



ICHOM

International Consortium for
Health Outcomes Measurement

PAEDIATRIC
FACIAL PALSY
DATA COLLECTION
REFERENCE GUIDE

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Measuring
results
that matter

Visual
Acuity

Paediatric
Facial
Palsy



We are thrilled that you are interested in measuring outcomes for paediatric patients with facial palsy 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.

Our aim is to make Standard Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. In order to have a guide from which we can benchmark outcomes, we require feedback from initial implementation efforts. As such, this Reference Guide may undergo revisions on a regular basis. If you have any suggestions or would like to provide feedback, please contact implement@ichom.org

Working Group Members for Paediatric Facial Palsy

The following individual dedicated both time and expertise to develop the ICHOM Standard Set for Paediatric Facial Palsy in partnership with ICHOM, under the leadership of Mr. Adriaan Grobbelaar, ICHOM Standard Set Chair and Consultant Plastic Surgeon at Royal Free NHS Foundation Trust, United Kingdom. The work was supported by Dr. Tessa Hadlock (Core Working Group member), Dr. Gregory Borschel (Core Working Group member) and Dr. Daniel Butler (ICHOM Research Fellow).

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Supporting Organisations

The Paediatric Facial Palsy Standard Set is made possible only through the support of the following organizations.

Thank you.



THE DIANNE AND MICHAEL BIENES CHARITABLE FOUNDATION INC.

Conditions and Treatment Approaches Covered for Paediatric Facial Palsy

For Paediatric Facial Palsy, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Congenital/Syndromic Acquired Unilateral (single- and multi-territory) Bilateral (single- and multi-territory)
Treatment Approaches	Medical treatment Surgery Eye care Physiotherapy/Occupational therapy Botulinum toxin Psychological support

ICHOM Standard Set for Paediatric Facial Palsy

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
Demographic factors				
All patients	Child date of birth	N/A	Baseline (To)	Parent-reported, Clinical, or Administrative data
	Sex	Sex at birth		
	Insurance status	N/A		
	Parental education			Parent-reported
Baseline clinical status				
All patients	Patient Comorbidities	N/A	Baseline (To)	Clinical
	Facial palsy aetiology			
	Potential for spontaneous resolution			
All patients	Uni- or bilateral Single or multiple facial nerve territories	N/A	Baseline (To)	
	Facial palsy severity			Clinical (eFACE)
Other				
All patients	Transferral of care	N/A	Baseline (To)	Clinical
Treatment				
All patients	Intervention	N/A	Ongoing (T ₁)	Clinical

Outcomes

Patient Population	Measure	Supporting Information	Timing	Data Source
Degree of health				
All patients	Appearance	Tracked eFACE	Baseline & Ongoing (T ₁ , T-P, T ₂ , TDS, TE)	Clinical (eFACE)
>8 years		Tracked with FACE-Q Kids questions		Patient-reported
<8 years	Mouth function	Tracked with Yes-No oral symptom questions		Parent-reported
>6 years	Visual acuity	Recorded with Snellen chart	Ongoing (TDS)	Clinical
All patients	Amblyopia	Tracked with Yes/No questions	Baseline & Ongoing (TDS)	Clinical
	Occular symptoms			
	Health-Related Quality of Life	Tracked with PROMIS Pediatric Global Health 7	Baseline & Ongoing (T ₁ , T-P, T ₂ , TDS, TE)	Patient/parent-reported
	Peer relationships	Tracked with PROMIS Pediatric Peer Relationships Short Form 8a		
Disutility of care				
All patients	Major complications from interventions and unplanned revisions	Adverse or unexpected event arising from intervention	Ongoing (T-P, T ₂)	Clinical/ Administrative data

Timings

We encourage measurement according to the time points included in the above table. Recognising that different countries have established practices and may take time to transition to these time points, we have agreed age categories for measurement that fit around the recommended specific ages:

To: Patient first encounter/visit

T₁: Prior to any new treatment (any invasive or non-invasive). Valid for 6 months if multiple interventions started within this period

T-P: This time point depends on the type of intervention - reflects the time of maximum treatment benefit and varies from 1 month to 2 years

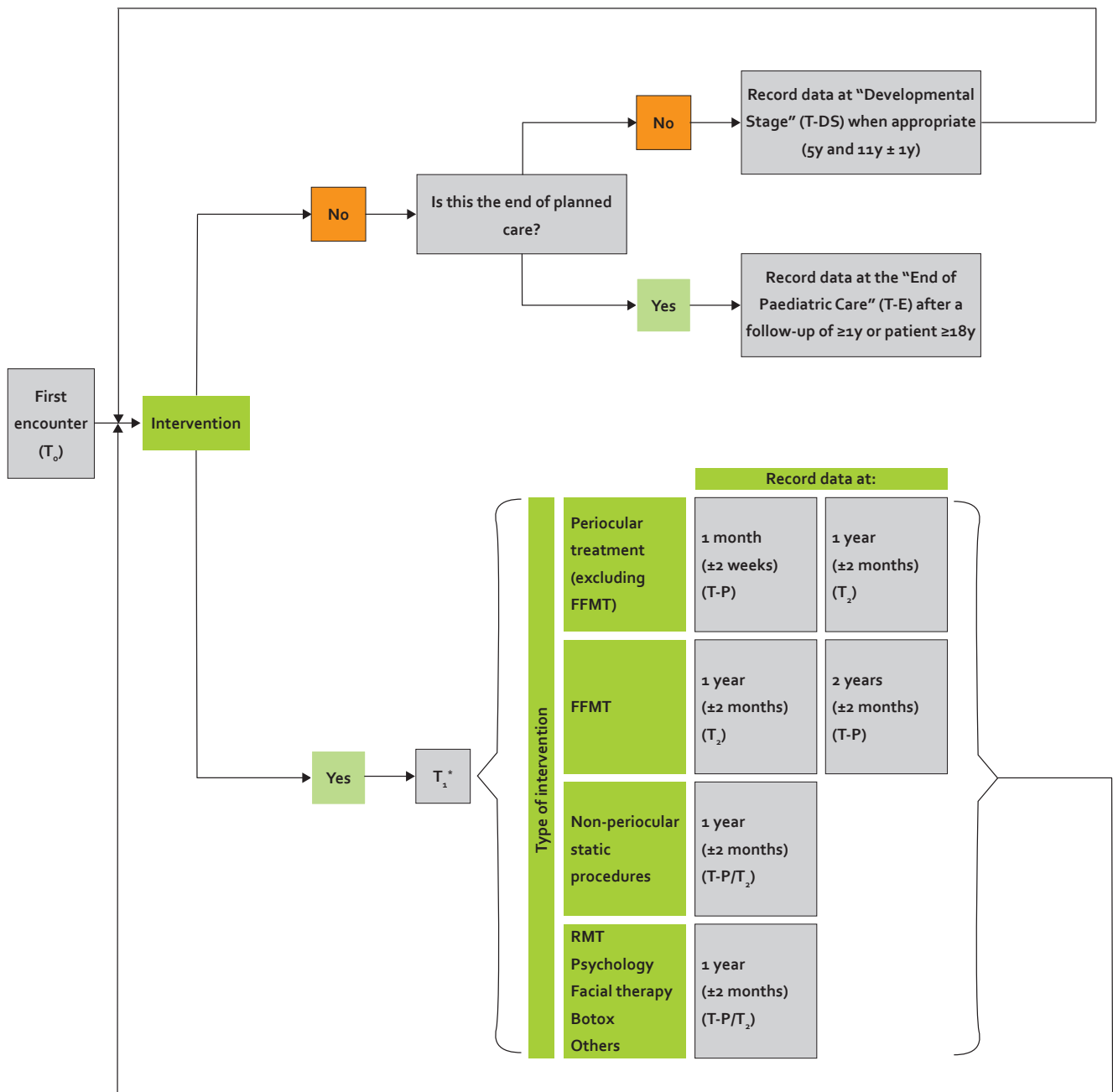
T₂: Treatment follow-up at one year after T₁

T-DS: Developmental stages: ages 5y and 11y

T-E: Should be completed at the end of paediatric care (16y to 18y) or when no further treatments are planned, and allow for >1 year follow-up

Follow-Up Algorithm

The following algorithm illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources.



Timepoints

T₀: Patient first encounter/visit

T₁: Prior to any new treatment (any invasive or non-invasive). Valid for 6 months if multiple interventions started within this period

T-P: This time point depends on the type of intervention - reflects the time of maximum treatment benefit and varies from 1 month to 2 years

T₂: Treatment follow-up at one year after T₁

T-DS: Developmental stages: ages 5y and 11y

T-E: Should be completed at the end of paediatric care (16y to 18y) or when no further treatments are planned, and allow for >1 year follow-up

Key

FFMT: Free functional muscle transfer

RMT: Regional muscle transfer

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

Paediatric Facial Palsy Survey Used	Licensing Information	Scoring Guide
eFACE - Clinician	<p>The FACE-Q Kids, authored by Dr Anne Klassen and Karen Wong, is the copyright of McMaster University (Copyright ©2017, McMaster University). The FACE-Q Kids, 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 Liaison Office at: milo@mcmaster.ca for licensing details.</p>	
FACE-Q-Kids - Patient		
Snellen Chart - Clinician		
PROMIS Paediatric Global Health 7 - Patient/Patient Representative	<p>PROMIS measures are copyrighted. All English, printable, PDF versions of PROMIS are publicly available for individual clinical trials, academic research studies, healthcare or clinical applications, community-based or educational programs, or other discrete applications with defined health measurement objectives. For all other uses, please refer to http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures for more information. Fee waivers can be requested for academic or other non-commercial use. Email help@HealthMeasures.net for additional queries on permissible use or to request non-English versions of PROMIS measures.</p>	<p>Please refer to http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures for more information.</p>
PROMIS Pediatric Peer Relationships Short Form 8a - Patient/Patient Representative		

The Growing ICHOM Community

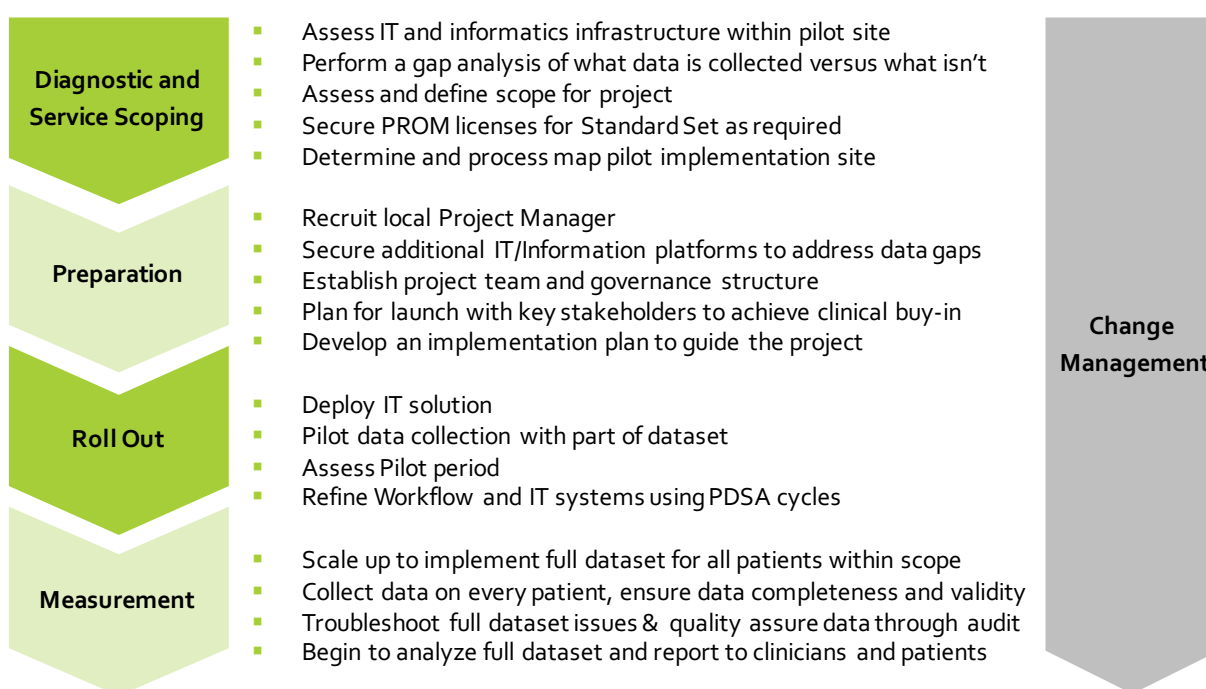


International Consortium for
Health Outcomes Measurement

There is a growing community of healthcare providers implementing the ICHOM Standard Sets. To support your organisation in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centered outcomes. For further information or to enquire about Implementation support offered by ICHOM, please contact the Implementation team: implement@ichom.org

Implementation framework:

The framework below, outlines the structured process to guide the implementation of an ICHOM Standard Set at your organisation. Typically an implementation project takes 9 months to complete.



ICHOM is also able to support organisations with a variety of support models:

1. Capacity building – direct advisory support
2. Community models – supporting a community of providers in outcomes adoption and innovation
3. Education – workshops and short courses regarding Value Based Healthcare and implementation skills

Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, we recommend following the 10 steps outlined below:^{*1}

Step 1	Preparation	Initial work carried out before the translation work begins
Step 2	Forward Translation	Translation of the original language, also called source, version of the instrument into another language, often called the target language
Step 3	Reconciliation	Comparing and merging more than one forward translation into a single forward translation
Step 4	Back Translation	Translation of the new language version back into the original language
Step 5	Back Translation Review	Comparison of the back-translated versions of the instrument with the original to highlight and investigate discrepancies between the original and the reconciled translation, which is then revised in the process of resolving the issues
Step 6	Harmonization	Comparison of back translations of multiple language versions with each other and the original instrument to highlight discrepancies between the original and its derivative translations, as well as to achieve a consistent approach to translation problems
Step 7	Cognitive Debriefing	Testing the instrument on a small group of relevant patients or lay people in order to test alternative wording and to check understandability, interpretation, and cultural relevance of the translation
Step 8	Review of Cognitive Debriefing Results and Finalisation	Comparison of the patients' or lay persons' interpretation of the translation with the original version to highlight and amend discrepancies
Step 9	Proofreading	Final review of the translation to highlight and correct any typographic, grammatical or other errors
Step 10	Final Report	Report written at the end of the process documenting the development of each translation

*These ten steps follow the ISPOR Principles of Good Practice: The Cross-Cultural Adaptation Process for Patient-Reported Outcomes Measures

¹ Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x.

For any questions about implementation please contact us at: implement@ichom.org

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Paediatric Facial Palsy 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:	All patients
Timing:	On all forms
Data Source:	Administrative or clinical
Type:	Numerical
Response Options:	According to institution

Patient Demographic Factors

Variable ID:	AGE
Variable:	Age
Definition:	Indicate the age at each clinical evaluation
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Clinical, parent-reported, or patient-reported
Type:	Single answer
Response Options:	Years and fractions

Variable ID:	SEX
Variable:	Sex
Definition:	Indicate the patient's sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	To
Data Source:	Clinical, parent-reported, or patient-reported
Type:	Single answer
Response Options:	1 = Male 2 = Female 999 = Undisclosed

Variable ID:	INSUR
Variable:	Insurance status
Definition:	Indicate the patient's insurance status
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms

Data Source: Administrative data
Type: Single answer
Response Options: 0 = Uninsured
 1 = Private insurance
 2 = Governmental insurance

Variable ID: PAREDCATION

Variable: Parent education

Definition: Please indicate the highest level of schooling completed by either parent (level of schooling defined in each country as per ISCED [International Standard Classification of Education])

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: To

Data Source: Parent-reported

Type: Single answer

Response Options: 0 = None
 1 = Early Childhood Education
 2 = Primary Education
 3 = Lower Secondary Education
 4 = Upper Secondary Education
 5 = Short-Cycle Tertiary Education
 6 = Bachelor's or Equivalent Level
 7 = Master's or Equivalent Level
 8 = Doctoral or Equivalent Level

Baseline Clinical Status

Variable ID: FP_AET

Variable: Facial palsy aetiology

Definition: Indicate the cause of the facial paralysis using the following groupings:

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: To

Data Source: Clinician

Type: Single answer

Response Options: 1 = Syndromic congenital
 2 = Isolated congenital
 3 = Infective acquired
 4 = Traumatic acquired
 5 = Neoplasm/compressive acquired
 6 = Iatrogenic acquired
 7 = Bell's acquired
 8 = Other

Variable ID: FP_RES

Variable: Facial palsy resolution

Definition: Indicate whether spontaneous (either complete or incomplete) resolution of the facial paralysis is observed.

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: TE

Data Source: Clinician

Type: Single answer

Response Options: 1 = Permanent
 2 = Resolving

Variable ID: FP_LAT

Variable: Facial palsy laterality

Definition: Indicate whether the facial paralysis is unilateral or bilateral

Supporting Definition: N/A

Inclusion Criteria:	All patients
Timing:	To
Data Source:	Clinician
Type:	Single answer
Response Options:	1 = Unilateral 2 = Bilateral
Variable ID:	FP_TER_U
Variable:	Facial palsy territory (unilateral)
Definition:	Indicate whether the facial paralysis involves multiple or a single facial nerve branch territory
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Unilateral" to FP_LAT
Timing:	To
Data Source:	Clinician
Type:	Single answer
Response Options:	1 = Single 2 = Multi-territory
Variable ID:	FP_TER_BI
Variable:	Facial palsy territory (bilateral)
Definition:	Indicate whether the facial nerve branch territory is symmetrical or asymmetrical
Supporting Definition:	N/A
Inclusion Criteria:	If "2 = Bilateral" to FP_LAT
Timing:	To
Data Source:	Clinician
Type:	Single answer
Response Options:	1 = Symmetrical single 2 = Symmetrical multi-territory 3 = Assymetrical
Variable ID:	FP_SEV
Variable:	Facial palsy severity
Definition:	Indicate the severity of the facial paralysis using the eFACE composite "Smile" score
Supporting Definition:	Based on eFACE
Inclusion Criteria:	All patients >3y
Timing:	To
Data Source:	Clinician
Type:	Single answer
Response Options:	Numerical value
Variable ID:	COMORB
Variable:	Patient Comorbidities
Definition:	Indicate whether the patient has any comorbidities
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Clinician
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	COMORB_PAED
Variable:	Comorbidities of paediatric patient
Definition:	Indicate if the patient has any of the following comorbidities
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to COMORB
Timing:	On all forms
Data Source:	Clinician
Type:	Multiple answer

Response Options: Separate multiple entries with ";"
 0 = No other diseases
 1 = Cardiac anomalies or dysfunction
 2 = GU anomalies or dysfunction
 3 = Developmental delay or learning difficulty
 4 = Psychiatric or behavior disorder
 5 = Infection or toxin mediated disease
 6 = GI anomalies or dysfunction
 7 = Other musculoskeletal anomalies or dysfunction
 8 = Other craniomaxillofacial anomalies
 9 = Pulmonary anomalies or dysfunction
 10 = Hematological anomalies or dysfunction
 11 = Immunological anomalies or dysfunction
 12 = Neurological anomalies or dysfunction

Other

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: All patients
Timing: To
Data Source: Clinician/Administrative data
Type: Single answer
Response Options: 0 = No
 1 = Yes
 999 = Unknown

Variable ID: AGETRANSIN
Variable: Age of transfer into your institution
Definition: Indicate the age of transfer into your institution
Supporting Definition: N/A
Inclusion Criteria: If "1 = Yes" to TOCIN
Timing: To
Data Source: Clinician/Administrative data
Type: Numerical value
Response Options: Numerical value of years and fractions

Variable ID: LOSSFUPERI
Variable: Loss to follow-up (perioperative)
Definition: Indicate if 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: All patients
Timing: T₁, TDS
Data Source: Clinician
Type: Single answer
Response Options: 0 = No
 1 = Yes
 999 = Unknown

Treatment

Variable ID: INTERVENTION
Variable: Intervention type
Definition: Indicate intervention type
Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: T1
Data Source: Clinician
Type: Multiple answer
 Separate multiple entries with ";"
Response Options: 1 = Medical treatment (systemic medical treatments in the management of their facial paralysis examples include oral steroids and oral antivirals)
 2 = Non-surgical eye protection (examples include eye taping and ocular lubricants)
 3 = Facial rehabilitation therapy
 4 = Psychological therapy (including occupational therapy) in the management of their facial paralysis
 5 = Surgical treatments
 6 = Botulinum toxin

Variable ID: FAC_SURG_INTERVENTION
Variable: Surgical intervention for facial paralysis
Definition: Indicate the type of surgical treatment
Supporting Definition: N/A
Inclusion Criteria: If "6 = Surgical treatments" to INTERVENTION
Timing: Ongoing
Data Source: Clinician
Type: Single answer
Response Options: 1 = Periocular procedure (non-FFMT)
 2 = Non-periocular static procedure
 3 = Non-periocular regional muscle transfer
 4 = Free functional muscle transfer (FFMT)
 5 = Direct nerve repair
 6 = Interpositional nerve graft
 7 = Cross facial nerve graft
 8 = Nerve transfer and cross face nerve graft
 9 = Nerve transfer

Variable ID: INTERVENTIONDATE
Variable: Date of intervention
Definition: Indicate the date of intervention
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Ongoing
Data Source: Clinician
Type: Date by DD/MM/YYYY
Response Options: DD/MM/YYYY

Outcomes

Degree of Health

Variable ID: REPORTING_SOURCE_PROM
Variable: Reporting source of PROM
Definition: Indicate who is completing the PROMs
Supporting Definition: PROMs refer to patient-, parent- or proxy-reported tools
Inclusion Criteria: All patients
Timing: On all forms
Data Source: Administrative
Type: Single answer
Response Options: 1 = Patient
 2 = Parent/proxy

Variable ID: VISACUUNCRT
Variable: Visual acuity using Snellen chart
Definition: Indicate the distance visual acuity measured uncorrected in the right eye
Supporting Definition: Use Snellen Chart to measure visual acuity
Inclusion Criteria: Age >6y
Timing: To, TDS, TE

Data Source:	Clinician
Type:	Single answer
Response Options:	
Variable ID:	VISACUCORRT
Variable:	Visual acuity using Snellen chart
Definition:	Indicate the distance visual acuity measured best corrected in the right eye
Supporting Definition:	Use Snellen Chart to measure visual acuity
Inclusion Criteria:	Age >6y
Timing:	To, TDS, TE
Data Source:	Clinician
Type:	Single answer
Response Options:	
Variable ID:	VISACUUNCLT
Variable:	Visual acuity using Snellen chart
Definition:	Indicate the distance visual acuity measured uncorrected in the left eye
Supporting Definition:	Use Snellen Chart to measure visual acuity
Inclusion Criteria:	Age >6y
Timing:	To, TDS, TE
Data Source:	Clinician
Type:	Single answer
Response Options:	
Variable ID:	VISACUCORLT
Variable:	Visual acuity using Snellen chart
Definition:	Indicate the distance visual acuity measured best corrected in the left eye
Supporting Definition:	Use Snellen Chart to measure visual acuity
Inclusion Criteria:	Age >6y
Timing:	To, TDS, TE
Data Source:	Clinician
Type:	Single answer
Response Options:	
Variable ID:	AMBLYOPIA_Qo1
Variable:	Evaluation of amblyopia
Definition:	Has the patient been evaluated to rule out ambliopia?
Supporting Definition:	
Inclusion Criteria:	All patients
Timing:	To, TDS
Data Source:	Clinician
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	OCULAR_SYMPT_o1
Variable:	Ocular symptoms
Definition:	Are you able to blink?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	OCULAR_SYMPT_o2
Variable:	Ocular symptoms
Definition:	Can you close your eyes?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms

Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	OCULAR_SYMPT_03
Variable:	Ocular symptoms
Definition:	Do your eyes make a lot of tears when you go outside in the sun or wind?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	OCULAR_SYMPT_04
Variable:	Ocular symptoms
Definition:	Do your eyes feel dry a lot?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	OCULAR_SYMPT_05
Variable:	Ocular symptoms
Definition:	Do your eyes look red when you look at them in the mirror?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	SPEECH_Q01
Variable:	Speech trouble
Definition:	Do you feel you/the child have trouble with your/their speech?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	PAIN
Variable:	Pain in face
Definition:	On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain imaginable, please indicate your average pain in your face over the last 7 days.
Supporting Definition:	N/A
Inclusion Criteria:	Age >8y
Timing:	On all forms
Data Source:	Patient-reported
Type:	Single answer
Response Options:	Numeric rating scale (0 - 10) or Visual Analog Scale
Variable ID:	eFACE
Variable:	eFACE scoring

Definition:	Indicate the severity of the facial paralysis using the eFACE composite "Smile" score
Supporting Definition:	Based on eFACE
Inclusion Criteria:	Age >3y
Timing:	On all forms
Data Source:	Clinician/Administrative data
Type:	Numerical value
Response Options:	Numerical
Variable ID:	FACEQF_Q01
Variable:	Question 1 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q02
Variable:	Question 2 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q03
Variable:	Question 3 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q04
Variable:	Question 4 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q05
Variable:	Question 5 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q06
Variable:	Question 6 of FACE-Q Kids Appearance of the Face

Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q07
Variable:	Question 7 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q08
Variable:	Question 8 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q09
Variable:	Question 9 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q10
Variable:	Question 10 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q11
Variable:	Question 11 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q12
Variable:	Question 12 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.

Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q13
Variable:	Question 13 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q14
Variable:	Question 14 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQF_Q15
Variable:	Question 15 of FACE-Q Kids Appearance of the Face
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	On all forms
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q01
Variable:	Question 1 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q02
Variable:	Question 2 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q03
Variable:	Question 3 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A

Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo4
Variable:	Question 4 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo5
Variable:	Question 5 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo6
Variable:	Question 6 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo7
Variable:	Question 7 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo8
Variable:	Question 8 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Qo9
Variable:	Question 9 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T ₁ , T ₂ , TDS, TE
Data Source:	Patient-reported

Variable ID:	FACEQMF_Q10
Variable:	Question 10 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q11
Variable:	Question 11 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q12
Variable:	Question 12 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	FACEQMF_Q13
Variable:	Question 13 of FACE-Q Kids Mouth function
Definition:	Please contact license holder for the questionnaire. If you wish to participate in the ICHOM benchmarking program and have secured a licence to use the tool, ICHOM will provide you with the technical specifications on how to collect the data.
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Variable ID:	ORALFUNC_Qo1
Variable:	Oral symptoms question 1
Definition:	Food falls out my child's mouth when they eat, more than I would expect for their age
Supporting Definition:	N/A
Inclusion Criteria:	Age <8y
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	ORALFUNC_Qo2
Variable:	Oral symptoms question 2
Definition:	Liquid falls out of my child's mouth when they drink, more than I would expect for their age
Supporting Definition:	N/A
Inclusion Criteria:	Age <8y
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No

	1 = Yes
Variable ID:	ORALFUNC_Qo3
Variable:	Oral symptoms question 3
Definition:	My child is has trouble chewing food
Supporting Definition:	N/A
Inclusion Criteria:	Age <8y
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	ORALFUNC_Qo4
Variable:	Oral symptoms question 4
Definition:	My child bites their cheeks a lot
Supporting Definition:	N/A
Inclusion Criteria:	Age <8y
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	PROMIS-CPGH7_Qo1
Variable:	CPaedGlobalo1 - Patient reported general health status
Definition:	In general, would you say your health is:
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-CPGH7_Qo2
Variable:	CPaedGlobalo2 - Global patient reported health-related QOL
Definition:	In general, would you say your quality of life is:
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-CPGH7_Qo3
Variable:	CPaedGlobalo3 - Patient reported general health status
Definition:	In general, how would you rate your physical health?
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good

	3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-CPGH7_Qo4
Variable:	CPaedGlobalo4 - Mood, global cognitive function
Definition:	In general, how would you rate your mental health, including your mood and your ability to think?
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-CPGH7_Qo5
Variable:	CPaedGlobalo5 - Sad
Definition:	How often do you feel really sad?
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Never 4 = Rarely 3 = Sometimes 2 = Often 1 = Always
Variable ID:	PROMIS-CPGH7_Qo6
Variable:	CPaedGlobalo6 - Fun with friends
Definition:	How often do you have fun with friends?
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Always 4 = Often 3 = Sometimes 2 = Rarely 1 = Never
Variable ID:	PROMIS-CPGH7_Qo7
Variable:	CPaedGlobalo7 - Parents listen to ideas
Definition:	How often do your parents listen to your ideas?
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	5 = Always 4 = Often 3 = Sometimes 2 = Rarely 1 = Never
Variable ID:	PROMIS-PPGH7_Qo1
Variable:	PPaedGlobalo1 - General health
Definition:	In general, would you say your child's health is:
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID:	PROMIS-PPGH7_Q02
Variable:	PPaedGlobal02 - Quality of life
Definition:	In general, would you say your child's quality of life is:
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-PPGH7_Q03
Variable:	PPaedGlobal03 - Physical health
Definition:	In general, how would you rate your child's physical health?
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-PPGH7_Q04
Variable:	PPaedGlobal04 - Mental health
Definition:	In general, how would you rate your child's mental health, including mood and ability to think?
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-PPGH7_Q05
Variable:	PPaedGlobal05 - Sad
Definition:	How often does your child feel really sad?
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Never 4 = Rarely 3 = Sometimes 2 = Often 1 = Always
Variable ID:	PROMIS-PPGH7_Q06
Variable:	PPaedGlobal06 - Fun with friends
Definition:	How often does your child have fun with friends?
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer

Response Options:	5 = Always 4 = Often 3 = Sometimes 2 = Rarely 1 = Never
Variable ID:	PROMIS-PPGH7_Qo7
Variable:	PPaedGlobalo7 - Parents listen to ideas
Definition:	How often does your child feel that you listen to his or her ideas?
Supporting Definition:	N/A
Inclusion Criteria:	Age 4-7 (if the patient is unable to respond to PROMIS CPGH7)
Timing:	To, T1, T2, TDS, TE
Data Source:	Parent-reported
Type:	Single answer
Response Options:	5 = Always 4 = Often 3 = Sometimes 2 = Rarely 1 = Never
Variable ID:	PROMIS-PEER_Qo1
Variable:	Pediatric Peer Relationships Short Form 8a - q5o18R1
Definition:	In the past 7 days, I felt accepted by other kids my age
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo2
Variable:	Pediatric Peer Relationships Short Form 8a - q5o58R1
Definition:	In the past 7 days, I was able to count on my friends
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo3
Variable:	Pediatric Peer Relationships Short Form 8a - q5o56R1
Definition:	In the past 7 days, I was able to talk about everything with my friends
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo4
Variable:	Pediatric Peer Relationships Short Form 8a - q1147R1
Definition:	In the past 7 days, I was good at making friends
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo5
Variable:	Pediatric Peer Relationships Short Form 8a - q5o55R1
Definition:	In the past 7 days, my friends and I helped each other out
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo6
Variable:	Pediatric Peer Relationships Short Form 8a - q233R2

Definition:	In the past 7 days, other kids wanted to be my friend
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo7
Variable:	Pediatric Peer Relationships Short Form 8a - q21oR1
Definition:	In the past 7 days, other kids wanted to be with me
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	PROMIS-PEER_Qo8
Variable:	Pediatric Peer Relationships Short Form 8a - q9o2oR1
Definition:	In the past 7 days, other kids wanted to talk to me
Supporting Definition:	N/A
Inclusion Criteria:	Age 8-18
Timing:	To, T1, T2, TDS, TE
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always
Variable ID:	INTERVENTION_COMP
Variable:	Complications
Definition:	Indicate whether there were any complications
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	T2
Data Source:	Clinician
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	INTERVENTION_COMP_TYPE
Variable:	Complication associated to interventions
Definition:	Indicate if the patient experienced any of the following complications
Supporting Definition:	N/A
Inclusion Criteria:	If "1 = Yes" to INTERVENTION_COMP
Timing:	T2
Data Source:	Clinician
Type:	Multiple answer
Response Options:	0 = No complication 1 = Bleeding that requires return to operation room, transfusion or haematoma that requires intervention 2 = Cellulitis, abscess and material related infection 3 = Dehiscence, skin flap necrosis, parotid fistula, re-exploration/failure of flap, hypertrophic/keloid scars 4 = Unplanned revision (an additional intervention >3 months following the primary intervention that had not previously been considered necessary in the course of treatment)
Variable ID:	INTERVENTION_COMP_DATE
Variable:	Date of complication
Definition:	Indicate when the complication was identified
Supporting Definition:	N/A

Inclusion Criteria:	If "1 = Yes" to INTERVENTION_COMP
Timing:	T2
Data Source:	Clinician
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY
Variable ID:	PATACT_Qo1
Variable:	Resources for condition
Definition:	Have you been provided with further resources such as psychological support or care?
Supporting Definition:	This question is not a health outcome it is intended to identify whether patients and their families need further support to cope with the condition
Inclusion Criteria:	All patients
Timing:	T1
Data Source:	Patient or Proxy-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PATACT_Qo2
Variable:	Information about condition and treatment
Definition:	Have you been provided adequate verbal/written information on your/your child's condition and treatment?
Supporting Definition:	This question is not a health outcome it is intended to identify whether patients and their families need further information to understand their condition and promote patient activation
Inclusion Criteria:	All patients
Timing:	T1
Data Source:	Patient or Proxy-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PATACT_Qo3
Variable:	Understanding condition and treatment
Definition:	Do you feel you understand your/your child's current treatment?
Supporting Definition:	This question is not a health outcome it is intended to identify whether patients and their families need further information to understand their condition and promote patient activation
Inclusion Criteria:	All patients
Timing:	T1
Data Source:	Patient or Proxy-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PATACT_Qo4
Variable:	Treatment satisfaction
Definition:	Are you happy with your/your child's overall outcome at this time?
Supporting Definition:	This question is not a health outcome it is intended to identify patient satisfaction and experience
Inclusion Criteria:	All patients
Timing:	T1
Data Source:	Patient or Proxy-reported
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = Unknown

Working Group Member Conflicts of Interest

At the beginning of the Working Group process, we ask all Working Group members to declare any conflicts of interest they have. We then circulate these within the Group to ensure transparency.

Name	Title	Declarations
Adriaan Grobbelaar	Consultant Plastic Surgeon, Working Group Chair	None declared
Daniel Butler	Plastic Surgery Specialist Registrar, ICHOM Research Fellow	None declared
Alethse De la Torre	Project Leader	None declared
Adelaida Martinez	Consultant Paediatric Neurologist	None declared
Akihiko Takushima	Professor of Plastic Surgery	None declared
Alexander Cardenas-Mejia	Associate Professor of Plastic Surgery	None declared
Carien Beurskens	Physiotherapist/Senior Researcher	None declared
Christopher Coombs	Professor of Plastic Surgery	None declared
Evangelina Vazquez Curiel	Coordinator at Pan-American Patients for Patient Safety Network	None declared
Faye Wachs	Professor of Sociology	None declared
Gregory Borschel	Consultant Plastic Surgeon	None declared
Jacqueline Diels	Facial Retraining Specialist	None declared
Jocelyne Copeland	Occupational Therapist	None declared
Kathleen Bogart	Assistant Professor of Psychology	None declared
Lisa Ishii	Associate Professor of Otolaryngology	None declared
Lisa McKinley	Executive Director at Facial Paralysis and Bell's Palsy Foundation	None declared
Louise Graham	Patient Representative	None declared
Mara Robinson	Physical Therapist	None declared
Raman Malhotra	Consultant Oculoplastic Surgeon	None declared
Sinikka Suominen	Associate Professor of Plastic Surgery	Herantis Pharma - personal fees
Teresa Gonzalez Otero	Consultant Maxillofacial Surgeon	None declared
Tessa Hadlock	Professor of Facial Plastic Surgery	None declared

Reference Guide Revisions

Reference Guide Version

Location within Reference Guide

Content Change

