



ICHOM

International Consortium for
Health Outcomes Measurement

Overall Pediatric Health DATA COLLECTION REFERENCE GUIDE

Version 1.0.0
Revised: February 25th, 2020



Measuring
results
that matter.

Overall

Pediatric Health



We are thrilled that you are interested in measuring outcomes for overall pediatric health and implementing the ICHOM Standard Set. The aim of this Reference Guide is to facilitate the process of implementing a standard set of measures and ensure collection of comparable data for global benchmarking and learning.

© 2020 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more standard outcome sets. Please cite as follows: ICHOM Overall Pediatric Health Working Group, OPH Standard Set, February 2020, (available at: <https://www.ichom.org/portfolio/overall-pediatric-health/>)

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and experts from around 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.

These 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 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 info@ichom.org

Working Group Members for Overall Pediatric Health

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Overall Pediatric Health in partnership with ICHOM, under the leadership of Kathy Jenkins, ICHOM Working Group Chair. The work was supported by Beatrix Algurén, Research Fellow, Jessily P. Ramirez, ICHOM Project Manager, and Nick Sillett, ICHOM Research Associate.

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Supporting Organizations

The Overall Pediatric Health Standard Set is made possible through the generous support of the following organizations.

Thank You.



Scope of the Overall Pediatric Health Standard Set

This is a foundational Standard Set that's meant to interface with other condition-specific standard sets. The Overall Pediatric Health Standard Set covers:

Conditions	All infants, children, and adolescents - regardless of condition
Population	Birth - 24 years
Treatment approaches	Independent of treatment or diagnosis

ICHOM Standard Set for Overall Pediatric Health

Case-Mix Variables

Variable	Measure	Supporting Information	Timing	Data Source
Demographic Factors				
Age	Patient year and month of birth	Used to calculate age	Baseline	Patient/Administrative
Sex	Biological sex of patient at birth		Baseline	Patient/Administrative
Diagnosis Profile				
Diagnosis	Prior and current diagnosis of disease or no presence of diagnosis	Conditions listed as ICD-10 Code	Baseline	Healthcare Provider
Lifestyle and Social Factors				
Parent Education Level	Highest level of education of either parent	None - Includes Early Childhood Education. Primary - includes primary and lower secondary education. Secondary - Includes upper secondary and short-cycle tertiary education. Tertiary - Includes Bachelor's, Master's or Doctoral education, or equivalent levels.	Baseline	Patient or Primary Caregiver
Primary Caregiver			With outcomes	Patient or Primary Caregiver
Respondent	Who is providing this information about the patient		With outcomes	Patient or Primary Caregiver

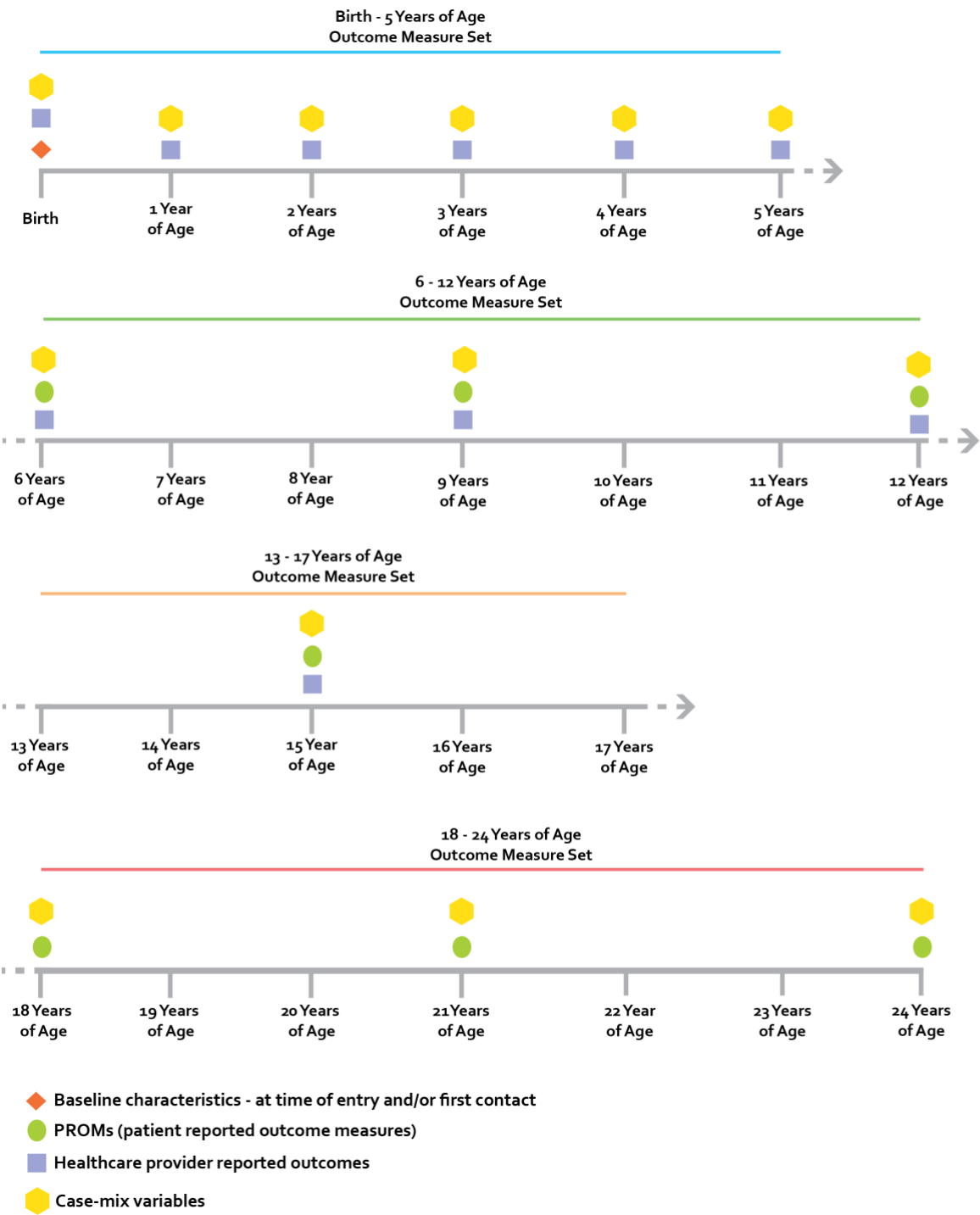
Outcomes

Measure	Supporting Information	Data Source
Mental Functioning		
Cognition: Intelligence	General mental functions, required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the lifespan.	Patient or Primary Caregiver
Mood	The appropriate designation for affective states that are about nothing specific or about everything about the world in general.	Patient or Primary Caregiver
Mental Health	Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.	Patient or Primary Caregiver
Coping	Conceptualized as being either a trait that relates to stable properties of a person, or as a state dealing with transient reactions that change with circumstances. In the latter, coping is defined as 'the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person'.	Patient
Self-Efficacy	A personal judgement of "how well one can execute courses of action required to deal with prospective situations," an individual's belief in his or her innate ability to achieve goals.	Patient
Self-Esteem	The individual's positive or negative attitude toward the self as a totality.	Patient
Social/General Functioning		
Communication	General and specific features of communicating by language, signs and symbols, including receiving and producing messages, carrying on conversations, and using communication devices and techniques.	Patient or Primary Caregiver, with Healthcare Provider
School Attendance	# of school days missed due to illness.	Patient or Primary Caregiver
Development	Holistic development sees the child as a whole person - physically, emotionally, intellectually, socially, morally, culturally and spiritually. Child development involves studying patterns of growth and development.	Patient or Primary Caregiver, with Healthcare Provider
Functioning	Umbrella term encompassing all body functions, activities and participation. Denotes the positive aspects of the interaction between an individual and that individual's contextual factors (environmental and personal factors).	Patient or Primary Caregiver
Health-Related Quality of Life	As health is a multidimensional, HRQoL is also multidimensional and incorporates domains related to physical, mental and emotional, and social functioning.	Patient or Primary Caregiver

Measure	Supporting Information	Data Source
Physical Functioning		
Eating	The ability to eat without limitation and in the absence of eating disorders.	Patient or Primary Caregiver, with Healthcare Provider
Fitness	Aerobic capacity functions related to the extent to which a person can exercise without getting out of breath.	Patient or Primary Caregiver
Growth	Changes in height, weight and body mass index (the physical aspect of development).	Healthcare Provider
Hearing	Sensory functions relating to sensing the presence of sounds and discriminating the location, pitch, loudness and quality of sounds.	Healthcare Provider
Nutrition	The intake of food considered in relation to the body's dietary needs.	Healthcare Provider
Pain	The absence of sensations of unpleasant feelings indicating potential or actual damage to some body structure.	Patient or Primary Caregiver
Physical Ability: Mobility	Movement by changing body position or location or by transferring from one place to another by carrying, moving or manipulating objects, by walking, running or climbing and by using various forms of transportation.	Patient or Primary Caregiver
Sleep	Includes the amount of sleeping and onset, maintenance of quality of sleep and functions of the sleep cycle such as in insomnia and narcolepsy.	Patient or Primary Caregiver
Survival	The opposite of being subject to death.	Healthcare Provider
Vision	Sensory functions relating to sensing the presence of light and sensing the form, size, shape and color of the visual stimuli.	Healthcare Provider
Sexual Health	Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.	Patient

Follow-Up Timeline

The following timeline illustrates when Standard Set variables should be collected from patients, primary caregivers, and healthcare providers. The outcomes defined above are measured by different patient- and healthcare provider-reported outcome measures at each of the four different age ranges. Outcomes and case-mix variables will be measured annually between birth and 5 years of age, then every three years for the subsequent ages. Baseline characteristics can either be collected at the point of entry into the healthcare system or during their first contact with the healthcare provider. The 'Respondent' and 'Primary Caregiver' case-mix variables will also be collected whenever outcomes are measured.



Collecting Patient, Parent, and Healthcare Provider-Reported Outcome Measures

Measure	Licensing Information	Scoring Information
PROMIS Parent Proxy Scale v1.0 - Global Health 7+2 - Parent	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The scale can either be scored using the online HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoringservice) where the data file can be uploaded and a Global Health score produced. This can also be scored by hand, where the summed raw scores from each item can be converted into T-score values using conversion tables found in the PROMIS Global Scoring Manual.
PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a - Parent	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The easiest way to use this instrument is with the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoringservice). However, these can be manually scored by calculating the raw score by summing the values of each item response. These total raw scores can then be converted to a T-score by using the conversion tables located in the Cognitive Function Scoring Manual from the HealthMeasures website.
PROMIS Pediatric Scale - Global Health 7+2 - Patient	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The scale can either be scored using the online HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoringservice) where the data file can be uploaded and a Global Health score produced. This can also be scored by hand, where the summed raw scores from each item can be converted into T-score values using conversion tables found in the PROMIS Global Scoring Manual.
NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0 - Patient	The NIH Toolbox Self-Efficacy CAT is free to use and available to download in a pdf format from the HealthMeasures website, in the 'NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0' page.	This tool can be hand-scored by summing the responses and, with a conversion table provided by HealthMeasures on their 'NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0' page, these can be converted into a T-score. The instructions for their interpretation are also provided on the same page.

AQoL 8D - Patient	The AQoL 8D is free to use and available to download in a pdf format from the website: www.aqol.com.au/ .	AQoL provides the online algorithms with which to score the tool, found at: https://www.monash.edu/business/che/aqol/using-aqol/scoring . For the AQoL 8D, to give a psychometric rating, the unweighted algorithms are to be used, these can either be used in Microsoft Excel or SPSS and their instructions for use are provided.
PROMIS Short Form v1.0 - Sleep Disturbance - 4a - Patient	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The easiest way to use this instrument is with the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoring-service). However, these can be manually scored by calculating the raw score by summing the values of each item response. These total raw scores can then be converted to a T-score by using the conversion tables located in the Sleep Disturbance Scoring Manual from the HealthMeasures website.
PROMIS Pool v2.0 - Sexual Function and Satisfaction : Screeners (Q. SFSCR202, SFSCR203, SFSCR204b p) - Patient	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The easiest way to use this instrument is with the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoring-service). However, these can be manually scored by calculating the raw score by summing the values of each item response. These total raw scores can then be converted to a T-score by using the conversion tables located in the Sexual Function and Satisfaction Scoring Manual from the HealthMeasures website.
PROMIS Short Form v2.0 - Cognitive Function 4a - Patient	Respondent-ready PDFs the instrument for all measurement systems are available at www.HealthMeasures.net in "Search & View Measures." These measures may be used in paper or electronic form for single use (i.e., solely for the user's own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The easiest way to use this instrument is with the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoring-service). However, these can be manually scored by calculating the raw score by summing the values of each item response. These total raw scores can then be converted to a T-score by using the conversion tables located in the Cognitive Function Scoring Manual from the HealthMeasures website.

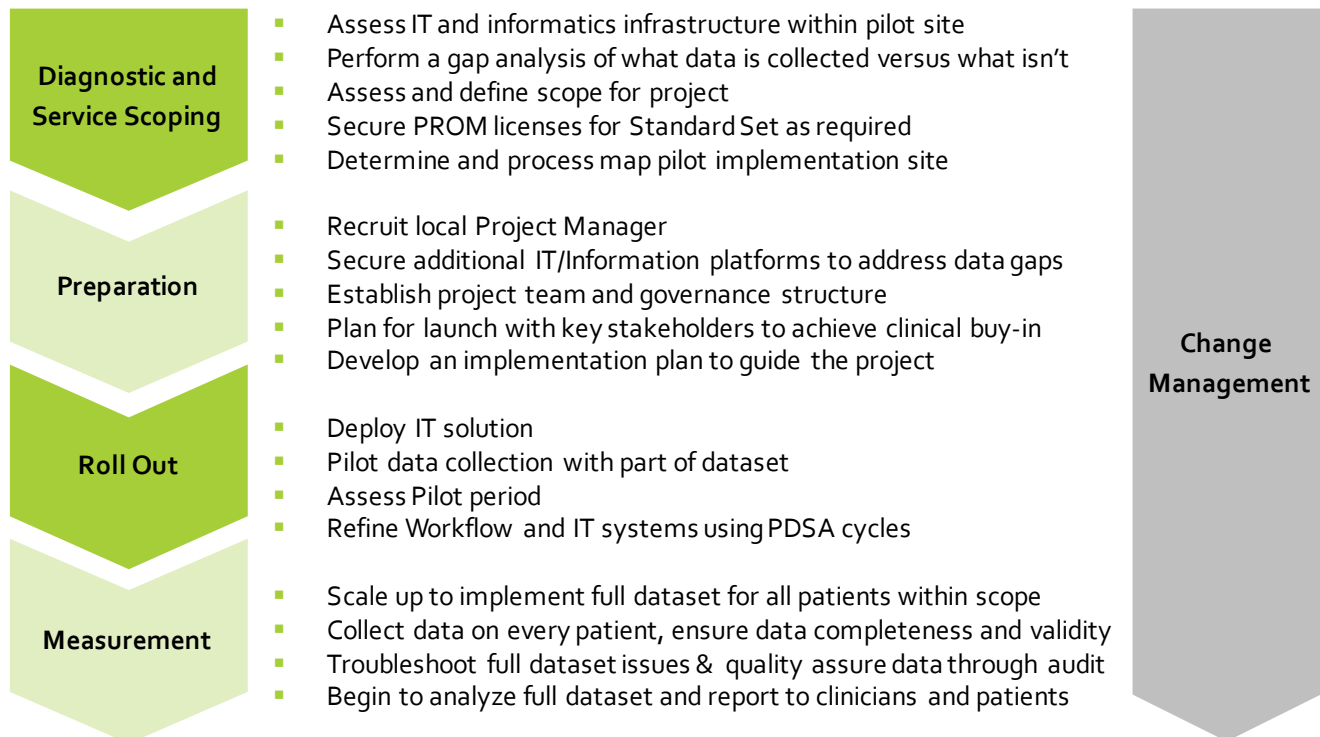
E-Chart Visual Acuity Test – Healthcare Provider	The E-Chart Visual Acuity Test requires no license and is freely available. E-charts and instructions for use are available online to download free of charge and can be used to carry out this test. https://www.provisu.ch/images/PDF/Echart_en.pdf	This test provides the healthcare provider with a Visual Acuity score, which is assigned by the line reached by the individual when undertaking the eye test. This value is to be recorded using ‘feet’ as the metric (for example: 20/20, 20/25, 20/30, etc.).
Snellen Visual Acuity Test– Healthcare Provider	The Snellen Visual Acuity Test requires no license and is freely available. Snellen charts and instructions for use are available online to download free of charge and can be used to carry out this test. https://www.provisu.ch/images/PDF/Snellenchart_en.pdf	This test provides the healthcare provider with a Visual Acuity score, which is assigned by the line reached by the individual when undertaking the eye test. This value is to be recorded using ‘feet’ as the metric (for example: 20/20, 20/25, 20/30, etc.).
WHO Growth Charts Early Years - Healthcare Provider	The Growth Charts are freely available without use of a licence from the World Health Organisation website (available at: https://www.who.int/childgrowth/standards/en/).	For the charts, the weight, length/height and head circumference, measurements of the child are recorded. These are plotted by age onto the specific Growth Chart for the child’s biological sex. The child’s centile should be recorded, either the exact centile it falls on or the two it falls between. These charts are available from: https://www.who.int/childgrowth/standards/en/
WHO Growth Charts School Age Years starting at 6 years of age - Healthcare Provider	The Growth Charts are freely available without use of a licence from the World Health Organisation website (available at: https://www.who.int/growthref/en/).	For the charts, the weight and height measurements of the child are recorded. These are plotted by age onto the specific Growth Chart for the child’s biological sex. The child’s centile should be recorded, either the exact centile it falls on or the two it falls between. These charts are available from: https://www.who.int/growthref/en/
CDC Milestone Checklist - Parent	This measure is available free of charge and without need of a licence from the developers at: https://www.cdc.gov/ncbddd/actearly/milestones/index.html . This is also available in Spanish.	This measure isn’t formally scored, but the milestones are shown for each age-group. These milestones are illustrated by pictures or videos in each age’s individual page and then checked by the respondent.

The Growing ICHOM Community

There is a growing community of healthcare providers implementing the ICHOM Standard Sets. To support your organization 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.

Implementation framework:

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



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, in line with its current license agreement, 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 Finalization	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.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Overall Pediatric Health 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_1YR (1 year of age); VARIABLEID_3YR (3 years of age), etc.

Case-Mix Variables

Demographic Factors

Variable ID: SEX

Variable: Sex

Definition: Indicate the patient's sex at birth

Supporting Definition: For statistical purposes, the following category codes, labels and definitions are preferred:

CODE 1 Male: Persons who have male or predominantly masculine biological characteristics, or male sex assigned at birth.

CODE 2 Female: Persons who have female or predominantly feminine biological characteristics, or female sex assigned at birth.

CODE 3 Other: Persons who have mixed or non-binary biological characteristics (if known), or a non-binary sex assigned at birth

The value meaning of 'Other' has been assigned to Code 3 for this value domain, which replaces 'Intersex or indeterminate' for the superseded value domain Sex code N. Terms such as 'indeterminate,' 'intersex', 'non-binary', and 'unspecified' are variously used to describe the 'Other' category of sex. The label 'Other' is used because a more descriptive term has not been widely agreed within the general community.

Sex refers to the chromosomal, gonadal and anatomical characteristics associated with biological sex. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient/Administrator

Type: Code

Response Options: 1 = Male
2 = Female
3 = Other
999 = Undisclosed

Variable ID: PEDSDOB

Variable: Date of Birth

Definition: Patient year and month of birth

Supporting Definition: Used to calculate age

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient/Administrator
Type: Numerical
Response Options: MM/YYYY

Diagnosis Profile

Variable ID: DIAG
Variable: Diagnosis
Definition: Prior and current diagnosis of disease or no presence of diagnosis.
Supporting Definition:
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Healthcare Provider
Type: List
Response Options: ICD-10 Code

Lifestyle and Social Factors

Variable ID: PAREDU
Variable: Parent Education Level
Definition: Highest level of education of either parent.
Supporting Definition: This is used as a proxy for socioeconomic status
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient or Primary Caregiver
Type: Single answer
Response Options: None - Includes Early Childhood Education.
Primary - includes primary and lower secondary education.
Secondary - Includes upper secondary and short-cycle tertiary education.
Tertiary - Includes Bachelor's, Master's or Doctoral education, or equivalent levels.

Variable ID: PCARER
Variable: Primary Caregiver
Definition: Relation of the primary caregiver to patient.
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: With outcomes
Data Source: Patient or Primary Caregiver
Type: Check all that apply
Response Options: Mother/Father
Other family member
Self
Other

Variable ID: RESPON
Variable: Respondent
Definition: Who is providing this information about the patient.
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: With outcomes
Data Source: Patient or Primary Caregiver
Type: Single answer
Response Options: Mother/Father
Other family member
Self
Other

Outcomes

School Attendance

Variable ID:	SCHOOLATT
Variable:	School Attendance
Definition:	Number of school days missed due to illness
Supporting Definition:	In the last year
Inclusion Criteria:	All patients
Timing:	Birth-5 years 6-12 years 13-17 years
Data Source:	Healthcare Provider or Patient
Type:	Numerical
Response Options:	Number of days

Survival

Variable ID:	VITALSTATUS
Variable:	Vital Status
Definition:	Indicate if the person is deceased, regardless of cause
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Birth-5 years 6-12 years 13-17 years
Data Source:	Healthcare Provider
Type:	Single answer
Response Options:	0 = No 1 = Yes

Variable ID:	CAUSEOFDEATH
Variable:	Cause of death
Definition:	Death attributable to disease
Supporting Definition:	N/A
Inclusion Criteria:	If responded "No" to "is the person alive"
Timing:	Birth-5 years 6-12 years 13-17 years
Data Source:	Healthcare Provider
Type:	Single answer
Response Options:	Text entry

Variable ID:	DEATHSOURCE
Variable:	Death - Source of information
Definition:	What is the source of the information on the person's death
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Birth-5 years 6-12 years 13-17 years
Data Source:	Healthcare Provider
Type:	Single answer

Response Options: Death certificate
Clinical records
Family/ Caregivers
Other

Patient-Reported Outcomes

Variable ID: PROPROXGH_Q01

Variable: Question 1 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2

Definition: Please respond to each question or statement by marking one box per row.
In general, would you say your child's health is:

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 6-12 Years

Data Source: Patient or Parent (Proxy)

Type: Single answer

Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPROXGH_Q02

Variable: Question 2 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2

Definition: In general, would you say your child's quality of life is:

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 6-12 Years

Data Source: Patient or Parent (Proxy)

Type: Single answer

Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPROXGH_Q03

Variable: Question 3 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2

Definition: In general, how would you rate your child's physical health?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 6-12 Years

Data Source: Patient or Parent (Proxy)

Type: Single answer

Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPROXGH_Q04

Variable: Question 4 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2

Definition: In general, how would you rate your child's mental health, including mood and ability to think?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 6-12 Years

Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPROXGH_Qo5
Variable: Question 5 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2
Definition: How often does your child feel really sad?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Always
2 = Often
3 = Sometimes
4 = Rarely
5 = Never

Variable ID: PROPROXGH_Qo6
Variable: Question 6 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2
Definition: How often does your child have fun with friends?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROPROXGH_Qo7
Variable: Question 7 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2
Definition: How often does your child feel that you listen to his or her ideas?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROPROXGH_Qo8
Variable: Question 8 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2
Definition: In the past 7 days...
My child got tired easily
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years

Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Often
5 = Almost Always

Variable ID: PROPROXGH_Q09
Variable: Question 9 of PROMIS Parent Proxy Scale v1.0 - Global Health 7+2
Definition: In the past 7 days...
My child had trouble sleeping when he/she had pain
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Often
5 = Almost Always

Variable ID: PROPROXCOG_Q01
Variable: **Question 1 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a**
Definition: Please respond to each question or statement by marking one box per row.
In the past 4 weeks...
I have to use written lists more often than other people my age so I will not forget things
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q02
Variable: Question 2 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: It is hard for me to pay attention to one thing for more than 5-10 minutes
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q03

Variable: Question 3 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: I have trouble keeping track of what I am doing if I get interrupted
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q04
Variable: Question 4 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: I have to read things several times to understand them
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q05
Variable: Question 5 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: I forget things easily
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q06
Variable: Question 6 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: I have to work really hard to pay attention or I make mistakes
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer

Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPROXCOG_Q07
Variable: Question 7 of PROMIS Parent Proxy Short Form v1.0 - Cognitive Function 7a
Definition: I have trouble remembering to do things like school projects or chores
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6-12 Years
13-17 Years
Data Source: Patient or Parent (Proxy)
Type: Single answer
Response Options: 1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time

Variable ID: PROPEDGH_Q01
Variable: **Question 1 of PROMIS Pediatric Scale v1.0 - Global Health 7+2**
Definition: In general, would you say your health is:
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPEDGH_Q02
Variable: Question 2 of PROMIS Pediatric Scale v1.0 - Global Health 7+2
Definition: In general, would you say your quality of life is:
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPEDGH_Q03
Variable: Question 3 of PROMIS Pediatric Scale v1.0 - Global Health 7+2
Definition: In general, how would you rate your physical health?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer

Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPEDGH_Qo4

Variable: Question 4 of PROMIS Pediatric Scale v1.0 - Global Health 7+2

Definition: In general, how would you rate your mental health, including your mood and your ability to think?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Poor
2 = Fair
3 = Good
4 = Very good
5 = Excellent

Variable ID: PROPEDGH_Qo5

Variable: Question 5 of PROMIS Pediatric Scale v1.0 - Global Health 7+2

Definition: How often do you feel really sad?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Always
2 = Often
3 = Sometimes
4 = Rarely
5 = Never

Variable ID: PROPEDGH_Qo6

Variable: Question 6 of PROMIS Pediatric Scale v1.0 - Global Health 7+2

Definition: How often do you have fun with friends?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROPEDGH_Qo7

Variable: Question 7 of PROMIS Pediatric Scale v1.0 - Global Health 7+2

Definition: How often do your parents listen to your ideas?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

Variable ID: PROPEDGH_Qo8
Variable: Question 8 of PROMIS Pediatric Scale v1.0 - Global Health 7+2
Definition: In the past 7 days...
I got tired easily

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Often
5 = Almost Always

Variable ID: PROPEDGH_Qo9
Variable: Question 9 of PROMIS Pediatric Scale v1.0 - Global Health 7+2
Definition: In the past 7 days...
I had trouble sleeping when I had pain

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Often
5 = Almost Always

Variable ID: NIHSEFF13-17_Qo1
Variable: **Question 1 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0**
Definition: Please respond to each question or statement by marking one box per row.
Please read the sentence and decide how true it is of you in general.
I can always manage to solve difficult problems if I try hard enough

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 13-17 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Qo2
Variable: Question 2 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: If someone tries to keep me from getting what I want, I can find a way to get what I want

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q03
Variable: Question 3 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: It is easy for me to stick to my goals and reach them
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q04
Variable: Question 4 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: I am confident that I could do a good job dealing with unexpected events
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q05
Variable: Question 5 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: Thanks to my talents and skills, I know how to handle unexpected situations
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q06
Variable: Question 6 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: I can solve most problems if I try hard enough
Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q07
Variable: Question 7 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: I can stay calm when facing difficulties because I can handle them
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q08
Variable: Question 8 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: When I have a problem, I can find several ways to solve it
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q09
Variable: Question 9 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: If I am in trouble, I can think of a solution
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: NIHSEFF13-17_Q10
Variable: Question 10 of NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
Definition: I can handle whatever comes my way
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 13-17 Years

Data Source: Patient
Type: Single answer
Response Options: 1 = Never
2 = Almost Never
3 = Sometimes
4 = Fairly Often
5 = Very Often

Variable ID: AQOL8_Qo1
Variable: Question 1 of AQoL-8D
Definition: Tick the box that best describes your situation as it has been over the past week
How much energy do you have to do the things you want to do? I am...
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = always full of energy
2 = usually full of energy
3 = occasionally energetic
4 = usually tired and lacking energy
5 = always tired and lacking energy

Variable ID: AQOL8_Qo2
Variable: Question 2 of AQoL-8D
Definition: How often do you feel socially excluded or left out?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = rarely
3 = sometimes
4 = often
5 = always

Variable ID: AQOL8_Qo3
Variable: Question 3 of AQoL-8D
Definition: How easy or difficult is it for you to get around by yourself outside your place of residence (e.g. to go shopping, visiting)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = getting around is enjoyable and easy
2 = I have no difficulty getting around outside my place of residence
3 = a little difficulty
4 = moderate difficulty
5 = a lot of difficulty
6 = I cannot get around unless somebody is there to help me.

Variable ID: AQOL8_Qo4
Variable: Question 4 of AQoL-8D
Definition: Does your health affect your role in your community (e.g. residential, sporting, church or cultural activities)?

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = my role in the community is unaffected by my health
2 = there are some parts of my community role I cannot carry out
3 = there are many parts of my community role I cannot carry out
4 = I cannot carry out any part of my community role

Variable ID: AQOL8_Qo5
Variable: Question 5 of AQoL-8D
Definition: How often do you feel sad?

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = rarely
3 = some of the time
4 = usually
5 = nearly all the time

Variable ID: AQOL8_Qo6
Variable: Question 6 of AQoL-8D
Definition: How often do you experience serious pain?
I experience it...
Supporting Definition: (* Include response 'once or twice a week')
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = very rarely
2 = less than once a week
3 = once or twice a week*
4 = three to four times a week
5 = most of the time.

Variable ID: AQOL8_Qo7
Variable: Question 7 of AQoL-8D
Definition: How much confidence do you have in yourself?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Complete confidence
2 = A lot
3 = A moderate amount
4 = A little
5 = None at all

Variable ID: AQOL8_Qo8
Variable: Question 8 of AQoL-8D
Definition: Do you normally feel calm and tranquil or agitated?
I am...

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = always calm and tranquil
2 = usually calm and tranquil
3 = sometimes calm and tranquil, sometimes agitated
4 = usually agitated
5 = always agitated

Variable ID: AQOL8_Q09
Variable: Question 9 of AQoL-8D
Definition: Does your health affect your relationship with your family?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = my role in the family is unaffected by my health
2 = there are some parts of my family role I cannot carry out
3 = there are many parts of my family role I cannot carry out
4 = I cannot carry out any part of my family role.

Variable ID: AQOL8_Q10
Variable: Question 10 of AQoL-8D
Definition: How satisfying are your close relationships (family and friends)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = very satisfying
2 = satisfying
3 = neither satisfying nor dissatisfying
4 = dissatisfying
5 = unpleasant
6 = very unpleasant

Variable ID: AQOL8_Q11
Variable: Question 11 of AQoL-8D
Definition: How well do you communicate with others (talking, signing, texting, being understood by others and understanding them)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = I have no trouble being understood
2 = I have some difficulty being understood by people who do not know me.
3 = I am understood only by people who know me.
4 = I cannot adequately communicate with others.

Variable ID: AQOL8_Q12
Variable: Question 12 of AQoL-8D
Definition: How often do you have trouble sleeping?
Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = almost never
3 = sometimes
4 = often
5 = all the time

Variable ID: AQOL8_Q13
Variable: Question 13 of AQoL-8D
Definition: How often do you feel worthless?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = almost never
3 = sometimes
4 = usually
5 = always

Variable ID: AQOL8_Q14
Variable: Question 14 of AQoL-8D
Definition: How often do you feel angry?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = almost never
3 = sometimes
4 = often
5 = all the time

Variable ID: AQOL8_Q15
Variable: Question 15 of AQoL-8D
Definition: How easy or difficult is it for you to move around (using any aids or equipment you need e.g. a wheelchair, frame or stick)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = I am very mobile
2 = I have no difficulty with mobility
3 = I have some difficulty with mobility (for example, going uphill)
4 = I have difficulty with mobility. I can go short distances only,
5 = I have a lot of difficulty with mobility. I need someone to help me
6 = I am bedridden.

Variable ID: AQOL8_Q16
Variable: Question 16 of AQoL-8D
Definition: Do you ever feel like hurting yourself?

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = rarely
3 = sometimes
4 = often
5 = all the time

Variable ID: AQOL8_Q17
Variable: Question 17 of AQoL-8D
Definition: How enthusiastic do you feel?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = extremely
2 = very
3 = somewhat
4 = not much
5 = not at all

Variable ID: AQOL8_Q18
Variable: Question 18 of AQoL-8D
Definition: How often did you feel worried in the last seven days?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = occasionally
3 = sometimes
4 = often
5 = all the time.

Variable ID: AQOL8_Q19
Variable: Question 19 of AQoL-8D
Definition: How difficult is it for you to wash, toilet, dress yourself, eat or care for your appearance?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = these things are very easy for me to do
2 = I have no real difficulty in doing these things
3 = I find some of these things difficult, but I manage to do them on my own
4 = many of these things are difficult, and I need help to do them
5 = I cannot do these things by myself at all.

Variable ID: AQOL8_Q20
Variable: Question 20 of AQoL-8D
Definition: How often do you feel happy?

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = all the time
2 = mostly
3 = sometimes
4 = almost never
5 = never

Variable ID: AQOL8_Q21
Variable: Question 21 of AQoL-8D
Definition: How much do you feel you can cope with life's problems?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = completely
2 = mostly
3 = partly
4 = very little
5 = not at all.

Variable ID: AQOL8_Q22
Variable: Question 22 of AQoL-8D
Definition: How much pain or discomfort do you experience:
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = none at all
2 = I have moderate pain
3 = I suffer from severe pain
4 = I suffer unbearable pain.

Variable ID: AQOL8_Q23
Variable: Question 23 of AQoL-8D
Definition: How much do you enjoy your close relationships (family and friends)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = immensely
2 = a lot
3 = a little
4 = not much
5 = I hate it

Variable ID: AQOL8_Q24
Variable: Question 24 of AQoL-8D
Definition: How often does pain interfere with your usual activities?
Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = rarely
3 = sometimes
4 = often
5 = always

Variable ID: AQOL8_Q25
Variable: Question 25 of AQoL-8D
Definition: How often do you feel pleasure?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = always
2 = usually
3 = sometimes
4 = almost never
5 = never

Variable ID: AQOL8_Q26
Variable: Question 26 of AQoL-8D
Definition: How much of a burden do you feel you are to other people?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Not at all
2 = A little
3 = A moderate amount
4 = A lot
5 = totally

Variable ID: AQOL8_Q27
Variable: Question 27 of AQoL-8D
Definition: How content are you with your life?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = extremely
2 = mainly
3 = moderately
4 = slightly
5 = not at all

Variable ID: AQOL8_Q28
Variable: Question 28 of AQoL-8D
Definition: How well can you see (using your glasses or contact lenses if they are needed)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years

Data Source: Patient
Type: Single answer
Response Options: 1 = I have excellent sight
2 = I see normally
3 = I have some difficulty seeing things sharply. (e.g. small print, objects in the distance, or watching television)
4 = I have a lot of difficulty seeing sharply.
5 = I only see general shapes.
6 = I am completely blind.

Variable ID: AQOL8_Q29
Variable: Question 29 of AQoL-8D
Definition: How often do you feel in control of your life?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = always
2 = mostly
3 = sometimes
4 = only occasionally
5 = never.

Variable ID: AQOL8_Q30
Variable: Question 30 of AQoL-8D
Definition: How much help do you need with jobs around your place of residence (e.g. preparing food, cleaning, gardening)?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = I can do all these tasks very easily without any help
2 = I can do these tasks relatively easily without help
3 = I can do these tasks only very slowly without help
4 = I cannot do most of these tasks unless I have help
5 = I can do none of these tasks by myself.

Variable ID: AQOL8_Q31
Variable: Question 31 of AQoL-8D
Definition: How often do you feel socially isolated?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = rarely
3 = sometimes
4 = often
5 = always

Variable ID: AQOL8_Q32
Variable: Question 32 of AQoL-8D
Definition: How well can you hear (using your hearing aid if needed)?
Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = I have excellent hearing
2 = I hear normally
3 = I have some difficulty hearing or I do not hear clearly (e.g. when there is background noise)
4 = I have difficulty hearing things clearly. Often, I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
5 = I hear very little
6 = I am completely deaf.

Variable ID: AQOL8_Q33
Variable: Question 33 of AQoL-8D
Definition: How often do you feel depressed?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = almost never
3 = sometimes
4 = often
5 = very often
6 = all the time

Variable ID: AQOL8_Q34
Variable: Question 34 of AQoL-8D
Definition: How happy are you with your close and intimate relationships?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = very happy
2 = generally happy
3 = neither happy nor unhappy
4 = generally unhappy
5 = very unhappy

Variable ID: AQOL8_Q35
Variable: Question 35 of AQoL-8D
Definition: How often did you feel in despair in the last seven days?
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = never
2 = occasionally
3 = sometimes
4 = often
5 = all the time.

Variable ID: PROSLE4A_Q01
Variable: Question 1 of PROMIS Short Form v1.0 - Sleep Disturbance - 4a
Definition: Please respond to each question or statement by marking one box per row.
In the past 7 days...
My sleep quality was

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

Variable ID: PROSLE4A_Q02
Variable: Question 2 of PROMIS Short Form v1.0 - Sleep Disturbance - 4a
Definition: My sleep was refreshing.

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

Variable ID: PROSLE4A_Q03
Variable: Question 3 of PROMIS Short Form v1.0 - Sleep Disturbance - 4a
Definition: I had a problem with my sleep

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer
Response Options: 1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

Variable ID: PROSLE4A_Q04
Variable: Question 4 of PROMIS Short Form v1.0 - Sleep Disturbance - 4a
Definition: I had difficulty falling asleep

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 18-24 Years
Data Source: Patient
Type: Single answer

Response Options: 1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

Variable ID: PROSEX_Q202

Variable: Question SFSCR202 of PROMIS Pool v2.0 - Sexual Function and Satisfaction: Screeners

Definition: In the past 30 days
Did you have any type of sexual activity?
(Examples of sexual activity are masturbation, oral sex, and sexual intercourse.)

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 18-24 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = No
2 = Yes

Variable ID: PROSEX_Q203

Variable: Question SFSCR203 of PROMIS Pool v2.0 - Sexual Function and Satisfaction: Screeners

Definition: In the past 30 days
Did you have any sexual activity with a partner?
(Examples of sexual activity with a partner are oral sex and sexual intercourse.)

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 18-24 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = No
2 = Yes

Variable ID: PROSEX_Q204bp

Variable: Question SFSCR204bp of PROMIS Pool v2.0 - Sexual Function and Satisfaction: Screeners

Definition: There are many reasons why people may not have had sexual activity during the month.
What are the reasons why you did not have sexual activity in the past 30 days?
Please read the list carefully and check every reason that applies to you, even if it happened only one time during the past 30 days.

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 18-24 Years

Data Source: Patient

Type: Single answer

Response Options: 1=Was not interested in having sexual activity
2=Difficulties with my erections (penis not hard or is painful) (MALE)
2=Dryness or pain in or around my vagina (FEMALE)
3=Difficulties with orgasm/climax
4=Don't enjoy sexual activity
5=Health condition (Specify)
6=No partner

7=Partner was away
 8=Partner was not interested in sexual activity
 9=Partner's health condition (Specify)
 10=Some other reason (Specify)

Variable ID:	PROSEX_Q204bp_specify
Variable:	Question SFSCR204bp_specify of PROMIS Pool v2.0 - Sexual Function and Satisfaction: Screeners
Definition:	Specify
Supporting Definition:	N/A
Inclusion Criteria:	If patients responded 5, 9 or 10 to PROSEX_Q204bp
Timing:	18-24 Years
Data Source:	Patient
Type:	Text entry
Response Options:	N/A
Variable ID:	PROCOG4A_Q01
Variable:	Question 1 of PROMIS Short Form v2.0 - Cognitive Function 4a
Definition:	Please respond to each question or statement by marking one box per row. In the past 7 days... My thinking has been slow
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	18-24 Years
Data Source:	Patient
Type:	Single answer
Response Options:	1 = Never 2 = Rarely (Once) 3 = Sometimes (Two or three times) 4 = Often (About once a day) 5 = Very often (Several times a day)
Variable ID:	PROCOG4A_Q02
Variable:	Question 2 of PROMIS Short Form v2.0 - Cognitive Function 4a
Definition:	It has seemed like my brain was not working as well as usual
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	18-24 Years
Data Source:	Patient
Type:	Single answer
Response Options:	1 = Never 2 = Rarely (Once) 3 = Sometimes (Two or three times) 4 = Often (About once a day) 5 = Very often (Several times a day)
Variable ID:	PROCOG4A_Q03
Variable:	Question 3 of PROMIS Short Form v2.0 - Cognitive Function 4a
Definition:	I have had to work harder than usual to keep track of what I was doing
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	18-24 Years
Data Source:	Patient
Type:	Single answer

Response Options: 1 = Never
2 = Rarely (Once)
3 = Sometimes (Two or three times)
4 = Often (About once a day)
5 = Very often (Several times a day)

Variable ID: PROCOG4A_Qo4

Variable: Question 4 of PROMIS Short Form v2.0 - Cognitive Function 4a

Definition: I have had trouble shifting back and forth between different activities that require thinking

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 18-24 Years

Data Source: Patient

Type: Single answer

Response Options: 1 = Never
2 = Rarely (Once)
3 = Sometimes (Two or three times)
4 = Often (About once a day)
5 = Very often (Several times a day)

Healthcare Provider-Reported Outcomes

Variable ID: E-CHART_VIS

Variable: Score from Visual Acuity Test using E-Chart

Definition: E-Chart score reported

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Birth - 5 Years
6 - 12 Years if Snellen test cannot be used

Data Source: Healthcare Provider

Type: Numerical

Response Options: E-Chart Score (in feet)

Variable ID: SNELLEN_VIS

Variable: Score from Visual Acuity Test using Snellen Chart

Definition: Snellen score reported

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 6 - 12 Years

Data Source: Healthcare Provider

Type: Numerical

Response Options: Snellen Score (in feet)

Variable ID: WHOGROWTH_EA_HC

Variable: WHO Early Ages Growth Chart Head Centile

Definition: Centile of Head Measurement

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Birth – 5 Years

Data Source: Healthcare Provider

Type: Value

Response Options: Centile

Variable ID: WHOGROWTH_EA_LHC

Variable: WHO Early Ages Growth Chart Length/Height Centile

Definition: Centile of either the Length or Height Measurement, depending on age

Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Birth – 5 Years
Data Source: Healthcare Provider
Type: Value
Response Options: Centile

Variable ID: WHOGROWTH_EA_WC
Variable: WHO Early Ages Growth Chart Weight Centile
Definition: Centile of the Weight Measurement
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: Birth – 5 Years
Data Source: Healthcare Provider
Type: Value
Response Options: Centile

Variable ID: WHOGROWTH_SA_HC
Variable: **WHO School Ages Growth Chart Height Centile**
Definition: Centile of the Height Measurement
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6 – 12 Years
13 – 17 Years
Data Source: Healthcare Provider
Type: Value
Response Options: Centile

Variable ID: WHOGROWTH_SA_WC
Variable: WHO School Ages Growth Chart Weight Centile
Definition: Centile of the Weight Measurement
Supporting Definition: N/A
Inclusion Criteria: All patients
Timing: 6 – 12 Years
13 – 17 Years
Data Source: Healthcare Provider
Type: Value
Response Options: Centile

Working Group Member Conflicts of Interests

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

Name	Affiliation	Declarations
Kathy Jenkins	Boston Children's Hospital, USA	None declared
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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
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