SUPPLEMENTARY MATERIAL

Content

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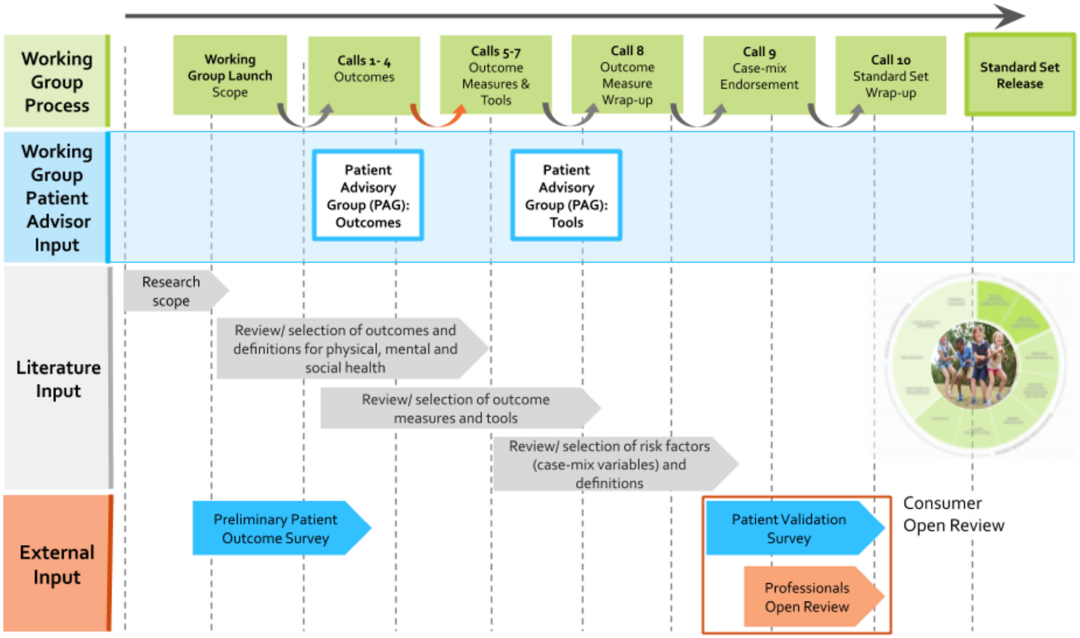
eTable 1. Overview of Working Group members.

Name	Title(s)	Country	Income Level*	Organization
Matthew O'Meara, MD	NSW Chief Paediatrician; Senior Staff Specialist Paediatric Emergency	Australia	High	NSW Health
Michael Morris	Founder of Samuel Morris Foundation; WG Patient Advisor	Australia	High	Samuel Morris Foundation
Aida Luiza R. Turquetto, PhD	Physiotherapy and Occupational Therapist of Cardiovascular Surgery Dept - Pediatric Unit	Brazil	Upper Middle	Heart Institute, University of Sao Paulo Medical School
Luiz F. Caneo, MD, PhD	Affiliate Professor of Cardiovascular Surgery Dept. - Pediatric Unit	Brazil	Upper Middle	Heart Institute, University of Sao Paulo Medical School
Anne F. Klassen, DPhil	Professor of Pediatrics	Canada	High	McMaster University
Emma J. Mew, MPH	Clinical Research Project Manager	Canada	High	Child Health Evaluative Sciences, Peter Gilgan Center for Research and Learning, The Hospital for Sick Children
Martin Offringa, MD, PhD	Neonatologist; Professor of Paediatrics; Senior Scientist	Canada	High	Department of Paediatrics, The Hospital for Sick Children, University of Toronto
Nancy J. Butcher, PhD,MSc	Senior Research Associate	Canada	High	The Hospital for Sick Children Research Institute, University of Toronto
Catalina Valencia Mayer, SLP, MSPH	Speech and Language Therapist; Assistant Professor of Health Research and Public Health	Colombia	Upper Middle	Fundación CINDA
Jaime A. Cespedes L., MD	Professor of Pediatrics; Head of the Pediatric Hospital and Postgraduate Pediatric Program.	Colombia	Upper Middle	Fundación Cardioinfantil - Instituto de Cardiología. Universidad del Rosario.
Kathleen McGreevy, MBA, PhD	Coordinator, Office of International Relations and the Promotion of Innovation	Italy	High	Meyer Children's Hospital
Klaus Peter Biermann, RN-MSN	Infection Control Nurse	Italy	High	Meyer Children's Hospital
Naira Pereyra, MD	Associate Professor of Pediatric Ophthalmology	Mexico	Upper Middle	PREVer Kids
Jan A. Hazelzet, MD, PhD	Chief Medical Officer; Associate Professor of Pediatrics	Netherlands	High	Erasmus University Medical Center
Salman Kirmani, MBBS, MD	Associate Professor of Department of Paediatrics and Child Health	Pakistan	Lower Middle	Aga Khan University
Ng Kee Chong, MBBS, MMed (Paeds), FAMS	Senior Consultant in Children's Emergency Medicine; Medical Board Chairman; Expertise in public health systems	Singapore	High	KK Women's and Children's Hospital
Carlos Rodrigo, MD, PhD	Chief Clinical Officer and Professor of Pediatrics; Head of Pediatrics	Spain	High	Germans Trias i Pujol University Hospital and Universitat Autònoma de Barcelona
Juan José Garcia-Garcia, MD, PhD	Chief of General Pediatrics	Spain	High	Hospital Sant Joan de Déu Barcelona, Spain and Universitat de Barcelona
John E. Chaplin, AFBPsS C.Psychol, PhD	Associate Professor of Experimental Pediatrics	Sweden	High	Sahlgrenska Academy at Gothenburg University, Institute of Clinical Sciences, Department of Pediatrics
Albie Alvarez-Cote	Founding Member of Milagros para Niños; WG Patient Advisor	United States	High	Milagros para Niños - Boston Children's Hospital
James M. Papp, MSW	Principal	United States	High	Mindful Metrics LLC

Kathy J. Jenkins, MD, MPH	Professor of Pediatrics; Pediatric Cardiologist; Executive Director of Center for Applied Pediatric Quality Analytics; Chair of the Working Group	United States	High	Harvard Medical School; Boston Children's Hospital
Timothy L. Switaj, MD, MBA, MHA	Primary Care Leadership; Quality Improvement	United States	High	U.S. Army

*as defined by the World Bank Group, April 2020 (https://data.worldbank.org/income-level/)

WG members were recruited in a two-step process. First, sponsorship opportunities were presented to children's hospitals. Then, the confirmed sponsors were asked to nominate WG members. Additionally, ICHOM recruited volunteers to expand the WG and enable broad representation of experience and geography. Recruitment included participants from low-income countries, however, these participants faced challenges, including unaffordable technology and lack of internet connectivity which ultimately precluded them from participating.

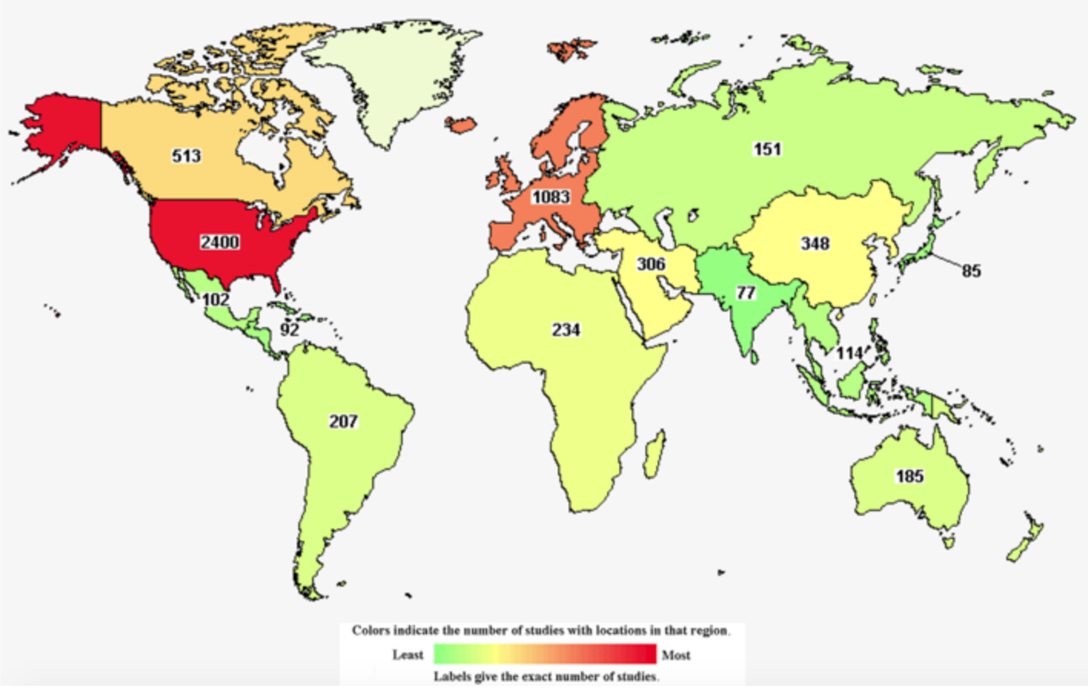


eFigure 1. Overall Pediatric Health Standard Set development process overview.

Between each call a survey was sent out to the Working Group, grey arrows indicate single round survey, orange arrow indicate a modified Delphi process. The PAG was hold with two patient advisors who lead patient advocacy foundations.

WG members were asked to rank outcomes using a 9-point Likert Scale via an electronic survey (Qualtrics Online Survey Platform was used for *all* electronic surveys in this consensus process), with the opportunity to give additional free text feedback.

The voting results of the first round and respondents' comments were anonymized and published for the WG members before voting in a second round. Inclusion of the specific health outcomes and measures in the Standard Set required that at least 80% of the WG members voted the outcome to be very important, i.e. the outcome needed to be ranked between 7-9 points (on a 9-point Likert Scale) in each voting round. During the subsequent WG videoconferences, results of each round were presented to the WG members and the items that did not reach consensus were discussed before being presented for a final (i.e. third) vote determined by a simple yes/no vote with a 70% cut-off for inclusion.



eFigure 2: Geographic overview of the scanned clinical trials, N=4345

Extracted outcomes from clinical trials on www.clinicaltrials.gov
Search terms: pediatric OR paediatric,
Included status: recruiting, not yet recruiting, active, not recruiting, enrolling by invitation studies
Results: N=4345 clinical trials

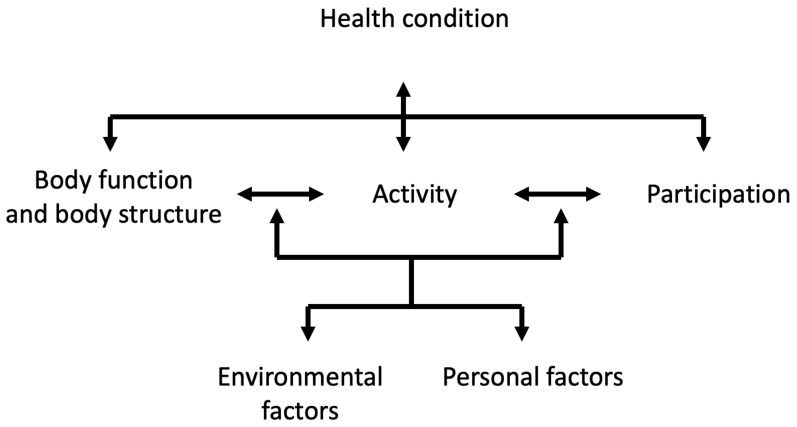
eTable 2. Search Strategy

Search Block	**Search terms**	**Combined with**	**Blocks combined with**	**Databases**
Population	child*, adolesc*, pediatric, paediatric, youth	**OR**	**AND**	• Cumulative Index to Nursing and Allied Health Literature (CINAHL), • the Education Resource Information Center (ERIC), • PsycINFO from the American Psychological Association (APA), the United States National Library of Medicine PubMed including Medical Literature Analysis and Retrieval System Online (Medline)
Outcomes	patient preference, instrument*, scale, measure*, patient reported outcome measures, quality of life, clinical outcome, functioning	**OR**		
	In order to receive a manageable amount of results, search terms were restricted to title and abstract from the last ten years, and limited to searches in PubMed and PsycINFO, with only reviews being extracted due to the otherwise tremendous amount of results (n=20740 and n=12751 respectively). Since reviews are expected to evaluate and summarize many existing outcome measures (including those published earlier than in the last ten years), we deem the strategy is appropriate to identify most of health outcomes that are important to measure.			
Age-ranges included	Age Groups: Infant, Newborn: birth-1 month, Infant: 1-23 months, Child, Preschool: 2-5 years, Child: 6-12 years, Adolescent: 13-18 years, All Infant, All Child			

eTable 3. Example of health outcomes identified by categorizing the extracted measures in accordance to the phenomenon/topic/ health outcome that they were considered to measure.

Instruments sorted from literature scan	Health outcomes
Culture Fair Intelligence Test-Revised (CFT 20-R) (Weiss)	Intelligence
Full-Scale Intelligence Quotient (FIQ)	
Kaufman Brief Intelligence Test, Second Edition (K-BIT 2)	
Stanford Binet Intelligence Scales (SB_5)	
Test of Nonverbal Intelligence (TONI) (Brown et al)	
the Kaufman Brief Intelligence Test, 2nd edition (KBIT-2)	
Wechsler Abbreviated Scale of Intelligence (WASI)	
Wechsler Adult Intelligence Scale-3rd Edition (WAIS-III)	
Wechsler Intelligence Scale for Children , Fourth Edition	
Wechsler Intelligence Test for Adults (WIE) (Aster et al)	
Neonatal Pain, Agitation, and Sedation (N-PASS) Scale	Pain
Pain Assessment Scale for Preterm Infants (PASPI)	
Pain Observation Scale for Young Children (POCIS)	
the Movement Assessment Battery for Children-2 (MABC2)	Movement
Active Movement Scale	
Movement ABC	
Movement Assessment Battery for Children	
Movement Disorder-Childhood Rating Scale	
Peabody Developmental Motor Scales-2 (PDMS-2)	Development (including
Battelle Developmental Inventory, Second Edition (BDI-2)	other domains as well, like
Bayley Scales of Infant Development (Bayley III)	cental health, self-concept,
Child development - mental rotation 3d test	Communication, anxiety)
Child development - New Reynell Developmental Scales	
DeMoulin Self-Concept Developmental Scale for Children	
Developmental Neuropsychological Assessment-Second Edition	
Developmental status - Brigance Early Childhood Screen II, Ages and	
Explore Early Development (SEED)	
Griffiths Mental Development Scales	
Kids' Empathic Development Scale (KEDS)	
National Institute of Child Health and Human Development (NICHD)	
NSMDA (Neurological, Sensory, Motor, Developmental Assessment)	
the Test of Gross Motor Development (TGMD)	
Developmental Disability-Child Global Assessment Scale	
Communication and Symbolic Behaviour Scales--Developmental Profile	
Language - MacArthur Communicative Development Inventory	
Revised Children's Manifest Anxiety Scale-Second Edition (RCMAS-2)	Anxiety
Anxiety - Spence Children's Anxiety Scale-Parent Report	
Anxiety and Related Emotional Disorders (screen child)	
Anxiety Disorders Interview Schedule for "DSM-IV"	
Beck Anxiety Inventory (BAI)	
Child Anxiety Impact Scale	
Multidimensional Anxiety Scale for Children (MASC)	

In order to assure that the identified outcomes reflect a holistic perspective encompassing the physical, mental and social functioning, these outcomes were mapped to the World Health Organization's International Classification of Functioning, Disability and Health (ICF), as a conceptual platform to capture health and health-related domains.



eFigure 3. The model and framework of the International Classification of Functioning, Disability and Health (ICF, World Health Organization (WHO), 2001).

In line with the definition of health by WHO as physical, mental and social well-being and not merely the absence of disease (1946), integrates the ICF the biomedical and psycho-social perspective of health, and models health and well-being as the result of the interactions of Body Functions and Anatomical Structures with individuals' Activities and Participation that are influenced by Environmental and Personal Factors.

eTable 4. Overview of the identified health and health-related outcomes regarding ICF Body Functions stratified by respective resource.

ICF framework	Health outcomes	Instruments from literature scan	Pediatric PROMIS	Pediatric *health* registries and surveys	Pediatric ongoing clinical trials
ICF Body Functions					
b1 Global and specific mental functions	Mental + cognition	15	√	√	114
	Intelligence	17			24
b1 Temperament & personality functions	Efficacy, self-esteem, mastery	15			52
	Coping	4			22
b1 Emotional functions	Depression	17	√	√	103
	Anxiety	22	√	√	152
	Worry, emotion mood	8			64
b1 Sleep functions	Sleep	8			109
b1 Energy and drive functions	Fatigue	3	√	√	40
b2 Sensory functions and pain	Visual/seeing	1		√	24
	Pain	4	√	√	283
	Hearing	3		√	22
b3 Voice and speech	see also "Communication"			√	8
b4 Functions of cardiovascular, haematological, immunological and respiratory systems	Blood pressure			√	107
	Heart rate				71
	Breath+respiratory	1			155
b5 Functions of the digestive, metabolic and endocrine system	Blood glucose			√	21
b7 Neuromuscular function (see also mobility)	Motor (e.g. gross)	11	√	√	50
	Fitness	2			19
	Physical ability	1	√		0
b8 Functions of skin and related structures	Eczema			√	16

eTable 5. Overview of the frequency of identified health and health-related outcomes regarding Activities & Participation stratified by respective resource.

ICF framework	Outcomes	Instruments from literature review	Pediatric PROMIS	Pediatric *health* registries and surveys	Pediatric ongoing clinical trials
ICF Activities and Participation					
d1 Learning and Applying knowledge	Learning (see also intelligence, mental and cognition functions)	2			21
	Writing	4			1
	Reading	6			14
d2 General tasks and demands	Stress	12	√		150
d3 Communication	Language, speech, word, conversation	18			51
d4 Mobility	Movement (see also b7)	6			34
d5 Self-care/looking after one´s health	Eating/nutrition	2		√	87
	Salt intake			√	0
	Sexual health	1			14
	Substance use (e.g. alcohol, tobacco)	2		√	
	Physical activity	1	√	√	119
	Dental hygiene			√	21
d7 Interpersonal interactions and relationships	Interaction	4	√	√	18
d8 Major life areas/engagement in play	Engagement in play	2			15
	School	3		√	71

eTable 6. Overview of the frequency of identified factors influencing health and health-related outcomes regarding Environmental factors stratified by respective resource

ICF framework	Factors influencing outcomes	Instruments from literature scan	Pediatric PROMIS	Pediatric *health* registries and surveys	Pediatric ongoing clinical trials
ICF Environmental factors				√	33
e3 Support	Support	10			66
e4 Attitudes	Attitudes	5			29
e5 Services, systems and policies	Safe neighborhoods			√	

eTable 7. Overview of the frequency of identified health and health-related outcomes stratified by respective resource

	Outcomes	Instruments from literature scan	Pediatric PROMIS	Pediatric *health* registries and surveys	Pediatric ongoing clinical trials
Others					
Overall functioning	Disability	12			71
	Family	21	√	√	9
	Behavior	34			213
	Participation	8			31
Quality of life	Quality of life, Health-related quality of life; Oral health-related quality of life; life satisfaction; well-being, health (global)	68	√ (life satisfaction)	√	443
Abuse, violence	Abuse, violence	2		√	9
Development	Developmental	19			114 (growth)
Mindfulness	Mindfulness	11			10
Parents' substance use (alcohol, tobacco, drugs)	Parents' substance use (alcohol, tobacco, drugs)			√	
	Parents' health			√	
Anthropometric					
	Weight			√	238
	Height			√	114
	Size at birth			√	
	BMI				137
Health condition					
	Asthma	6	√	√	114
	ADHD	3			22
	Autism	13			59
	Burn	4			39
	Depression (see depression above)	17			34 (anxiety, bipolar, psychosis)
	Diabetes	6			130
	Cancer	2			111
	Leukemia	0			173
	Brain injuries/ cerebral palsy	4			87
	Mortality			√	
	Morbidity			√	

eTable 8. ICHOM's tool selection criteria.

Topic	Description
Scope Alignment	• Exclude condition-specific tools (i.e. Breast Cancer, Low Back Pain, Dementia, etc.) • Exclude PREMs and *process* measure tools (i.e. room cleanliness, wait times, etc.)
Coverage of Outcomes	• Tool must address outcomes voted for inclusion by the Working Group • Preference given to tools which cover the most outcomes
Scientific Acceptability & Clinical Utility	• Tools must have demonstrated good reliability (>0.7), validity, and responsiveness (sensitivity to change) • Tools should have demonstrated clinical utility by inclusion of meaningful scores for overall health, mental health, physical health, social health • Tools should have appropriate recall period
Patient Burden	• Tools should not be too long and burdensome for patients to complete • Tools with more than 100 questions will not be considered
Language Translations	• Tool must be available in English • Translations should be available in several other languages
Implementation	• Tools must be able to be implement within diverse, international, clinical settings. • Copyright & Licensing – ensure fees for use of tools are not too expensive as to become a barrier to uptake/adoption of the final OPH Standard Set

eTable 9. Example of systematic evaluation of identified measures and tools in accordance with ICHOM criteria.

Tool	Reliability (≥ 0.7)	Valididty	Covers OPH Age Range (Y/N)	Proxy (Y/N)	Self (Y/N)	Recall Period	PRO (Y/N)	Clinical Measure (Y/N)	# Questions in Tool	Completion Time	Copyright & Licensing Fees			# Languages
											Are there fees? (Y/N)	If yes, fee amount?	Criteria for fee	
AQoL-8D	Y (test in patients)	Y	Y(14+)	N	Y	7 days	Y	N	35	5 min	N			5
ITQoL	N (0.5-0.7)		Y (2months-5years)	Y	N	past 4 weeks, in general	Y	N	97	30-45mins	N			24
ITQoL-SF47	N (0.5-0.7)	Y	Y (2months-5years)	Y	N	past 4 weeks, in general	Y	N	47	30 mins	N			40
KIDSCREEN-52	Y	Y	Y (8-18)	Y	Y	last week	Y	N	52	15-20 min	N		free after registration	>30
PROMIS Scale v1.2 - Global Health	Y	Y	Y (18+)	N	Y	7 days	Y	N	10	2 min	N			14
PROMIS Pediatic scale- Global Health 7+2	Y		Y (8-17)	N	Y	7 days, in general	Y	N	9	2 min	N			14
PROMIS Parent Proxy Scale v1.0 - Global Health 7+2	Y	y	Y (5-17)	Y	N	7 days, in general	Y	N	9	2 min	N			14
KIDSCREEN-27	Y	Y	Y (8-18)	Y	Y	last week	Y	N	27	10 min	N		free after registration	35
KINDL ®	Y	Y	Y (4-16)	N	Y	last week	Y	N	24+6, 12 for age 4-7	5-10min	N		free after registration	15
PROMIS Pediatric Profile-25	Y	Y	Y(8-17, 5-17 proxy)	Y	Y	past 7 days	Y	N	25		N			4+1
Pre-School Language Scale-4	Y	Y	Y (0-7: 11)	N	N		N	Y		20-45 min	Y	823 US Dollars	Certification needed	4
NutriSTEP	Y (most questions)	Y	Y (18months-5y)	Y	N	3 days	Y	N	17	< 10 min	N			1
FLACC Behavioral Scale	y	y	Y (2months-7y)	N	N		N	Y	5	2-5 min (observation)	N		certification needed	9
NIH Toolbox - Sensation - Visual Acuity Test (3+)	Y	Y	Y (3+)	N	N		N	y	na	3 min	N		extra equipment is needed	na
PROMIS Peadiatric SF - Sleep Disturbance	Y	Y	Y(8-17, 5-17 proxy)	Y	Y	past 7 days	Y	N	15 (SV 4 or 8 items)	5-10 min	N			2

eTable 10. Example of the content-mapping of the measures to the agreed upon OPH outcomes.

TOOLS	15D®	16D®	17D ®	AQoL-8D	ITQoL	ITQoL-SF47	KIDSCREEN-52	PROMIS Scale v1.2 - Global Health	PROMIS Pediatic scale-Global Health 7+2
AGE RANGES	(16+ yrs)	(12-15yrs)	(8-11yrs)	(14 +yrs)	(2 mos-5 yrs)	(2 mos-5 yrs)	(8-18yrs)	(18+ yrs)	(8-17 yrs)
Administration Mode	Self/ Proxy	Self/ Proxy	Self/ Proxy	Self	Proxy	Proxy	Self/ Proxy	Self	Self
Outcomes:	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*	*Tool covers outcome*	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*	*Tool covers outcome (Y/N)*
Mental Functioning									
Cognition: Intelligence	Y	Y	Y	N	Y	Y	N	N	N
Coping	N	N	N	Y	N	N	Y	N	N
Mood	Y	Y	Y	Y	N	N	Y	Y	Y
Self-efficacy	N	N	N	Y	N	N	Y	N	N
Self-esteem	N	N	N	Y	N	N	N	N	N
Mental Health	Y	Y	Y	Y	Y	Y	Y	Y	Y
Social/ General Functioning									
Communication	Y	Y	Y	N	Y	Y	N	N	N
School Attendance	N	N	N	N	N	N	Y	N	N
Functioning	Y	Y	Y	Y	N	N	Y	Y	Y
Development	N	N	N	N	Y	Y	N	N	N
HRQoL	Y	Y	Y	Y	Y	Y	Y	Y	Y
Physical Functioning									
Survival	ICHOM	ICHOM	ICHOM	ICHOM	ICHOM	ICHOM	ICHOM	ICHOM	ICHOM
Hearing	Y	Y	Y	N/A	N	N	N	N	N
Vision	Y	Y	Y	N/A	N	N	N	N	N
Eating	Y	Y	Y	N	Y	Y	N	N	N
Nutrition	N	N	N	N	N	N	N	N	N
Growth	N	N	N	N	Y	Y	N	N	N
Physical ability: mobility	Y	Y	Y	Y	Y	Y	Y	Y	Y
Fitness	Y	Y	Y	N	N	N	N	Y	Y
Pain-free	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sleep	Y	Y	Y	N	N	N	N	Y	Y
Sexual Health	Y	N	N	N	N	N	N	N	N
# Outcomes Covered By Tool:	**14**	**13**	**13**	**9**	**9**	**9**	**9**	**8**	**8**
	M	**M**	**M**	**M**	**M**	**M**	**M**	**M**	**M**

eTable 11. Example of tool package 1 for age-range birth to 5 years

Recommendation 1 (Birth - 5 yrs)

- Total Outcomes Covered: **12**
- Total # of Questions: **20-39**
- Total time to completion: **30-41 mins**

Tool	All Psychometric Properties (Y/N)	Outcomes Covered (#)	Time to completion (mins)	# of Questions	# of Languages	Fee (Y/N)
CDC Milestone Checklist	N/A	Cognition: Intelligence, Mood, Mental Health, Functioning, Development, Communication, Physical Ability: Mobility **(7)**	10 - 15	10-29	2	N
NIH Toolbox - Sensation - Visual Acuity Test (3+) [Equipment Needed]	Clinical Measure	Vision **(1)**	3	-	1	N
WHO Growth Charts Early Yrs [Trained Admin]	Clinical Measure	Growth, Nutrition **(2)**	15 - 20	6	1	N
School Attendance	-	School Attendance **(1)**	1	1	-	N
ICHOM Standard Measure	-	Survival **(1)**	1 - 2	3	-	N

eTable 12. Example of tool package 2 for age-range birth to 5 years

Recommendation 2 (Birth - 5 yrs)

- Total Outcomes Covered: **14**
- Total # of Questions: **57**
- Total time to completion: ***45 - 56 mins***

Tool	All Psychometric Properties (Y/N)	Outcomes Covered (#)	Time to completion (mins)	# of Questions	# of Languages	Fee (Y/N)
ITQoL	Y	Cognition: Intelligence, Mental Health, Communication, Development, HRQoL, Eating, Growth, Physical Ability: Mobility, Pain-free. **(9)**	25-30	47	40	N
NIH Toolbox - Sensation - Visual Acuity Test (3+) [Equipment Needed]	Clinical Measure	Vision **(1)**	3	-	1	N
WHO Growth Charts Early Yrs [Trained Admin]	Clinical Measure	Growth, Nutrition **(2)**	15 - 20	6	1	N
School Attendance	-	School Attendance **(1)**	1	1	-	N
ICHOM Standard Measure	-	Survival **(1)**	1 - 2	3	-	N

eTable 13. Overview of the identified case-mix variables following the search for outcome measures.

Case-Mix	Type	Response option 1	Response option 2
Age	Demographic	years since birth	
Gender	Demographic	male, female, others	
Diagnose	Clinical	ICD-code	
Race	Demographic		
Treatment/surgical procedure	Treatment		
Parent income	Demographic	amount of salary	
Etnicity	Demographic		
Parent occupation/employment	Demographic	full time, part time, unemployed, home, retired, student, other	
Relationship	Demographic	Mother; father; other	parents, sibling, other relative, non-relative, missing, adolescent/young adult with a disability
Marital status	Demographic	married/de facto, single/never married, single/widowed, single/divorced	
Parent education	Demographic	primary, high school, trade, university, other	high school, graduated high school, some postsecondary, graduated postsecondary
Disability	Clinical		
Diagnose/disability severity	Clinical		
Migration	Demographic		
Socioeconomic status	Demographic	""The Family Affluence Scale (FAS), a socioeconomic indicator to be filled in by children, includes family car ownership, having own unshared room, the number of computers at home, and times the child spent on holidays in the past 12 months. The cross-cultural validity of the FAS has been shown in multinational surveys across 27 and 35 countries [27].""	
Public health insurance	Demographic	yes/no	
Premature birth	Clinical		
Postoperative analgesia / pharmacological influence	Treatment		
Neighbourhood	Demographic	Large city or metropolitan area (greater than 200000), urbanized area (between 50 000 and 200 000), town or small city (between 2500 and 50000), rural area or town (less than 500),	
Parents age at child birth	Demographic		
Social class	Demographic	low, middle, high	
Parent-reported chronic conditions of child	Demographic		
Parent-reported medical consumption	Demographic	with a low and a high parent-reported medical consumption	
Years since diagnosis	Clinical		
Spasticity	Clinical		
Treatment modality	Treatment		

eTable 14. Sampling strategy for patient validation survey.

Country	Institutional review board (IRB) exemption review
United States	Advarra Institutional Review Board (Pro00038212)
Colombia*	Ethics Committee for Clinical Research in Colombia (Comité de Ética en Investigación Clínica, CEIC-4187-2019)
Singapore*	The survey was carried out as a quality improvement initiative not needing IRB approval
United Kingdom	Patient Validation was exempt as it did not qualify as research needing ethical approval

A convenience sample of parents and caregivers of children and adolescents in Colombia, Singapore, the United States, and the United Kingdom were asked to validate the outcomes that reached consensus based on the Delphi-process. These four countries were chosen based on their ability to obtain an institutional review board (IRB) exemption review in a timely fashion. In the United States, the ethics and institutional review board (IRB) exemption for the survey was carried out by Advarra Institutional Review Board (Pro00038212) and in Colombia by the Ethics Committee for Clinical Research in Colombia (Comité de Ética en Investigación Clínica, CEIC-4187-2019). In Singapore, the survey was carried out as a quality improvement initiative not needing IRB approval. In the United Kingdom, the Patient Validation was also exempt as it did not qualify as research needing ethical approval. Between November 2019 and January 2020, an electronic survey was sent asking participants to rank the importance of these outcomes using a 9-point Likert Scale with an opportunity to give additional free text comments.

*Participants included parents and caregivers of children receiving pediatric care and surveys were administered while their child waited to receive care.

eTable 15. Overview of Patient Validation Survey respondent characteristics, N=270

	n	%
Country		
Colombia	86	32
Singapore	161	59
United Kingdom	5	2
United States of America	18	7
Number of children		
1	111	41
2	97	36
3	46	17
4	5	2
≥ 5	3	1
Sex of children		
Male	92	34
Female	84	31
Male and Female	89	33
Age-range of children		
0-5 years	143	53
6-7 years	51	19
8-12 years	105	39
13-17 years	51	19
18-24 years	35	13
Number of healthcare appointments in the last year		
0	11	4
1-4	149	55
5-9	78	29
≥ 10	32	12
Satisfied with child's healthcare (range 1-5)		
Unsatisfied (1)	3	1
Somewhat satisfied (2-3)	59	22
Completely satisfied (4-5)	208	77

eTable 16. Overview of characteristics of the healthcare providers that participated in the professionals open review, N=51

	n	%
Country		
Argentina	1	2
Australia	2	4
Brazil	2	4
Canada	1	2
Colombia	2	4
Malaysia	1	2
Netherlands	6	12
Portugal	1	2
Singapore	7	14
Spain	18	35
Sweden	1	2
United Arab Emirates	1	2
United Kingdom	2	4
United States of America	6	12
Profession		
Physician	37	72
Nurse	3	6
Healthcare Administration	7	14
Researcher	1	2
Policy Advisor	2	4
Other	1	2