



# ICHOM

International Consortium for  
Health Outcomes Measurement

## Preterm and Hospitalized Newborn Health **DATA COLLECTION REFERENCE GUIDE**

Version 1.0.0  
Revised: August 10<sup>th</sup>, 2020



Preterm and  
Hospitalized

Newborn  
Health

Measuring

results

that matter



We are thrilled that you are interested in measuring outcomes for preterm and hospitalized newborn health 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.

© 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 Preterm and Hospitalized Newborn Health Group, NEO Standard Set, August 2020, (available at: <https://www.ichom.org/portfolio/preterm-and-hospitalized-newborn-health/>)

# 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 [info@ichom.org](mailto:info@ichom.org)

## Working Group Members for Preterm and Hospitalized Newborn Health

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Preterm and Hospitalized Newborn Health in partnership with ICHOM, under the leadership of Andreas W. Flemmer, ICHOM Standard Set Chair. The work was supported by Esther Schouten and Johanna Steckermeier, ICHOM Research Fellows, Jessily P. Ramirez and Nick Sillett, ICHOM Project Managers and Christina Nielsen, ICHOM Research Associate.

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# Supporting Organizations

The Preterm and Hospitalized Newborn Health Standard Set is made possible only through the support of the following the European Foundation for the Care of Newborn Infants (EFCNI).

Thank You.



## Scope Preterm and Hospitalized Newborn Health Standard Set

For preterm and hospitalized newborn health, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Preterm with no lower limit; hospitalized neonates
Stages	From birth to 5 years of age
Treatment approaches	Physical Functioning, Mental Functioning, Social Functioning
Excluded conditions	Diagnosis of genetic disease or severe malformation; Rare conditions (1:2000)

# ICHOM Standard Set for Preterm and Hospitalized Newborns

## Case-Mix Variables

Variable	Measure	Supporting Information	Timing	Data Source
Demographic Factors				
Sex of Child	The patient's sex at birth	Mapping of the ICHOM definition of level of education to the level of schooling as defined by ISCED [International Standard Classification ICHOM mapping ' <b>None</b> ': Level 0: Early Childhood Education; designed with a holistic approach to support children's early cognitive, physical, social and emotional development and introduce young children to organized instruction outside of the family context to develop some of the skills needed for academic readiness and to prepare them for entry into primary education. Designed for children 0-2 years Level 1: Primary Education; designed to provide students with fundamental skills in reading, writing, and mathematics (i.e. literacy and numeracy) and establish a solid foundation for learning and understanding core areas of knowledge, personal and social development, in preparation for lower secondary education. Typically lasts until ages 10-12	Baseline	Parent/ Administrative
Parent Education Level	Highest level of education achieved by either parent	ICHOM mapping ' <b>Primary</b> ': Level 2: Lower secondary education; lays the foundation for lifelong learning and human development upon which education systems may then expand further educational opportunities. Students enter between ages 10-13 and usually finish between 14-16 years. Level 3: Upper secondary education, designed to complete secondary education in preparation for tertiary education or provide skills relevant to employment, or both. Students usually enter between 14-16 and finish by ages 17-18.  ICHOM mapping ' <b>Secondary</b> ': Level 4: Post-secondary non-tertiary education; provides learning experiences building on secondary education, preparing for labour market entry as well as tertiary education. The content of level 4 programmes is not sufficiently complex to be regarded as tertiary education, although it is clearly post-secondary. Level 5: short-cycle tertiary education;	Baseline /annually	Parent

designed to provide participants with professional knowledge, skills, and competencies. Typically, they are practically-based, occupationally-specific, and prepare students to enter the labour market.

ICHOM mapping 'Tertiary':  
 Level 6: Bachelor's or equivalent level; often designed to provide participants with intermediate academic and/or professional knowledge, skills and competencies, leading to a first degree or equivalent qualification  
 Level 7: Master's or equivalent level; designed to provide participants with advanced academic and/or professional knowledge, skills and competencies, leading to a second degree or equivalent qualification.  
 Level 8: Doctoral or equivalent level; designed primarily to lead to an advanced research qualification)

Parental Relationship Status	Indicate the parent's current relationship status	Framed as a patient-reported measure, but can be collected from other sources	Baseline/annually	Parent
Number of Children	Number of children of the parent		Baseline/annually	Parent
Multiples	Indicate if the child is a multiple		Baseline	Parent/Administrative
Parent Support	If sociopsychological support is available to the parent and if the parent has used this support		Annually	Parent
Country of Birth	The country the child was born in		Baseline	Parent/Administrative
Booking Status Inborn or Outborn	The setting where the child was born	Setting levels adapted from WHO/UNICEF definitions for births attended by skilled individuals (SAB). Criteria expanded to include health facilities with neonatal intensive care units (NICU).	Baseline	Administrative/Clinician
<b>Lifestyle Factors</b>				
Maternal Body Mass Index	Body mass index of the mother during the first trimester pregnancy		Baseline	Clinician/Healthcare provider
Maternal Drug Use	History of drug use by the mother during pregnancy	Includes illegal drug use, alcohol and smoking	Baseline	Parent/Clinician/Healthcare provider
<b>Clinical Factors</b>				
Previous History of Neonatal Death	Has there been a previous history of neonatal death for either parent?		Baseline	Parent/Administrative

Postpartum Parental Distress or Depression	Diagnosis of postpartum depression, perinatal depression, or PTSD		Baseline/ annually	Clinician /Healthcare provider
Maternal Diabetes	Diagnosis of maternal diabetes		Baseline	Clinician /Healthcare provider
Complications During Pregnancy	Gestational diabetes, hypertension, or pre-eclampsia during pregnancy		Baseline	Clinician /Healthcare provider
Mode of Delivery	Vaginal, instrumental, or cesarean delivery		Baseline	Clinician /Healthcare provider
Complications During Delivery	Shoulder dystocia or asphyxia during delivery		Baseline	Clinician /Healthcare provider
Birth Weight	Weight of the child at birth	In grams	Baseline	Clinician /Healthcare provider
Gestational Age	Gestational age of the child	In completed weeks	Baseline	Clinician /Healthcare provider
Nosocomial Infections Following Birth	Number of nosocomial infections during initial hospitalization		Baseline	Clinician /Healthcare provider
Hypoxic-ischemic Encephalopathy	Diagnosis of Hypoxic-ischemic encephalopathy and its severity		Baseline	Clinician /Healthcare provider
Respiratory Distress Syndrome	Diagnosis of respiratory distress syndrome		Baseline	Clinician /Healthcare provider
Immediate Infections During Infancy	Diagnosis of necrotizing enterocolitis		Baseline	Clinician /Healthcare provider
Other Diagnoses	Diagnosis of cerebral palsy, metabolic disease or acquired infectious disease after discharge	Acquired infectious disease is defined by any severe infection that has required intravenous antibiotics.	Baseline/ annually	Clinician /Healthcare provider
<b>Treatment-Related Factors</b>				
Antenatal Steroids	If the mother received antenatal steroids		Baseline	Clinician /Healthcare provider
Neonatal Resuscitation	If child required chest compressions		Baseline	Clinician /Healthcare provider
Ventilation	Use of respiratory support		Baseline	Clinician /Healthcare provider

Parenteral Nutrition	If the child required parenteral nutrition and its duration	Baseline and annually	Clinician /Healthcare provider
Surgical Exposure	If the child has required surgical intervention	Baseline and annually	Clinician /Healthcare provider



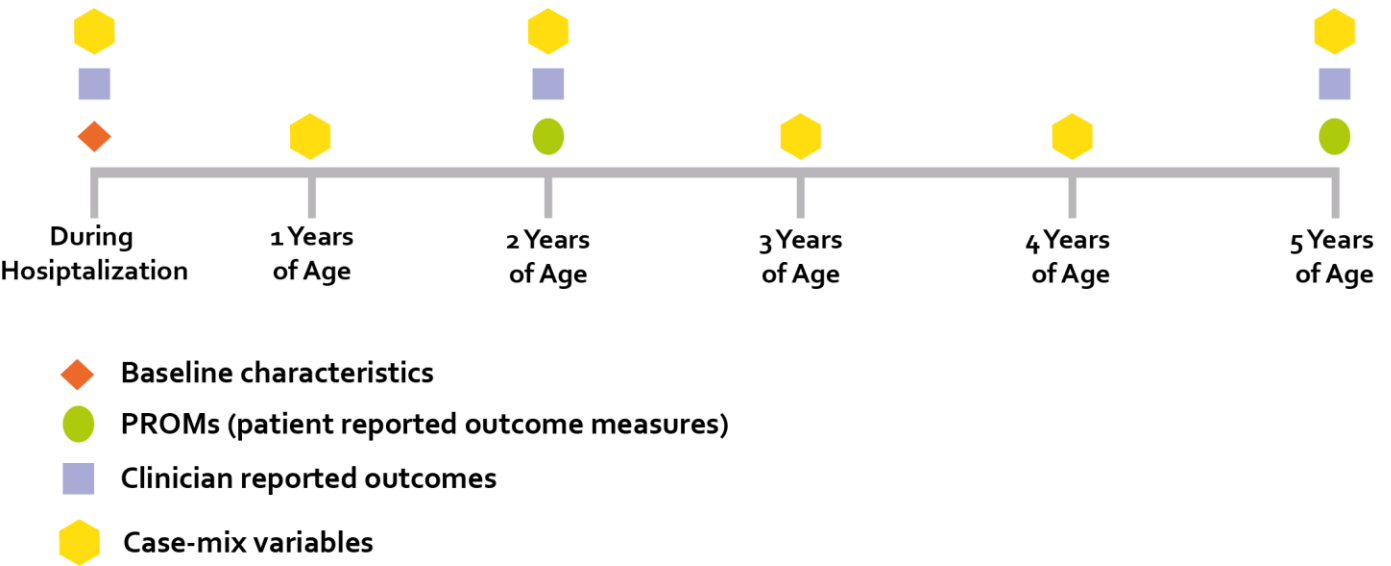
## Outcomes

Outcome	Timing	Measure	Supporting Definition/Information	Data Source
<b>Mental Functioning</b>				
Behavior	2 Years of Age, 5 Years of Age	Strengths and Difficulties Questionnaire (SDQ) at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	Behavioral actions that influence functioning in society.	Parent Proxy
Neuro-development	2 Years of Age	PARCA-R	Functioning of the brain that affects a child's behavior, vision, hearing and movement.	Parent Proxy
Anxiety	2 Years of Age, 5 Years of Age	Strengths and Difficulties Questionnaire (SDQ) at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	An emotion characterized by an unpleasant state of inner turmoil, often accompanied by nervous behavior and feeling physically unwell.	Parent Proxy
Depression	2 Years of Age	Strengths and Difficulties Questionnaire (SDQ)	A medical illness that negatively affects how a child feels, the way we think and act. It is characterized by feelings of sadness and/or loss of interest in activities once enjoyed.	Parent Proxy
Cognition	2 Years of Age, 5 Years of Age	PARCA-R at 2 years of age; CDC Milestone Checklist at 5 years of age	The ability to learn, think, remember, reason and make decisions.	Parent Proxy
<b>Social Functioning</b>				
Communication	2 Years of Age, 5 Years of Age	PARCA-R at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	The ability to express thoughts, feelings and wishes to others and being understood.	Clinician /Healthcare provider or patient
Social Functioning	2 Years of Age, 5 Years of Age	Strengths and Difficulties Questionnaire (SDQ) at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	The ability to interact easily and successfully with others.	Parent Proxy
Relationship with Others	2 Years of Age, 5 Years of Age	Strengths and Difficulties Questionnaire (SDQ) at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	The ability to establish a connection with others which provides security, happiness and meaning to life.	Parent Proxy
Impact on Family	All Timepoints	Parental Stressor Scale: NICU during hospitalization; Strengths and Difficulties Questionnaire (SDQ) at 2 years of age; and TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	The effect of the medical circumstances of caring for a preterm or hospitalized newborn patient that influences family life of any kind.	Parent Proxy
Health-Related Quality of Life	5 Years of Age	TNA-AZL Preschool Children Quality of Life	A person's perception of his/her ability to achieve the goals, expectations and standards he or she values of importance; being able to	Parent Proxy

			fulfil the duties required to be self-sufficient for the activities of daily life.	
Schooling	5 Years of Age	If the child has entered mainstream schooling, if applicable, and if they're receiving special educational needs.	The ability to participate in educational activity in any kind of structured way.	Parent Proxy
<b>Physical Functioning</b>				
Pulmonary Function	All Timepoints	If the child was discharged from the NICU on oxygen, if there have been any unexpected readmissions in the past year due to pulmonary issues, and if the child has been prescribed bronchodilators or inhaled steroids	Describes the extent to which somebody can breathe without any support.	Clinician/ Administrative
Disability	2 Years of Age	M-CHAT-R Autism Screener	Refers to a problem in body function which results in a difficulty encountered by an individual in executing a task or action.	Clinician /Healthcare provider or Patient
Motor Function	2 Years of Age, 5 Years of Age	PARCA-R at 2 years of age; TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) at 5 years of age	The ability to learn, execute and control specific movements.	Clinician /Healthcare provider or Patient
Sensory Issues		<i>The working group chose not to include a measure at this time for sensory issues because there was not a free, feasible measure.</i>	An aversion to processing information through specific senses like touch.	
Hearing	All Timepoints	The Working Group did not recommend a specific test for this outcome. It is left to each institution's discretion as to which test they use.	The ability to perceive sounds by the ears sufficiently to cope in daily life/communicate.	Clinician /Healthcare provider
Vision	2 Years of Age, 5 Years of Age	Kay Picture Test Screening Book	The ability to see.	Clinician /Healthcare provider
Readmission	All Timepoints	Acute Care Readmission Measure (Local National Measure)	Readmission to the hospital after being discharged from the primary hospital stay.	Clinician /Healthcare provider
Survival	All Timepoints	ICHOM Standard Measure	Being alive after experiencing a serious medical problem.	Clinician /Healthcare provider
Sleep	5 Years of Age	TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL)	The primary activity of the brain during early development, which impacts mental and physical development.	Parent Proxy
Feeding, Nutrition and Growth	All Timepoints	WHO Growth Charts Early Years at all timepoints; clinician-administered questions about feeding during hospitalization and at 2 years of age	The ability to receive a proper intake of food in order to develop, metabolize and repair.	Clinician /Healthcare provider
Pain	5 Years of Age	TNA-AZL Preschool Children Quality of Life Questionnaire	An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.	Parent Proxy

# Follow-Up Timeline

The following timeline illustrates when Standard Set variables should be collected from patients and clinicians.



# Collecting Patient-Reported Outcome and Clinical Measures

Measure – (reporter)	Licensing Information	Scoring Information
Parental Stressor Scale: NICU - <b>Patient</b>	The PSS: NICU Questionnaire is free to download or print. To request use of the tool, please email <a href="mailto:mmiles@email.unc.edu">mmiles@email.unc.edu</a> . The PSS:NICU is available in many languages including Spanish, Portuguese, Swedish, Icelandic, Turkish and Arabic. Translations must be obtained from the researcher who did the translation. Written permission in the form of email is requested for any changes an investigator makes to the instrument or to translate into other languages.	The available metrics allow scoring for stress occurrence levels, overall stress levels, and number of stressors experienced. The measures are captured by asking parent how stressful each item has been for them on a scale of 1 (not at all stressful) to 5 (extremely stressful).
WHO Growth Charts Early Years- <b>Clinician</b>	The Growth Charts are freely available without use of a licence from the World Health Organisation website (available at: <a href="https://www.who.int/childgrowth/standards/en/">https://www.who.int/childgrowth/standards/en/</a> ).	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: <a href="https://www.who.int/childgrowth/standards/en/">https://www.who.int/childgrowth/standards/en/</a>
Hearing Screening Test – <b>Clinician</b>	The Working Group did not recommend a specific test for this. It is left to each institution's discretion as to which test. they can use to assess if the child has hearing abnormalities.	For the purposes of the standard set, the only information that is recommended to collect is if hearing abnormalities have been identified.
PARCA-R - <b>Patient</b>	The Parent Report of Children's Abilities-Revised (PARCA-R) is freely available at <a href="https://www2.le.ac.uk/partnership/parca-r/parca-r-resources">https://www2.le.ac.uk/partnership/parca-r/parca-r-resources</a> . This tool is available in 14 languages and can be completed either online or on a printed copy.	This can either be scored by hand or automatically by using the online questionnaire and score calculator. If you are not using the online version, the PARCA-R gives a raw score as well as standard scores and percentiles.
Strengths and Difficulties Questionnaire 2-4, with Impact Supplement (SDQ) - <b>Patient</b>	The Strengths and Difficulties Questionnaire (SDQ) is freely available for download at <a href="https://www.sdqinfo.org/py/sdqinfo/bo.py">https://www.sdqinfo.org/py/sdqinfo/bo.py</a> . This set recommends use of the 2-4 version of the measure with the Impact Supplement. It is available in multiple languages and does not require a licence to use.	Instructions for scoring the SDQ are available from <a href="https://www.sdqinfo.org/py/sdqinfo/co.py">https://www.sdqinfo.org/py/sdqinfo/co.py</a> . Scoring can be done by hand as well as by the online scoring tool, available at <a href="https://sdqscore.org">https://sdqscore.org</a>

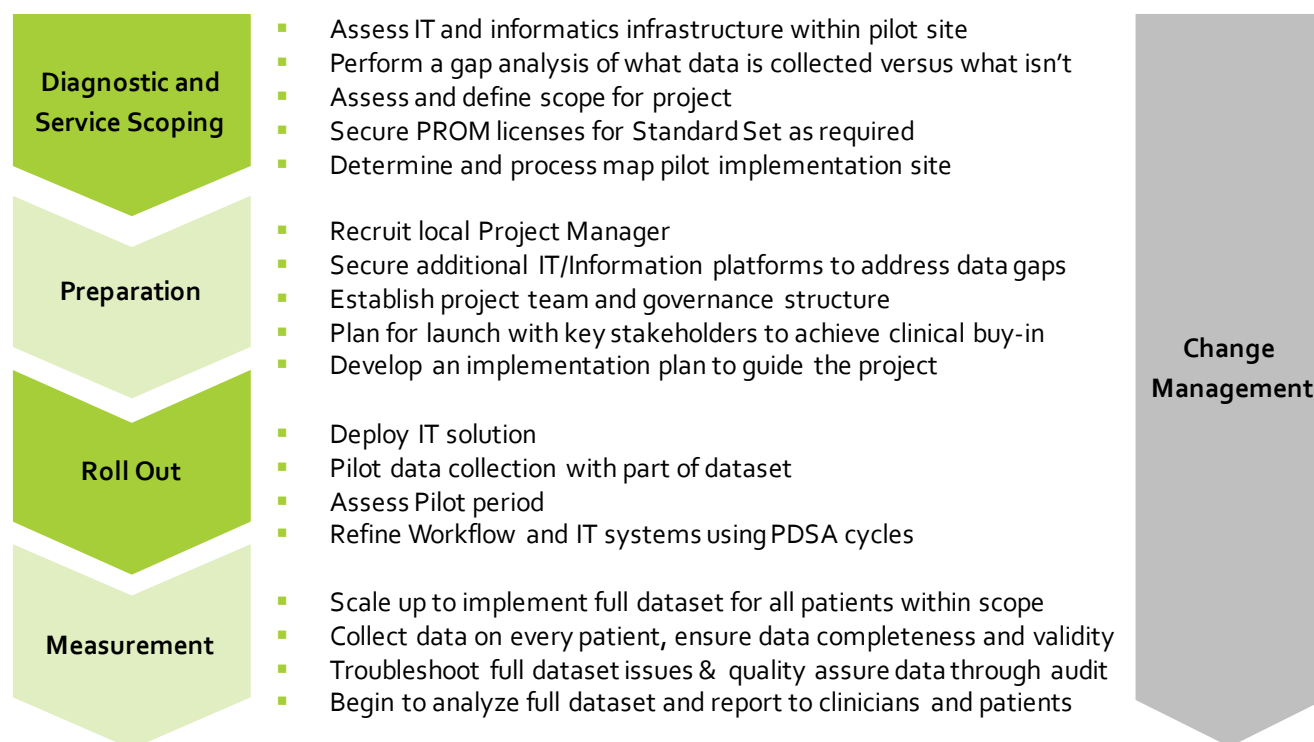
M-CHAT-R Autism Screener - <b>Patient</b>	The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from <a href="https://mchatscreen.com/">https://mchatscreen.com/</a>	The scoring algorithm for M-CHAT-R can be found at <a href="https://mchatscreen.com/mchat-rf/scoring/">https://mchatscreen.com/mchat-rf/scoring/</a> . The test will generate a total score that will indicate the risk of an autism diagnosis.
Kay Picture Test Screening Book- <b>Clinician</b>	The Kay Picture Test Screening Book is available to buy at: <a href="https://kaypictures.co.uk/product/kay-picture-test-screening-book/">https://kaypictures.co.uk/product/kay-picture-test-screening-book/</a> . It is comprised of a book with single and linear crowded testing options. If this measure is unavailable for an institution, then it is recommended to use another vision test that provides a LogMAR score and is suitable for children of 2 and 5 years of age.	This test will provide a LogMAR score that will be recorded by the clinician.
CDC Milestone Checklist - <b>Patient</b>	This measure is available free of charge and without need of a license from the developers at: <a href="https://www.cdc.gov/ncbddd/actearly/milestones/index.html">https://www.cdc.gov/ncbddd/actearly/milestones/index.html</a> . This is also available in Spanish.	This measure isn't formally scored, but the milestones are shown for each age-group. This standard set recommends the use of the cognition milestones to be used at the 5 years of age timepoint. These milestones are illustrated by pictures or videos in each age's individual page and then checked by the respondent. The milestones can be used to recommend if a child is developmentally behind and could require further formal cognitive testing. The form of this cognitive test would then be at the discretion of the institution.
TNA-AZL Preschool Children Quality of Life Questionnaire (TAPQOL) - <b>Patient</b>	The TAPQOL is freely available at <a href="https://www.tno.nl/en/focus-areas/healthy-living/roadmaps/youth/questionnaires-to-measure-health-related-quality-of-life/">https://www.tno.nl/en/focus-areas/healthy-living/roadmaps/youth/questionnaires-to-measure-health-related-quality-of-life/</a> , but must fill in a registration form. The questionnaire is available in 19 languages.	The TAPQOL asks parents to answer questions about their children to assess their health-related quality of life by with a series of responses that best describes their child. An SPSS file and reference data are supplied with the measure that will allow calculation of the scale scores.

## 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.



### ICHOM is also able to support organizations 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, if permitted by its license, we recommend following the 10 steps outlined below:<sup>\*1</sup>

<b>Step 1</b>	Preparation	Initial work carried out before the translation work begins
<b>Step 2</b>	Forward Translation	Translation of the original language, also called source, version of the instrument into another language, often called the target language
<b>Step 3</b>	Reconciliation	Comparing and merging more than one forward translation into a single forward translation
<b>Step 4</b>	Back Translation	Translation of the new language version back into the original language
<b>Step 5</b>	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
<b>Step 6</b>	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
<b>Step 7</b>	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
<b>Step 8</b>	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
<b>Step 9</b>	Proofreading	Final review of the translation to highlight and correct any typographic, grammatical or other errors
<b>Step 10</b>	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 <sup>1</sup> 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 Preterm and Hospitalized Newborn 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\_DURINGHOSPITAL (During Hospitalization); VARIABLEID\_2YR (2 year follow-up); VARIABLEID\_5YR (5 year follow-up), etc.

## Case-Mix Variables

### Demographic Factors

<b>Variable ID:</b>	N/A
<b>Variable:</b>	Patient ID
<b>Definition:</b>	Indicate the patient's medical record number
<b>Supporting Definition:</b>	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
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	On all forms
<b>Data Source:</b>	Administrative or clinical
<b>Type:</b>	Numerical
<b>Response Options:</b>	According to institution
<b>Variable ID:</b>	SEX
<b>Variable:</b>	Sex of the child
<b>Definition:</b>	Please indicate the patient's sex at birth.
<b>Supporting Definition:</b>	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.
<b>Inclusion Criteria:</b>	
<b>Timing:</b>	All patients

<b>Data Source:</b>	Baseline
<b>Type:</b>	Parent/Administrator
<b>Response Options:</b>	Code
<b>Variable ID:</b>	PAREDU
<b>Variable:</b>	Parent Education Level
<b>Definition:</b>	Highest level of education achieved by either parent
<b>Supporting Definition:</b>	This is used as a proxy for socioeconomic status
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline/Annually
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0=None- Includes Early Childhood Education 1=Primary- includes primary and lower secondary education. 2=Secondary- includes upper secondary and short-cycle tertiary education 3=Tertiary- includes Bachelor's, Master's or Doctoral education, or equivalent levels
<b>Variable ID:</b>	RELATIONSHIP_STATUS_PAR
<b>Variable:</b>	Parental Relationship Status
<b>Definition:</b>	A parent's current relationship status
<b>Supporting Definition:</b>	Framed as a patient-reported measure, but can be collected from other sources. Displayed as: "Please indicate your current relationship status "
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline/Annually
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0= Not married/partnered 1= Married/partnered 2= Divorced/separated 3= Widowed 4= Unknown
<b>Variable ID:</b>	NUM_CHILD
<b>Variable:</b>	Number of children
<b>Definition:</b>	How many children have you had?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline/Annually
<b>Data Source:</b>	Parent
<b>Type:</b>	Numerical
<b>Response Options:</b>	Number of children
<b>Variable ID:</b>	MULT
<b>Variable:</b>	Multiples
<b>Definition:</b>	Is the child a multiple?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Parent/Administrator
<b>Type:</b>	Single answer
<b>Response Options:</b>	1= No 2=Twins 3=Triplets 4=Quadruplets
<b>Variable ID:</b>	PARSUP
<b>Variable:</b>	Parent Support
<b>Definition:</b>	Is sociopsychological support available to you?

<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Annually
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No
<b>Variable ID:</b>	PAR-SUPa
<b>Variable:</b>	Parent Support(a)
<b>Definition:</b>	Have you used this in the last year?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	If responded "Yes" to "Is sociopsychological support available to you?"
<b>Timing:</b>	Annually
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No
<b>Variable ID:</b>	BIRTH_CNTRY
<b>Variable:</b>	Country of birth
<b>Definition:</b>	What country was the child born in?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Parent/Administrator
<b>Type:</b>	Single answer
<b>Response Options:</b>	Country name
<b>Variable ID:</b>	BOOK_STATUS
<b>Variable:</b>	Booking status inborn or outborn
<b>Definition:</b>	What setting was the child born in?
<b>Supporting Definition:</b>	Setting levels adapted from WHO/UNICEF definitions for births attended by skilled individuals (SAB). Criteria expanded to include health facilities with neonatal intensive care units (NICU).
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician / Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	0= Home birth without skilled individuals present 1= Home birth with skilled individuals present 2= Institutional birth at health facility without a NICU 3= Institutional birth at health facility with a NICU

## Lifestyle Factors

<b>Variable ID:</b>	MATRNAL_BMI
<b>Variable:</b>	Maternal Body Mass Index
<b>Definition:</b>	What was the body mass index of the mother during the first trimester of the pregnancy?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Numerical
<b>Response Options:</b>	BMI in kg/m <sup>2</sup>
<b>Variable ID:</b>	MATRNAL_DRUG_USE
<b>Variable:</b>	Maternal Drug Use

<b>Definition:</b>	Is there a known history of maternal drug use (including smoking, alcohol, and illegal drug use) during pregnancy?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician / Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 999=Unknown
<b>Variable ID:</b>	MATRNAL_DRUG_USE(A)
<b>Variable:</b>	Maternal Drug Use (A)
<b>Definition:</b>	Type of maternal drug use
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	If responded "Yes" to "Is there a known history of maternal drug use (including smoking, alcohol, and illegal drug use)?"
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician / Healthcare provider
<b>Type:</b>	Multiple
<b>Response Options:</b>	1= Smoking 2= Alcohol 3= Illegal drug use

## Baseline Clinical Factors

<b>Variable ID:</b>	PREV_HIS_NEO_DEATH
<b>Variable:</b>	Previous History of neonatal death
<b>Definition:</b>	Has there been a previous history of neonatal death for either parent?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Parent/Administrator
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 999=Unknown
<b>Variable ID:</b>	POST_PARTM_DISTRESS
<b>Variable:</b>	Postpartum Parental Distress or depression
<b>Definition:</b>	Was either parent diagnosed with postpartum depression? Perinatal depression? Post-traumatic stress disorder?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline/Annually
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Multiple
<b>Response Options:</b>	1=Postpartum depression 2=Perinatal depression 3=PTSD
<b>Variable ID:</b>	MATRNAL_DIA
<b>Variable:</b>	Maternal Diabetes
<b>Definition:</b>	Was the mother diagnosed with maternal diabetes?
<b>Supporting Definition:</b>	N/A

**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** PREG\_COMPS  
**Variable:** Complications during pregnancy  
**Definition:** Did the mother suffer any of these complications during pregnancy: gestational diabetes, hypertension, pre-eclampsia?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Multiple  
**Response Options:** 1=Gestational diabetes  
2=Hypertension  
3=Pre-eclampsia

---

**Variable ID:** DELIVERY\_MODE  
**Variable:** Mode of Delivery  
**Definition:** Was the mode of delivery vaginal, instrumental or cesarean?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Vaginal  
2=Instrumental  
3=Cesarean delivery

---

**Variable ID:** DELIV\_COMPS  
**Variable:** Complications during delivery  
**Definition:** Did the mother suffer any of these complications during delivery: shoulder dystocia, asphyxia?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Multiple  
**Response Options:** 1=Shoulder dystocia  
2=Asphyxia

---

**Variable ID:** BRTH\_WEIGHT  
**Variable:** Birth weight  
**Definition:** What was the birth weight of the child in grams?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Numerical  
**Response Options:** Weight in grams

---

**Variable ID:** GES\_AGE  
**Variable:** Gestational Age  
**Definition:** What was the gestational age of the child in completed weeks?  
**Supporting Definition:** N/A

<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Numerical
<b>Response Options:</b>	Number of completed weeks
<b>Variable ID:</b>	NOSO_INFECTNS
<b>Variable:</b>	Nosocomial infections following birth
<b>Definition:</b>	How many nosocomial infections were there during initial hospitalization?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Numerical
<b>Response Options:</b>	Number of nosocomial infections during hospitalization
<b>Variable ID:</b>	HYP_ISCH_ENCEPHO
<b>Variable:</b>	Hypoxic-ischemic encephalopathy
<b>Definition:</b>	Was the child diagnosed with hypoxic-ischemic encephalopathy?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 999=Unknown
<b>Variable ID:</b>	HYP_ISCH_ENCEPHOa
<b>Variable:</b>	Hypoxic-ischemic encephalopathy(a)
<b>Definition:</b>	Was this mild/moderate or severe?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	If responded "Yes" to "Was the child diagnosed with hypoxic-ischemic encephalopathy?"
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician/Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Mild 2=Moderate 3=Severe
<b>Variable ID:</b>	RESP_DISTRESS_SYN
<b>Variable:</b>	Respiratory Distress Syndrome
<b>Definition:</b>	Was the child diagnosed with respiratory distress syndrome?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline
<b>Data Source:</b>	Clinician /Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 999=Unknown
<b>Variable ID:</b>	RESP_DISTRESS_SYNa
<b>Variable:</b>	Respiratory Distress Syndrome(a)
<b>Definition:</b>	Was this mild/moderate or severe?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline

**Data Source:** Clinician/Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Mild  
2=Moderate  
3=Severe

---

**Variable ID:** INFANCY\_INFECTNS  
**Variable:** Immediate infections during infancy  
**Definition:** Was the child diagnosed with necrotizing enterocolitis?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** OTHER\_DIAG  
**Variable:** Other Diagnoses  
**Definition:** Has the child ever been diagnosed with cerebral palsy, metabolic disease or acquired infectious disease after discharge?  
**Supporting Definition:** Acquired infectious disease is defined by any severe infection that has required intravenous antibiotics.  
**Inclusion Criteria:** All patients  
**Timing:** Baseline/Annually  
**Data Source:** Clinician /Healthcare provider  
**Type:** Multiple  
**Response Options:** 1=Cerebral Palsy  
2=Metabolic disease  
3=Acquired infectious disease

---

## Treatment Related Factors

---

**Variable ID:** ANT\_STEROIDS  
**Variable:** Antenatal Steroids  
**Definition:** Was the mother administered antenatal steroids?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician/Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** NEO\_RESUSCITATION  
**Variable:** Neonatal Resuscitation  
**Definition:** Did the infant require resuscitation with chest compression?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline  
**Data Source:** Clinician /Healthcare provider  
**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** VENTILATION  
**Variable:** Need for Ventilation  
**Definition:** Was there any type of respiratory support?

**Supporting**  
**Definition:** N/A

**Inclusion Criteria:** All patients  
**Timing:** Baseline

**Data Source:** Clinician /Healthcare provider  
**Type:** Single

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** VENTILATIONa  
**Variable:** Ventilation Date  
**Definition:** When was the baby off support?

**Supporting**  
**Definition:** N/A

**Inclusion Criteria:** If responded "Yes" to "Was there any type of respiratory support?"  
**Timing:** Baseline

**Data Source:** Clinician/Healthcare provider  
**Type:** Date

**Response Options:** MM/DD/YYYY

---

**Variable ID:** VENTILATIONb  
**Variable:** Duration of Oxygen  
**Definition:** How long was the baby on oxygen?

**Supporting**  
**Definition:** N/A

**Inclusion Criteria:** If responded "Yes" to "Was there any type of respiratory support?"  
**Timing:** Baseline

**Data Source:** Clinician/Healthcare provider  
**Type:** Value

**Response Options:** Number of days on respiratory support

---

**Variable ID:** INTRA\_FLUID\_INTAKE  
**Variable:** Parenteral Nutrition  
**Definition:** Did the child require parenteral nutrition?

**Supporting**  
**Definition:** N/A

**Inclusion Criteria:** All patients  
**Timing:** Baseline

**Data Source:** Clinician /Healthcare provider  
**Type:** Single

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** INTRA\_FLUID\_INTAKEa  
**Variable:** Parenteral Nutrition Duration  
**Definition:** How long was this required?

**Supporting**  
**Definition:** N/A

**Inclusion Criteria:** If responded "Yes" to "Did the child require parenteral nutrition?"  
**Timing:** Baseline



<b>Data Source:</b>	Clinician/Healthcare provider
<b>Type:</b>	Value
<b>Response Options:</b>	Number of days on parenteral nutrition
<b>Variable ID:</b>	SURG_EXPOSURE
<b>Variable:</b>	Surgical Exposure
<b>Definition:</b>	Any surgical intervention on the infant?
<b>Supporting Definition:</b>	
<b>Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline/Annually
<b>Data Source:</b>	Clinician/Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 999=Unknown

## Outcomes

### Impact on Family

<b>Variable ID:</b>	PSSNICU_Qo1
<b>Variable:</b>	<b>Question 1 of Parental Stressor Scale: NICU</b>
<b>Definition:</b>	The presence of monitors and equipment
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful
<b>Variable ID:</b>	PSSNICU_Qo2
<b>Variable:</b>	Question 2 of Parental Stressor Scale: NICU
<b>Definition:</b>	The constant noises of monitors and equipment
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful
<b>Variable ID:</b>	PSSNICU_Qo3
<b>Variable:</b>	Question 3 of Parental Stressor Scale: NICU
<b>Definition:</b>	The sudden noises of monitor alarms
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients

**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Qo4  
**Variable:** Question 4 of Parental Stressor Scale: NICU  
**Definition:** The other sick babies in the room  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Qo5  
**Variable:** Question 5 of Parental Stressor Scale: NICU  
**Definition:** The large number of people working in the unit  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Qo6  
**Variable:** Question 6 of Parental Stressor Scale: NICU  
**Definition:** Tubes and equipment on or near my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful

---

5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Qo7
<b>Variable:</b>	Question 7 of Parental Stressor Scale: NICU
<b>Definition:</b>	Bruises, cuts or incisions on my baby
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Qo8
<b>Variable:</b>	Question 8 of Parental Stressor Scale: NICU
<b>Definition:</b>	The unusual color of my baby (for example looking pale or yellow jaundiced)
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Qo9
<b>Variable:</b>	Question 9 of Parental Stressor Scale: NICU
<b>Definition:</b>	My baby's unusual or abnormal breathing patterns
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Q10
<b>Variable:</b>	Question 10 of Parental Stressor Scale: NICU
<b>Definition:</b>	The small size of my baby
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Code

---

**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q11  
**Variable:** Question 11 of Parental Stressor Scale: NICU  
**Definition:** The wrinkled appearance of my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q12  
**Variable:** Question 12 of Parental Stressor Scale: NICU  
**Definition:** Having a machine (respirator) breathe for my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q13  
**Variable:** Question 13 of Parental Stressor Scale: NICU  
**Definition:** Seeing needles and tubes put in my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q14  
**Variable:** Question 14 of Parental Stressor Scale: NICU

**Definition:** My baby being fed by an intravenous or tube  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q15  
**Variable:** Question 15 of Parental Stressor Scale: NICU  
**Definition:** When my baby seemed to be in pain  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q16  
**Variable:** Question 16 of Parental Stressor Scale: NICU  
**Definition:** When my baby looked sad  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q17  
**Variable:** Question 17 of Parental Stressor Scale: NICU  
**Definition:** The limp and weak appearance of my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious

---

2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q18  
**Variable:** Question 18 of Parental Stressor Scale: NICU  
**Definition:** Jerky or restless movements of my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q19  
**Variable:** Question 19 of Parental Stressor Scale: NICU  
**Definition:** My baby not being able to cry like other babies  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q20  
**Variable:** Question 20 of Parental Stressor Scale: NICU  
**Definition:** Being separated from my baby  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
2= A little stressful  
3= Moderately stressful  
4= Very stressful  
5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q21  
**Variable:** Question 21 of Parental Stressor Scale: NICU  
**Definition:** Not feeding my baby myself  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients

**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q22  
**Variable:** Question 22 of Parental Stressor Scale: NICU  
**Definition:** Not being able to care for my baby myself (for example, diapering, bathing)  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q23  
**Variable:** Question 23 of Parental Stressor Scale: NICU  
**Definition:** Not being able to hold my baby when I want  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful  
 5= Extremely stressful

---

**Variable ID:** PSSNICU\_Q24  
**Variable:** Question 24 of Parental Stressor Scale: NICU  
**Definition:** Feeling helpless and unable to protect my baby from pain and painful procedures  
**Supporting Definition:** Indicate how stressful this has been for you  
**Inclusion Criteria:** All patients  
**Timing:** During Hospitalization  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** N/A  
 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious  
 2= A little stressful  
 3= Moderately stressful  
 4= Very stressful

---

5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Q25
<b>Variable:</b>	Question 25 of Parental Stressor Scale: NICU
<b>Definition:</b>	Feeling helpless about how to help my baby during this time
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful

---

<b>Variable ID:</b>	PSSNICU_Q26
<b>Variable:</b>	Question 26 of Parental Stressor Scale: NICU
<b>Definition:</b>	Not having time alone with my baby
<b>Supporting Definition:</b>	Indicate how stressful this has been for you
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	During Hospitalization
<b>Data Source:</b>	Patient or Parent (Proxy)
<b>Type:</b>	Code
<b>Response Options:</b>	N/A 1= Not at all stressful- the experience did not cause you to feel upset, tense, or anxious 2= A little stressful 3= Moderately stressful 4= Very stressful 5= Extremely stressful

---

## Survival

---

<b>Variable ID:</b>	VITALSTATUS
<b>Variable:</b>	Vital Status
<b>Definition:</b>	Indicate if the person has deceased, regardless of cause
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	All Timepoints
<b>Data Source:</b>	Administrative or clinical
<b>Type:</b>	Single answer
<b>Response Options:</b>	0= No 1= Yes 999= Unknown

---

<b>Variable ID:</b>	DEATHDATE
<b>Variable:</b>	Date of death
<b>Definition:</b>	The date of death of the person
<b>Supporting Definition:</b>	It is recommended that in cases where all components of the date of death are not known or where an estimate is arrived at from age, a valid date be used together with a flag to indicate that it is an estimate. For record identification and/or the derivation of other metadata items that require accurate date of death information, estimated dates of death should be identified by a date accuracy indicator to prevent inappropriate use of date of death data. The linking of client records from diverse sources, the sharing of patient data, and data analysis for



research and planning all rely heavily on the accuracy and integrity of the collected data. In order to maintain data integrity and the greatest possible accuracy an indication of the accuracy of the date collected is critical. The collection of Date accuracy indicator may be essential in confirming or refuting the positive identification of a person. For this reason it is strongly recommended that the data element Date accuracy indicator also be recorded at the time of record creation to flag the accuracy of the data.

**Inclusion Criteria:** If responded "Yes" to "Indicate if the person is deceased, regardless of cause"

**Timing:** All Timepoints

**Data Source:** Administrative or clinical

**Type:** Date

**Response Options:** None

---

**Variable ID:** CAUSEOFDEATH

**Variable:** Cause of death

**Definition:** Indicate the cause of death

**Supporting Definition:** N/A

**Inclusion Criteria:** If responded "Yes" to "Indicate if the person is deceased, regardless of cause"

**Timing:** All Timepoints

**Data Source:** Administrative or clinical

**Type:** Text entry

**Response Options:** N/A

---

## Pulmonary Function

---

**Variable ID:** PULMNRY\_FUNCNTN\_Q01

**Variable:** Pulmonary Function Question 1

**Definition:** Was the child discharged from the NICU on oxygen?

**Supporting Definition:** N/A

**Inclusion Criteria:** All patients

**Timing:** Baseline

**Data Source:** Clinician/Healthcare provider

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** PULMNRY\_FUNCNTN\_Q02

**Variable:** Pulmonary Function Question 2

**Definition:** Have there been any unexpected readmissions in the past year due to pulmonary issues?

**Supporting Definition:** N/A

**Inclusion Criteria:** All patients

**Timing:** Annually

**Data Source:** Clinician/Healthcare provider

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** PULMNRY\_FUNCNTN\_Q03

**Variable:** Pulmonary Function Question 3

**Definition:** Has the child been prescribed bronchodilators or inhaled steroids?

**Supporting Definition:** N/A

**Inclusion Criteria:** All patients

**Timing:** Baseline/Annually

**Data Source:** Clinician/Healthcare provider

**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
999=Unknown

---

## Feeding, Nutrition and Growth

---

**Variable ID:** WHOGROWTH\_EA\_WC  
**Variable:** WHO Early Ages Growth Chart Weight Centile  
**Definition:** Centile of Weight Measurement  
**Supporting Definition:** Indicate the weight in kilograms  
**Inclusion Criteria:** All patients  
**Timing:** All Timepoints  
**Data Source:** Trained Admin  
**Type:** Value  
**Response Options:** Centile

---

**Variable ID:** WHOGROWTH\_EA\_HC  
**Variable:** WHO Early Ages Growth Chart Head Centile  
**Definition:** Centile of Head Measurement  
**Supporting Definition:** Indicate the head circumference in centimeters  
**Inclusion Criteria:** All patients  
**Timing:** All Timepoints  
**Data Source:** Trained Admin  
**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:** Indicate the length/height in centimeters  
**Inclusion Criteria:** All patients  
**Timing:** All Timepoints  
**Data Source:** Trained Admin  
**Type:** Value  
**Response Options:** Centile

---

**Variable ID:** FEEDING\_TYPE  
**Variable:** Type of feeding  
**Definition:** Was the child breastfed?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** Baseline, annually up to 2 years of age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** FEEDING\_TYPEa  
**Variable:** Feeding exclusively on breast milk  
**Definition:** Was this exclusively on human milk?  
**Supporting Definition:** N/A  
**Inclusion Criteria:** If responded "Yes" to "Was the child breastfed?"  
**Timing:** Baseline, annually up to 2 years of age  
**Data Source:** Parent  
**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** FEEDING\_TYPEb

**Variable:** Breast milk fortification

**Definition:** Was this fortified?

**Supporting Definition:** N/A

**Inclusion Criteria:** If responded "Yes" to "Was this exclusively on human milk?"

**Timing:** Baseline, annually up to 2 years of age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

**Variable ID:** FEEDING\_TYPEc

**Variable:** Formula strength

**Definition:** If fed on formula, what strength was used?

**Supporting Definition:** N/A

**Inclusion Criteria:** If responded "No" to "Was the child breastfed?"

**Timing:** Baseline, annually up to 2 years of age

**Data Source:** Parent

**Type:** Value (with units)

**Response Options:** Formula strength

---

**Variable ID:** FEEDING\_TYPED

**Variable:** Formula fortification

**Definition:** If fed on formula, was it fortified?

**Supporting Definition:** N/A

**Inclusion Criteria:** If responded "No" to "Was the child breastfed?"

**Timing:**

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
999=Unknown

---

## Hearing and Vision

---

**Variable ID:** HEARING\_TEST

**Variable:** Hearing Screening Test Result

**Definition:** If hearing screening test has identified hearing issues for the child

**Supporting Definition:** The specific hearing screening test is left at the discretion of institutions. This variable is only present to identify if abnormalities are identified.

**Inclusion Criteria:** All patients

**Timing:** All Timepoints

**Data Source:** Clinician

**Type:** Single answer

**Response Options:** 1= Normal result  
2= Abnormal result

---

**Variable ID:** KAY\_PICTURE

**Variable:** Kay Picture Test Result

**Definition:** LogMAR Score from Kay Picture Screening Test Book

**Supporting Definition:** N/A

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age, 5 Years of Age

**Data Source:** Clinician

**Type:** Value  
**Response Options:** LogMAR Score

---

## Readmission

---

**Variable ID:** READMINS  
**Variable:** Unplanned Readmissions  
**Definition:** Number of unplanned readmissions, within 30 days post-discharge  
**Supporting Definition:** N/A  
**Inclusion Criteria:** All patients  
**Timing:** All Timepoints  
**Data Source:** Administrative or clinical  
**Type:** Value  
**Response Options:** Number of readmissions

---

## Patient/Parent Reported Outcomes

---

**Variable ID:** PARCA-R\_PLAY\_Q01  
**Variable:** Question 1 of PARCA-R 'Your Child's Play' Section  
**Definition:** Does your child copy things you do such as cuddling a teddy? (Try it out if not sure by cuddling a teddy and then giving it to your child. Say: Now you cuddle teddy)  
**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.  
  
Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q02  
**Variable:** Question 2 of PARCA-R 'Your Child's Play' Section  
**Definition:** When you hide a toy in full view of your child, will s/he look for it and find it? (Try this out by covering a small toy with a cloth or a cup and seeing if s/he uncovers the toy)  
**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.  
  
Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q03

**Variable:** Question 3 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child put a simple piece, such as a square or an animal, into the correct place in a puzzle board?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q04

**Variable:** Question 4 of PARCA-R 'Your Child's Play' Section

**Definition:** Some toys have several holes or openings with different shapes, such as a circle, triangle, and star. Could your child put the shapes into the right openings?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q05

**Variable:** Question 5 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child stack two small blocks or toys on top of each other?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Qo6

**Variable:** Question 6 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child put together, by him/herself, a puzzle or something similar where the pieces fit together?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Qo7

**Variable:** Question 7 of PARCA-R 'Your Child's Play' Section

**Definition:** If so, can s/he do this for a puzzle with ten or more pieces?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** If responded "Yes" to "Can your child put together, by him/herself, a puzzle or something similar where the pieces fit together?"

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes

2=No

3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Qo8

**Variable:** Question 8 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child mark on a piece of paper using the tip of a crayon, pencil, or chalk?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes

2=No

3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Qo9

**Variable:** Question 9 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child draw a more or less straight line on paper?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes

2=No

3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q10

**Variable:** Question 10 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child turn, or try to turn, pages of a book one at a time?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q11

**Variable:** Question 11 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever pretend that one object, such as a block, is another object, such as a car or a telephone?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q12

**Variable:** Question 12 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child stack three small blocks or toys on top of each other by him/herself?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.



**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q13

**Variable:** Question 13 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever pretend to do things? For example, riding a horse or making a cup of tea?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q14

**Variable:** Question 14 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child push a car along the floor with the wheels on the floor?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q15

**Variable:** Question 15 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child look with interest at pictures in a book?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q16

**Variable:** Question 16 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child point to pictures in a book?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q17

**Variable:** Question 17 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child try to copy things you do, such as stirring with a spoon in a cup?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q18

**Variable:** Question 18 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child stack seven small blocks or toys on top of each other by him/herself?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q19

**Variable:** Question 19 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child point or show where people or objects are when you ask: "Where is the light?" "Where is Daddy?" or "Where is Teddy?"

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q20

**Variable:** Question 20 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever pretend that two dolls are playing together, or are talking to each other, or one is feeding the other?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q21

**Variable:** Question 21 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever play pretend games with another child, pretending to be someone else, such as a mummy, daddy, policeman, or nurse?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q22

**Variable:** Question 22 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever play any game with another child that involves taking turns?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q23

**Variable:** Question 23 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child every copy some action shortly (within a few minutes) after s/he has seen it?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q24

**Variable:** Question 24 of PARCA-R 'Your Child's Play' Section

**Definition:** Can your child fetch something, such as a toy, from another room by him/herself when you ask?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q25

**Variable:** Question 25 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child know where some things belong, such as, that his/her toys belong in a box?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes

2=No

3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q26

**Variable:** Question 26 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever save or put to one side a biscuit (or snack) for later, on his/her own?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes

2=No

3=Don't Know

---

**Variable ID:** PARCA-R\_COG\_Q27

**Variable:** Question 27 of PARCA-R 'Your Child's Play' Section

**Definition:** Have you ever seen your child get together three or more toys before beginning to play with them?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months

to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q28

**Variable:** Question 28 of PARCA-R 'Your Child's Play' Section

**Definition:** Have you ever seen your child sort things (blocks, other toys) into groups or piles that go together on his/her own?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q29

**Variable:** Question 29 of PARCA-R 'Your Child's Play' Section

**Definition:** If your child wants something out of reach, does s/he go and find a chair or box to stand on?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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<b>Variable ID:</b>	PARCA-R_COG_Q30
<b>Variable:</b>	Question 30 of PARCA-R 'Your Child's Play' Section
<b>Definition:</b>	When your child uses or plays with a telephone, does s/he speak into the mouthpiece not the earpiece?
<b>Supporting Definition:</b>	As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.
	Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 3=Don't Know
<b>Variable ID:</b>	PARCA-R_COG_Q31
<b>Variable:</b>	Question 31 of PARCA-R 'Your Child's Play' Section
<b>Definition:</b>	When your child drinks from a cup, is s/he careful about putting it down, trying not to spill it?
<b>Supporting Definition:</b>	As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.
	Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No 3=Don't Know
<b>Variable ID:</b>	PARCA-R_COG_Q32
<b>Variable:</b>	Question 32 of PARCA-R 'Your Child's Play' Section
<b>Definition:</b>	Does your child try to turn doorknobs, twist tops, or screw lids on or off jars?
<b>Supporting Definition:</b>	As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.



Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q33

**Variable:** Question 33 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child recognize him/herself when looking in the mirror?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_COG\_Q34

**Variable:** Question 34 of PARCA-R 'Your Child's Play' Section

**Definition:** Does your child ever use his/her index (first) finger to point to show an interest in something?

**Supporting Definition:** As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then select Yes. If you know that your child would not be able to do it, then select No. If you are not sure whether or not your child can do it, then select Don't know.

Please keep in mind that these questions are for children ranging from 18 months to 4 years of age. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No  
3=Don't Know

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**Variable ID:** PARCA-R\_LANG\_LIST

**Variable:** PARCA-R 'What Your Child Can Say' Section

**Definition:** Children understand many more words than they can say. Here, we are only interested in the words your child says. Please select all the words you have heard your child say. If your child uses a different pronunciation of a word – e.g., "tend" for pretend, or "duce" for juice – select it anyway.

Please keep in mind that this is only a sample of words; your child may know many other words not on this list. If your child is not yet using any words, please go straight to the next section.

**Supporting Definition:** N/A

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** List

**Response Options:** 1=Baa baa  
2=Cream cracker  
3=Bed  
4=Carry  
5=Last  
6=Meow  
7=Juice  
8=Bedroom  
9=Chase  
10=Tiny  
11=Ouch/ow  
12=Meat  
13=Settee/sofa  
14=Pour  
15=Wet  
16=Uh-oh/oh dear  
17=Milk  
18=Oven/cooker  
19=Finish  
20=After  
21=Woof woof  
22=Peas  
23=Stairs  
24=Fit  
25=Day  
26=Bear  
27=Hat  
28=Flag  
29=Hug/cuddle  
30=Tonight  
31=Bird  
32=Necklace  
33=Rain  
34=Listen  
35=Our  
36=Cat  
37=Shoe  
38=Star

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39=Like  
40=Them  
41=Dog  
42=Sock  
43=Swing  
44=Pretend  
45=This  
46=Duck  
47=Chin  
48=School  
49=Rip/tear  
50=Us  
51=Horse  
52=Ear  
53=Sky  
54=Shake  
55=Where  
56=Aeroplane  
57=Hand  
58=Zoo  
59=Taste  
60=Beside  
61=Boat  
62=Leg  
63=Friend  
64=Gentle  
65=Down  
66=Car  
67=Pillow  
68=Mummy/mum  
69=Think  
70=Under  
71=Ball  
72=Comb  
73=Person  
74=Wish  
75=All  
76=Book  
77=Lamp/torch  
78=Bye/byebye  
79=All gone  
80=Much  
81=Game  
82=Plate  
83=Hi/hello  
84=Cold  
85=Could  
86=Sandwich  
87=Rubbish  
88=No  
89=Fast  
90=Need to  
91=Fish  
92=Tray

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93=Shopping  
 94=Happy  
 95=Would  
 96=Sauce  
 97=Towel  
 98=Thank you  
 99=Hot  
 100=If

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**Variable ID:** PARCA-R\_LANG\_Q01

**Variable:** Question 1 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** Does your child ever talk about past events or people who are not present? For example, a child who saw a carnival last week might later say "carnival", "clown", or "band".

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Often  
 2=Sometimes  
 3=Not yet

---

**Variable ID:** PARCA-R\_LANG\_Q02

**Variable:** Question 2 PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** Does your child ever talk about something that is going to happen in the future? For example, saying "choo-choo" or "bus" before you leave the house on a trip, or saying "swing" when you are going to the park?

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Often  
 2=Sometimes  
 3=Not yet

---

**Variable ID:** PARCA-R\_LANG\_Q03

**Variable:** Question 3 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** Does your child ever talk about objects that are not present? For example, asking about a missing toy not in the room, or asking about someone not present?

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Often  
2=Sometimes  
3=Not yet

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**Variable ID:** PARCA-R\_LANG\_Qo4  
**Variable:** Question 4 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** Does your child understand if you ask for something that is not in the room? For example, would s/he go to the bedroom to get a teddy bear when you say "Where's the bear?"

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Often  
2=Sometimes  
3=Not yet

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**Variable ID:** PARCA-R\_LANG\_Qo5  
**Variable:** Question 5 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** Does your child know who things belong to? For example, a child might point to mummy's shoe and say "Mummy".

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Often  
2=Sometimes  
3=Not yet

---

**Variable ID:** PARCA-R\_LANG\_Qo6  
**Variable:** Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** Has your child started to put together words yet, such as "Daddy gone" or "Doggie bite"?

**Supporting Definition:** We would like to know how your child uses or understands words. Please select one answer for each question below.

Keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age

**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Often  
2=Sometimes  
3=Not yet

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**Variable ID:** PARCA-R\_LANG\_Q07  
**Variable:** Question 7 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** (Talking about something happening right now)

A – I make tower  
B – I making towe

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – I make tower  
2=B – I making towe

---

**Variable ID:** PARCA-R\_LANG\_Q08  
**Variable:** Question 8 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** (Talking about something that already happened)

A – Daddy pick me up  
B – Daddy picked me up

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – Daddy pick me up  
2=B – Daddy picked me up

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**Variable ID:** PARCA-R\_LANG\_Q09  
**Variable:** Question 9 of PARCA-R 'How Your Child Uses and Understands Words' Section  
**Definition:** A – That my truck  
B – That's my truck

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – That my truck  
2=B – That's my truck

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**Variable ID:** PARCA-R\_LANG\_Q10  
**Variable:** Question 10 of PARCA-R 'How Your Child Uses and Understands Words' Section

<b>Definition:</b>	A – Baby crying B – Baby is crying
<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=A – Baby crying 2=B – Baby is crying
<b>Variable ID:</b>	PARCA-R_LANG_Q11
<b>Variable:</b>	Question 11 of PARCA-R 'How Your Child Uses and Understands Words' Section
<b>Definition:</b>	A – There a doggie B – There's a doggie
<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=A – There a doggie 2=B – There's a doggie
<b>Variable ID:</b>	PARCA-R_LANG_Q12
<b>Variable:</b>	Question 12 of PARCA-R 'How Your Child Uses and Understands Words' Section
<b>Definition:</b>	A – Coffee hot B – That coffee hot
<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=A – Coffee hot 2=B – That coffee hot
<b>Variable ID:</b>	PARCA-R_LANG_Q13
<b>Variable:</b>	Question 13 of PARCA-R 'How Your Child Uses and Understands Words' Section
<b>Definition:</b>	A – I no do it B – I can't do it
<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age

**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=A – I no do it  
2=B – I can't do it

---

**Variable ID:** PARCA-R\_LANG\_Q14

**Variable:** Question 14 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** A – I like read stories  
B – I like to read stories

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – I like read stories  
2=B – I like to read stories

---

**Variable ID:** PARCA-R\_LANG\_Q15

**Variable:** Question 15 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** A – Biscuit Mummy  
B – Biscuit for Mummy

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – Biscuit Mummy  
2=B – Biscuit for Mummy

---

**Variable ID:** PARCA-R\_LANG\_Q16

**Variable:** Question 16 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** A – Don't read book  
B – Don't want you read that book

**Supporting Definition:** For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B

**Inclusion Criteria:** Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=A – Don't read book  
2=B – Don't want you read that book

---

**Variable ID:** PARCA-R\_LANG\_Q17

**Variable:** Question 17 of PARCA-R 'How Your Child Uses and Understands Words' Section

**Definition:** A – Baby want eat  
B – Baby want to eat



<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=A – Baby want eat 2=B – Baby want to eat
<b>Variable ID:</b>	PARCA-R_LANG_Q18
<b>Variable:</b>	Question 18 of PARCA-R 'How Your Child Uses and Understands Words' Section
<b>Definition:</b>	A – Look at me B – Look at me dancing
<b>Supporting Definition:</b>	For EACH PAIR of sentences below – A and B – please select the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, select B
<b>Inclusion Criteria:</b>	Patients who answered "Sometimes" or "Often" to Question 6 of PARCA-R 'How Your Child Uses and Understands Words' Section'
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=A – Look at me 2=B – Look at me dancing

## Behavior, Social Functioning, Relationships with Others, Anxiety, Depression, Impact on Family

<b>Variable ID:</b>	SDQ_Q01
<b>Variable:</b>	<b>Question 1 of Strengths and Difficulties Questionnaire</b>
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Considerate of other people's feelings
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q02
<b>Variable:</b>	<b>Question 2 of Strengths and Difficulties Questionnaire</b>
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Restless, overactive, cannot stay still for long
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True

<b>Variable ID:</b>	SDQ_Q03
<b>Variable:</b>	Question 3 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Often complains of headaches, stomach-aches or sickness
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q04
<b>Variable:</b>	Question 4 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Shares readily with other children (treats, toys, pencils etc.)
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q05
<b>Variable:</b>	Question 5 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Often has temper tantrums or hot tempers
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q06
<b>Variable:</b>	Question 6 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Rather solitary, tends to play alone
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q07
<b>Variable:</b>	Question 7 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Generally obedient, usually does what adults request
<b>Inclusion Criteria:</b>	All patients

**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Qo8  
**Variable:** Question 8 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Many worries, often seems worried  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Qo9  
**Variable:** Question 9 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Helpful if someone is hurt, upset or feeling ill  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q10  
**Variable:** Question 10 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Constantly fidgeting or squirming  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q11  
**Variable:** Question 11 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Has at least one good friend  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

<b>Variable ID:</b>	SDQ_Q12
<b>Variable:</b>	Question 12 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Often fights with other children or bullies them
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q13
<b>Variable:</b>	Question 13 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Often unhappy, down-hearted or tearful
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q14
<b>Variable:</b>	Question 14 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Generally liked by other children
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q15
<b>Variable:</b>	Question 15 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Easily distracted, concentration wanders
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q16
<b>Variable:</b>	Question 16 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Nervous or clingy in new situations, easily loses confidence
<b>Inclusion Criteria:</b>	All patients

**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q17  
**Variable:** Question 17 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Kind to younger children  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q18  
**Variable:** Question 18 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Often argumentative with adults  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q19  
**Variable:** Question 19 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Picked on or bullied by other children  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

**Variable ID:** SDQ\_Q20  
**Variable:** Question 20 of Strengths and Difficulties Questionnaire  
**Definition:** Please give your answer on the basis of the child's behaviour over the last six months or this school year  
**Supporting Definition:** Often volunteers to help others (parents, teachers, other children)  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
1= Somewhat True  
2= Certainly True

---

<b>Variable ID:</b>	SDQ_Q21
<b>Variable:</b>	Question 21 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Can stop and think things out before acting
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q22
<b>Variable:</b>	Question 22 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Can be spiteful to others
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q23
<b>Variable:</b>	Question 23 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Gets on better with adults than with other children
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q24
<b>Variable:</b>	Question 24 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Many fears, easily scared
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	0 = Not True 1= Somewhat True 2= Certainly True
<b>Variable ID:</b>	SDQ_Q25
<b>Variable:</b>	Question 25 of Strengths and Difficulties Questionnaire
<b>Definition:</b>	Please give your answer on the basis of the child's behaviour over the last six months or this school year
<b>Supporting Definition:</b>	Sees tasks through to the end, good attention span
<b>Inclusion Criteria:</b>	All patients

**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 0 = Not True  
 1= Somewhat True  
 2= Certainly True

---

## Disability

---

**Variable ID:** M-CHAT-R\_Q01  
**Variable:** Question 1 of M-CHAT-R Autism Screener  
**Definition:** If you point at something across the room, does your child look at it? (For example, if you point at a toy or an animal, does your child look at the toy or animal?)  
**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
 2=No

---

**Variable ID:** M-CHAT-R\_Q02  
**Variable:** Question 2 of M-CHAT-R Autism Screener  
**Definition:** Have you ever wondered if your child might be deaf?  
**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
 2=No

---

**Variable ID:** M-CHAT-R\_Q03  
**Variable:** Question 3 of M-CHAT-R Autism Screener  
**Definition:** Does your child play pretend or make-believe? (For example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)  
**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
 2=No

---

**Variable ID:** M-CHAT-R\_Q04  
**Variable:** Question 4 of M-CHAT-R Autism Screener  
**Definition:** Does your child like climbing on things? (For example, furniture, playground, equipment, or stairs)  
**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no  
**Inclusion Criteria:** All patients  
**Timing:** 2 Years of Age  
**Data Source:** Parent  
**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Qo5

**Variable:** Question 5 of M-CHAT-R Autism Screener

**Definition:** Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Qo6

**Variable:** Question 6 of M-CHAT-R Autism Screener

**Definition:** Does your child point with one finger to ask for something or to get help? (For example, pointing to a snack or toy that is out of reach?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Qo7

**Variable:** Question 7 of M-CHAT-R Autism Screener

**Definition:** Does your child point with one finger to show you something interesting? (For example, pointing to an airplane in the sky or a big truck in the road?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Qo8

**Variable:** Question 8 of M-CHAT-R Autism Screener

**Definition:** Is your child interested in other children? (For example, does your child watch other children, smile at them, or go to them?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Qo9

**Variable:** Question 9 of M-CHAT-R Autism Screener



**Definition:** Does your child show you things by bringing them to you or holding them up for you to see- not to get help but just to share? (For example, showing you a flower, a stuffed animal, or a toy truck?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q10

**Variable:** Question 10 of M-CHAT-R Autism Screener

**Definition:** Does your child respond when you call his or her name? (For example, does her or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q11

**Variable:** Question 11 of M-CHAT-R Autism Screener

**Definition:** When you smile at your child, does he or she smile back at you?

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q12

**Variable:** Question 12 of M-CHAT-R Autism Screener

**Definition:** Does your child get upset by everyday noises? (For example, does your child scream or cry to noise such as a vacuum cleaner or loud music?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q13

**Variable:** Question 13 of M-CHAT-R Autism Screener

**Definition:** Does your child walk?

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q14

**Variable:** Question 14 of M-CHAT-R Autism Screener

**Definition:** Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q15

**Variable:** Question 15 of M-CHAT-R Autism Screener

**Definition:** Does your child try to copy what you do? (For example, wave bye-bye, clap, or make a funny noise when you do)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q16

**Variable:** Question 16 of M-CHAT-R Autism Screener

**Definition:** If you turn your head to look at something, does your child look around to see what you are looking at?

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q17

**Variable:** Question 17 of M-CHAT-R Autism Screener

**Definition:** Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say "look" or "watch me"?)

**Supporting Definition:** If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no

**Inclusion Criteria:** All patients

**Timing:** 2 Years of Age

**Data Source:** Parent

**Type:** Single answer

**Response Options:** 1=Yes  
2=No

---

**Variable ID:** M-CHAT-R\_Q18

**Variable:** Question 18 of M-CHAT-R Autism Screener

<b>Definition:</b>	Does your child understand when you tell him or her to do something? (For example, if you don't point, can your child understand "put the bok on the chair" or "bring me the blanket"?)
<b>Supporting Definition:</b>	If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No
<hr/>	
<b>Variable ID:</b>	M-CHAT-R_Q19
<b>Variable:</b>	Question 19 of M-CHAT-R Autism Screener
<b>Definition:</b>	If something new happens, does your child look at your face to see how you feel about it? (For example, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)
<b>Supporting Definition:</b>	If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No
<hr/>	
<b>Variable ID:</b>	M-CHAT-R_Q20
<b>Variable:</b>	Question 20 of M-CHAT-R Autism Screener
<b>Definition:</b>	Does your child like movement activities? (For example, being swung or bounced on your knee)
<b>Supporting Definition:</b>	If you have seen your child do the behavior a few times, but he or she does not usually do it, the please answer no
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	2 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No

## Development

<b>Variable ID:</b>	CDC_COGNITION_CHECK
<b>Variable:</b>	CDC 5 Years of Age Cognition Checklist
<b>Definition:</b>	Did the child not achieve any of the cognition milestones?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Clinician/Healthcare provider
<b>Type:</b>	Single answer
<b>Response Options:</b>	1=Yes 2=No
<hr/>	
<b>Variable ID:</b>	CDC_COGNITION_CHECK(a)
<b>Variable:</b>	CDC 5 Years of Age Cognition Checklist further testing
<b>Definition:</b>	Did this warrant further cognitive testing?
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age

**Data Source:** Clinician/Healthcare provider  
**Type:** Single answer  
**Response Options:** 1=Yes  
2=No

---

## **Sleep, Feeding, Pulmonary Function, HRQoL, Pain, Motor Function, Relationships with others, Social Functioning, Impact on Family, Communication, Behavior, Anxiety**

---

**Variable ID:** TAPQOL\_Q01

**Variable:** Question 1 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Stomach-ache or abdominal pain?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q01a

**Variable:** Question 1a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had stomach-ache or abdominal pain in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Stomach-ache or abdominal pain?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q02

**Variable:** Question 2 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Colic (abdominal cramps)?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q02a

**Variable:** Question 2a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had colic (abdominal cramps) in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Colic (abdominal pain)?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q03

**Variable:** Question 3 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Eczema?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q03a

**Variable:** Question 3a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had eczema in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Eczema?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q04

**Variable:** Question 4 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Itching?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q04a

**Variable:** Question 4a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had itching in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Itching?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q05

**Variable:** Question 5 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Dry skin?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:**  
0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Qo5a

**Variable:** Question 5a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had dry skin in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Dry skin?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:**  
0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Qo6

**Variable:** Question 6 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Bronchitis?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:**  
0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Qo6a

**Variable:** Question 6a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had bronchitis in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Bronchitis?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:**  
0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Qo7

**Variable:** Question 7 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Difficulty breathing or lung problems?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Qo7a

**Variable:** Question 7a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had difficulty breathing or lung problems in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Difficulty breathing or lung problems?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Qo8

**Variable:** Question 8 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Shortness of breath?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Qo8a

**Variable:** Question 8a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had shortness of breath in the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Shortness of breath?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL-Qo9

**Variable:** Question 9 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** In the last 3 months has your child had: Nausea?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Qo9a

**Variable:** Question 9a of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** If your child had had nausea in the last 3 months: At those times, my child felt:  
**Supporting Definition:**  
**Inclusion Criteria:** If responded "Occasionally" or "Often" to "In the last 3 months has your child had: Nausea?"  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q10  
**Variable:** Question 10 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How did your child sleep over the last 3 months? Did your child sleep restlessly?  
**Supporting Definition:**  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q10a  
**Variable:** Question 10a of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** If your child has slept restlessly over the last 3 months: At those times, my child felt:  
**Supporting Definition:**  
**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child sleep over the last 3 months: Did your child sleep restlessly?"  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q11  
**Variable:** Question 11 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How did your child sleep over the last 3 months? Did your child lie awake at night?  
**Supporting Definition:**  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q11a  
**Variable:** Question 11a of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** If your child has lied awake at night over the last 3 months: At those times, my child felt:  
**Supporting Definition:**



**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child sleep over the last 3 months? Did your child lie awake at night?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q12

**Variable:** Question 12 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** How did your child sleep over the last 3 months? Did your child cry during the night?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q12a

**Variable:** Question 12a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has cried during the night over the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child sleep over the last 3 months? Did your child cry during the night?"

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q13

**Variable:** Question 13 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** How did your child sleep over the last 3 months? Did your child have trouble sleeping through the night?

**Supporting Definition:**

**Inclusion Criteria:** All patients

**Timing:** 5 Years of Age

**Data Source:** Parent

**Type:** Code

**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q13a

**Variable:** Question 13a of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** If your child has had trouble sleeping through the night over the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child sleep over the last 3 months? Did your child have trouble sleeping through the night?"

**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q14  
**Variable:** Question 14 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How did your child eat and drink over the last 3 months? Did your child have a poor appetite?

**Supporting Definition:**

**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q14a  
**Variable:** Question 14a of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** If your child has had a poor appetite over the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child eat and drink over the last 3 months? Did your child have a poor appetite?"  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Well  
1= Not very well  
2= Unwell  
3= Very unwell

---

**Variable ID:** TAPQOL\_Q15  
**Variable:** Question 15 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How did your child eat and drink over the last 3 months? Did your child have difficulty eating enough?

**Supporting Definition:**

**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q15a  
**Variable:** Question 15a of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** If your child has had difficulty eating enough over the last 3 months: At those times, my child felt:

**Supporting Definition:**

**Inclusion Criteria:** If responded "Occasionally" or "Often" to "How did your child eat and drink over the last 3 months? Did your child have difficulty eating enough?"  
**Timing:** 5 Years of Age  
**Data Source:** Parent

<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q16
<b>Variable:</b>	Question 16 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How did your child eat and drink over the last 3 months? Did your child refuse to eat?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q16a
<b>Variable:</b>	Question 16a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has refused to eat over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Occasionally" or "Often" to "How did your child eat and drink over the last 3 months? Did your child refuse to eat?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q17
<b>Variable:</b>	Question 17 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's behaviour over the last 3 months?
<b>Supporting Definition:</b>	My child was short-tempered
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q18
<b>Variable:</b>	Question 18 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's behaviour over the last 3 months?
<b>Supporting Definition:</b>	My child was aggressive
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q19
<b>Variable:</b>	Question 19 of TNA-AZL Preschool Children Quality of Life Questionnaire

**Definition:** How was your child's behaviour over the last 3 months?  
**Supporting Definition:** My child was fussy, irritated  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q20  
**Variable:** Question 20 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How was your child's behaviour over the last 3 months?  
**Supporting Definition:** My child was angry  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q21  
**Variable:** Question 21 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How was your child's behaviour over the last 3 months?  
**Supporting Definition:** My child was restless or impatient with me  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q22  
**Variable:** Question 22 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How was your child's behaviour over the last 3 months?  
**Supporting Definition:** My child was rebellious/defiant with me  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q23  
**Variable:** Question 23 of TNA-AZL Preschool Children Quality of Life Questionnaire  
**Definition:** How was your child's behaviour over the last 3 months?  
**Supporting Definition:** I could not manage my child  
**Inclusion Criteria:** All patients  
**Timing:** 5 Years of Age  
**Data Source:** Parent  
**Type:** Code  
**Response Options:** 0= Never  
1= Occasionally  
2= Often

---

**Variable ID:** TAPQOL\_Q24

<b>Variable:</b>	Question 24 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Cheerful
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<hr/>	
<b>Variable ID:</b>	TAPQOL_Q25
<b>Variable:</b>	Question 25 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Content
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<hr/>	
<b>Variable ID:</b>	TAPQOL_Q26
<b>Variable:</b>	Question 26 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Happy
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<hr/>	
<b>Variable ID:</b>	TAPQOL_Q27
<b>Variable:</b>	Question 27 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Fearful
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<hr/>	
<b>Variable ID:</b>	TAPQOL_Q28
<b>Variable:</b>	Question 28 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Tense
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<hr/>	

<b>Variable ID:</b>	TAPQOL_Q29
<b>Variable:</b>	Question 29 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Worried
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q30
<b>Variable:</b>	Question 30 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Energetic
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q31
<b>Variable:</b>	Question 31 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Active
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q32
<b>Variable:</b>	Question 32 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's mood in the last 3 months?
<b>Supporting Definition:</b>	Lively
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q33
<b>Variable:</b>	Question 33 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's behaviour with other children over the last 3 months?
<b>Supporting Definition:</b>	My child was able to play nicely with other children
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally

2= Often

---

<b>Variable ID:</b>	TAPQOL_Q34
<b>Variable:</b>	Question 34 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's behaviour with other children over the last 3 months?
<b>Supporting Definition:</b>	My child was at ease with other children
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often

---

<b>Variable ID:</b>	TAPQOL_Q35
<b>Variable:</b>	Question 35 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	How was your child's behaviour with other children over the last 3 months?
<b>Supporting Definition:</b>	My child was self-assured with other children
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often

---

<b>Variable ID:</b>	TAPQOL_Q36
<b>Variable:</b>	Question 36 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty walking?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= No 1= Yes, a little 2= Yes, a lot 3= Is not walking (yet)

---

<b>Variable ID:</b>	TAPQOL_Q36a
<b>Variable:</b>	Question 36a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty walking over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Yes, a little", "Yes, a lot" or "Is not walking (yet)" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty walking?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell

---

<b>Variable ID:</b>	TAPQOL_Q37
<b>Variable:</b>	Question 37 of TNA-AZL Preschool Children Quality of Life Questionnaire

<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty running?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= No 1= Yes, a little 2= Yes, a lot 3= Is not walking (yet)
<b>Variable ID:</b>	TAPQOL_Q37a
<b>Variable:</b>	Question 37a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty running over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Yes, a little", "Yes, a lot" or "Is not walking (yet)" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty running?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q38
<b>Variable:</b>	Question 38 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty climbing stairs without help?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= No 1= Yes, a little 2= Yes, a lot 3= Is not walking (yet)
<b>Variable ID:</b>	TAPQOL_Q38a
<b>Variable:</b>	Question 38a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty climbing the stairs without help over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Yes, a little", "Yes, a lot" or "Is not walking (yet)" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty climbing the stairs without help?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell



<b>Variable ID:</b>	TAPQOL_Q39
<b>Variable:</b>	Question 39 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty keeping balance?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= No 1= Yes, a little 2= Yes, a lot 3= Is not walking (yet)
<b>Variable ID:</b>	TAPQOL_Q39a
<b>Variable:</b>	Question 39a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty keeping balance over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Yes, a little" or "Yes, a lot" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty keeping balance?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q40
<b>Variable:</b>	Question 40 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty understanding what others were saying?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q40a
<b>Variable:</b>	Question 40a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty understanding what others were saying over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Occasionally" or "Often" to "Over the last 3 months, compared with other children of the same age did your child have: Difficulty understanding what others were saying?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell

<b>Variable ID:</b>	TAPQOL_Q41
<b>Variable:</b>	Question 41 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty talking clearly?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q41a
<b>Variable:</b>	Question 41a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty talking clearly over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Occasionally" or "Often" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty talking clearly?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q42
<b>Variable:</b>	Question 42 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty expressing himself/herself?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
<b>Variable ID:</b>	TAPQOL_Q42a
<b>Variable:</b>	Question 42a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty expressing himself/herself over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Occasionally" or "Often" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty expressing himself/herself?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
<b>Variable ID:</b>	TAPQOL_Q43

<b>Variable:</b>	Question 43 of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	Over the last 3 months, compared with other children of the same age, did your child have: Difficulty explaining what he/she wants?
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Never 1= Occasionally 2= Often
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<b>Variable ID:</b>	TAPQOL_Q43a
<b>Variable:</b>	Question 43a of TNA-AZL Preschool Children Quality of Life Questionnaire
<b>Definition:</b>	If your child has had difficulty explaining what he/she wants over the last 3 months: At those times, my child felt:
<b>Supporting Definition:</b>	
<b>Inclusion Criteria:</b>	If responded "Occasionally" or "Often" to "Over the last 3 months, compared with other children of the same age, did your child have: Difficulty explaining what he/she wants?"
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= Well 1= Not very well 2= Unwell 3= Very unwell
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<b>Variable ID:</b>	SCHOOLING
<b>Variable:</b>	Schooling of child
<b>Definition:</b>	Please indicate the child's current education
<b>Supporting Definition:</b>	N/A
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	5 Years of Age
<b>Data Source:</b>	Parent
<b>Type:</b>	Code
<b>Response Options:</b>	0= In a mainstream school 1= In a mainstream school with special educational needs support 2= In a special educational needs school 3= Home schooled 4= Not entered into mainstream schooling 5= Not started school as they are below the minimum school starting age
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<sup>1</sup> For international benchmarking work, the amount of alcohol consumed by each patient should be converted by multiplying ALCFREQ x ALCAMT x country- or region-specific number of grams per unit of alcohol

<sup>2</sup> Acute kidney injury is defined using KDIGO guidelines as "An increase in serum creatinine (SCR) by >0.3mg/dL (>26.5 µmol/l) within 48 hours; or an increase in SCR to >1.5 times baseline, which is known or presumed to have occurred within the prior 7 days; or urine volume <0.5ml/kg/h for 6 hours."

<sup>3</sup> All responses to the Access to care questions (ACCESPROF, ACCESPROFREAS, ACCESMED, ACCESMEDREAS) should be measured at baseline and included as case-mix variables in the analysis. These questions should be repeated annually and the presence or absence of financial barriers used as an outcome (i.e. whether or not the patient selects "Difficulty paying for it" as a response option to ACCESMEDREAS and ACCESPROFREAS).

# 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
Jasper Been	Erasmus University MC – Sophia Children’s Hospital, the Netherlands	None declared
Selina Bentoom	African Foundation for Premature Babies and Neonatal Care, Ghana	None declared
Ilein Bolaños González	Con Amor Vencerás, Mexico	Abbvie- In kind (Support to make awareness campaign on prematurity and RSV)
Jeanie Cheong	Murdoch Children’s Research Institute, Australia	None declared
Mandy Daly	Irish Neonatal Health Alliance, Ireland	None declared
Andreas W. Flemmer	Div. Neonatology, Dr. v. Hauner Children's, LMU University Hospital, Munich, Germany	None declared
Linda Johnston	University of Toronto, Canada	None declared
Haresh Kirpalani	Children’s Hospital of Philadelphia, USA	None declared
Silke Mader	European Foundation for the Care of Newborn Infants (EFCNI)	EFCNI- Sponsorship (EFCNI receives unrestricted and restricted grants from several industry partners, but is with a contract ensured that they have no influence in our work or projects.)
Arti Maria	Atal Bihari Vajpayee Institute of Medical Sciences (ABVIMS), New Delhi; Dr. Ram Manohar Lohia Hospital, New Delhi, India	None declared
Alicia Matijasevich	Departamento de Medicina Preventiva, Faculdade de Medicina FMUSP, Universidade de São Paulo, SP, Brazil	None declared
Rashmi A. Mittal	KK Women’s and Children’s Hospital, Singapore	None declared
Kunda Mutesu-Kapembwa	University Teaching Hospital /Women and Newborn Hospital, Neonatology Department, Lusaka, Zambia	None declared
Josef Neu	University of Florida, USA	Infant Bacterial Therapeutics- Research Grant
Christina Nielsen	ICHOM, USA	None declared
Naira Pereyra	Hospital Star Medica Infantil, Mexico	None declared
Kylie Pussell	Miracle Babies Foundation, Australia	None declared
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Johanna Steckermeier	Ludwig Maximilians University of Munich, Germany	None declared
Eleni Vavouraki	Ilitominon, Greece	None declared
James Webbe	Imperial College London, UK	None declared
Dieter Wolke	University of Warwick, UK	Co-creator and author for the PARCA-R assessment and validation.
Kojo Yeboah-Antwi	Father Thomas Alan Rooney Memorial Hospital, Ghana	None declared
Jennifer Zeitlin	INSERM, France	None declared

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# Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.0		

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