: I have to eat slowly.
Supporting Definition: N/A
Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus
Timing: 8, 12, 22 years
Reporting Source: Patient-reported
Type: Single answer
Response Options: 1 = Always
 2 = Often
 3 = Sometimes
 4 = Never

Oral Health

Variable ID: DENTALHEALTH_PedsD
Variable: dmft: overall dental health: decayed
Definition: Indicate the number of decayed deciduous (pediatric) teeth
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 12 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: Numerical value of decayed teeth

Variable ID: DENTALHEALTH_PedsM
Variable: dmft: overall dental health: missing
Definition: Indicate the number of missing deciduous (pediatric) teeth
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 5, 12 years
Reporting Source: Clinician-reported
Type: Single answer
Response Options: Numerical value of missing teeth

Variable ID: DENTALHEALTH_PedsF
Variable: dmft: overall dental health: filled
Definition: Indicate the number of filled deciduous (pediatric) teeth
Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia

Timing:	5, 12 years
Reporting Source:	Clinician-reported
Type:	Single answer
Response Options:	Numerical value of filled teeth
Variable ID:	COHIPOSS_Qo1
Variable:	Question 1 of COHIP OSS
Definition:	Choose the answer the best describes you in the past 3 months regarding your teeth, mouth, or face.
	1. Have you had pain in your teeth (toothache)?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Fairly often 4 = Almost all of the time
Variable ID:	COHIPOSS_Qo2
Variable:	Question 2 of COHIP OSS
Definition:	2. Have you had discolored teeth or spots on your teeth?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Fairly often 4 = Almost all of the time
Variable ID:	COHIPOSS_Qo3
Variable:	Question 3 of COHIP OSS
Definition:	3. Have you had crooked teeth or spaces between your teeth?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Fairly often 4 = Almost all of the time
Variable ID:	COHIPOSS_Qo4
Variable:	Question 4 of COHIP OSS
Definition:	4. Have you had bad breath?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes

	3 = Fairly often 4 = Almost all of the time
Variable ID:	COHIPOSS_Q05
Variable:	Question 5 of COHIP OSS
Definition:	5. Have you had bleeding gums?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Fairly often 4 = Almost all of the time

Appearance

Variable ID:	EARHRQOL_Q1
Variable:	Question 1 of Ear HrQoL
Definition:	The following questions are also related to appearance, but in more detail. We would like you to answer by giving a score from 1 to 5, using the scale below: 1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
	Section A: We've marked out 9 key areas of a 'normal' ear below. We'd like you to find them on your reconstructed ear and give them a score using the scale above. 1) Helical rim
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q2
Variable:	Question 2 of Ear HrQoL
Definition:	2) Scaphoid fossa
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q3
Variable:	Question 3 of Ear HrQoL
Definition:	3) Conchal bowl

Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 8, 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 1 = Very dissatisfied
 2 = Quite dissatisfied
 3 = Alright
 4 = Quite satisfied
 5 = Very satisfied

Variable ID: EARHRQOL_Q4
Variable: Question 4 of Ear HrQoL
Definition: 4) Anti-tragus

Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 8, 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 1 = Very dissatisfied
 2 = Quite dissatisfied
 3 = Alright
 4 = Quite satisfied
 5 = Very satisfied

Variable ID: EARHRQOL_Q5
Variable: Question 5 of Ear HrQoL
Definition: 5) Triangular fossa

Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 8, 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 1 = Very dissatisfied
 2 = Quite dissatisfied
 3 = Alright
 4 = Quite satisfied
 5 = Very satisfied

Variable ID: EARHRQOL_Q6
Variable: Question 6 of Ear HrQoL
Definition: 6) Anti-helix

Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 8, 12, 22 years
Reporting Source: Patient/parent-reported
Type: Single answer
Response Options: 1 = Very dissatisfied
 2 = Quite dissatisfied
 3 = Alright
 4 = Quite satisfied
 5 = Very satisfied

Variable ID: EARHRQOL_Q7
Variable: Question 7 of Ear HrQoL
Definition: 7) Tragus

Supporting Definition: N/A
Inclusion Criteria: Patients with craniofacial microsomia
Timing: 8, 12, 22 years
Reporting Source: Patient/parent-reported

Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q8
Variable:	Question 8 of Ear HrQoL
Definition:	8) Incisura
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q9
Variable:	Question 9 of Ear HrQoL
Definition:	9) Lobe
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q10
Variable:	Question 10 of Ear HrQoL
Definition:	Section B: How satisfied are you with the following (again please use the scale above): 10) The size of your ear? (Big or small)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q11
Variable:	Question 11 of Ear HrQoL
Definition:	11) The projection of your ear? (How much it sticks out)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied

2 = Quite dissatisfied
 3 = Alright
 4 = Quite satisfied
 5 = Very satisfied

Variable ID:	EARHRQOL_Q12
Variable:	Question 12 of Ear HrQoL
Definition:	12) The position of your ear? (Too high or low; see Picture I)
Supporting Definition:	Reference Picture 1
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q13
Variable:	Question 13 of Ear HrQoL
Definition:	13) The rotation of your ear? (How much your ear tilts)
Supporting Definition:	Reference Picture 2
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q14
Variable:	Question 14 of Ear HrQoL
Definition:	14) The skin covering your ear? (quality, colour, hair)
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied
Variable ID:	EARHRQOL_Q15
Variable:	Question 15 of Ear HrQoL
Definition:	15) The scars around your ear and scalp?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	8, 12, 22 years
Reporting Source:	Patient/parent-reported
Type:	Single answer
Response Options:	1 = Very dissatisfied 2 = Quite dissatisfied 3 = Alright 4 = Quite satisfied 5 = Very satisfied

Variable ID:	PATCFM_Q1A
Variable:	Question 1A of PAT-CFM
Definition:	Orbit Right Size
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = OS 0 Normal 1 = OS 1 Abnormal size 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q1B
Variable:	Question 1B of PAT-CFM
Definition:	Orbit Right Displacement
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = OD 0 Normal 1 = OD 1 Inferior orbital displacement 2 = OD 2 Superior orbital displacement 3 = UA 4 = S 5 = AT
Variable ID:	PATCFM_Q2A
Variable:	Question 2A of PAT-CFM
Definition:	Orbit Left Size
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = OS 0 Normal 1 = OS 1 Abnormal size 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q2B
Variable:	Question 2B of PAT-CFM
Definition:	Orbit Left Displacement
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = OD 0 Normal 1 = OD 1 Inferior orbital displacement 2 = OD 2 Superior orbital displacement 3 = UA

	4 = S 5 = AT
Variable ID:	PATCFM_Q3A
Variable:	Question 3A of PAT-CFM
Definition:	Occlusal Plane Right
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = No Can't OP 0 1 = 1-5 degrees OP 1 2 = 6-15 degrees OP 2 3 = >15 degrees OP 3 4 = UA 5 = S 6 = AT
Variable ID:	PATCFM_Q3B
Variable:	Question 3B of PAT-CFM
Definition:	Occlusal Plane Left
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = No Can't OP 0 1 = 1-5 degrees OP 1 2 = 6-15 degrees OP 2 3 = >15 degrees OP 3 4 = UA 5 = S 6 = AT
Variable ID:	PATCFM_Q4A
Variable:	Question 4A of PAT-CFM
Definition:	Chin Point Right
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = AT Not deviated CP 0 1 = Not deviated CP 1 2 = UA 3 = S
Variable ID:	PATCFM_Q4B
Variable:	Question 4B of PAT-CFM
Definition:	Chin Point Left
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers

Response Options: 0 = AT Not deviated CP 0
1 = Not deviated CP 1
2 = UA
3 = S

Variable ID: PATCFM_Q5A

Variable: Question 5A of PAT-CFM

Definition: Mandible Right

Supporting Definition: A graphic is part of this question (to be distributed by PRO developer once license obtained)

Inclusion Criteria: Patients with craniofacial microsomia

Timing: 5, 8, 12, 22 years

Reporting Source: Clinician-reported

Type: Multiple answers

Response Options: 0 = Normal Mo
1 = Mild hypoplasia M1
2 = Moderate hypoplasia M2A
3 = Moderate severe hypoplasia M2B
4 = Severe hypoplasia M3
5 = UA
6 = S
7 = AT

Variable ID: PATCFM_Q5B

Variable: Question 5B of PAT-CFM

Definition: Mandible Left

Supporting Definition: A graphic is part of this question (to be distributed by PRO developer once license obtained)

Inclusion Criteria: Patients with craniofacial microsomia

Timing: 5, 8, 12, 22 years

Reporting Source: Clinician-reported

Type: Multiple answers

Response Options: 0 = Normal Mo
1 = Mild hypoplasia M1
2 = Moderate hypoplasia M2A
3 = Moderate severe hypoplasia M2B
4 = Severe hypoplasia M3
5 = UA
6 = S
7 = AT

Variable ID: PATCFM_Q7A

Variable: Question 7A of PAT-CFM

Definition: Ear Right

Supporting Definition: A graphic is part of this question (to be distributed by PRO developer once license obtained)

Inclusion Criteria: Patients with craniofacial microsomia

Timing: 5, 8, 12, 22 years

Reporting Source: Clinician-reported

Type: Multiple answers

Response Options: 0 = Normal Eo
1 = All parts present, mild deformity E1
2 = Auricle 1/2-2/3 of predicted size, not all parts present E2
3 = Severely malformed, often peanut shaped E3
4 = Anotia E4
5 = UA
6 = S
7 = AT

Variable ID: PATCFM_Q7B

Variable:	Question 7B of PAT-CFM
Definition:	Ear Left
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = Normal Eo 1 = All parts present, mild deformity E1 2 = Auricle 1/2-2/3 of predicted size, not all parts present E2 3 = Severely malformed, often peanut shaped E3 4 = Anotia E4 5 = UA 6 = S 7 = AT
Variable ID:	PATCFM_Q8A
Variable:	Question 8A of PAT-CFM
Definition:	Nerve Right Brow
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NB 0 normal 1 = NB 1 Brow palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q8B
Variable:	Question 8b of PAT-CFM
Definition:	Nerve Left Brow
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NB 0 normal 1 = NB 1 Brow palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q9A
Variable:	Question 9A of PAT-CFM
Definition:	Nerve Right Orbic
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NO 0 normal orbic 1 = NO 1 Orbicularis oculi palsy 2 = UA

	3 = S 4 = AT
Variable ID:	PATCFM_Q9B
Variable:	Question 9B of PAT-CFM
Definition:	Nerve Left Orbic
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NO 0 normal orbic 1 = NO 1 Orbicularis oculi palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q10A
Variable:	Question 10A of PAT-CFM
Definition:	Nerve Right Smile
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NS 0 normal smile 1 = NS 1 Smile palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q10B
Variable:	Question 10B of PAT-CFM
Definition:	Nerve Left Smile
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NS 0 normal smile 1 = NS 1 Smile palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q11A
Variable:	Question 11A of PAT-CFM
Definition:	Nerve Right Lip
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NL 0 normal lip 1 = NL 1 Lower lip palsy 2 = UA

	3 = S 4 = AT
Variable ID:	PATCFM_Q11B
Variable:	Question 11B of PAT-CFM
Definition:	Nerve Left Lip
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = NL 0 normal lip 1 = NL 1 Lower lip palsy 2 = UA 3 = S 4 = AT
Variable ID:	PATCFM_Q12A
Variable:	Question 12A of PAT-CFM
Definition:	Soft Tissue Right
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = So Normal 1 = S1 Minimal soft tissue deficiency 2 = S2 Moderate soft tissue deficiency 3 = S3 Severe soft tissue deficiency 4 = UA 5 = S 6 = AT
Variable ID:	PATCFM_Q12B
Variable:	Question 12B of PAT-CFM
Definition:	Soft Tissue Left
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = So Normal 1 = S1 Minimal soft tissue deficiency 2 = S2 Moderate soft tissue deficiency 3 = S3 Severe soft tissue deficiency 4 = UA 5 = S 6 = AT
Variable ID:	PATCFM_Q13A
Variable:	Question 13A of PAT-CFM
Definition:	Lateral Cleft Right
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported

Type:	Multiple answers
Response Options:	0 = LC 0 No cleft 1 = LC 1 Cleft terminates medial to anterior border of masseter 2 = LC 2 Cleft terminates lateral to anterior border of masseter 3 = UA 4 = S 5 = AT
Variable ID:	PATCFM_Q13B
Variable:	Question 13A of PAT-CFM
Definition:	Lateral Cleft Left
Supporting Definition:	A graphic is part of this question (to be distributed by PRO developer once license obtained)
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	5, 8, 12, 22 years
Reporting Source:	Clinician-reported
Type:	Multiple answers
Response Options:	0 = LC 0 No cleft 1 = LC 1 Cleft terminates medial to anterior border of masseter 2 = LC 2 Cleft terminates lateral to anterior border of masseter 3 = UA 4 = S 5 = AT
Variable ID:	CLEFTQFACE_Q01
Variable:	Question 1 of Cleft-Q Appearance of the Face
Definition:	HOW DOES YOUR FACE LOOK? Answer each question by circling one number. Please answer thinking of how your face looks NOW. How much do you like... 1: ...how your face looks when you look your best?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Q02
Variable:	Question 2 of Cleft-Q Appearance of the Face
Definition:	2: ...how your face looks when you are ready to go out (like to a party)?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Q03
Variable:	Question 3 of Cleft-Q Appearance of the Face
Definition:	3: ...the shape of your face (e.g., round or oval)?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip

	and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo4
Variable:	Question 4 of Cleft-Q Appearance of the Face
Definition:	4: ...how your face looks in photos?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo5
Variable:	Question 5 of Cleft-Q Appearance of the Face
Definition:	5: ...how well both sides of your face match?
Supporting Definition:	A graphic is part of this question (contact PRO developer for access)
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo6
Variable:	Question 6 of Cleft-Q Appearance of the Face
Definition:	6: ...how your face looks when you smile?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo7
Variable:	Question 7 of Cleft-Q Appearance of the Face
Definition:	7: ...how your face looks when you laugh?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer

Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo8
Variable:	Question 8 of Cleft-Q Appearance of the Face
Definition:	8: ...how your face looks from the side (your profile)?
Supporting Definition:	A graphic is part of this question (contact PRO developer for access)
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQFACE_Qo9
Variable:	Question 9 of Cleft-Q Appearance of the Face
Definition:	9: ...how your face looks up close?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo1
Variable:	Question 1 of Cleft-Q Appearance of the Jaws
Definition:	HOW DO YOUR JAWS LOOK? Answer each question by circling one number. Please answer thinking of how your jaws look NOW. How much do you like... 1. ...the size of your jaws?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo2
Variable:	Question 2 of Cleft-Q Appearance of the Jaws
Definition:	2. ...the shape of your jaws?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all

	2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo3
Variable:	Question 3 of Cleft-Q Appearance of the Jaws
Definition:	3. ...how your jaws look in the mirror?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo4
Variable:	Question 4 of Cleft-Q Appearance of the Jaws
Definition:	4. ...how your jaws look in photos?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much 1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo5
Variable:	Question 5 of Cleft-Q Appearance of the Jaws
Definition:	5. ...how your jaws look when your mouth is closed?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much 1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Qo6
Variable:	Question 6 of Cleft-Q Appearance of the Jaws
Definition:	6. ...how your jaws look when you smile?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported

Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQJAW_Q07
Variable:	Question 7 of Cleft-Q Appearance of the Jaws
Definition:	7. ...how your jaws look from the side (your profile)?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQDENTAL_Q01
Variable:	Question 1 of Cleft-Q Appearance of the Teeth
Definition:	HOW DO YOUR TEETH LOOK? Answer each question by circling one number. Please answer thinking of how your teeth look NOW. How much do you like... 1: ...the size of your teeth?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQDENTAL_Q02
Variable:	Question 2 of Cleft-Q Appearance of the Teeth
Definition:	2: ...how close together your teeth are?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all

2 = A little bit
 3 = Quite a bit
 4 = Very much

Variable ID:	CLEFTQDENTAL_Qo3
Variable:	Question 3 of Cleft-Q Appearance of the Teeth
Definition:	3: ...how your teeth look when you smile?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQDENTAL_Qo4
Variable:	Question 4 of Cleft-Q Appearance of the Teeth
Definition:	4: ...how your teeth look from the side (your profile)?
Supporting Definition:	A graphic is part of this question (contact PRO developer for access)
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQDENTAL_Qo5
Variable:	Question 5 of Cleft-Q Appearance of the Teeth
Definition:	5: ...how straight your teeth look?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip
Timing:	8, 12, 22 years
Reporting Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much1 = Not at all 2 = A little bit 3 = Quite a bit 4 = Very much
Variable ID:	CLEFTQDENTAL_Qo6
Variable:	Question 6 of Cleft-Q Appearance of the Teeth
Definition:	6: ...showing your teeth when you smile?
Supporting Definition:	N/A
Inclusion Criteria:	Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip

and alveolus, patients with cleft lip

Timing: 8, 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much
1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much

Variable ID: CLEFTQDENTAL_Qo7

Variable: Question 7 of Cleft-Q Appearance of the Teeth

Definition: 7: ...how your teeth look up close?

Supporting Definition: N/A

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip

Timing: 8, 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much
1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much

Variable ID: CLEFTQDENTAL_Qo8

Variable: Question 8 of Cleft-Q Appearance of the Teeth

Definition: 8: ...how your top and bottom teeth meet when you bite?

Supporting Definition: A graphic is part of this question (contact PRO developer for access)

Inclusion Criteria: Patients with cleft lip and palate, patients with cleft palate, patients with cleft lip and alveolus, patients with cleft lip

Timing: 8, 12, 22 years

Reporting Source: Patient-reported

Type: Single answer

Response Options: 1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much
1 = Not at all
2 = A little bit
3 = Quite a bit
4 = Very much

Burden of Care

Variable ID: POSTOPCOMP

Variable: Post-operative complications

Definition: Indicate if the patient experienced any of the following complications

Supporting Definition: Select all that apply:

Inclusion Criteria: Patients with craniofacial microsomia

Timing: 30 days and 6 months post-operatively

Reporting Source: Clinical

Type: Multiple answer

Response Options: 0 = None
1 = Bleeding requiring unexpected return

- 2 = Bleeding requiring unexpected transfusion
- 3 = Infection: abscess
- 4 = Infection: graft material
- 5 = Loss of vision
- 6 = Loss of globe
- 7 = Wound: flap necrosis
- 8 = Iatrogenic injury to cornea/globe
- 9 = Iatrogenic injury to nerve(s)
- 10 = Iatrogenic injury to permanent teeth
- 11 = Respiratory distress requiring mechanical ventilation
- 12 = Ankylosis of mandible/temporomandibular joints
- 13 = Hardware failure: dentofacial orthopaedics
- 14 = Hardware failure (exposure of infection)
- 15 = Death

Variable ID:	ARIDATE
Variable:	Date of arrival
Definition:	If patient was hospitalized please indicate the date the patient first arrived
Supporting Definition:	Date used to calculate total length of stay and post-procedure length of stay
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	30 days and 6 months post-operatively
Reporting Source:	Administrative data
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY at arrival

Variable ID:	DISDATE
Variable:	Date of discharge
Definition:	Indicate the date the patient was discharged
Supporting Definition:	Date used to calculate total length of stay
Inclusion Criteria:	Patients with craniofacial microsomia
Timing:	30 days and 6 months post-operatively
Reporting Source:	Administrative data
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY at discharge

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.1	Data Dictionary	Item response correction for CLEFTQDENT, EARHRQOL and ICS variables
1.0.2	Outcome Measures	Inserted Phenotypic Assessment Tool- Craniofacial Microsomia (PAT-CFM) scoring guide
1.0.3	Contact Information	Removed inactive email address: ichomteam@ichom.org
1.0.4	Collecting Patient-, Parent-, and Clinician- Reported Outcome Measures	Added copyright/licensing information for the CLEFT-Q tool
1.0.4	Appendix	Added licensing details to the scoring guide for the CLEFT-Q tool
1.0.4	Data Dictionary	Updated the CLEFT-Q variables in line with the newest version of the CLEFT-Q
1.0.4	Data Dictionary	Updated wording and response options for all CLEFT-Q variables

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