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A Systematic Review of Generic Multidimensional Patient-Reported Outcome Measures for Children, Part I: Descriptive Characteristics

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ABSTRACT

Objectives: To identify generic, multidimensional patient-reported outcome measures (PROMs) for children up to 18 years old and describe their characteristics and content assessed using the International Classification of Functioning, Disability and Health Children and Youth version (ICF-CY). **Methods:** The search strategy, developed by an information specialist, included four groups of terms related to "measure," "health," "children and young people," and "psychometric performance." The search was limited to publications from 1992. Five electronic databases and two online-specific PROM databases were searched. Two groups of reviewers independently screened all abstracts for eligible PROMs. Descriptive characteristics of the eligible PROMs were collected, and items and domains of each questionnaire were mapped onto the ICF-CY chapters. **Results:** We identified 35 PROMs, of which 29 were generic PROMs and 6 were preference-based measures. Many PROMs cover a range of aspects of health; however, social functioning is represented most often. Content covered differs both in which aspects of health are assessed and whether individual questions focus on functioning (what the subject can or does do) and/or well-being (how the subject feels about a certain aspect of his or her health). **Conclusions:** A broad variety of PROMs is available to assess children's health. Nevertheless, only a few PROMs can be used across all age ranges to 18 years. When mapping their content on the ICF-CY, it seems that most PROMs exclude at least one major domain, and all conflate aspects of functioning and well-being in the scales.

Keywords: children and young people, health-related quality of life, patient-reported outcome measures, review.

Introduction

There has been growing and sustained focus on patient-reported outcome measures (PROMs in the United Kingdom and patient-reported outcomes in the United States) [1,2]. It has been suggested that PROMs should be considered as outcome measures in clinical trials [2,3], and as key performance indicators for evaluating health systems [4]. PROMs assess a patient's health at a single point in time, and are collected through short, self-completed questionnaires.

Health outcomes can be considered within the biopsychosocial framework expressed through the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [5]. PROMs aim to assess key aspects of health, which are largely components of the ICF under the rubric of health status or health-related quality of life.

Some PROMs are condition-specific, designed for use by people with a particular health problem; other PROMs are generic and appropriate for anyone to report their health. PROMs can be domain-specific, and focus on particular aspects of health (e.g., mental health or physical functioning), or be multidimensional instruments with subscales that assess different aspects of health.

Using PROMs with children presents conceptual and methodological challenges [6–8]. Age-appropriate content, developmentally appropriate and accessible formats, and the utility of parent proxy-reports are among the key issues debated [7,8]. When selecting PROMs for a specific purpose, it is necessary to understand both what is being assessed and how robust (valid and reliable) the measurement is. Systematic reviews of PROMs for children have previously cataloged available instruments, and identified gaps in the evidence regarding their validity and reliability [9–11]. Scale development methodology has evolved in recent years, and Rasch analysis is commonly used and expected [12]. Methods for appraising the evidence of psychometric performance on measures have also become more standardized [13].

Conflicts of interest: The authors have no conflicts of interest to disclose.

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We carried out a systematic review of generic, multidimensional PROMs for children to take account of methodological developments and any recent emerging evidence. In this first of two related articles, we describe currently available PROMs for children in terms of their purpose and format, and map the constructs assessed by the PROMs using the ICF Children and Youth Version (ICF-CY) [14]. In the second article, we critically appraise published evidence of their psychometric performance.

Methods

The systematic review was conducted following the general principles published by the UK National Health Service Centre for Reviews and Dissemination [15]. The protocol was published online [16].

Types of Instruments (Inclusion/Exclusion Criteria)

We included generic, multidimensional PROMs designed for children up to the age of 18 years, and completed by either the child or the parent (as a proxy). Instruments requiring interview-administration, or where the respondent was not the parent or the child (e.g., teacher), were excluded. Condition-specific and single-domain instruments (e.g., assessing only emotional functioning) were excluded.

Search Strategy

The aim of the search for this part of the study was to identify all existing eligible PROMs. The search strategy was designed and run by an experienced information specialist and developed in consultation with topic and methodological experts. Two existing search filters, COnsensus-based Standards for the selection of health status Measurement INstruments [17] and the Oxford PROM Group [18], informed the strategy. The COnsensus-based Standards for the selection of health status Measurement INstruments filter was designed for PubMed only, which is not an effective or efficient interface for running searches across multiple databases, or downloading large numbers of records into a reference management software. The Oxford filter is not specific to children and therefore also required customizing. The strategy used a combination of Medical Subject Heading terms and free text terms. MEDLINE (via OvidSP), EMBASE, PsychINFO (via OvidSP), AMED (via OvidSP), and Cumulative Index to Nursing and Allied Health (via EBSCOhost) were searched on March 20 and 21, 2012, using four groups of terms: 1) general names for instruments, 2) multidimensional health construct terms, 3) terms to describe children and young people, and 4) key terms relevant to psychometric performance. The search was limited to the preceding 30 years (from 1992), as the team agreed that it was unlikely that PROMs had been developed before this date; subsequent citations of any PROMs developed before this date will have been captured. An example of the search strategy used on MEDLINE is provided (see Appendix 1 in Supplemental Materials found at http://dx.doi.org/10.1016/j.jval.2014.12.006); the other search strategies are available on request from the authors.

Two groups of reviewers independently screened all titles and abstracts to identify articles in which potentially eligible PROMs were cited (Group 1: A.J., V.S., and S.B.; Group 2: C.M., J.T.C., M.R., DM., R.W., and R.A.). Discrepancies were discussed and resolved with the arbitration of a third reviewer (either C.M. or A.J.), where necessary. If necessary, the full-text article was retrieved to verify whether a cited PROM was eligible.

Additional electronic searches were carried out using the Oxford PROM database [19] and ProQolid [20]. We also checked, manually, the reference lists of several pertinent systematic and structured reviews [9–11,21] to verify whether we had included all potentially eligible PROMs.

Data Extraction and Analysis

Data were extracted using standardized, piloted data extraction forms using information available from the development article, questionnaire, and Web sites. For each included candidate PROM, the following were extracted: name and acronym of the PROM, the purpose of measurement, number of items, age range, the responder (child and/or parent as proxy), response options, completion time, recall period, key reference article, health domains assessed, and methods for scoring. Data were extracted by one reviewer (A.J.) and checked by a second reviewer (K.A.), with disagreements resolved by discussion with a third (C.M.), where necessary.

The content assessed by each PROM was mapped to the ICF-CY [14], broadly following linking rules developed for this purpose [22]. Items and domains of each questionnaire were inspected and coded to the ICF-CY chapters by one reviewer (A.J.) and checked by a second (C.M.), with disagreements resolved by discussion. Constructs not represented in the ICF-CY were recorded separately.

Results

The electronic searches yielded 13,770 results. This resulted in 131 PROMs being identified as potentially eligible. Further review of these PROMs resulted in the identification of 35 PROMs meeting the inclusion criteria (Fig 1) [23–37]. Although some PROMs have various versions, designed for different

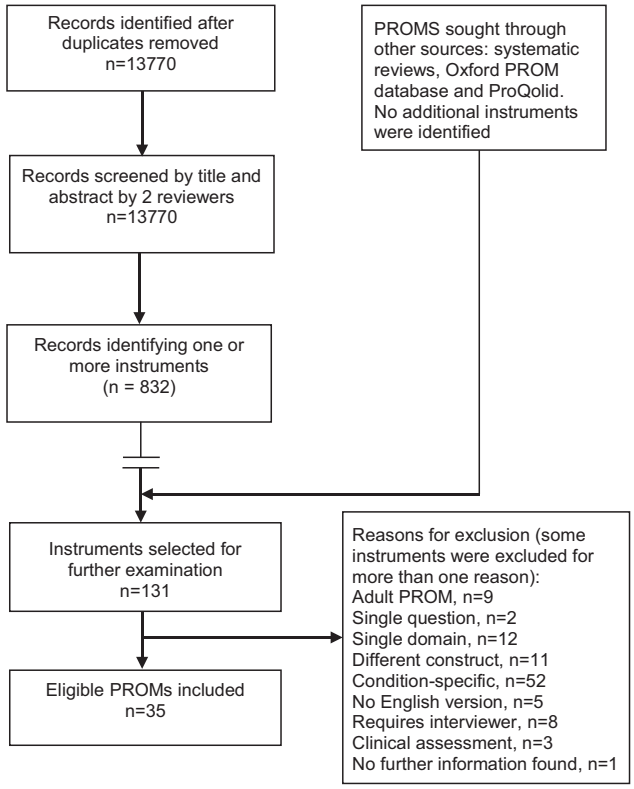

Fig. 1 – Flowchart of search results and selection process. *Note.* **Interruption in the arrow highlights where the numbers change from record screened to PROMs considered. PROMs, patient-reported outcome measures.**

age groups and/or child or parent proxy responders and/or short/long forms, these were counted as single instruments (Table 1).

Age Range

The search identified four generic PROMs that are intended to cover the full age range in children from birth up to 18 years and have different versions for different age groups: Auto Questionnaire Enfant Imagé Child Pictured Self-Report (five versions), Functional Status II Revised (four versions), Pediatric Quality of Life Inventory, version 4.0 (six versions), and TNO-AZL (four versions). The Revidierter Kinder Lebensqualitätsfragebogen (KINDL) has three age-specific versions, starting from age 4 years; Child Health and Illness Profile has two versions covering children and young people from 6 to 17 years. The remaining PROMs use the same version across a defined age range.

Responder

Just over half of the PROMs, 18 of 35, offer both self-report and proxy-report versions, the only difference being that the items are phrased to address the salient responder. Five PROMs provide only a proxy-report version: Comprehensive Health Status Classification System - Preschool, Functional Status II Revised, Health and Life Functioning Scale, Warwick Child Health and Morbidity Profile, and Infant Toddler Quality of Life Questionnaire; three of these target children younger than 5 years [30,38,39]. Twelve PROMs have only a self-report version [23,34,35,37,40–47].

Scaling and Scoring

PROMs were broadly of three types: 1) multi-item questionnaires solely providing a summary score; 2) multi-item, multidomain scales, yielding both domain-specific scores and a summary score; and 3) preference-based measures (PBMs). The scores for the former two are typically determined directly from categorical responses to items in the questionnaires, for example, the sum of scores from responses in each scale. Scales in Healthy Pathways [48,49] and KIDSCREEN-52 [50] have been developed using Rasch analysis.

This search identified six PBMs for children: 16 Dimensional, Assessment of Quality of Life Mark 2, 6D adolescents, Child Health Utility 9D, EuroQol five-dimensional questionnaire for youth, Health Utilities Index, and Comprehensive Health Status Classification System – Preschool [23,29,38,40,51,52]. PBMs are typically multi-item questionnaires using single items to assess different aspects of health, as with other PROMs. PBMs, however, use these descriptions of health status to assign a single index score between 1 and 0, where 1 equates to full health and 0 is equivalent to dead [53,54]. The scores used are based on a valuation of health states, using preference elicitation methods, by a reference population, commonly either a sample of patients or the general public.

Number of Items

The number of items in the questionnaires ranges from six (Dartmouth Primary Care Cooperative Information Project [COOP] and Brief Multidimensional Student Life Satisfaction Scale) to 138 (Child Health and Illness Profile- Adolescent Edition). Half of the questionnaires incorporate standard descriptive sociodemographic questions that do not contribute to the scoring [25,27,31,32,36,43,55–59]. This can be as little as sex, date of birth, and date of completion, whereas others ask about living conditions and family composition.

Response Options

Most questionnaires use a Likert-type response scale. Questionnaires using a visual analogue scale (VAS) include Childhood Health Assessment Questionnaire (pain and overall well-being use a VAS), Exeter Quality of Life Measure (each statement is rated on a VAS scale ranging from “Not like me” to “Exactly like me”), and EuroQol five-dimensional questionnaire for youth (in which general health is rated using a VAS). The Child Health and Illness Profile - Child Edition self-report version uses a set of circles of increasing sizes as response options. Facial expressions are used in the self-report Pediatric Quality of Life Inventory version for children aged 5 to 7 years, and in three self-report versions of Auto Questionnaire Enfant Imagé Child Pictured Self-Report and Personal Wellbeing Index School Children, and also to rate “how you feel” in the How Are You.

Five questionnaires incorporate illustrations: Child Health and Illness Profile - Child Edition (two illustrations, one at each end of the scale, representing the response extremes, and a “fun break” page is provided on which a child can make a drawing), COOP (each response option is illustrated with a drawing), Exeter Quality of Life Measure, and 17 Dimensional (each statement is accompanied by a picture).

Six questionnaires ask respondents to rate each item on three different scales, for example, how well you function regarding the aspect of health probed and how upset and how satisfied you are about that [27,41,46,60–62]. Two questionnaires use a fictional character to describe a health status; the responder is then invited to rate how much the presented health status matches his or her health status, and how much he or she would want to be like that [44,45].

Recall Period

Most questionnaires use a recall period ranging from today to the past 4 weeks. Four questionnaires go beyond that recall period of 4 weeks: Child Health Questionnaire and Infant Toddler Quality of Life Questionnaire include one global change item comparing your health status to 1 year ago, Nordic Quality of Life Questionnaire for children uses a 3-month recall period, and the Quality of Life Questionnaire for Children (QOLQC) uses a 12-month recall period. Five PROMs do not state the recall period [24,39,44,61,63], and five PROMs include items with no clearly specified recall period and ask for a global impression, for example, “usually” [29,64] or “in general” [26,30,37,65]. We have no information on the recall period of the Child’s Health Self-Concept Scale.

Completion Time

Completion time is linked with the number of items of the questionnaire. The complexity of the task and the response options (VAS scale vs. three-point Likert scale), however, also influence the completion time: for example, 20 minutes for the 12-item Exeter Quality of Life Measure. All six PBMs can be completed in less than 10 minutes according to the reference article or the PROM manual. Questionnaire versions of 20 PROMs can be completed in up to 15 minutes [24,26,28,32–34,36,37,39,42,43,45,47,56–58,63,65–70]; questionnaire versions of 14 PROMs require between 15 and 30 minutes for completion [27,30,31,41,44,49,55,59,61,71–76]. Two questionnaires [25,46] might take 30 to 45 minutes to fill in.

Mapping Content Using the ICF

The content of five PROMs is more or less equally devoted to “body structures and functions” and “activities and participation” [23,30,36,55,72]. All other questionnaires mostly focus on domains of “activities and participation,” and less on body

Table 1 – General characteristics of all versions of the identified PROMs for children up to 18 years old.

Acronym and name	Author (year)	Purpose	No. of items	Age range (y)	Responder	Response options	Completion time (min)	Recall period	Domains/dimensions
QUALIN (Infant's quality of life)	Manificat et al. (1999) [79]	To assess children's perceived satisfaction with different life domains	34 1–3	Up to 1 1–3	Proxy Proxy	Six-point response scale rating agreement	10	Not stated	No information
AUQUEI Ours (Auto Questionnaire Enfant Imagé / Child Pictured Self Report)	Manificat and Dazord (1998) [24]	To assess children's perceived satisfaction with several pediatric life domains	28	3–6	Self (by interview)	Four-level response continuum (happy–sad faces)	10–15	Not stated	Leisure, family environment, duties, and external world/ autonomy
AUQUEI Soleil (Auto Questionnaire Enfant Imagé / Child Pictured Self Report)	Gayral-Taminh et al. (2005) [88]	To assess children's perceived satisfaction with several pediatric life domains	33	6–10	Self	Four-level response continuum (happy–sad faces)	15	Not stated	Leisure, separation, duties, parents
OK.ado questionnaire (Adolescent quality of life questionnaire)	Manificat and Dazord (2002) [89]	To assess children's perceived satisfaction with several adolescent life domains	33	11–18	Self	Five-level response continuum (happy–sad faces)	10	Not stated	Leisure and relationships, school, family, self-esteem, and self-image
CHAQ (Child Health Assessment Questionnaire)	Singh et al. (1994) [66]	To measure functional status (functional ability in daily living activities)	30 30	8–18 0–18	Self Proxy	Four-level difficulty scale + VAS (pain and overall well-being)	<10	Past week	Dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities + (VAS) pain, overall well-being
CHIP-CE CRF (Child Health and Illness Profile - Child Edition Child-Report Form)	Riley et al. (2004) [55]	To broadly describe the health of children so that infrequent but important differences in health could be identified	45	6–11	Self	Five graduated circle responses (frequency) with cartoons at beginning/end	20	Past 4 wk	Satisfaction, comfort, resilience, risk avoidance, achievement
CHIP-CE PRF (Child Health and Illness Profile - Child Edition Parent-Report Form) [45]	Riley et al. (2004) [71]	To broadly describe the health of children so that infrequent but important differences in health could be identified	45	6–11	Proxy	Five-option frequency scale (never–always)	15	Past 4 wk	Satisfaction, comfort, resilience, risk avoidance, achievement
CHIP-CE PRF (Child Health and Illness Profile - Child Edition Parent-Report Form) [76]	Riley et al. (2004) [71]	To broadly describe the health of children so that infrequent but important differences in health could be identified	76	6–11	Proxy	Five-option frequency scale (never–always)	20	Past 4 wk	Satisfaction (health, self), comfort (physical & emotional, restricted activity), resilience (family involvement, physical activity, social problem-solving), risk avoidance, achievement (academic performance, peer relations)
CHIP-AE (Child Health and Illness Profile - Adolescent Edition)	Riley et al. (1998) [25]	To broadly describe the health of adolescents so that infrequent but important differences in health can be identified	138	11–17	Self	Mostly five-option frequency scale (no days to 15–28 days)	30–45	Past 4 wk	Satisfaction, discomfort, resilience, risks, achievement
CHQ-PF28 (Child Health Questionnaire Parent Short Form)	Kurtin et al. (1994) [26]	To measure the physical and psychosocial well-being of CYP	28	5–18	Proxy	Response options vary from four to six levels	5–10	Past 4 wk; global health items: in general; global change items: as compared with 1 y ago	General health, change in health, physical functioning, bodily pain, limitations in school work and activities with friends, behavior, mental health, self-esteem, time and emotional impact on the parent, limitations in family activities and family cohesion

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CHQ-PF50 (Child Health Questionnaire Parent Long Form)	Landgraf et al. (1998) [67]	To measure the physical and psychosocial well-being of CYP	50	5–18	Proxy	Response options vary from four to six levels	10–15	Past 4 wk; global health items: in general; global change items: as compared with 1 y ago	General health, change in health, physical functioning, bodily pain, limitations in school work and activities with friends, behavior, mental health, self-esteem, time and emotional impact on the parent, limitations in family activities and family cohesion
CHQ-87 (Child Health Questionnaire Self-Report [87 version])	Landgraf and Abetz (1997) [72]	To measure the physical and psychosocial well-being of CYP	87	10 and older	Self	Response options vary from four to six levels	16–25	Past 4 wk; global health items: in general; global change items: as compared with 1 y ago	General health, change in health, physical functioning, bodily pain, limitations in school work and activities with friends, behavior, mental health, self-esteem, time and emotional impact on the parent, limitations in family activities and family cohesion
CHRS (Children's Health Ratings Scale)	Maylath (1990) [65]	To assess a child's perception of general health	17	9–12	Self and proxy	Five-point response scale rating agreement	5	Today or "in general"	No information
CHSCS (Child's Health Self-Concept Scale)	Hester (1984) [41]	To measure a child's perceptions of his or her health and health-related behaviors	45	7–13	Self	Four-point Likert scale: more positive health perception to more negative health perception	20–30	No information	Activity exercise, personal grooming, physical, nutrition, behavior, emotional, dental health, sleep, friends, substance use, general health, and family
COOP/WONCA Charts (Dartmouth Primary Care Cooperative Information Project)	Nelson et al. (1987) [90]	To assess adolescents' health and social problems (using a single-item picture-and-words charts)	6	Adolescent	Self	Five-point Likert-type scale with descriptors and cartoons	4–5	During the past month	Physical fitness, emotional feelings, school work, social support, family communications, health habits
CQoL (Child Quality of Life Questionnaire)	Wasson et al. (1994) [42]	To measure the child's function, together with his or her own upset and satisfaction for each of the domains measured	15	9–15	Self and proxy	Seven-point Likert scale rating of function, upset, and satisfaction	10–15	Over the past month	Activities, appearance, communication, continence, depression, discomfort, eating, family, friends, mobility, school, sight, self-care, sleep, worry, overall
DHP-A (Duke Health Profile - Adolescent version)	Parkerson et al. (1990) [43]	To assess a child's health and emotional well-being	17	13–18	Self	Three-point response scale rating agreement	5	Today or past week	Physical health, mental health, social health, general health, perceived health, self-esteem
ExQoL (Exeter Quality of Life Measure)	Eiser et al. (2000) [44]	Computer-based assessment of quality of life as a result of perceived discrepancies between a child's actual and ideal self	12	6–12	Self	VAS scale: Not like me–Exactly like me	20	Not used	Symptoms (sleep, aches, food allergies, sickness), social well-being, school achievements, physical activity, worry, and family relationships
FSIIR (Functional Status II Revised, Long version, infants)	Stein and Jessop (1990) [28]	Describes children's functional status in the previous 2 wk	22	Up to 1	Proxy	Three-point Likert scales rating difficulty and to which extent this is due to illness	20	Last 2 wk	General health, responsiveness
FSIIR (Functional Status II Revised, Long version, toddlers)	Stein and Jessop (1990) [28]	See above	30	1–2	Proxy	See above	5–30	Last 2 wk	General health, responsiveness
FSIIR (Functional Status II Revised, Long version, preschoolers)	Stein and Jessop 1990 [28]	See above	40	2–4	Proxy	See above	15–30	Last 2 wk	General health, activity

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FSIIR (Functional Status II Revised, Long version, school-age children)	Stein and Jessop (1990) [28]	See above	40	4 and older	Proxy	See above	15–30	Last 2 wk	General health, interpersonal functioning
FSIIR-7 (Functional Status II Revised 7 item)	Stein and Jessop (1990) [28]	See above	7	0–16	Proxy	See above	10	Last 2 wk	General health
FSIIR-14 (Functional Status II Revised 14 item)	Stein and Jessop (1990) [28]	See above	14	0–16	Proxy	See above	10	Last 2 wk	General health
GCQ (Generic Children's Quality of Life Measure)	Collier (1997) [45]	To assess discrepancy between a child's perception of his or her actual and desired life	25	6–14	Self	Five-point Likert scale: 1) child most like you, 2) child you would like to be	15	Today	Perceived and preferred quality of life
HALFS (Health and Life Functioning Scale)	Bastiaens et al. (2004) [63]	To assess a child's functioning on different life domains	10	6–12	Proxy	Three-point response scale rating frequency of the statement	5	Not stated	Functioning in general health, academics, leisure, family relations, social life
HAY (How Are You)	Le Coq et al. (2000) [60]	To assess physical, psychological, and social functioning by referring to the gap between the child's expectations and the child's capabilities	32	8–12	Self and proxy	Four-point response scale rating frequency, quality of performance, and feelings (not in proxy version)	20	Previous 7 d	Physical functioning, cognitive functioning, social functioning, physical complaints
Healthy Pathways (SR) (Healthy Pathways Self-Report) Healthy Pathways (PR) (Healthy Pathways Parent-Report)	Bevans et al. (2010) [49] Bevans et al. (2012) [48]	To broadly describe the health of youth in transition from childhood to adolescence and identify differences in health	88 88	9–11 9–11	Self Proxy	Five-point Likert scale	20	Past 4 wk	Comfort, energy, resilience, risk avoidance, subjective well-being, achievement
ITQOL (Infant Toddler Quality of Life Questionnaire long version)	Klassen et al. (2003) [30]	To assess the core dimensions of health according to the World Health Organization for preschool children	97	Up to 5	Proxy	Response options vary from four to six levels	20	Most scales: past 4 wk; global change items: compared with 1 y ago	Physical functioning, growth & development, bodily pain, temperament & moods, general behavior, getting along, general health perceptions, parental impact (emotional, time), family activities, family cohesion, change in health
ITQOL SF47 (Infant Toddler Quality of Life Questionnaire [short version])	Landgraf et al. (2013) [69]	To assess the core dimensions of health according to the World Health Organization for preschool children	47	Up to 5	Proxy	Varying from four to six levels	10	Most scales: past 4 wk; global change items: compared with 1 y ago	Physical functioning, growth & development, bodily pain, temperament & moods, general behavior, getting along, general health perceptions, parental impact (emotional, time), family activities, family cohesion, change in health
KIDSCREEN-52	Ravens-Sieberer et al. (2005) [31]	To assess children's health and well-being; can be used as a screening, monitoring, and evaluation tool	52	8–18	Self and proxy	Five-point Likert scale assessing frequency or intensity	15–20	Last week	Physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), financial resources

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KIDSCREEN-27	Ravens-Sieberer et al. (2007) [57]	To assess children's health and well-being; can be used as a screening, monitoring, and evaluation tool	27	8–18	Self and proxy	Five-point Likert scale assessing frequency or intensity	10–15	Last week	Physical well-being, psychological well-being, autonomy & parents, peers & social support, and school environment
KIDSCREEN-10	Ravens-Sieberer et al. (2010) [56]	To assess children's health and well-being; can be used as a screening, monitoring, and evaluation tool	10	8–18	Self and proxy	Five-point Likert scale assessing frequency or intensity	5	Last week	Physical activity, depressive moods and emotions, social and leisure time, relationship with parents and peers, cognitive capacities, and school performance
KINDL Kiddy-KINDLR	Ravens-Sieberer and Bullinger (1998) [58]	To assess the physical, mental, and social well-being of children and adolescents using age-appropriate versions	12	4–7	Self by interview	Three-point Likert scale assessing frequency	15	Last week	Physical health, family functioning, self-esteem, social functioning, school functioning
KINDL Kid-KINDLR	Ravens-Sieberer and Bullinger (1998) [58]	To assess the physical, mental, and social well-being of children and adolescents using age-appropriate versions	24	8–12	Self and proxy	Five-point Likert-scale assessing frequency	5–10	Last week	Physical health, family functioning, self-esteem, social functioning, school functioning
KINDL Kiddo-KINDLR	Ravens-Sieberer and Bullinger (1998) [32]	To assess the physical, mental, and social well-being of children and adolescents using age-appropriate versions	24	13–16	Self and proxy	Five-point Likert-scale assessing frequency	5–10	Last week	Physical health, emotional well-being, family functioning, self-esteem, social functioning, school functioning
CAT-SCREEN (A computer-assisted version)		To assess the physical, mental, and social well-being of children and adolescents using age-appropriate versions	24 24	6–12 13–16	Self		10–20		Physical well-being, emotional well-being, self-esteem, family, friends, and everyday functioning (school)
Nordic QoLQ (Nordic Quality of Life Questionnaire for children)	Lindström and Köhler (1991, 1993) [91,92]	To assess health and welfare of children and young people	60	12–18 2–18	Self Proxy	Different for all questions	20	3 mo	Global sphere, external sphere, interpersonal and personal sphere
PedsQL Infant Scales	Varni et al. (2011) [78]	To assess the core dimensions of health according to the World Health Organization (WHO) as well as school functioning using age- appropriate versions	36 45	1–12 mo 13–24 mo	Proxy Proxy	Five-point Likert scale rating frequency	10–15	Past month	Physical functioning, physical symptoms, emotional functioning, social functioning, cognitive functioning
PedsQL (Pediatric Quality of Life Inventory Trade Mark 4.0 Generic Core Scales)	Varni et al. (1999) [33]	To assess the core dimensions of health according to WHO as well as school functioning using age-appropriate versions	21 23	2–4 5–7 8–12 13–18	Self Self and proxy	Five-point Likert scale rating frequency	10–15	Past month	Physical functioning, emotional functioning, social functioning, school functioning
PedsQL SF15 (Pediatric Quality of Life Inventory Trade Mark 4.0 Generic Core Scales Short Form 15)	Chan et al. (2005) [93]	To assess the core dimensions of health according to the WHO as well as school functioning using age-appropriate versions	15	2–4 5–7 8–12 13–18	Proxy Self	Five-point Likert scale rating frequency	5–6	Past month	Physical functioning, emotional functioning, social functioning, school functioning

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ComQOL-S5 (Comprehensive Quality of Life Scale - School version, Fifth edition)	Cummins (1997) [27]	To describe current health status and perceived importance and satisfaction with selected life domains	21	11–18	Self	Mostly five-point Likert scale rating frequency, importance, and satisfaction	15–20	Stated for each items	Material well-being, health, productivity, intimacy, safety, place in community, emotional well-being
PWI-PS (Personal Wellbeing Index Preschool)	Cummins and Lau (2005) [61]	To assess degree of satisfaction with seven life domains	7	Up to 5	Proxy	11-point happiness scale	10–20	Not stated (today)	Standard of living, health, life achievement, personal relationships, personal safety, community-connectedness, future security
PWI-SC (Personal Wellbeing Index School Children)	Cummins and Lau (2005) [62]	To assess degree of satisfaction with seven life domains	7	5–18	Self	10-point scale ranging from very sad to very happy	10–20	Not stated (today)	Standard of living, health, life achievement, personal relationships, personal safety, community-connectedness, future security
QOLQA/TQOLQA (Quality of Life Questionnaire for Adolescents [Chinese, Japanese, and Taiwanese versions]	Wang et al. (2000) [35]	To assess HRQOL in adolescents for cross-cultural comparison in Asian countries	70	Adolescents*	Self	Five-point Likert scale rating intensity or frequency	No indication	Not stated	Physical, psychological, independence, social relationship, environment)
TQOLQA, Short version (Quality of Life Questionnaire for Adolescents [Taiwanese version])	Fuh et al. (2005) [94]	To assess HRQOL in adolescents for cross-cultural comparison in Asian countries	38	Adolescents†	Self	Five-point Likert scale rating frequency	No indication	Not stated	Family, residential environment, personal competence, social relationships, physical appearance, psychological well-being, pain)
QOLQC (Quality of Life Questionnaire for Children)	Bouman et al. (1999) [70]	To assess three broad domains of functioning in children: physical, psychological, and social functioning	118	8–12	Self or proxy	Three-point response scale rating frequency	15	Last 12 mo	Physical complaints & limitations & handicaps, general well-being, cognitive functioning, self-concept, anxious-depressed feelings, relation with parents & peers, school functioning, social conflicts, leisure activities
QoLP-AV (Quality of Life Profile: Adolescent Version)	Raphael et al. (1996) [46]	To assess quality of life in three broad domains of adolescent functioning: being, belonging, and becoming	54	14–20	Self	Five-point Likert scale rating importance, satisfaction, control, and opportunities	40	Not stated (today)	Being: physical, psychological, spiritual; Belonging: physical, social, community; Becoming: practical, leisure, growth
SLSS (Student Life Satisfaction Scale)	Huebner (1991) [34]	To assess satisfaction with life as a whole	7	7–14	Self	Six-point Likert scale rating agreement	<5	Past several weeks	Family, friends, school, living environment, self
MSLSS (Multidimensional Student Life Satisfaction Scale)	Huebner (1994) [95]	To assess satisfaction with life as a whole and specific life domains	40	8–18	Self	Six-point Likert scale rating agreement	10	Past several weeks	Family, friends, school, living environment, self
Brief MSLSS (Brief Multidimensional Student Life Satisfaction Scale)	Seligson et al. (2003) [96]	To assess satisfaction with life as a whole and specific life domains	6	8–18	Self	Seven-point Likert scale rating satisfaction	<5	Past several weeks	Family, friends, school, living environment, self
MSLSS-A (Multidimensional Student Life Satisfaction Scale Adolescent version)	Gilligan and Huebner (2007) [97]	To assess satisfaction with life as a whole and specific life domains	53	8–18	Self	Six-point Likert scale rating agreement	15	Past several weeks	Family, same-sex friends, school, opposite-sex friends, living environment, and self
TAPQOL TNO-AZL (Questionnaire for Preschool Children's	Fekkes et al. (2000) [36]	To assess CYP's health status, weighted by the emotional	32 43	Up to 18 mo 18 mo to 6 y	Proxy Proxy	Three-point scale rating frequency of occurrence and	10	Recent weeks	Stomach problems, skin problems, lung problems, sleeping problems, appetite,

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Health-Related Quality of Life)		response of the children themselves to their health status problems				four-point scale rating the child's state			problem behavior, anxiety, liveliness, social functioning, motor functioning, communication
TACQOL (TNO-AZL Questionnaire for Children's Health-Related Quality of Life)	Vogels et al. (1998) [75]	To assess CYP's health status, weighted by the emotional response of the children themselves to their health status problems	63 63	8–15 6–15	Self Proxy	Three-point scale rating frequency of occurrence and four-point scale rating the child's state	10–20	Recent weeks	Body functioning, motor functioning, cognition, peer interaction, positive and negative emotions
TAAQOL (TNO-AZL Questionnaire for Adult Health-Related Quality of Life)	Bruil et al. (2001) [74]	To assess a person's health status, weighted by the emotional response of the person to his or her health status problems	45	16 and older	Self	Three-point scale rating frequency of occurrence and four-point scale rating the impact	10-20	Last month	Gross and fine motor functioning, pain, sleeping, cognitive and social functioning, daily activities, sexual activity, vitality, happiness, depressive moods, aggressiveness
VSP-A (Vécu et Santé Perçue de l'Adolescent)	Simeoni et al. (2000) [47]	To discriminate between adolescents with different health conditions and predicting their health status	36	11–17	Self	Five-point scale indicating frequency or intensity	<15	Last 4 wk	Psychological well-being, energy/vitality, friends, parents, leisure, school
WCHMP (Warwick Child Health and Morbidity Profile)	Spencer and Coe (1996) [39]	To assess parent-reported health and morbidity in infancy and childhood	10	Up to 5	Proxy	Four response options and free text	10	Not stated	General health status, acute minor illness, behavioral, accident, acute significant illness, hospital admission, immunization, chronic illness, functional health, HRQOL
YQoL-S (Youth Quality of Life instrument-Surveillance version)	Edwards et al. (2002) [37]	To assess adolescents' perceived quality of life in a broad sense	13	11–18	Self	Five-point Likert scales with anchors for each point; 11-point rating scales with anchors each side of the scale	5–10	In general or , during the past month	Relation parents, future aspirations, loneliness, confidence, joy/happiness, satisfaction, lust for life, overall quality of life
YQoL-R (Youth Quality of Life instrument - Research version)	Patrick et al. (2002) [76]	To assess adolescents' perceived quality of life in a broad sense	56	11–18	Self	Five-point Likert scale with anchors for each point; 11-point rating scales with anchors each side of the scale	15–20	In general or during the past month	Sense of self, social relationships, culture and community, and general quality of life
Preference-based measures									
16D (16 Dimensional)	Apajasalo et al. (1996) [23]	A function and symptoms profile, used to create a preference-based score of HRQOL for economic evaluations	16	12–15	Self	Five ordinal levels on each dimension, by which more or less of the attribute is distinguished	5–10	Today	Mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, school and hobbies, mental function, discomfort and symptoms, depression, distress, vitality, appearance, friends
17D (17 Dimensional)	Apajasalo et al. (1996) [77]	A function and symptoms profile, used to create a preference-based score of HRQOL for economic evaluations	17	8–11	Self	Five ordinal levels on each dimension, by which more or less of the attribute is distinguished	5–10	Today	Mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, school and hobbies, learning and memory, discomfort and symptoms, depression, distress, vitality, appearance, friends, concentration

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Table 1 – *continued*

AQoL-6D (Assessment of Quality of Life Mark 2, 6D adolescents)	Moodie et al. (2010) [40]	A function and symptoms profile, used to create a preference-based score of HRQOL for economic evaluations	20	15 and older	Self	Six ordinal levels, by which more or less of the attribute is distinguished	5–10	Past week	Physical ability, social and family relationships, mental health, coping, pain, vision, hearing and communication
CHU-9D (Child Health Utility 9D)	Stevens (2009) [51]	A symptoms and function profile, used to create a preference-based score of HRQOL	9	7–11‡	Self and proxy	Five ordinal levels, by which more or less of the attribute is distinguished	3–5	Today/last night	Worried, sad, pain, tired, annoyed, schoolwork, sleep, daily routine, activities
EQ-5D-Y (EuroQol five-dimensional questionnaire for youth)	Wille et al. (2010) [52]	A function and symptoms profile, used to create a preference-based score of HRQOL	5- and 100-point VAS	7–12	Self and proxy	Three ordinal levels (no, some, severe problems), and a VAS for overall health	A few minutes	Today	Mobility, self-care, usual activities, pain or discomfort, feeling worried/sad/unhappy. General health
HUI2 (Health Utilities Index 2)	Torrance et al. (1996) [29]	A function and symptoms profile, used to create a preference-based score of HRQOL	7 7	12 and older 5 and older	Self Proxy	Three to five ordinal levels, by which more or less of the attribute is distinguished	8–10	Different versions: usually, past 4 wk, past 2 wk, past week	Sensation, mobility, emotion, cognitive, self-care, pain, fertility
HUI3 (Health Utilities Index 3)	Feeny et al. (2002) [64]	A function and symptoms profile, used to create a preference-based score of HRQOL	8 8	12 and older 5 and older	Self Proxy	Five to six ordinal levels, by which more or less of the attribute is distinguished	8–10	Different versions: usually, past 4 wk, past 2 wk, past week	Vision, hearing, speech, ambulation/mobility, pain, dexterity, emotion, cognition
CHSCS-PS (Comprehensive Health Status Classification System - Preschool)	Saigal et al. (2005) [38]	A function and symptoms profile for infants	12	2–5	Proxy	Three to five ordinal levels of functioning	<10	Past week	Vision, hearing, speech, mobility, dexterity, self-care, emotion, learning and remembering, thinking and problem solving, pain, behavior and general health

CYP, children and young people; HRQOL, health-related quality of life; Min, minutes; VAS, Visual Analogue Scale; WHO, World Health Organization; Wk, week; Y, year.

* QOLQA: Tested in 12- to 15-y-olds.

† TQOLQA (short version): Tested in 13- to 15-y-olds.

‡ CHU-9D: Used in 7- to 17-y-olds, tested in 5- to 7-y-olds.

structures and functions (Table 2). The ICF-CY chapters covered most commonly are mental functions, interpersonal interactions and relationships, major life areas, and community, social, and civic life. PROMs covering more ICF-CY chapters (10 or more areas) are the longer questionnaires [23,25,30,36,40,69,71,7274, 75,77,78]. Questionnaires specifically developed for younger children (5 years and younger) tend to include more items capturing body functions than do other questionnaires [30,36,69,78].

The ICF-CY framework provides an indication which aspects of health are being assessed by each PROM. The topic of a question, how it is phrased, and the response options, however, provided all potentially contribute to the specific response of the person answering the questionnaire and therefore determine the content the PROM assesses. Questions asking a person what he or she does, or can do, mainly assess functioning. Other questions ask a person how he or she feels about a certain aspect of health, thereby focusing on well-being. Mostly, a combination of these different ways of asking questions and assessing health is used (Table 2, last two rows). Those questionnaires that target young children tend to assess functioning rather than well-being [30,36,69,78,79]. Seven PROMs only assess how well a child or young person performs, not how he or she feels about it [28,30, 41,43,59,63,66].

Discussion

We identified 35 generic multidimensional PROMs for children and young people, encompassing a broad variety of design, formatting, and age coverage. Most questionnaires use Likert-type scale response options; six questionnaires use circles of increasing size, or illustrative facial expressions as alternatives to descriptive text and tick boxes. Five questionnaires incorporate cartoons or pictures to illustrate the questions. These approaches are mostly incorporated in questionnaires specifically designed for age groups younger than 7 or 12 years. Five instruments have at least one item rated on a VAS. The completion time typically varies with the number of items; however, some questionnaires with few items are cognitively demanding and thus require more time. The process of assessing the content of the PROMs using the ICF-CY highlighted that not only content but also the way questions are phrased, and the response options used, can lead to a response being about different aspects of health, which adds further complexity. There is variation in the coverage of the ICF-CY domains, but we did see that social functioning, described as interpersonal interactions and relationships, major life areas, and community, social, and civic life according to the ICF-CY, was assessed by nearly all PROMs.

Comparing our results with those of previous reviews is difficult because each review applied different inclusion and exclusion criteria [9,10,21]. We compared the questionnaires identified here with those of previous reviews, and those missing in our list were not deemed eligible for our review. Distinct from other systematic reviews on health-related quality-of-life measurements for children [10,80,81], the most recent in 2008, our review described the content using the ICF-CY. The use of a common framework to describe content has proven to be advantageous [82]. We reviewed the content of the items and constructs assessed by the questionnaires using methods similar to those used by other authors [83,84]. We used an independent checking method for quality assuring the mapping process as a proportionate use of resources. A more stringent approach is for coding to be conducted by two reviewers independently, and their results compared; we accept that this is a potential limitation of our methodology. The mapping process identified significant shortcomings of PROMs and the mapping process. First, mapping the items on the ICF revealed another distinction between instruments, sometimes noticeable only when also taking into account the response options. Some PROMs assess a child's functioning (as in what the child can do), whereas others assess a child's well-being (as in how a child feels about his or her situation/status). All the PROMs appear to conflate these concepts. Therefore, two questionnaires covering the same aspects of health might generate quite different scores. Describing the content of PROMs using the ICF is likely to lead to a loss of information, without reference to the context and precise focus of the question. Second, when carrying out the assessment, many items could not be mapped readily on the ICF and some items could not be allocated to any of the ICF chapters [85].

The ISPOR Good Research Practices Task Force for Developing Pediatric Patient-Reported Outcomes has examined carefully the presentational, cognitive requirements and practical administration requirements to ensure questionnaires are age and developmentally appropriate. The ISPOR guidance sets out five good practices relevant for PROMs for children and young people: 1) attention to developmental differences and age-based criteria for PROM administration; 2) establishing content validity using concept elicitation to inform item generation, and cognitive interviews to assess and refine all aspects of the draft instrument; 3) consideration of whether proxy-report is necessary; 4) ensuring that the instrument is designed and formatted appropriately for the target age group; and 5) considering cross-cultural issues [6,8]. Although a range of PROMs is available, few provide age-specific versions for the complete childhood spectrum up to 18 years; many of these, including all the PBMs, were originally developed for a fairly limited age range. Rather than develop further new instruments, efforts could be made to create and test versions so as to cover the strata of childhood age spectrum in ways that are acceptable to children and young people [8,82]. It should be determined that the measurement across versions is reliable and valid, so that trajectories of health status can be determined and followed up over several years.

A potential limitation is that our electronic searches were only since 1992, having assumed that it was unlikely that eligible PROMs would have been developed before this date, and any eligible ones would have been cited since. Our search preceded the search for studies examining measurement properties in the second of this pair of articles [86], hence will be a couple of years old by the time of publication. Key purposes of reporting dates in systematic review articles are for transparency and to inform those who might want to update reviews in the future, and we remain aware at the time of writing of any other PROMs that would be eligible.

Using the ICF-CY for mapping the constructs assessed is very helpful to guide the selection of an appropriate instrument; nevertheless, there should be attention to whether functioning or well-being is being measured. Further development of PROMs should include establishing content validity, particularly for those instruments that conflate functioning and well-being in the same scales, to ensure that children and young people understand the items and believe that the instrument adequately represents the concept of health. In addition, when assessing the content, it appeared that there is little difference between self-reported and parent-reported versions. Empirical evidence, however, suggests higher child-parent agreement for observable physical domains than for nonobservable emotional domains [87]. Five questionnaires that target young children up to 5 years do indeed focus more on assessing aspects of health within the ICF-CY body structure and function domains and use a functioning rather than well-being approach [30,36,69,78,79]. Last, we believe that further efforts are required to ensure that the instruments are designed appropriately for children and young people to complete expediently. Twelve of 51 self-reported versions consist of 50 or more items, 22 of 51 self-reported

Table 2 – Content description of questionnaires using ICF-CY.

Aspect of health	QUALIN	AUQUEI Ours	AUQUEI Soleil	OK. Ado	CHAQ	CHIP-CE CRF	CHIP-CE PRF [45]	CHIP-CE PRF [76]	CHIP-AE	CHQ-PF28	CHQ-PF50	CHQ-87
ICF-CY: Body functions												
Mental	x	x	x	x		x	x	x	x	x	x	x
Sensory and pain	x				x	x	x	x	x	x	x	x
Voice and speech	x								x			x
Cardiovasc, haem, immuno, & resp						x	x	x	x	x	x	
Digestive, metabolic, & endocrine									x			
Genitourinary and reproductive				x					x			
Neuromusculoskeletal and movement							x	x	x	x	x	x
Skin and related						x	x	x	x			
ICF-CY: Activities and participation												
Learning and applying knowledge			x	x	x	x	x	x	x			
General tasks and demands		x	x			x		x	x			x
Communication	x						x	x	x			x
Mobility		x	x		x		x	x	x	x	x	x
Self-care	x	x	x	x	x	x			x			x
Domestic life					x							
Interp interactions and relationships	x	x	x	x		x	x	x	x	x	x	x
Major life areas	x	x	x	x		x	x	x	x	x	x	x
Community, social, and civic life	x	x	x	x		x	x	x	x		x	x
Other (not defined by the ICF-CY)												
General health - Not defined		x	x	x	x	x	x	x		x	x	x
Mental health - Not defined										x	x	
Physical health - Not defined						x	x	x		x	x	x
Environment					x							
Accidents/injuries									x			
Achievements in life				x								
Being able to do what you want to do				x								
Challenging/risk-taking behavior	x					x	x	x	x	x	x	x
Food	x	x	x	x					x			
Functional status												
Functioning of family						x				x	x	x
Future aspirations		x	x	x								
Having fun (enjoyment)	x									x	x	x
Health condition/treatment	x	x	x	x	x	x		x	x	x	x	
Health habits									x			
Making decisions												
Quality of life												
Satisfaction with life										x		
Measuring functioning or well-being												
Functioning	x				x	x	x	x	x	x	x	x
Well-being		x	x	x		x	x		x	x	x	x

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	ITQOL (Short)	ITQOL (Long)	CHRS	CHSCS	COOP	CQoL	DHP-A	ExQoL	FSIIR (Infants)	FSIIR (Toddlers)	FSIIR (Preschool)	FSIIR (School age)	FSIIR-7	FSIIR-14	GCQ	HALFS
ICF-CY: Body functions																
Mental	x	x	x	x		x	x	x	x	x	x	x		x	x	x
Sensory and pain	x	x				x	x	x	x							x
Voice and speech	x	x							x		x	x				
Cardiovasc, haem, immuno, & resp				x	x			x								
Digestive, metabolic, & endocrine	x	x		x				x	x	x	x	x		x		
Genitourinary and reproductive						x										
Neuromusculoskeletal and movement	x	x								x	x	x				
Skin and related																
ICF-CY: Activities and participation																
Learning and applying knowledge	x	x														
General tasks and demands		x														
Communication		x				x			x	x	x	x	x	x		
Mobility	x	x			x	x	x		x	x						
Self-care	x	x		x		x			x	x	x	x	x	x	x	x
Domestic life																
Interp interactions and relationships	x	x		x	x	x	x	x							x	x
Major life areas					x	x		x							x	x
Community, social, and civic life	x	x				x	x	x		x	x	x			x	x
Other (not defined by the ICF-CY)																
General health - Not defined	x	x	x	x		x										
Mental health - Not defined	x	x			x											
Physical health - Not defined	x	x	x		x			x							x	
Environment				x												
Accidents/injuries																
Achievements in life																
Being able to do what you want to do															x	
Challenging/risk-taking behavior	x	x							x	x	x	x		x		
Food				x												
Functional status																
Functioning of family	x	x				x									x	
Future aspirations																
Having fun (enjoyment)				x					x	x	x	x	x	x	x	
Health condition/ treatment*			x				x		x	x	x	x	x	x		
Health habits					x		x									
Making decisions															x	
Quality of life																
Satisfaction with life															x	

continued on next page

Table 2 – *continued*

Measuring functioning or well-being																
Functioning	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Well-being			x		x	x		x							x	

	HAY	Healthy Pathways	KIDSCREEN-52	KIDSCREEN-27	KIDSCREEN-10	KINDL-Kiddy	KINDL-Kid	KINDL-Kiddo	Nordic QoLQ	PedsQL	PedsQL Infant	PedsQL SF15
ICF-CY: Body functions												
Mental		x	x	x	x	x	x	x	x	x	x	
Sensory and pain		x				x	x	x		x	x	
Voice and speech											x	
Cardiovasc, haem, immuno, & resp		x	x	x	x						x	
Digestive, metabolic, & endocrine											x	
Genitourinary and reproductive												
Neuromusculoskeletal and movement	x	x	x							x	x	x
Skin and related											x	
ICF-CY: Activities and participation												
Learning and applying knowledge		x		x					x		x	
General tasks and demands						x	x	x				
Communication												
Mobility	x	x	x	x						x	x	x
Self-care			x							x		
Domestic life										x		
Interp interactions and relationships		x	x	x	x	x	x	x	x	x	x	x
Major life areas	x	x	x	x	x	x	x	x	x	x	x	x
Community, social, and civic life	x								x	x		x
Other (not defined by the ICF-CY)												
General health - Not defined		x	x	x	x							
Mental health - Not defined												
Physical health - Not defined						x	x	x				
Environment		x	x	x								
Accidents/injuries									x			
Achievements in life		x										
Being able to do what you want to do			x	x	x		x	x		x		
Challenging/risk-taking behavior											x	
Food												
Functional status												
Functioning of family			x				x	x	x			
Future aspirations												x
Having fun (enjoyment)		x	x	x	x	x	x	x				
Health condition/treatment*	x				x	x	x	x	x	x		
Health habits												
Making decisions			x									
Quality of life												
Satisfaction with life		x	x									

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Measuring functioning or well-being													
Functioning	x	x	x	x	x	x	x	x	x	x	x	x	x
Well-being	x	x	x	x	x	x	x	x	x		x		x

	ComQOL-S5	PWI-PS	PWI-SC	(T) QOLQA	QOLQC	QOLP-AV	SLSS	MSLSS	Brief MSLSS	MSLSS-A	TAPQOL	TACQOL	TAAQOL
ICF-CY: Body functions													
Mental	x			x	x	x		x		x	x	x	x
Sensory and pain				x	x						x	x	x
Voice and speech											x		
Cardiovasc, haem, immuno, & resp						x					x	x	
Digestive, metabolic, & endocrine											x	x	
Genitourinary and reproductive						x							x
Neuromusculoskeletal and movement					x						x	x	x
Skin and related											x		
ICF-CY: Activities and participation													
Learning and applying knowledge				x	x	x					x	x	x
General tasks and demands				x									x
Communication											x	x	
Mobility					x						x	x	x
Self-care					x	x					x	x	
Domestic life													
Interp interactions and relationships	x	x	x	x	x	x		x	x	x	x	x	x
Major life areas	x			x	x	x		x	x	x		x	x
Community, social, and civic life	x	x	x		x	x		x		x		x	x
Other (not defined by the ICF-CY)													
General health - Not defined	x	x	x										
Mental health - Not defined						x					x		
Physical health - Not defined					x	x							
Environment	x	x	x			x		x	x	x			
Accidents/injuries													
Achievements in life	x	x	x	x									
Being able to do what you want to do	x						x						
Challenging/risk-taking behavior					x						x		
Food						x							
Functional status													
Functioning of family					x			x	x	x		x	
Future aspirations		x	x	x		x							
Having fun (enjoyment)				x	x						x	x	x
Health condition/treatment	x				x						x	x	
Health habits				x		x							
Making decisions						x							
Quality of life				x									
Satisfaction with life		x	x	x	x	x	x		x				
Measuring functioning or well-being													
Functioning	x			x	x						x	x	x
Well-being	x	x	x	x	x	x	x	x	x	x		x	x

	VSP-A	WCHMP	YQoL-S	YQoL-R	16D	17D	AQoL-6D	CHU-9D	EQ-5D-Y	HUI2	HUI3	CHSCS-PS
ICF-CY: Body functions												
Mental	x		x	x	x	x	x	x	x	x	x	x
Sensory and pain					x	x	x	x	x	x	x	x
Voice and speech					x	x	x			x	x	x
Cardiovasc, haem, immuno, & resp	x				x	x						
Digestive, metabolic, & endocrine					x	x						
Genitourinary and reproductive				x	x	x				x		

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Table 2 – *continued*

Neuromusculoskeletal and movement											x	x	x
Skin and related					x	x							
ICF-CY: Activities and participation													
Learning and applying knowledge				x		x					x	x	x
General tasks and demands				x			x	x					
Communication	x				x		x					x	
Mobility					x	x	x		x		x	x	x
Self-care					x	x	x	x	x		x		x
Domestic life													
Interp interactions and relationships	x		x	x	x	x	x						
Major life areas	x			x	x	x	x	x					
Community, social, and civic life	x			x	x	x	x	x					
Other (not defined by the ICF-CY)													
General health - Not defined		x			x	x			x				
Mental health - Not defined	x				x		x						
Physical health - Not defined													
Environment				x									
Accidents/injuries		x											
Achievements in life													
Being able to do what you want to do				x									
Challenging/risk-taking behavior		x											
Food													
Functional status		x											
Functioning of family	x			x									
Future aspirations	x		x	x									
Having fun (enjoyment)	x		x	x		x							
Health condition/treatment*		x			x	x							
Health habits													
Making decisions				x									
Quality of life		x											
Satisfaction with life	x		x	x									
Measuring functioning or well-being													
Functioning	x	x	X*	x	x	x	x	x	x	x	x	x	
Well-being	X*	X*	x	x	X*	x	x	x	X*	X*	X*		

AQoL-6D, Assessment of Quality of Life Mark 2, 6D adolescents; AUQUEI Ours, Auto Questionnaire Enfant Imagé Child Pictured Self-Report; AUQUEI Soleil, Auto Questionnaire Enfant Image Child Pictured Self Report; Brief MSLSS, Brief Multidimensional Student Life Satisfaction Scale; Cardiovasc, cardiovascular; CHAQ, Child Health Assessment Questionnaire; CHIP-AE, Child Health and Illness Profile - Adolescent Edition; CHIP-CE CRF, Child Health and Illness Profile - Child Edition Child Report Form; CHIP-CE PRF, Child Health and Illness Profile - Child Edition Parent Report Form; CHQ-87, Child Health Questionnaire Self-Report (87 version); CHQ-PF28, Child Health Questionnaire Parent Short Form; CHQ-PF50, Child Health Questionnaire Parent Long Form; CHRS, Children's Health Ratings Scale; CHSCS, Child's Health Self-Concept Scale; CHSCS-PS, Comprehensive Health Status Classification System - Preschool; ComQOL-S5, Comprehensive Quality of Life Scale-School version, Fifth edition; COOP, Dartmouth Primary Care Cooperative Information Project; CqoL, Child Quality of Life Questionnaire; CHU-9D, Child Health Utility 9D; DHP-A, Duke Health Profile - Adolescent version; ExQoL, Exeter Quality of Life Measure; EQ-5D-Y, EuroQol five-dimensional questionnaire for youth; FSIIR (Infants), Functional Status II Revised, Long version, infants; FSIIR (Toddlers), Functional Status II Revised, Long version, toddlers; FSIIR (Preschool), Functional Status II Revised, Long version, preschoolers; FSIIR (School age), Functional Status II Revised, Long version, school-age children; FSIIR-7, Functional Status II Revised 7 item; FSIIR-14, Functional Status II Revised 14 item; GCQ, Generic Children's Quality of Life Measure; HALFS, Health and Life Functioning Scale; HAY, How Are You; HUI2, Health Utilities Index Mark 2; HUI3, Health Utilities Index Mark 3; ICF-CY, International Classification of Functioning, Disability and Health Children and Youth version; Interp, interpersonal; ITQOL (Long), Infant Toddler Quality of Life Questionnaire (long version); ITQOL (Short), Infant Toddler Quality of Life Questionnaire (short version); MSLSS, Multidimensional Student Life Satisfaction Scale; MSLSS-A, Multidimensional Student Life Satisfaction Scale Adolescent version; Nordic QoLQ, Nordic Quality of Life Questionnaire for children; OK.Ado, Adolescent quality of life questionnaire; PedsQL, Pediatric Quality of Life Inventory; PedsQL Infant, Pediatric Quality of Life Inventory Infant scales; PedsQL SF15, Pediatric Quality of Life Inventory Short-Form 15; PWI-PS, Personal Wellbeing Index Preschool; PWI-SC, Personal Wellbeing Index School Children; QOLP-AV, Quality of Life Profile: Adolescent Version; QOLQC, Quality of Life Questionnaire for Children; QUALIN, Infant's quality of life; resp, response; 17D, 17 Dimensional; 16D, 16 Dimensional; SLSS, Student Life Satisfaction Scale; (T)QOLQA, Quality of Life Questionnaire for Adolescents (Taiwanese version); TAAQOL, TNO-AZL Questionnaire for Adult Health-Related Quality of Life; TACQOL, TNO-AZL Questionnaire for Children's Health-Related Quality of Life; TAPQOL, TNO-AZL Questionnaire for Preschool Children's Health-Related Quality of Life; VSP-A, Vécu et Santé Perçue de l'Adolescent; WCHMP, Warwick Child Health and Morbidity Profile; YQoL-R, Youth quality of Life instrument-research version; YQoL-S, Youth quality of Life instrument-surveillance version.

* Well-being is assessed as an item assessing emotional functioning, not for other topics.

questionnaires require 15 minutes or more to complete, 31 of 51 have a recall period of at least 4 weeks or do not state the recall period clearly, and only 5 questionnaires include cartoons or pictures to illustrate the questions.

As well as considering the constructs assessed, general characteristics, and practical factors, those selecting PROMs need to consider evidence of the psychometric properties of the instruments in the specific population and language they are considering administering the questionnaires. We have carried out such an appraisal for English-language versions of generic multidimensional PROMs in non–condition-specific groups in a related second article [86].

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Supplemental Materials

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