



Systematic Review of Conceptual, Age, Measurement and Valuation Considerations for Generic Multidimensional Childhood Patient-Reported Outcome Measures

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Abstract

Background and Aims Patient-reported outcome measures (PROMs) for children (aged ≤ 18 years) present methodological challenges. PROMs can be categorised by their diverse underlying conceptual bases, including functional, disability and health (FDH) status; quality of life (QoL); and health-related quality of life (HRQoL). Some PROMs are designed to be accompanied by preference weights. PROMs should account for childhood developmental differences by incorporating age-appropriate health/QoL domains, guidance on respondent type(s) and design. This systematic review aims to identify generic multidimensional childhood PROMs and synthesise their characteristics by conceptual basis, target age, measurement considerations, and the preference-based value sets that accompany them.

Methods The study protocol was registered in the Prospective Register of Systematic Reviews (CRD42021230833), and reporting followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. We conducted systematic database searches for generic multidimensional childhood PROMs covering the period 2012–2020, which we combined with published PROMs identified by an earlier systematic review that covered the period 1992–2011. A second systematic database search identified preference-based value sets for generic multidimensional PROMs. The PROMs were categorised by conceptual basis (FDH status, QoL and HRQoL) and by target age (namely infants and pre-schoolers aged < 5 years, pre-adolescents aged 5–11, adolescents aged 12–18 and multi-age group coverage). Descriptive statistics assessed how PROM characteristics (domain coverage, respondent type and design) varied by conceptual basis and age categories. Involvement of children in PROM development and testing was assessed to understand content validity. Characteristics of value sets available for the childhood generic multidimensional PROMs were identified and compared.

Results We identified 89 PROMs, including 110 versions: 52 FDH, 29 QoL, 12 HRQoL, nine QoL-FDH and eight HRQoL-FDH measures; 20 targeted infants and pre-schoolers, 29 pre-adolescents, 24 adolescents and 37 for multiple age groups. Domain coverage demonstrated development trajectories from observable FDH aspects in infancy through to personal independence and relationships during adolescence. PROMs targeting younger children relied more on informant report, were shorter and had fewer ordinal scale points. One-third of PROMs were developed following qualitative research or surveys with children or parents for concept elicitation. There were 21 preference-based value sets developed by 19 studies of ten generic multidimensional childhood PROMs: seven were based on adolescents' stated preferences, seven were from adults from the perspective of or on behalf of the child, and seven were from adults adopting an adult's perspective. Diverse preference elicitation methods were used to elicit values. Practices with respect to anchoring values on the utility scale also varied considerably. The range and distribution of values reflect these differences, resulting in value sets with notably different properties.

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Conclusion Identification and categorisation of generic multidimensional childhood PROMs and value sets by this review can aid the development, selection and interpretation of appropriate measures for clinical and population research and cost-effectiveness-based decision-making.

Key Points for Decision Makers

Our systematic review identified 110 versions of generic multidimensional patient-reported outcome measures (PROMs) for children (aged ≤ 18 years) spanning childhood age groups and conceptual bases of functional, disability and health status, quality of life and health-related quality of life.

A supplementary systematic review identified 21 preference-based value sets for ten PROMs designed to be accompanied by preference-based value sets.

Our catalogues of (1) PROMs categorised by target age group, conceptual bases and related characteristics (domain coverage, respondent type and design) and (2) value sets appraised for their development and statistical features can aid the development, selection and interpretation of appropriate childhood PROMs for clinical and population research and cost-effectiveness-based decision-making.

1 Background

Patient-reported outcome measures (PROMs) enable direct assessment of health status, health-related quality of life (HRQoL) or quality of life (QoL) by patients or individuals [1–3]. They are used extensively as outcome instruments and can support patient-centred care [2, 4]. The use of PROMs in childhood populations (aged ≤ 18 years) presents methodological challenges compared to application in adults. One challenge is to account for age-based biopsychosocial developmental differences between children and adults and across children of different ages [5–7]. Distinguishing the age or age group of the target childhood population is important for content validity or concept coverage of the childhood PROM, its capacity for child self-report, appropriate design, and the culturally appropriate age for child self-report [2].

There are many ways that PROMs can be categorised. They can be divided into generic measures and disease or condition-specific measures, and further into domain-specific measures and multidimensional measures [4, 8].

Generic measures have the advantage of allowing comparisons across conditions and interventions. Multidimensional measures can be both generic and condition-specific and capture the multifaceted nature of concepts including health, QoL or HRQoL. PROMs can thus be further categorised by the concept(s) they seek to measure through their descriptive systems. There are multiple definitions of these concepts in the literature, with terms often used interchangeably [3, 9]. In this paper, we draw on the categories arising from a synthesis of definitions of functioning, disability, health, HRQoL and QoL used by the World Health Organization (WHO). In this taxonomy, a QoL/HRQoL measure can be distinguished from a functional, disability and health (FDH) measure by its reflection of the individual respondent's *perception*, or subjective judgement of importance, of their assessed status [3]. Specifically, an FDH measure captures the 'interactions among body structures and function, and activities and participation in the context of the environment and personal factors', whilst QoL is 'a person's *perception* of [his/her] position in life', where perception involves a subjective judgement over how the position relates to his/her goals, expectations, standards, enjoyment or concerns and not just a self-report of the position. HRQoL represents the individual's '*perception* of his/her *health and health-related* states' where 'health' represents a narrower domain than 'position in life' (p. 1086) [3].

PROMs can be accompanied by preference-based value sets which produce an overall index when applied to the multidimensional states generated by the descriptive systems [8]. PROMs accompanied by preference-based value sets are often referred to as multi-attribute utility instruments in the literature [10]. The value sets accompanying these measures use stated preference methods including standard gamble (SG) and time trade-off (TTO) to trade-off between a health state and mortality risk or life expectancy, respectively [11]. A key aspect of these methods is their ability to yield values that are anchored on a scale with 0 = dead and 1 = full health, as required for the use of values for estimating quality-adjusted life years (QALYs) in cost-utility analysis. Negative values are theoretically possible and represent health states considered worse than being dead. Discrete choice experiments (DCE) can also be used to elicit stated preferences for value sets for PROMs, although the resulting values lie on a latent scale unless accompanied by additional methods to allow anchoring at dead = 0 [12].

Decision makers around the world have shown a preference for country-specific value sets reflecting underlying differences in preferences of different populations [13–15].

There are considerable methodological challenges that arise in valuing childhood PROMs. Among them, there is contention around whose preferences are relevant, with some instruments offering both adult- and child-elicited value sets [16]. Eliciting values from children themselves may help to ensure that health services are relevant to their needs [17, 18], particularly when adults' and children's preferences differ [19]. However, there are practical and ethical issues surrounding the age at which children can be asked to participate in stated preference studies, especially where these include tasks that involve trade-offs with life expectancy. Both SG and TTO may impose high cognitive and/or emotional burden on children relative to DCE or best–worst scaling (BWS) tasks [17]. Where values are used to inform the allocation of healthcare resources financed primarily from taxation, a common normative position is that these should be based on the preferences of the adult general public [12, 20]. However, valuing childhood PROMs using adults' preferences also raises issues. For example, it is unclear whether the respondent should be asked to think about themselves as a child, their child or another child [20].

Several systematic reviews of generic multidimensional childhood PROMs have been published since 2000 [3, 4, 21–26]. The most recent, by Janssens et al., identified 63 unique versions of PROMs (including eight accompanied by value sets) published between 1992 and 2011 [4]. Their review tabulated the characteristics of PROMs, including target age range, respondent type, domain coverage and several design features (e.g. number of items, response options and recall period) [4]. That review also mapped the domains of the PROMs onto the WHO's International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY) framework [27], but noted the shortcoming of conflating the domains of FDH and QoL/HRQoL measures that have a different conceptual basis. It did not distinguish between types of informant response as recommended by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guideline, i.e. *proxy* if the informant infers the child's perception of health/QoL states and *observer* if the informant focuses on observable traits without inferring perception [2]. Moreover, little attention was paid to differences in characteristics of measures across age groups, or the value set features. Fayed and colleagues distinguished between FDH and QoL/HRQoL measures; however, their search period was limited to 2004–2008 [3]. Cremeens et al. [21] and Grange et al. [24] limited their reviews to 3- to 8-year-olds and < 5 year olds, respectively, which hinders comparisons of PROM characteristics across all childhood age groups. Finally, Chen and Ratcliffe previously reported on the features of nine childhood PROMs

accompanied by value sets, but this was not a systematic review [10]. These gaps in previous studies inform the aim and objectives of this systematic review.

2 Aim and Objectives

This systematic review aims to generate a comprehensive catalogue of generic multidimensional childhood PROMs that rely on child self- and/or informant-report (hereafter childhood PROMs for brevity in accordance with the ISPOR guideline [2]) and the value sets that accompany them. In doing so, we aim to inform the development, selection and interpretation of childhood PROMs for clinical and population research and cost-effectiveness-based decision-making. Accordingly, the objectives are to:

1. Systematically identify generic multidimensional childhood PROMs and preference-based value sets that accompany them.
2. Categorise the PROMs according to conceptual basis and target age group and evaluate their methodological features according to the ISPOR good research practice recommendations on the use of childhood PROMs [2].
3. Catalogue the value sets that exist for childhood PROMs, compare the methods that have been used to produce them and report the characteristics of the resulting value sets.

3 Methods

A pre-specified protocol outlining the systematic review methods was developed and registered with the Prospective Register of Systematic Reviews (CRD42021230833). For reporting purposes, the review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [28]. See the Supplementary Information for the PRISMA checklist for this paper (see the electronic supplementary material).

3.1 Data Sources and Study Selection

Two independent systematic database searches were conducted. The first aimed to identify primary development studies for generic multidimensional childhood PROMs published between 1 January 2012 and 16 October 2020. Studies identified in the search were pooled with those published between 1 January 1992 and 20 March 2012 identified in the earlier systematic review by Janssens et al. [4]. A second search was conducted without date limits on 18 February 2021 to identify preference-based value sets for generic multidimensional childhood PROMs. This was constructed

around measures identified by the first search that reported the development of a value set or the objective to develop a value set or to inform economic evaluations. Developers of PROMs were also contacted to confirm whether, to the best of their knowledge, there was no missing published value set.

Both systematic searches covered seven academic databases (Medline, Embase, PsycInfo via Ovid, EconLit via Proquest, CINAHL via EBSCOHost, Scopus and Web of Science) and one grey literature database (PROQOLID). The Medline search strategy for the first and second searches are presented in Tables A and B in the Supplementary Information (see the electronic supplementary material). Searches were limited to English language texts. In both searches, references were imported into Endnote X9 and duplicates were removed. References were then exported into Covidence [29], where two researchers independently reviewed the titles and abstracts of identified articles. If an article received two approvals, it proceeded to the next stage, with disagreements referred to a third reviewer for the final assessment. Full text articles were independently reviewed by two reviewers with disagreements again referred to the third reviewer for final assessments.

The inclusion criteria for the systematic search of PROMs were as follows: studies reporting the development of a generic multidimensional childhood (aged ≤ 18 years) PROM and studies published in the English language. Conference abstracts with sufficient information (i.e. containing at least the acronym/name of the instrument(s), the aim/motivation of development, whether a general childhood population was targeted, and the multidimensionality of the instrument) were included alongside full text articles. Studies in adults only and animals were excluded, as were commentaries, single case reports and secondary application of PROMs. References of included studies were searched, including those published before 1 January 2012. The inclusion criteria for the systematic search to identify value sets were as follows: studies reporting the development of a value set for one or more generic multidimensional childhood PROM; the value set was anchored on a 0–1 scale required for the use of the values in QALY estimation; and studies (including full text articles and a user's manual [no conference abstracts were identified]) published in the English language. Studies that only reported values for a sub-set of the health states described by a childhood PROM were excluded.

3.2 Data Extraction

For the first review that identified generic multidimensional childhood PROMs, data for each measure were extracted independently by two reviewers per article from a pool of eight reviewers, with disagreements resolved through

discussion. For the second review that identified preference-based value sets, data for each value set were extracted by one reviewer, with a 20% check performed by a second reviewer. For the identified generic multidimensional childhood PROMs, the following characteristics were extracted according to proformas in Excel: acronym/name of the instrument, name of author(s)/developer(s), development year and country(ies), aim/motivation of development, target age range, background concept (e.g. definition of health/QoL adopted before commencing PROM development), development methods (e.g. focus groups with children for item selection), role of children in development, level of child's perception captured, respondent type (e.g. child, proxy, observer), administration mode (e.g. by self, by interviewer), recall period, domains covered, number of items, response options and method for score generation (other than value set application).

For the identified value sets of the generic multidimensional childhood PROMs, the following characteristics were extracted: acronym/name of the instrument, name of author(s)/developer(s), valuation year and country(ies), methods for selecting valued health states, number of valued health states, sampling methods for valuation including target population, recruitment strategies, response rates, sample size, representativeness of sample and reasons for exclusion, and stated preference data collection methods. The latter included elicitation technique(s) (e.g. SG, TTO, DCE), the approach taken to anchoring at 0–1, characteristics of respondents, perspective and administration mode, and modelling methods. Finally, the properties of the value sets were examined (e.g. value range, proportion of health states with negative values). As some of these properties were not reported in the papers, we coded the value set algorithms based on the published results and calculated the index scores for all potential health states according to the classification system of the instruments.

3.3 Data Synthesis

Using a method similar to that of Fayed et al. [3], the generic multidimensional childhood PROMs identified were categorised by conceptual basis. The wording and response options for measure items were reviewed independently by two reviewers per article from a pool of eight reviewers. Measures with 75% or more of items that captured a child's perception (i.e. relation to enjoyment, satisfaction, goals, expectations, standards or concerns) on health or broader position in life were labelled HRQoL or QoL measures, respectively. Measures with 25% or fewer items capturing a child's perception were labelled FDH measures. Those with between 25 and 75% of items capturing a child's perception were labelled hybrid HRQoL-FDH or QoL-FDH measures. Fayed and colleagues similarly described the hybrid nature

of many measures: e.g. the General Health Questionnaire was classified as ‘FDH and QoL/HRQoL’, the HUI as ‘FDH (with one HRQoL/QoL attribute)’ and the KIDSCREEN as ‘HRQoL/QoL (with some functioning features)’. Instead of these mixed descriptions, this study specifies cut-off levels to allow for comparison across a wide range of measures.

Distinguishing between QoL and HRQoL was particularly challenging given the overlap between health and position in life. Indeed, Fayed et al. do not make this distinction in their results, grouping QoL and HRQoL under the same category [3]. A two-step pragmatic approach was taken: (1) refer to the stated aim/motivation of the study prior to measure development or use (e.g. some studies gave the definition of QoL or HRQoL and underlying constructs [30, 31]), and if still unclear, then (2) categorise as HRQoL measures if more than 50% of the domains cover body functioning, disabilities and daily activities (e.g. mobility, pain, vision, anxiety, depressive symptoms, chronic illness, dressing and grooming) that would constitute the concept of FDH as defined by Fayed et al. [3].

When step (1) in this pragmatic approach could not be applied (i.e. the study used conceptual labels without clearly defining them), we did not automatically apply the conceptual labels given to PROMs by the developer(s). Fayed et al. documented the discrepancies between the conceptual bases as labelled by developers and secondary applications of PROMs and those as classified by their review. For example, Fayed et al. noted that the HUI and the PedsQL were labelled as HRQoL/QoL measures in the primary and secondary literature but are more accurately labelled FDH measures [3]. In the current review, conceptual bases were similarly assigned according to extracted data rather than existing labels (unless clearly defined), but we did not document the discrepancies as was done by Fayed et al.

For measures that use informant responses, the informant type was classified according to the ISPOR guideline [2], namely proxy for QoL/HRQoL measures (since informants infer the child’s subjective perception) and observer for FDH measures (since no such inference is made). For hybrid QoL/HRQoL-FDH measures, the informant type was labelled hybrid proxy-observer.

Following the ISPOR good research practices guideline [2], we explored differences in measurement characteristics for PROMs targeted at different age groups. The ISPOR guideline’s age cut-offs were used to categorise the measures by their target age group: less than 5 years, covering infants, toddlers or pre-schoolers; 5–7 years for younger pre-adolescents; 8–11 years for older pre-adolescents; and 12–18 years for adolescents. We then explored how the characteristics of the measures (including range of domains covered, respondent and informant type, and other design features) varied by conceptual basis and target age. In cases where target ages were not clearly specified, inferences were made

from the study aim and development methods to assign the target age category.

The level of content validity of each PROM was assessed according to whether children of the target age were involved in (1) the development of the measure, including qualitative research for domain and item elicitation, and (2) assessment of comprehension using cognitive interviews and/or pilot/feasibility studies. Note that appraisals of other psychometric properties such as construct validity and internal consistency are not reported here but in forthcoming work. Cultural issues present in the initial instrument development (as opposed to subsequent translations and secondary cross-cultural adaptations of the developed instrument) were similarly described.

For the review of value sets for generic multidimensional childhood PROMs, data were analysed using narrative synthesis. Summary tables were used to describe the bibliography/setting, sampling methods, preference data collection methods and statistical features of the identified value sets. Separate summaries of the modelling methods are presented for two categories of preference elicitation techniques: TTO, SG and rating scales (RS); DCEs and BWS.

4 Results

4.1 Search Results

Figure 1 shows the PRISMA flow diagram for the first search that identified primary studies developing generic multidimensional childhood PROMs published between 1 January 2012 and 16 October 2020.

Thirty-four eligible studies were identified that described 26 PROMs. Sixty-three PROMs included in the review by Janssens et al. [4] that met the inclusion criteria were included to give 89 PROMs in total. Fourteen PROMs were accompanied or designed to be accompanied by preference-based value sets. Figure 2 shows the PRISMA flow diagram for the identification of value sets for these 14 PROMs. Nineteen studies were identified in total that described 21 value sets.

4.2 Overview of Generic Multidimensional Childhood Patient-Reported Outcome Measures (PROMs)

Table 1 provides an overview of the characteristics of the identified generic multidimensional childhood PROMs that are not accompanied by or designed to be accompanied by preference-based value sets, while Table 2 does so for PROMs designed to be accompanied by preference-based value sets. Some measures have several versions, and Table 1 includes all distinct versions, providing a total of 110 unique measures (for example, the PedsQL 4.0 Generic Core Scales

are composed of age-specific modules for toddlers, young children, children and teens [32]). Of the 110 measures, 52 are FDH measures, 29 are QoL measures, 12 are HRQoL measures, nine are hybrid QoL-FDH measures, and eight are hybrid HRQoL-FDH measures. Seventeen measures (reflecting two versions each for HUI2 and HUI3 and two variants of the EQ-5D-Y) are designed to be accompanied by preference-based value sets. The measures were primarily developed in high-income countries (using the 2021 World Bank classifications [33]), with only seven (6%) developed in lower- or middle-income country (LMIC) settings as part of an international development process [34–40].

4.3 Characteristics of Measure by Age Category

Age groups 5–7 and 8–11 were combined for the subsequent descriptions of measure characteristics because relatively few measures targeted these age groups. This generated three rather than four age categories for the subsequent descriptions. Overall, there were 20 measures that targeted children less than 5 years, 29 that targeted children aged 5–11 years and 24 that targeted adolescents aged 12–18 years. Thirty-seven measures covered multiple age groups. Table C in the Supplementary Information (see the electronic supplementary material) organises the included measures by the above four target age group categories.

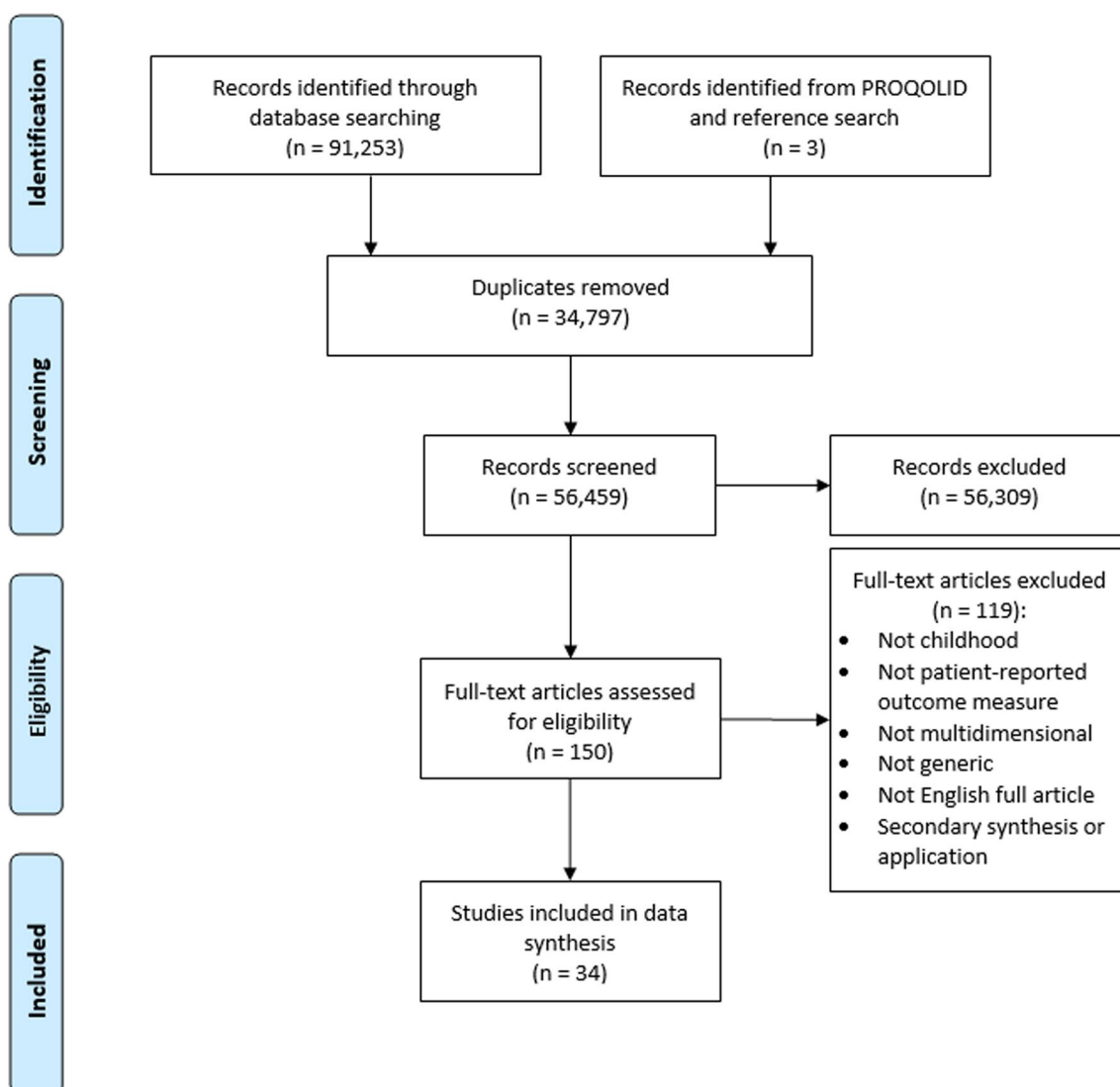


Fig. 1 The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for database searches for studies developing generic multidimensional childhood patient-reported outcome measures published between 1 January 2012 and 16 October 2020

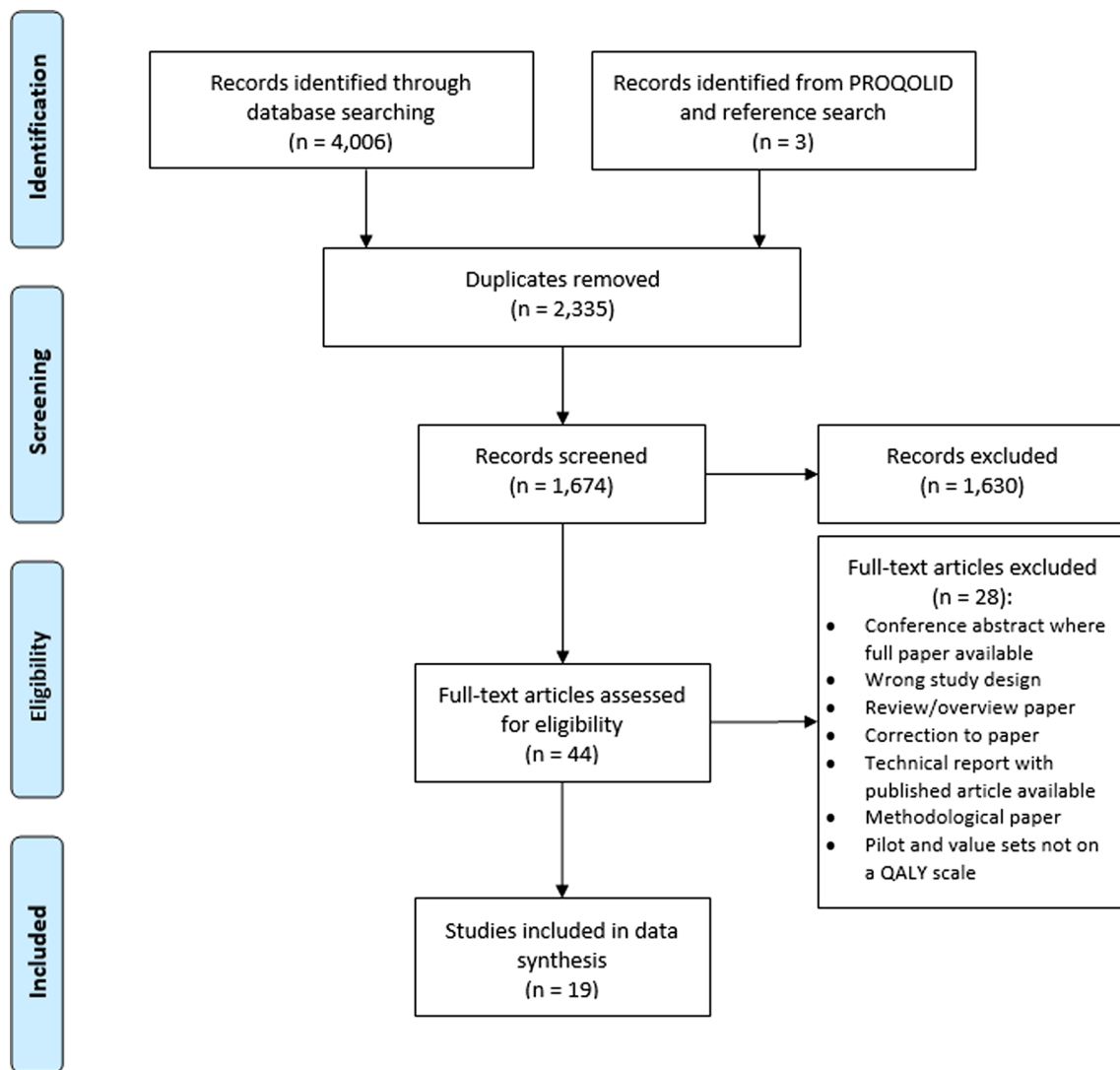


Fig. 2 The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for database searches for valuation studies for generic multidimensional childhood PROMs

identified by search strategies. *PROM* patient-reported outcome measure, *QALY* quality-adjusted life year

4.3.1 Conceptual Basis

Figure 3 shows the number of identified PROMs by age category according to their conceptual basis. The proportion of measures designed to elicit the child's perception of their status (i.e. QoL, HRQoL and QoL/HRQoL-FDH measures) varied between four out of 20 (20%) for the infants, toddlers or pre-schoolers category and 18 out of 24 (75%) for adolescents. Twenty of 37 (54%) measures with multi-age group coverage were designed to elicit the child's perception of their status.

4.3.2 Domain Coverage

Table 3 lists in alphabetical order the domains covered by generic multidimensional childhood PROMs stratified by age category and conceptual basis. Moreover, domains that are unique to each age category are presented in bold and underlined.

Thirty-one domains were unique to infants, toddlers or pre-schoolers, of which 25 were unique to FDH measures and six to HRQoL measures. There were ten unique domains for pre-adolescents, 25 for adolescents and 16 for the multi-age coverage category. The unique domains were concentrated in FDH measures (19 of 25; 76%) for infants, toddlers or pre-schoolers, and in QoL measures (16 of 25; 64%) for adolescents.

Table 1 Summary of characteristics of included generic multidimensional childhood patient-reported outcome measures not designed to be accompanied by preference-based value sets^a

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
1	ACHWM: Aboriginal Children's Health and Well-Being Measure	Young [48]; Canada	8–18	Yes (QoL)	Child	By staff; computer tablet	General	Spiritual; emotional; physical; mental (<i>n</i> = 4)	65	Frequency, degree of importance, yes/no (60 items); open-ended (5) [item average]
2	QUALIN: Infant's Quality of Life	Manificat [88, 106]; France	0–3	No (FDH)	Observer	By self	General	Psychomotor development; family environment; psychological; sociability (<i>n</i> = 4)	33	5-point scale [item average]
3	AUQUEI Nursery: Child Pictured Self Report Nursery version	Manificat [88, 107]; France	3–6	Yes (QoL)	Child, aided by parents	By self	General	Family life; Social life; activities at school and leisure; health (<i>n</i> = 4)	28	4-level pictorial happy-sad faces (26 items); open-ended (2) [item average]
4	AUQUEI Primary: AUQUEI for primary school child	Manificat (2002) ^c [88]; France	6–11	Yes (QoL)	Child, aided by parents	By self	General	Family life; social life; activities at school and leisure; health (<i>n</i> = 4)	33	4-level pictorial happy-sad faces for satisfaction (31 items); open-ended (2) [item average]
5	OKado: Adolescent quality of life	Manificat (2002b) [61]; France	11–18	Yes (QoL)	Child	By self	General	Leisure and relationships; school; family; self-esteem (<i>n</i> = 4)	34	5-point scale [item average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
6	CHAQ: Child Health Assessment Questionnaire	Singh [62]; US	8–19	No (FDH)	Child; Observer	By self	Past week	Dressing and grooming; arising; eating; walking; hygiene; reach; grip; activities. Also: aids/devices for functioning; activities needing assistance; VAS pain; VAS wellbeing (<i>n</i> = 8 + Aids/VAS)	34	4-point scale for functioning (30 items); VAS (2); list of aids used (1); list of activities needing assistance (1) [highest item score in domain as domain score; domain average]
7	CHAQ Informant only	Singh [62]	1–7	No (FDH)	Observer	By self	Past week	See CHAQ	34	See CHAQ
8	CHAQ38: CHAQ revised version, 38 items	Lam [108]; Canada	5–19	No (FDH)	Child; observer	By self	Past week	Same domains as CHAQ plus 8 additional items on age-appropriate physical activities and challenges	38	4- or 5-point scale [item average]
9	CHAQ38 Information only	Lam [108]	< 5	No (FDH)	Observer	By self	Past week	See CHAQ38	38	See CHAQ38
10	CHIP-AE: Child Health and Illness Profile—Adolescent Edition	Starfield [7, 109]; US	11–17	No (FDH)	Child	By self	Past 4 weeks	Satisfaction; comfort; resilience; risk avoidance; achievement; disorders (<i>n</i> = 6)	107; 46 disease-specific items	5-point scale [item average per subdomain; subdomain average]
11	CHIP-CE CRF: Child Health and Illness Profile—Child Edition Child-Report Form	Riley [110]; US	6–11	No (FDH)	Child	By self	Past 4 weeks	Satisfaction; comfort; resilience; risk avoidance; achievement (<i>n</i> = 5)	45	5 graduated circle responses with cartoons at beginning/end [item average per subdomain; subdomain average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
12	CHIP-CE PRF: CHIP-CE Parent-Report Form (long version)	Riley (2004b) [111]; US	6–11	No (FDH)	Observer	By self	Past 4 weeks	Satisfaction; comfort; resilience; risk avoidance; achievement (<i>n</i> = 5)	76	5-point scale [item average per subdomain; subdomain aver- age]
13	CHIP-CE PRF (short ver- sion)	Riley (2004b) [111]; US	6–11	No (FDH)	Observer	By self	Past 4 weeks	Satisfaction; comfort; resilience; risk avoidance; achievement (<i>n</i> = 5)	45	5-point scale [item average per subdomain; subdomain aver- age]
14	CHQ-PF50: Child Health Questionnaire Parent Form (long version)	Landgraf [112]; US	5–18	Some (HRQoL- FDH)	Proxy observer	By self; mail	Past 4 weeks; general for global health and family cohesion; com- pared to last year for change in health	Physical functioning; bodily pain; role function- ing, physical; role, emo- tional; role, behavioural; general health perception; self-esteem; mental health; general behav- iour; change in health; parental time impact; family activi- ties; family cohesion (<i>n</i> = 13)	50	4- to 6-point scale [item sum per domain]

Table 1 (continued)

#	Acronym: name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
15	CHQ-PF28: CHQ-PF (short version)	Raat [113]; US	5–18	Some (HRQoL-FDH)	Proxy-observer	By self	Past 4 weeks; general for global health and family cohesion; compared to last year for change in health	Physical functioning; bodily pain; role functioning; physical; role, emotional or behavioural; general health perception; self-esteem; mental health; general behaviour; change in health; parental emotional impact; parental time impact; family activities; family cohesion (<i>n</i> = 13)	28	4- to 6-point scale [item sum per domain]
16	CHQ-CF87: CHQ Child Form (long version)	Landgraf [114]; US	10–18	Some (HRQoL-FDH)	Child	By self	Past 4 weeks; general for global health and family cohesion; compared to last year for change in health	Physical functioning; bodily pain; role functioning, physical; role, emotional; role, behavioural; general health perceptions; self-esteem; mental health; general behaviour; change in health; family activities; family cohesion (<i>n</i> = 12)	87	4- to 6-point scale [item sum per domain]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
17	CHQ-CF45: CHQ-CF (short version)	Landgraf [52]; US, The Netherlands	10–18	Some (HRQoL-FDH)	Child	By self; paper or online	Past 4 weeks; general for global health and family cohesion; compared to last year for change in health	Physical functioning; Bodily pain; role functioning; physical; role, emotional or behavioural; general health perceptions; self-esteem; mental health; getting along; global behaviour; change in health; family activities; family cohesion (<i>n</i> = 12)	45	4- to 6-point scale [item sum per domain]
18	CHRS: Children's Health Ratings Scale	Maylath [115]; US	9–12	Yes (HRQoL)	Child, aided by staff; proxy	By self	Current; general	No domain structure but includes a range of questions on general health perceptions	17	5-point scale [item sum]
19	CHSCS: Child's Health Self-Concept Scale	Hester [116]; US	5–13	Yes (HRQoL)	Child	By self, aided by staff before start	General	Psychosocial; physical health; healthiness; values; energy (<i>n</i> = 5)	34	4-point scale: binary choice for positive or negative perception on health issue; 2-point scale on strength of perception [not stated]
20	ComQOL-S5: Comprehensive Quality of Life Scale—School version, 5th edition	Gullone [54]; Australia	11–18	Some (QoL ^d)	Child	By self	Past three months; general	Material wellbeing; health; productivity; intimacy; safety; place in community; emotional wellbeing (<i>n</i> = 7)	21	5-point scale for frequency, importance and satisfaction [item sum weighted by importance score]

Table 1 (continued)

#	Acronym: name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
21	COOP Charts: Dartmouth Primary Care Cooperative Information Project Charts	Wasson [95]; US	12–21	Yes (HRQoL)	Child	By self	Past month	Physical fitness; emotional feelings; school work; social support; family communications; health habits (<i>n</i> = 6)	6	5-point scale with descriptors and cartoons (picture-and-word chart) [item average]
22	CQoL: Child Quality of Life	Graham [117]; UK	9–15	Yes (QoL)	Child; proxy	By self	Past month	Activities; appearance; communication; continence; depression; discomfort; eating; family; friends; sight; mobility; school; self-care; sleep; worry; global QoL (<i>n</i> = 15)	45	7-point scale [item average per subdomain; subdomain average]
23	DHP-A: Duke Health Profile—Adolescent version	Vo [118]; France	12–19	Yes (HRQoL)	Child	By self	Past week	Physical health; mental health; social health; general health; perceived health; self-esteem; anxiety; depression; pain; disability (<i>n</i> = 10)	17	3-point scale [item sum per domain]
24	ExQoL: Exeter Quality of Life	Eiser [41]; UK	6–12	Yes (QoL)	Child	By self, supervised; computer	General	Symptoms; social wellbeing; School achievements; physical activity; worry; family relationships (<i>n</i> = 6)	12	12 pictures, each rated twice using VAS—(1) 'like me'; (2) 'I would like to be' [item average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
25	FSIIR Infants: Functional Status II Revised, long version, Infants	Stein [119]; US	0–1	No (FDH)	Observer	By interviewer	Past 2 weeks	General health; total functional status; responsiveness (<i>n</i> = 3)	20	3-point scales for function difficulty and extent due to illness [item sum as proportion of maximum] See <i>FSIIR Infants</i>
26	FSIIR Toddlers	Stein [119]; US	1–2	No (FDH)	Observer	By interviewer	Past 2 weeks	General health; total functional status; responsiveness (<i>n</i> = 3)	28	See <i>FSIIR Infants</i>
27	FSIIR Pre-schoolers	Stein [119]; US	2–3	No (FDH)	Observer	By interviewer	Past 2 weeks	General health; total functional status; activity (<i>n</i> = 3)	38	See <i>FSIIR Infants</i>
28	FSIIR School children	Stein [119]; US	4–16	No (FDH)	Observer	By interviewer	Past 2 weeks	General health; total functional status; Interpersonal functioning (<i>n</i> = 3)	39	See <i>FSIIR Infants</i>
29	FSIIR-14: FSIIR 14 items (short version)	Stein [119]; US	0–16	No (FDH)	Observer	By interviewer	Past 2 weeks	No domain structure but includes a range of questions on general health	14	See <i>FSIIR Infants</i>
30	GCO: Generic Children's Quality of Life	Collier [120]; UK	6–14	Yes (QoL)	Child; proxy	By self	General	General affect; peer relationships; attainments; relationships with parents; general satisfaction (<i>n</i> = 5)	25	5-point scales for: perceived self and preferred self; based on story child characters [item sum]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
31	HAY: How Are You	Le Coq [121]; The Netherlands	8–12	Yes (HRQoL)	Child	By self	Past week	Generic domains: physical; cognitive; social; physical complaints. asthma-specific domains (<i>n</i> = 5)	32	4-point scale rating frequency, quality of performance and related feelings [item sum per subdomain as proportion of maximum]
32	HDQ Age 6: Health Dialogue Questionnaire for Age 6	Holmström 2012 [122]; Sweden	6	Some (HRQoL-FDH)	Proxy-observer	By school nurse	Not stated	Physical; mental; social (<i>n</i> = 3)	15	5-point scale [positive response as proportion of total questions]
33	HDQ Age 10	Holmström (2012b) [123]; Sweden	10	Some (HRQoL-FDH)	Child, aided by parent	By school nurse	Not stated	Physical; mental; social (<i>n</i> = 3)	15	See <i>HDQ Age 6</i>
34	HDQ Age 13	Olofsson [124]; Sweden	13	Some (HRQoL-FDH)	Child, aided by parent	By school nurse	Not stated	Physical; mental; social (<i>n</i> = 3)	15	See <i>HDQ Age 6</i>
35	HDQ Age 16	Kristiansen [125]; Sweden	16	Some (HRQoL-FDH)	Child, aided by parent	By school nurse	Not stated	Physical; mental; social (<i>n</i> = 3)	22	See <i>HDQ Age 6</i>
36	Healthy Pathways CRS: Healthy Pathways Child-Report Scales	Bevans [42]; US	10–12	Yes (HRQoL)	Child	Schools with computer access: by self; computer. No access: by self for 6th graders; by interviewer for 4th/5th; paper	Past 4 weeks	Comfort; energy; resilience; risk avoidance; subjective wellbeing; achievement (<i>n</i> = 6)	88	5-point scale [item average per subdomain]
37	Healthy Pathways PRS: Healthy Pathways Parent-Report Scales	Bevans [92]; US	10–12	Yes (HRQoL)	Proxy	By self	Past 4 weeks	Comfort; energy; resilience; risk avoidance; wellbeing; achievement (<i>n</i> = 6)	59	5-point scale [item average per subdomain]

Table 1 (continued)

#	Acronym: name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
38	ILC : Inventory of Life quality in Children and adolescents	Jozefiak (2016) ^a [126]; Germany	10–16	Yes (QoL)	Child	By self	Past week	Global QoL; school performance; family functioning; social integration; interests and hobbies; physical health; mental health (<i>n</i> = 7)	7	5-point scale [item average]
39	ITQOL : Infant Toddler Quality of Life (long version)	Klassen [127]; Canada	2 months–5 years	No (FDH)	Observer	By self; mail	Past 4 weeks; general for global health; compared to last year for change in health	Physical; growth and development; bodily pain; temperament/moods; general behaviour; getting along; general health perceptions; change in health; parental impact—emotional; time; mental; family cohesion; general health (<i>n</i> = 13)	103	5-point scale except 4-point scale for parental time impact [item average per domain]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
40	ITQOL SF47: ITQOL Short Form	Landgraf [128]; The Netherlands	2 months–5 years	No (FDH)	Observer	By self	Past 4 weeks; general for global health; compared to last year for change in health	Physical; growth and development; bodily pain; temperament/moods; general behaviour; getting along; general health perceptions; change in health; parental impact—emotion; time; mental; family cohesion; general health (<i>n</i> = 13)	47	5-point scale except for 4-point scale for parental time impact [item average per domain]
41	Kiddy-KINDL CQ: Kiddy-KINDL Children's Questionnaire	Ravens-Sieberer (1998) ^f [89]; Germany	4–6	Some (QoL-FDH)	Child	By interviewer	Past week	Physical health; emotion; self-esteem; family; friends; school (<i>n</i> = 6)	12	3-point scale [item average]
42	Kiddy-KINDL PQ: Kiddy-KINDL Parents' Questionnaire	Ravens-Sieberer [89]; Germany	3–6	Some (QoL-FDH)	Proxy-observer	By self	Past week	Physical health; emotion; self-esteem; family; friends; school; child behaviour (<i>n</i> = 7)	46	5-point scale [item average]
43	Kid-KINDL CQ: Kid-KINDL Children's Questionnaire	Ravens-Sieberer [89]; Germany	7–13	Some (QoL-FDH)	Child	By self	Past week	Physical health; emotion; self-esteem; family; friends; school (<i>n</i> = 6)	24	5-point scale [item average]
44	Kiddo-KINDL AQ: Kiddo-KINDL Adolescents' Questionnaire	Ravens-Sieberer [89]; Germany	14–17	Some (QoL-FDH)	Child	By self	Past week	Physical health; emotion; self-esteem; family; friends; school (<i>n</i> = 6)	24	5-point scale [item average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
45	Kid- & Kiddo-KINDL PQ: Kid- & Kiddo-KINDL Parents' Questionnaire	Ravens-Sieberer [89]; Germany	7–17	Some (QoL-FDH)	Proxy-observer	By self	Past week	Physical health; emotion; self-esteem; family; friends; school (<i>n</i> = 6)	24	5-point scale [item average]
46	KINDL CAT-SCREEN: KINDL Computer Assisted Touch version	Ravens-Sieberer [43]; Germany	6–17	Some (QoL-FDH)	Child	By self; computer assisted (visual and audio)	Past week	Physical health; emotion; self-esteem; family; friends; school (<i>n</i> = 6)	24	5-point scale [item average]
47	KID-SCREEN-52	Ravens-Sieberer (2003); [56, 57]; 13 European countries ^g	8–18	Yes (QoL)	Child; proxy	By self	Past week	Physical wellbeing; psychological wellbeing; moods and emotions; self-perception; autonomy; parent relations and home life; social support and peers; school environment; social acceptance; financial resources (<i>n</i> = 10)	52	5-point scale [Rasch score]
48	KID-SCREEN-27	Ravens-Sieberer [58]; 13 European countries ^g	8–18	Yes (QoL)	Child; proxy	By self	Past week	Physical wellbeing; psychological wellbeing; parent relations and autonomy; social support and peers; school environment (<i>n</i> = 5)	27	5-point scale [Rasch score]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
49	KID-SCREEN-10	Ravens-Sieberer [59]; 13 European countries ^g	8–18	Yes (QoL)	Child; proxy	By self	Past week	Physical activity; depressive moods and emotions; social and leisure time; relationship with parents; relationship with peers; cognitive and school performance (<i>n</i> = 6)	10	5-point scale [Rasch score]
50	Kids-CAT: KIDSCREEN Computerized Adaptive Test	Devine (2015); Barthel [46, 129]; Germany	7–17	Yes (QoL)	Child	By self; computerized adaptive test	Past week	Physical wellbeing; psychological wellbeing; parent relationships; social support and peers; school wellbeing; chronic-generic QoL (<i>n</i> = 6)	42 ^h	5-point scale [Rasch score]
51	MCWBS: Multidimensional Child Well-Being Scale	Jiang [34]; China	10–15	No (FDH)	Child	By self, aided by staff before start	General	Physical; psychological; social; educational (<i>n</i> = 4)	30	5-point scale [not stated]
52	Nordic QoLQ: Nordic Quality of Life Questionnaire for children	Lindström [130]; 5 Nordic countries ⁱ	12–18	Some (QoL ^d)	Child and parent; proxy-observer	By self; mail	Past 3 months	External conditions; interpersonal conditions; psychological conditions (<i>n</i> = 3)	25	Unclear [item score dichotomised and averaged]
53	Nordic QoLQ Informant only	Lindström [130]	2–11	Some (QoL ^d)	Proxy-observer	By self; mail	Past three months	See <i>Nordic QoLQ</i>	25	See <i>Nordic QoLQ</i>

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
54	PedsQL GCS Toddler: Pediatric Quality of Life Inventory 4.0 Generic Core Scales, Toddler	Varni (2001) ¹ [32]; US	2–4	No (FDH)	Observer	By self (paper); by interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]
55	PedsQL GCS Young Child	Varni [32]; US	5–7	No (FDH)	Child; observer	Child: by interviewer, informant; by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	Child: 3-level pictorial faces, Informant: 5-point scale [item average per domain]
56	PedsQL GCS Child	Varni [32]; US	8–12	No (FDH)	Child; observer	Child and informant: by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]
57	PedsQL GCS Teen	Varni [32]; US	13–18	No (FDH)	Child; observer	Child and informant: by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]
58	PedsQL SF15 Toddler: PedsQL 4.0 Short Form, Toddler	Chan (2005) ¹ [131]; US	2–4	No (FDH)	Observer	By self (paper); by interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]
59	PedsQL SF15 Young Child	Chan [131]; US	5–7	No (FDH)	Child; observer	Child: by interviewer, informant; by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	Child: 3-level pictorial faces, Informant: 5-point scale [item average per domain]
60	PedsQL SF15 Child	Chan [131]; US	8–12	No (FDH)	Child; observer	Child and informant: by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
61	PedsQL SF15 Teen	Chan [131]; US	13–18	No (FDH)	Child; observer	Child and informant: by self or interviewer (telephone)	Past month (past week for acute version)	Functioning: physical; emotional; social; school (<i>n</i> = 4)	23	5-point scale [item average per domain]
62	PedsQL Infant Scales (1–12 months)	Varni (2011) ⁱ [132]; US	1–12 months	No (FDH)	Observer	By self; mail	Past month (past week for acute version)	Functioning: physical; emotional; social; cognitive; physical symptoms (<i>n</i> = 5)	36	5-point scale [item average per domain]
63	PedsQL Infant Scales (1–24 months)	Varni [132]; US	13–24 months	No (FDH)	Observer	By self; mail	Past month (past week for acute version)	Functioning: physical; emotional; social; cognitive; physical symptoms (<i>n</i> = 5)	45	5-point scale [item average per domain]
64	P-MYMOP: Paediatric Measure Yourself Medical Outcomes Profile	Ishaque [133]; Australia	7–11	Yes (HRQoL)	Child, aided by parent	By self	Past week	Symptom 1; Symptom 2; activity impairment; general wellbeing (child specifies symptoms and activity impairment affecting her most) (<i>n</i> = 4)	4	7-point pictorial faces [item average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
65	PQ-LES-Q: Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire	Endicott [63]; US	6–17	Yes (QoL)	Child	By self, unassisted as far as possible	Past week	Health, mood/feelings; school/learning; helping at home; getting along with friends; getting along with family; play/free time; getting things done; love/affection; getting/buying things; place you live at; paying attention; energy level; feelings about yourself; global QoL (<i>n</i> = 15)	15	5-point scale [item sum as proportion of maximum]
66	PROMIS PIB: Patient-Reported Outcomes Measurement Information System—Pediatric Item Banks	Varni [44]; US	8–17	No (FDH)	Child; observer	By self; computer	Past week	Mobility; upper extremity; peer relationships; depressive symptoms; anxiety; anger; pain interference; lack of energy; tired; asthma impact (<i>n</i> = 10)	165	5-point scale [Rasch score]
67	PROMIS PIB SF: PROMIS PIB Short Form	DeWalt [45]; US	8–17	No (FDH)	Child	By self; computer	Past week	Mobility; upper extremity; peer relationships; depressive symptoms; anxiety; anger; pain interference; fatigue (<i>n</i> = 8)	64	5-point scale [Rasch score]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
68	PROMIS PIB CAT: PROMIS PIB Computerized Adaptive Test	Varni [47]; US	8–17	No (FDH)	Child	By self; computer	Past week	Mobility; upper extremity; peer relationships; depressive symptoms; anxiety; anger; pain interference; fatigue (<i>n</i> = 8)	5–12 items per domain	5-point scale [Rasch score]
69	PROMIS PGH7: PROMIS Pediatric Global Health 7-item	Forrest [53]; US	8–17	No (FDH)	Child; observer	By self; online	General	General health; quality of life; physical health; mental health; sad; fun with friends; parents listen to ideas (<i>n</i> = 7)	7	5-point scale [item sum]
70	PROMIS PGH7 Informant only	Forrest [53]	5–7	No (FDH)	Observer	By self; online	General	See PROMIS PGH7	7	See PROMIS PGH7
71	PROMIS EC: PROMIS Early Childhood	Blackwell [87]; US	1–5	No (FDH)	Observer	By self	Past week/month	(A) Global health. (B) Mental health: anger; anxiety; depressive symptoms; positive affect; engagement—curiosity; engagement—persistence; self-control—adaptability; Self-control—self-regulation. (C) Social relationships. (D) Physical health: physical activity; sleep health (<i>n</i> = 12)	138	Not yet developed

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
72	PWI-SC: Personal Wellbeing Index, School Children	Cummins [64]; Australia	5–18	Yes (QoL)	Child	By self or interviewer	Current	Standard of living; health; life achievement; personal relationships; personal safety; community-connectedness; future security; global QoL (<i>n</i> = 7)	7	11-point scale (happiness) [item average]
73	PWI-SC8: PWI-SC, 8 items	Vaqu�-Crusellas [134]; Spain	10–12	Yes (QoL)	Child	By self, in classroom with adult help available)	Current	Standard of living; health; life achievement; personal relationships; personal safety; community-connectedness; future security; food satisfaction (<i>n</i> = 8)	8	11-point scale (happiness) [item average]
74	QLQC: Quality of Life Questionnaire for Children	Bouman [135]; The Netherlands	8–12	Yes (QoL)	Child; proxy	By self	Past 2 months	Physical: complaints; limitations; handicaps. Psychological: general wellbeing; cognitive; self-concept; anxious-depressed. social relations: parents (child-report only); siblings; peers; school; social conflicts; leisure-time activities (<i>n</i> = 13)	81	3-point scale [item sum]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
75	QLSI-C: Quality of Life Systemic Inventory for Children	Etienne [30]; Belgium	8–12	Yes (QoL)	Child	By interviewer	Current	Physical; emotional; cognitive; social; family functioning (<i>n</i> = 5)	20	Multi-component state-goal gap identification approach ^k [item average weighted by importance and rate of progress to goal] <i>See QLSI-C</i>
76	QLSI-C Tablet: QLSI-C Tablet version	Touch��que [49]; Belgium	8–12	Yes (QoL)	Child	By self; tablet	Current	Physical; emotional; cognitive; social; family functioning (<i>n</i> = 5)	20	<i>See QLSI-C</i>
77	QoL-C: Quality of Life Scale for Children	Thompson [6]; UK	4–9	No (FDH)	Child; observer	Age 47: by interviewer, age 8–9: by self in class, informant: by self; mail	Today	Moving; looking after myself; doing usual activities; having pain; feeling worried, sad or unhappy; global health VAS (<i>n</i> = 5 + VAS)	5	3-level pictorial faces; VAS [item sum]
78	QOLPAV: Quality of Life Profile: Adolescent Version	Raphael [136]; Canada	15–18	Yes (QoL)	Child	By staff in groups	Not stated	Being (physical, psychological, spiritual); belonging (physical, social, community); becoming (practical, leisure, growth) (<i>n</i> = 3)	54	5-point scales: importance; enjoyment and satisfaction. Control and opportunity scores for context [item average per subdomain; subdomain average]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
79	QOLQA : Quality of Life Questionnaire for Adolescents	Wang [35]; Japan; China	12–15	Yes (QoL)	Child	By self	General	Physical; psychological; independence; social relationship; environment (<i>n</i> = 5)	70	5-point scale [item average per domain; domain average]
80	QOLQA-Taiwan : QOLQA Taiwanese version	Fuh [65]; Taiwan	13–15	Yes (QoL)	Child	By self	General	Family; residential environment; personal competence; social relationships; physical appearance; psychological wellbeing; pain (<i>n</i> = 7)	38	5-point scale [item average per domain]
81	SLSS : Student Life Satisfaction Scale	Huebner [137]; US	8–14	Yes (QoL)	Child	By group, questions read by staff	Past several weeks	No domain structure but includes a range of questions on life satisfaction ¹	7	4-point scale [item sum]
82	MSLSS : Multidimensional SLSS	Huebner [138]; US	8–14	Yes (QoL)	Child	By group, questions read by staff	General	Family; friends; school; living environment; self (<i>n</i> = 5)	40	4-point scale [item average per domain]
83	MSLSS Brief	Seligson [55]; US	11–14	Yes (QoL)	Child	By self	General	Family; friends; school; living environment; self (<i>n</i> = 5)	5	7-point scale. Importance rating scores obtained to weight each domain [item average per domain; domain average weighted by importance scores]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
84	MSLSS-A: MSLSS Adolescent version	Gilligan [139]; US	14–18	Yes (QoL)	Child	By self	General	Family; same-sex friends; school; living environment; self; opposite-sex relationship (<i>n</i> = 6)	53	6-point scale [item average per domain; domain average]
85	TACQOL: TNO-AZL questionnaire for Children's health-related Quality of Life	Vogels [31]; Theunissen [140]; The Netherlands	8–15	Yes (HRQoL)	Child; Proxy	By self	Past few weeks	Pain and symptoms; motor functioning; autonomy; cognitive functioning; social functioning; global positive emotional functioning; global negative emotional functioning (<i>n</i> = 7)	53	3-point scale for severity; 4-point scale for child's emotional response to item; combined into 3-point ordinal scale with range 0–2 ^m [item sum per domain]
86	TACQOL Informant only	See TACQOL	6–7	Yes (HRQoL)	Proxy	By self	Past few weeks	See TACQOL	53	See TACQOL
87	TAPQOL: TNO-AZL questionnaire for Preschool children's health-related Quality of Life	Fekkes [141]; The Netherlands	1–5	Yes (HRQoL)	Proxy	By self	Past 3 months	Sleeping; appetite; lung problems; stomach problems; skin problems; motor lems; motor functioning; problem behaviour; social functioning; communication; positive mood; anxiety; liveliness (<i>n</i> = 12)	43	3-point scale for severity; 4-point scale for child's emotional response to item; combined into 5-point ordinal scale with range 0–4 ⁿ [item sum per domain]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
88	TedQL	Lawford [142]; UK	3–8	Yes (QoL)	Child; proxy	Child; by interviewer ^a ; informant: by self	Current	Physical competence; peer acceptance; maternal acceptance; psychological functioning; cognitive functioning (<i>n</i> = 5)	23	Two 4-level scales: colour circles vs. linear scale. Circles took less time and more internally consistent [item average as proportion of maximum]
89	VSP-A : Vecu et Sante Percue de l'Adolescent	Simeoni [143]; France	11–17	Yes (HRQoL)	Child	By self	Past month	Psychological wellbeing; energy/vitality; friends; parents; leisure; school (<i>n</i> = 6)	40	5-point scale [item average per domain]
90	WCHMP : Warwick Child Health and Morbidity Profile	Spencer [144]; UK	0–5	No (FDH)	Observer	By self or interviewer	Not stated	General health status; acute minor illness; behavioural; accident; acute significant illness; hospital admission; immunization; chronic illness; functional health; HRQoL (<i>n</i> = 10)	10	4-point scale and free text for detail [no scoring]
91	WHOQOL-BREF	Izutsu [36]; Bangladesh	11–18	Yes (QoL)	Child	By interviewer (due to low literacy)	Past 2 weeks	Physical; psychological; social relationships; environmental; global QoL and health satisfaction (<i>n</i> = 4)	26	5-point scale [item sum per domain]
92	YQoL-R : Youth Quality of Life instrument—Research version	Edwards (2002); Patrick [145, 146]; US	12–18	Yes (QoL)	Child	By self	General	Sense of self; social relationships; environment; general quality of life (<i>n</i> = 4)	41	11-point scale [item sum per domain]

Table 1 (continued)

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
93	YQoL-S: YQoL—Surveillance version	Topolski [147]; US	12–18	Yes (QoL)	Child	By self	General; past month	Contextual; perceptual (<i>n</i> = 2)	10	5-point scale for Contextual items; 11-point scale for perceptual [item sum for Perception domain]

FDH functioning, disability and health, *HRQoL* health-related quality of life, *QoL* quality of life, *VAS* visual analogue scale

^aMeasures arranged alphabetically; family of measures (e.g. QUALIN, AUQUEI Nursery, AUQUEI Primary, OK.ado) arranged together

^bDenotes whether the measure items capture child respondent's perception (i.e. his/her enjoyment, satisfaction, expectations, standards and concerns) on health, health-related aspect or position in life: 'yes' if more than 75% of items did; 'no' if less than 25% of items did; 'some' if between 25% and 75% of items did. 'Yes' implies that the measure is predominantly a QoL or HRQoL measure; 'no' predominantly an FDH measure; and 'some' a mix of QoL/HRQoL and FDH

^cThis article is a review of AUQUEI by instrument developers. The primary development study is not available in English

^dContains subjective QoL and objective position in life items. Though the latter do not capture perception, they are associated with QoL rather than health. Hence, the measure is categorised as QoL, not QoL-FDH

^eThis article is a secondary application study of ILC in Norway. The primary development study was set in Germany and is not available in English

^fSee also questionnaire forms on website: <https://www.kindl.org/english/questionnaires/>

^gAustria, Germany, Switzerland, Spain, France, The Netherlands, Greece, Hungary, Ireland, Poland, Sweden, UK and Czech Republic

^hDevine [46] reports that there are 155 items in total across item banks excluding chronic-generic QoL. Barthel [129] reports that the average number of items answered per child is around 42

ⁱDenmark, Norway, Sweden, Finland and Iceland

^jSee also questionnaire forms on website: <https://www.pedsq.org/index.html>

^k(1) Adjust arrows on pictorial sundial to indicate the gap the between desired and current states for each item. (2) Indicate how quickly one is advancing or moving away from the goal. (3) Value the importance of each item on 7-point scale. (4) Four scores are produced for each item: (i) State score—distance between current and ideal states; (ii) Goal score—distance between goal and ideal state; (iii) Gap score (= QoL score)—distance between current state and goal weighted by speed of improvement and rank score; (iv) Rank score—importance of each item

^l: 'My life is going well'; 'My life is just right'; 'I would like to change many things'; 'I wish I had a different kind of life'; 'I have a good life'; 'I have what I want in life'; 'My life is better than most kinds'

^mNo problem; problem without emotional response; problem with emotional response

ⁿHas problem and child feels bad; has problem and feels 'quite bad'; has problem and feels 'fine'; has no problem. For social functioning, problem behaviour, anxiety, positive mood and liveliness, only 3-point frequency scale used with score ranging 0–2

^oChildren were interviewed using two medium-sized teddy bears (one which is good at the given activity and the other bad at the activity) and asked to rate how much they liked doing what the bears are doing

Table 2 Summary of characteristics of included generic multidimensional childhood patient-reported outcome measures designed to be accompanied by preference-based value sets^a

#	Acronym; name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
1	16D : 16-Dimensional Health-Related Measure	Apajalalo [18]; Finland	12–15	No (FDH)	Child; observer	By self or interviewer	Today	Mobility; vision; hearing; breathing; sleeping; eating; speech; excretion; school and hobbies; mental function; discomfort and symptoms; depression; distress; vitality; appearance; friends (<i>n</i> = 16)	16	5-point scale [value set available]
2	17D	Apajalalo [67]; Finland	8–11	No (FDH)	Child; observer	By interviewer	Today	Mobility; vision; hearing; breathing; sleeping; eating; school and hobbies; mental function; discomfort and symptoms; depression; distress; vitality; appearance; friends; concentration (<i>n</i> = 17)	17	5-point scale [value set available]
3	AHUM : Adolescent Health Utility Measure	Beusterien [78]; UK	12–18	No (FDH)	Child	By interviewer	Today	Self-care; pain; mobility; strenuous activities; self-image; health perceptions (<i>n</i> = 6)	6	4- to 7-point scale [value set available]
4	AQoL-6D Adolescent : Assessment of Quality of Life, 6-Dimensional, Adolescent	Moodie [37]; Australia, New Zealand, Fiji, Tonga	15–18	No (FDH)	Child	By self	Past week	Physical ability; social and family relationships; mental health; coping; pain; vision, hearing and communication (<i>n</i> = 6)	20	4- to 6-point scale [value set available]
5	CH-6D : Child Health—6 Dimensions	Kang [50]; South Korea	7–12; 16–18	No information	Child	By self; mobile	Not stated	Not stated (<i>n</i> = 6)	6	3- to 4-point scale [value set planned/in development]
6	CHSCS-PS : Comprehensive Health Status Classification System—Pre-school	Saigal [60]; Canada, Australia	2–5	No (FDH)	Observer (clinicians, parents)	By self	Past week	Vision; hearing; speech; mobility; dexterity; self-care; emotion; learning and remembering; thinking and problem solving; pain; behaviour; general health (<i>n</i> = 12)	12	3- to 5-point scale [value set planned/in development]

Table 2 (continued)

#	Acronym: name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, n)	Items n	Response options [scoring method]
7	HUI2: Health Utilities Index 2	Torrance [75]; Canada	8–18	No (FDH)	Child	By self or interviewer ^c	General	Sensation; mobility; emotion; cognition; self-care; pain; fertility (n = 7) See <i>HUI2</i>	7	3- to 5-point scale [value set available]
8	HUI2 Informant only	Torrance [75]	5–8	No (FDH)	Observer	By self or interviewer	General	See <i>HUI2</i>	7	See <i>HUI2</i>
9	HUI3: Health Utilities Index 3	Furlong [148]; Canada	8–18	No (FDH)	Child	By self or interviewer ^c	General	Vision; hearing; speech; ambulation/mobility; pain; dexterity; emotion; cognition (n = 8) See <i>HUI3</i>	8	5- to 6-point scale [value set available]
10	HUI3 Informant only	Furlong [148]	5–8	No (FDH)	Observer	By self or interviewer	General	See <i>HUI3</i>	8	See <i>HUI3</i>
11	CHU9D: Child Health Utility 9D	Stevens [84, 149]; UK	7–11	No (FDH)	Child; observer	By self	Today/last night	Worried; sad; annoyed; tired; pain; sleep; daily routine; school work/homework; able to join in activities (n = 9)	9	5-point scale [value set available]
12	EQ-5D-Y: EuroQoL 5-Dimensional questionnaire for Youth	Wille [38]; 7 countries ^d	8–15	No (FDH)	Child; observer	By self	Today	Mobility; self-care; usual activities; pain/discomfort; feeling worried/sad/unhappy; general health VAS (n = 5 + VAS) See <i>EQ-5D-Y</i>	5	3-point scale + VAS [value set available]
13	EQ-5D-Y Proxy: EQ-5D-Y for informant	Gusi, Verstraete [40, 150]; Spain, South Africa	3–7	No (FDH)	Observer	By self (mail) or interviewer (telephone)	Today	See <i>EQ-5D-Y</i>	5	See <i>EQ-5D-Y</i>
14	EQ-5D-Y-5L: EQ-5D-Y, 5 levels	Kreimeier [151]; Germany, Spain, Sweden, UK	8–15	No (FDH)	Child	By self	Today	Mobility; self-care; usual activities; pain/discomfort; feeling worried/sad/unhappy; general health VAS (n = 5 + VAS)	5	5-point scale + VAS [value set planned/in development]
15	IQI: Infant health-related Quality of life Instrument	Jabrayilov [51]; UK, New Zealand, Singapore	0–1	No (FDH)	Observer	By self; mobile	Today	Sleeping; feeding; breathing; stooling/poo; mood; skin; interaction (n = 7)	7	4-point scale [value set available]

Table 2 (continued)

#	Acronym: name	Reference; country	Target age (years)	Perception captured (category) ^b	Respondent type	Administration mode	Recall period	Domains (number, <i>n</i>)	Items <i>n</i>	Response options [scoring method]
16	QWB: Quality of Well-Being scale	Kaplan [152, 153]; US	N/A	No (FDH)	Child; observer	by self or interviewer	Functional level: general, symptoms: past 3 days except today	Mobility; physical activity; social activity; symptom-problem complex (<i>n</i> = 4)	61	2- to 4-point scale [value set available]
17	TANDI: Toddler and Infant health related quality of life instrument	Verstraete (2020b); (2020c) [39, 154]; South Africa	0–3	No (FDH)	Observer	By self; mail	Today	Movement; play; pain; relationships; communication; eating; general health VAS (<i>n</i> = 6)	6	3-point scale [value set planned/in development]

FDH functioning, disability and health, *HRQoL* health-related quality of life, *QoL* quality of life, *VAS* visual analogue scale, *N/A* Not applicable

^aMeasures arranged alphabetically; family of measures (e.g. CHSCS-PS, HUI2 and HUI3) arranged together

^bDenotes whether the measure items capture child respondent's perception (i.e. his/her enjoyment, satisfaction, expectations, standards and concerns) on health, health-related aspect or position in life: 'yes' if more than 75% of items did; 'no' if less than 25% of items did; 'some' if between 25% and 75% of items did. 'Yes' implies that the measure is predominantly a QoL or HRQoL measure; 'no' predominantly an FDH measure; and 'some' a mix of QoL/HRQoL and FDH

^cInterviewer-administered for age 8–12

^dGermany, Spain, South Africa, Italy, Sweden, The Netherlands and the UK

4.3.3 Respondent/Informant Type and Other Measure Characteristics

Table 4 summarises the respondent and informant types and design features of measures by age category.

Measures targeting younger age groups were more likely to rely on informant report. For example, of the 25 measures compatible with observer report only, 16 (64%) targeted children aged less than 5, and none targeted adolescents. Of the 44 measures designed primarily for child report, 18 (41%) targeted adolescents, and one (2%) targeted children aged less than 5.

Of 76 measures compatible with child self-report, 49 (65%) were designed for self-administration using non-electronic or electronic modes of data collection. Overall, there were 14 measures (13%) that used electronic data collection from children or informants: seven using computers at study locations [41–47], four using tablets or mobiles [48–51] and three via the internet from non-study locations [52, 53].

Shorter recall periods were used for younger age groups. Of 13 measures compatible with child self-report that had a recall period of current/today, seven (54%) targeted children aged 5–11, while two (15%) targeted adolescents.

The numbers of domains and items tended to be lower for measures targeting younger age groups. Of 42 measures compatible with child self-report that had more than five domains, 13 (31%) targeted adolescents and eight (19%) targeted children aged 5–11. Of 28 measures compatible with child self-report that had more than 30 items, ten (36%) targeted adolescents and six (21%) targeted children aged 5–11. Two measures used computerized adaptive tests [46, 47] that tailored the number of items according to respondents' previous answers.

Most measures (102 of 110; 93%) used some form of ordinal scale with a pre-defined number of response points (e.g. Likert scale). Six measures used a visual analogue scale (VAS) alongside a Likert scale. Eleven measures used pictorial or narrative aids for child self-reports.

The vast majority of measures without value sets (78 of 93; 84%) used unweighted sums, averages or proportion of maximum scores as scoring methods. Four measures without value sets elicited importance scores from children, with items weighted to produce the overall QoL score [30, 49, 54, 55]. The KIDSCREEN and PROMIS groups of measures used item response theory scoring [44–47, 56–59].

4.4 Content Validity of Measures

Table D in the Supplementary Information (see the electronic supplementary material) describes the background concepts and development methods for measures, including whether and how children (or parents/primary caregivers in case of infants, toddlers or pre-schoolers) were involved in

the development and pilot-testing processes. The development of 21 of the 110 measures (19%) involved qualitative research with or surveys of children for domain and item elicitation. Nine measures were based on adapting existing adult measures: one conducted focus groups with adolescents [37]; two cognitive interviews [6, 38]; one feasibility testing [60]; and five made little or no mention of children’s involvement [54, 61–64]. Twenty-three measures reported no involvement of children, relying on clinical and/or research expertise for domain/item elicitation, using statistical techniques for item selection (e.g. for short-form development), or provided little detail on development. Among measures with multi-age group coverage, nine of the 37 measures (24%) conducted qualitative research with children.

Seven measures addressed cultural issues in initial measure development. The ACHWM aimed to develop a culturally appropriate model of health and wellbeing for Aboriginal communities in Canada [48]. The QOLQA and QOLQA-Taiwan aimed to develop measures appropriate for Asian adolescents [35, 65]. The development of the IQI involved interviews with parents of infants aged 0–3 years from New Zealand, Singapore and the UK to assess cross-cultural interpretability [51]. Izutsu et al. adapted the existing English version of the WHOQOL-BREF for Bangladeshi adolescents and identified the need for interviewer administration due to low literacy rates in this context [36]. Finally, the KIDSCREEN measures were developed across 13 European countries specifically for cross-cultural relevance [57]; while the development of the EQ-5D-Y similarly included seven countries [38].

4.5 Characteristics of Preference-Based Value Sets for Childhood PROMs

The characteristics of 21 preference-based value sets developed by 19 studies of ten generic multidimensional childhood PROMs are summarised in Table 5. The CH-6D, CHSCS-PS, EQ-5D-Y-5L and TANDI, which have been designed as generic multidimensional childhood PROMs with the accompaniment of a value set as an objective, did not have value sets publicly available at the time of the review. The 21 value sets were predominately developed in high-income countries with the exception of those developed for Fiji and Tonga (AQoL-6D Adolescents) [37] and China (CHU9D) [66]. BWS and DCEs increased in frequency of use in recent valuation studies, with TTO and SG techniques largely utilised at least a decade ago, unless used for the specific purpose of anchoring the DCE/BWS to the QALY scale. The respondent types from which the value sets were derived differ across measures, ranging from school children and students (16D, AQoL-6D, CHU9D [Australia and China]) through to parents/caregivers (17D, HUI2, IQI), with general population adult samples forming the most prevalent source of values overall (AHUHM, CHU9D [UK and The Netherlands], EQ-5D-Y, HUI2, HUI3, QWB, IQI).

The size of the samples from which the value sets were derived differed markedly between valuation studies, ranging from 115 (17D, parents of children [67]) to 4155 (EQ-5D-Y US value set, adults [68]). Some studies conducted complementary TTO experiments to assist with anchoring [66, 69–71] or used a particular type of DCE that includes

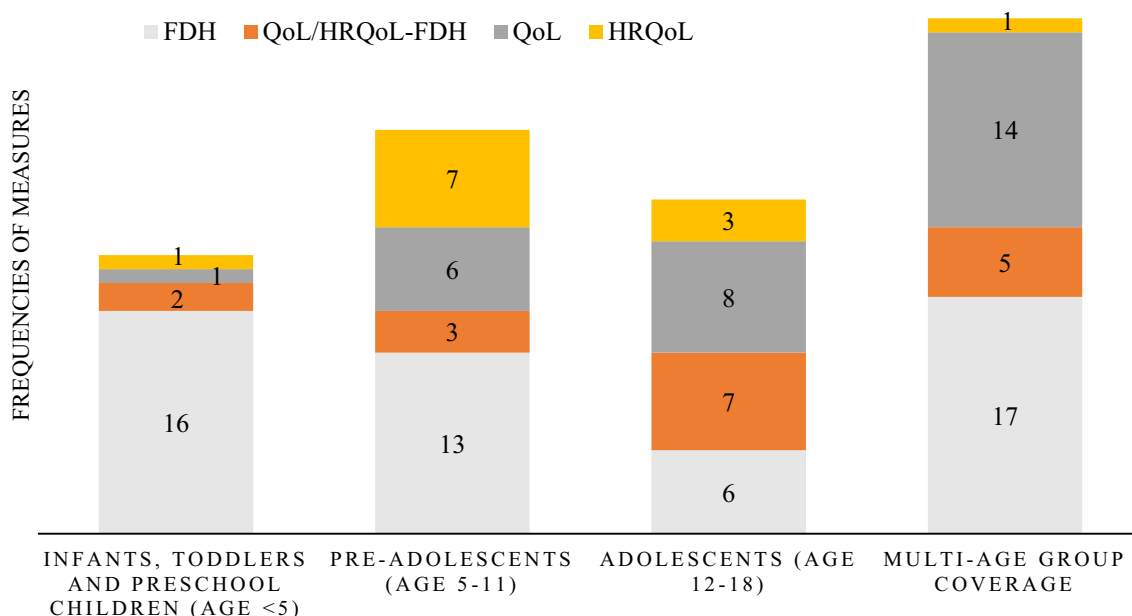


Fig. 3 Number of identified generic multidimensional childhood PROMs by conceptual basis and age category. *FDH* functioning, disability and health, *HRQoL* health-related quality of life, *PROM* patient-reported outcome measure, *QoL* quality of life

Table 3 Domains covered by included patient-reported outcome measures by age category and conceptual basis. Domains unique to age category are highlighted in bold and underlined

Age category	Underlying conceptual basis	Domains
Infants, toddlers or pre-schoolers (age < 5) ^a	FDH	<i>Accident</i> ; activities; activities needing assistance; <i>Acute minor illness</i> ; <i>Acute significant illness</i> ; aids/devices for functioning; anger; anxiety; arising; behaviour; bodily pain; breathing; change in health over past over; chronic illness; cognitive functioning; communication; depressive symptoms; dexterity; dressing and grooming; eating; emotion; emotional functioning; <i>Engagement—Curiosity</i> ; <i>Engagement—Persistence</i> ; Family cohesion; <i>Family environment</i> ; <i>Feeding</i> ; general behaviour; general health; general health perceptions; getting along; global health; grip; <i>Growth and development</i> ; hearing; <i>Hospital admission</i> ; Hygiene; <i>Immunisation</i> ; <i>Interaction</i> ; <i>Learning and remembering</i> ; mobility; mood; movement; pain; parental impact—emotion; <i>Parental impact—General health</i> ; <i>Parental impact—Mental</i> ; parental impact—time; physical activity; physical challenges; physical functioning; <i>Physical symptoms</i> ; play; positive affect; <i>Psychomotor development</i> ; <i>Psychopathological elements</i> ; reach; relationships; <i>Responsiveness</i> ; school functioning; self-care; <i>Self-control—Adaptability</i> ; <i>Self-control—Self-regulation</i> ; <i>Skin</i> ; Sleep; <i>Sociability</i> ; Social functioning; Social relationships; Speech; <i>Stooling</i> ; <i>Temperaments and moods</i> ; <i>Thinking and problem solving</i> ; total functional status; VAS general health; VAS pain; VAS wellbeing; vision; walking
	QoL/HRQoL-FDH	Child behaviour; emotion; family; friends; physical health; school; self-esteem
	QoL	Activities at school and leisure; family life; global health; social life
	HRQoL	Anxiety; <i>Appetite</i> ; communication; <i>Liveliness</i> ; <i>Lung problems</i> ; motor functioning; positive mood; <i>Problem behaviour</i> ; <i>Skin problems</i> ; sleeping; social functioning; <i>Stomach problems</i>
Pre-adolescents (age 5–11) ^b	FDH	<i>Able to join activities</i> ; achievement; <i>Annoyed</i> ; appearance; breathing; cognition; comfort; concentration; <i>Daily routine</i> ; depression; dexterity; discomfort and symptoms; distress; doing usual activities; eating; emotion; emotional functioning; excretion; feeling worried, sad or unhappy; fertility; friends; fun with friends; general health; hearing; mental function; mental health; mobility; looking after myself; moving; pain; parents listen to ideas; physical functioning; physical health; QoL; resilience; risk avoidance; sad; satisfaction; school and hobbies; school functioning; school work; self-care; sensation; Sleeping; Social functioning; speech; tired; VAS global health; vision; vitality; worried
	QoL/HRQoL-FDH	Emotion; family; friends; mental; physical; physical health; school; self-esteem; social
	QoL	Activities at school and leisure; anxious-depressed; cognitive; community connectedness; emotional; family functioning; family life; family relationships; <i>Food satisfaction</i> ; future security; general wellbeing; global health; health; leisure-time activities; life achievement; personal relationships; personal safety; physical; physical activity; physical complaints; physical handicaps; physical limitations; relation with parents; relation with peers; <i>Relation at school</i> ; <i>Relation with siblings</i> ; school achievements; <i>Self-concept</i> ; Social; <i>Social conflicts</i> ; social life; social wellbeing; standard of living; symptoms; Worry
	HRQoL	Achievement; <i>Activity impairment</i> ; asthma-specific; autonomy; cognitive; cognitive functioning; comfort; energy; general health perceptions; general wellbeing; global negative emotional functioning; global positive emotional functioning; healthiness; motor functioning; pain and symptoms; physical; physical complaints; physical health; psychosocial; resilience; risk avoidance; social; social functioning; symptoms; <i>Values</i> ; wellbeing
Adolescents (age 12–18) ^c	FDH	Achievement; appearance; breathing; comfort; <i>coping</i> ; depression; discomfort and symptoms; <i>Disorders</i> ; distress; eating; emotional functioning; excretion; friends; health perceptions; mental function; mental health; <i>Physical ability</i> ; physical functioning; resilience; risk avoidance; satisfaction; school and hobbies; school functioning; self-image; sleeping; social and family relationships; social functioning <i>Strenuous activities</i> ; vision, hearing and communications; vitality
	QoL/HRQoL-FDH	Bodily pain; change in health; emotion; <i>Emotional wellbeing</i> ; external conditions; family; family activities; family cohesion; friends; general behaviour; general health perceptions; getting along; global behaviour; health; interpersonal conditions; <i>Intimacy</i> ; <i>Material wellbeing</i> ; mental; mental health; physical; physical functioning; physical health; <i>Place in community</i> ; productivity; psychological conditions; role functioning—behavioural; role functioning—emotional; role functioning—physical; school; <i>Safety</i> ; self-esteem; social
	QoL	<i>Becoming</i> ; <i>Being</i> ; <i>Belonging</i> ; <i>Contextual factors to QoL</i> ; <i>Environment</i> ; family; general QoL; global QoL and health satisfaction; <i>Independence</i> ; leisure and relationships; living environment; <i>Opposite-sex relationship</i> ; pain; <i>Perceptual factors to QoL</i> ; <i>Personal competence</i> ; physical; physical appearance; psychological; psychological wellbeing; residential environment; <i>Same-sex friends</i> ; school; self; self-esteem; <i>Sense of self</i> ; social relationship
	HRQoL	Anxiety; depression; <i>Disability</i> ; emotional feelings; energy/vitality; <i>Family communications</i> ; friends; general health; <i>Health habits</i> ; leisure; mental health; pain; parents; perceived health; <i>Physical fitness</i> ; physical health; psychological wellbeing; school; school work; self-esteem; <i>Social health</i> ; social support

Table 3 (continued)

Age category	Underlying conceptual basis	Domains
Multi-age group coverage ^d	FDH	Activities; activities needing assistance; aids/devices for functioning; ambulation; anger; anxiety; arising; asthma impact; cognition; depressive symptoms; dexterity; dressing and grooming; eating; <i>Educational</i> ; emotion; fatigue; feeling worried/sad/unhappy; fertility; fun with friends; general health; grip; hearing; hygiene; <i>Interpersonal functioning</i> ; lack of energy; mental health; mobility; pain; pain interference; parents listen to ideas; peer relationships; physical; physical activity; physical challenges; physical health; psychological; QoL; sad; self-care; sensation; social; <i>Social activity</i> ; speech; symptom-problem complex; tired; total functional status; <i>Upper extremity</i> ; usual activities; VAS general health; VAS pain; VAS wellbeing; vision; walking
	QoL/HRQoL-FDH	Bodily pain; change in health; emotion; external conditions; family; family activities; family cohesion; friends; general behaviour; general health perception; interpersonal conditions; mental health; parental impact—emotion; parental impact—time; physical functioning; physical health; psychological conditions; role functioning—behavioural; role functioning—emotional; role functioning—physical; school; self-esteem
	QoL	Activities; appearance; <i>Attainments</i> ; autonomy; chronic-generic QoL; cognitive and school performance; cognitive functioning; communication; community connectedness; <i>Continence</i> ; depression; depressive moods and emotions; discomfort; eating; emotional; energy level; family; family functioning; feelings about yourself; <i>Financial resources</i> ; friends; future security; general affect; general satisfaction; getting along with friends; getting along with family; <i>Getting/buying things</i> ; getting things done; global QoL; health; <i>Helping at home</i> ; interests and hobbies; Life achievement; <i>Life satisfaction</i> ; living environment; love/affection; maternal acceptance; mental; mental health; mobility; mood; moods and emotions; parent relationship; parent relations and home life; parent relations and autonomy; paying attention; peer acceptance; peer relationship; personal relationships; personal safety; physical; physical activity; <i>Physical competence</i> ; physical health; physical wellbeing; place you live at; play/free time; <i>Psychological functioning</i> ; psychological wellbeing; school; <i>School environment</i> ; school performance; <i>School wellbeing</i> ; self; self-care; self-perception; sight; sleep; social and leisure times; social acceptance; <i>Social integration</i> ; social support and peers; <i>Spiritual</i> ; standard of living; worry
	HRQoL	Autonomy; cognitive functioning; global negative emotional functioning; global positive emotional functioning; motor functioning; pain and symptoms; social functioning

FDH functioning, disability and health, *HRQoL* health-related quality of life, *QoL* quality of life, *VAS* visual analogue scale

^aVersions for this category (see Table 1 for full names of measures): QUALIN; AUQUEI Nursery; CHAQ38 Informant only; FSIIR Infants; FSIIR Toddlers; FSIIR Pre-schoolers; ITQOL; ITQOL SF47; Kiddy-KINDL CQ; Kiddy-KINDL PQ; PedsQL GCS Toddler; PedsQL SF15 Toddler; PedsQL Infant Scales (1–12 months); PedsQL Infant Scales (13–24 months); PROMIS EC; TAPQOL; WCHMP; CHSCS-PS; IQI; TANDI

^bVersions for this category: AUQUEI Primary; CHIP-CE CRF; CHIP-CE PRF; CHIP-CE PRF (short-form); CHRS; CHSCS; ExQoL; HAY; HDQ Age 6; HDQ Age 10; Healthy Pathways CRS; Healthy Pathways PRS; Kid-KINDL CQ; PedsQL GCS Young Child; PedsQL GCS Child; PedsQL SF15 Young Child; PedsQL SF15 Child; P-MYMOP; PROMIS PGH7 Informant only; PWI-SC8; QLQC; QLSI-C; QLSI-C Tablet; QoL-C; TACQOL Informant only; 17D; HUI2 Informant only; HUI3 Informant only; CHU9D

^cVersions for this category: OK.ado; CHIP-AE; CHQ-CF87; CHQ-CF45; ComQOL-S5; COOP Charts; DHP-A; HDQ Age 13; HDQ Age 16; Kiddo-KINDL AQ; Nordic QoLQ; PedsQL GCS Teen; PedsQL SF15 Teen; QOLPAV; QOLQA; QOLQA-Taiwan; MSLSS-A; VSP-A; WHO-QOL-BREF; YQoL-R; YQoL-S; 16D; AHUM; AQoL-6D Adolescent

^dVersions for this category: ACHWM; CHAQ; CHAQ Informant only; CHAQ38; CHQ-PF50; CHQ-PF28; CQoL; FSIIR School children; FSIIR-14; GCQ; ILC; Kid- & Kiddo-KINDL PQ; KINDL CAT-SCREEN; KIDSCREEN-52; KIDSCREEN-27; KIDSCREEN-10; Kids-CAT; MCWBS; Nordic QoLQ Informant only; PQ-LES-Q; PROMIS PIB; PROMIS PIB SF; PROMIS PIB CAT; PROMIS PGH7; PWI-SC; SLSS; MSLSS; MSLSS Brief; TACQOL; TedQL; CH-6D; EQ-5D-Y; EQ-5D-Y Proxy; EQ-5D-Y-5L; HUI2; HUI3; QWB

a life year attribute (which is commonly referred to as DCE_{TTO}) [72] to assist with anchoring. Studies using BWS and DCE generally used larger sample sizes than more traditional approaches to health state valuation such as RS, TTO and SG (supplementary Figure S1, see the electronic supplementary material) [73]. Studies employing DCE and BWS approaches in relatively large samples also tended to be administered in self-complete online surveys. In contrast, TTO and SG were more likely to be administered in smaller samples and in an interview format due to their greater complexity and iterative nature [73].

Seven value sets were elicited from adolescents using RS for the 16D [18], TTO for AQoL-6D Adolescents (four value sets) [37] and BWS for CHU9D [66, 74]. One study elicited values from young adults to anchor the Ratcliffe 2015 value set for the CHU9D [74]. Amongst the remaining studies that sampled adult populations, five studies eliciting country-specific value sets for the EQ-5D-Y or HUI2 asked adult respondents to express their preferences from the perspective of a child aged 7 and 10 years [68] or 10 years [70, 71, 75, 76]. The HUI2 value sets [75, 76] added additional context by specifically asking the adult to imagine the child

Table 4 Frequencies of alternative characteristics of measures by target age category

	Target age category				
	Age < 5 N = 20	Age 5–11 N = 29	Age 12–18 N = 24	Multi-age N = 37	Total N = 110
Respondent and informant^a type—number of measures (%)					
Designed primarily for child report	1 (2.3)	9 (20.5)	18 (40.9)	16 (36.4)	44 (40.0)
Child report, aided by adult (e.g. parent)	1 (16.7)	3 (50.0)	2 (33.3)	0 (0.0)	6 (5.5)
Compatible with child and proxy ^b	0 (0.0)	2 (20.0)	1 (10.0)	7 (70.0)	10 (9.1)
Compatible with child and observer	0 (0.0)	7 (43.8)	3 (18.8)	6 (37.5)	16 (14.5)
Compatible with proxy report only ^b	2 (22.2)	3 (33.3)	0 (0.0)	4 (44.4)	9 (8.2)
Compatible with observer report only	16 (64.0)	5 (20.0)	0 (0.0)	4 (16.0)	25 (22.7)
Administration mode—number of measures (%)					
Compatible with child self-report					
By self, non-electronic	0 (0.0)	8 (21.1)	15 (39.5)	15 (39.5)	38 (50.0)
By self, electronic	0 (0.0)	3 (27.3)	1 (9.1)	7 (63.6)	11 (14.5)
By self or staff/interviewer	0 (0.0)	2 (28.6)	3 (42.9)	2 (28.6)	7 (9.2)
By group or aided	1 (14.3)	2 (28.6)	1 (14.3)	3 (42.9)	7 (9.2)
By staff/interviewer	1 (7.7)	6 (46.2)	4 (30.8)	2 ^c (15.4)	13 (17.1)
Compatible only with informant report					
By self, non-electronic	11 (50.0)	6 (27.3)	0 (0.0)	5 (22.7)	22 (64.7)
By self, electronic	1 (50.0)	1 (50.0)	0 (0.0)	0 (0.0)	2 (5.9)
By self or staff/interviewer	3 (75.0)	0 (0.0)	0 (0.0)	1 (25.0)	4 (11.8)
By staff/interviewer	3 (50.0)	1 (16.7)	0 (0.0)	2 (33.3)	6 (17.6)
Recall period—number of measures (%)					
Compatible with child self-report					
Current/Today	0 (0.0)	7 (53.8)	2 (15.4)	4 (30.8)	13 (17.1)
General	1 (5.3)	3 (15.8)	6 (31.6)	9 (47.4)	19 (25.0)
Less than month (4 weeks)	1 (4.8)	3 (14.3)	4 (19.0)	13 (61.9)	21 (27.6)
Month (4 weeks) or more	0 (0.0)	7 (38.9)	9 (50.0)	2 (11.1)	18 (23.7)
Unclear	0 (0.0)	1 (20.0)	3 (60.0)	1 (20.0)	5 (6.6)
Compatible only with informant report					
Current/Today	2 (66.7)	0 (0.0)	0 (0.0)	1 (33.3)	3 (8.8)
General	1 (25.0)	3 (75.0)	0 (0.0)	0 (0.0)	4 (11.8)
Less than month (4 weeks)	7 (58.3)	1 (8.3)	0 (0.0)	4 (33.3)	12 (35.3)
Month (4 weeks) or more	7 (53.8)	3 (23.1)	0 (0.0)	3 (23.1)	13 (38.2)
Unclear	1 (50.0)	1 (50.0)	0 (0.0)	0 (0.0)	2 (5.9)
Number of domains—number of measures (%)					
Compatible with child self-report					
With ≤ 5 domains	1 (2.9)	13 (38.2)	11 (32.4)	9 (26.5)	34 (44.7)
With > 5 domains	1 (2.4)	8 (19.0)	13 (31.0)	20 (47.6)	42 (55.3)
Compatible only with informant report					
With ≤ 5 domains	8 (57.1)	3 (21.4)	0 (0.0)	3 (21.4)	14 (41.2)
With > 5 domains	10 (50.0)	5 (25.0)	0 (0.0)	5 (25.0)	20 (58.8)
Number of items—number of measures (%)					
Compatible with child self-report					
With ≤ 30 items	2 (4.2)	15 (31.3)	14 (29.2)	17 (35.4)	48 (63.2)
With > 30 items	0 (0.0)	6 (21.4)	10 (35.7)	12 (42.9)	28 (36.8)
Compatible only with informant report					
With ≤ 30 items	8 (47.1)	4 (23.5)	0 (0.0)	5 (29.4)	17 (50.0)
With > 30 items	10 (58.8)	4 (23.5)	0 (0.0)	3 (17.6)	17 (50.0)
Response option^d					
Compatible with child self-report					
With < 5 points on scale	1 (6.3)	6 (37.5)	1 (6.3)	8 (50.0)	16 (21.1)

Table 4 (continued)

	Target age category				
	Age < 5 N = 20	Age 5–11 N = 29	Age 12–18 N = 24	Multi-age N = 37	Total N = 110
With ≥ 5 points on scale	1 (1.9)	11 (20.4)	24 (44.4)	18 (33.3)	54 (71.1)
Non-point option/unclear ^c	0 (0.0)	5 (83.3)	1 (16.7)	0 (0.0)	6 (7.9)
Compatible only with informant report					
With < 5 points on scale	7 (58.3)	1 (8.3)	0 (0.0)	4 (33.3)	12 (35.3)
With ≥ 5 points on scale	10 (50.0)	7 (35.0)	0 (0.0)	3 (15.0)	20 (58.8)
Non-point option/unclear	1 (50.0)	0 (0.0)	0 (0.0)	1 (50.0)	2 (6.1)
Scoring method					
Unweighted sum/average/proportion	15 (19.2)	22 (28.2)	20 (25.6)	21 (26.9)	78 (70.9)
Rasch score	0 (0.0)	0 (0.0)	0 (0.0)	7 (100.0)	7 (6.4)
Weighted sum/average/proportion	0 (0.0)	2 (50.0)	1 (25.0)	1 (25.0)	4 (3.6)
Value set application	3 (17.6)	4 (23.5)	3 (17.6)	7 (41.2)	17 (15.5)
Unclear	2 (50.0)	1 (25.0)	0 (0.0)	1 (25.0)	4 (3.6)

FDH functioning, disability and health, *HRQoL* health-related quality of life, *QoL* quality of life

^aInformant responds to the questionnaire instead of child self-report. Two informant types are proxy if the informant infers the child's perception on health/QoL items and observer if not

^bApplicable to both child and proxy after changing question wording from first- to third-person reference; includes versions of QoL/HRQoL-FDH measures that require informant to be both proxy and observer

^cOne version was administered by staff using computer tablet

^dEleven measures used pictorial/narrative aid: one for age < 5; seven for age 5–11; one for age 12–18; two for multi-age

^eExamples of non-point option are visual analogue scale and sundial approach in QLSI-C

living in the health state for the remainder of their life expectancy, with death at age 70. Two value sets were elicited from adults on behalf of the child [67, 77]. The remaining seven studies [72, 78–83] elicited health state preferences from adults who were asked to value health states from the perspective of their own health.

There were noticeable variations in the features of the value sets depending on the setting and valuation protocols adopted. For example, there are several value sets for the CHU9D, including the UK general adult population value set based on SG [79], the Dutch general adult population value set based on the DCE_{TTO} [72] and Australian [74] and Chinese [66] adolescent value sets based on BWS. Variation in the rank order of the most important domains is evident and illustrated in Table 5, with adolescents in China ranking the ability to join in activities and tired domains as most important, adolescents in Australia placing greater importance on mental health domains (e.g. sad, annoyed) and adults in both the UK and the Netherlands placing greater importance on physical health domains (e.g. pain and sleep). However, these differences may be due to the differences in valuation protocol, the sample characteristics and differences in preferences between countries

The range of health state values and the percentage of negative health state values (health states considered worse than being dead) differs across value sets within measures

(Fig. 4 shows the value range by perspective, and supplementary Figure S2 shows the range by elicitation method). For example, the worst health state described by the CHU9D had a value of 0.337 in the UK general population value set, in contrast to the Australian [69], Chinese [66] and The Netherlands [72] value sets, where the worst health state had values of −0.1059, 0.0563 and −0.568, respectively. The UK general population and Chinese adolescent CHU9D value sets have no health states valued at worse than being dead, whereas the Australian adolescent and The Netherlands general population value sets have 0.19 and 5.17% of health states, respectively, valued at worse than being dead.

Similarly, when drawing comparisons between different instruments, marked differences are evident in the range of values for value sets and in the proportions of health states that are valued at worse than being dead, with most studies reporting no negative health state values [18, 37, 66, 67, 71, 77, 79, 83]. However, some studies report relatively high proportions of health states valued at worse than being dead: e.g. 21% for the Slovenian EQ-5D-Y value set [70], whilst the publicly available Canadian algorithm for the HUI3 suggests that as many as 78% of health states are valued as worse than being dead [80]. The latter's value range and proportion of negative values is noticeably greater than all other value sets. A potential reason for the high proportion could be the multiplicative function used for HUI3 valuation tasks

as compared to the more common additive functional form used by other measures (supplementary Figs. S3a and S3b). More broadly, differences in modelling approaches can be as important as differences in the stated-preference methods used in determining the overall characteristics of value sets. Supplementary Tables E and F contain further detail on the valuation tasks and modelling methods for studies using two classes of methods for value set development (RS, TTO and SG [Table E, see the electronic supplementary material]; and DCE and BWS [Table F, see the electronic supplementary material]).

5 Discussion

This systematic review has generated an up-to-date and comprehensive catalogue of generic multidimensional childhood PROMs and the value sets that accompany them. The outputs can be used to inform the development, selection and interpretation of measures and value sets across a range of research contexts, including research designed to inform patient-centred care and research designed to inform cost-effectiveness-based decision-making. Specifically, the description provided of PROM characteristics such as target age range and domain coverage—alongside evidence on their psychometric performance explored in a forthcoming systematic review—should aid decisions around measure selection and, where appropriate measures are currently not available, measure development. Likewise, the granulated descriptions and categorisations of measures and value sets should aid interpretation of the outputs produced by measures across a range of methodological characteristics.

The review is the first to comprehensively catalogue generic multidimensional childhood PROMs according to the conceptual basis using definitions identified and outlined by the author team. It hence builds on the previous work by Fayed et al., who highlighted ways in which the terms health status, QoL and HRQoL are often used interchangeably in the literature despite important conceptual differences [3]. This is similarly noted by Karimi and Brazier [9], although their suggestion that the term HRQoL be reserved only to describe health utilities does not distinguish between measurement (*individual* perception incorporated into the descriptive systems of HRQoL measures) and valuation (*societal* preferences used to derive value sets) considerations. The latter may be appropriate for informing societal resource allocation decisions, while the former is more suited to informing clinical decisions for individuals [84], although the dichotomy is not absolute. Therefore, appropriate selection of childhood PROMs for research and decision making necessitates careful consideration of the context within which they are to be used.

The ISPOR guidelines for application of childhood PROMs recommend end users consider the applicability of characteristics of measures across children of different ages [2]. For example, a key consideration is the health/QoL domain coverage of PROMs targeted at particular age groups. This review describes the methods adopted to elicit relevant domains and items from children of different ages or their parents/caregivers and updates the content validity assessment conducted by Janssens et al. [85]. Moreover, our review catalogues the resulting domains by conceptual basis and target age group, highlighting those that are unique to each category and aiding instrument selection by the end user's target childhood population and domains of interest. Previous reviews have listed domain coverage, but only for individual instruments and not by conceptual and age categories [4, 10, 22, 25, 26]. The review identifies unique domains across developmental stages from infancy to adolescence, with a focus on observable FDH aspects (e.g. responsiveness, appetite) during the first 5 years of life replaced by increased focus on self-perception of activities and immediate relations during pre-adolescence (e.g. activity impairment, relation with siblings), followed by heightened awareness of personal independence and wider relations during adolescence (e.g. personal competence, opposite-sex relationships).

The emphasis on age-specific content should be balanced by the ability to generate outcomes that are comparable across childhood age groups and between children and adults; the latter is particularly important for research informing life-course healthcare decision-making [86]. The development of early childhood (age 1–5 years) versions of PROMIS sought to balance the two priorities by eliciting relevant domains and items from parents while minimising changes to the recall period and question wording of adult PROMIS measures [87]. Likewise, we identified nine measures that adapted existing adult measures, three after conducting qualitative research or cognitive interviews with children [6, 37, 38]. Significantly, two of these measures that were adapted with childhood input—QoL-C for age 4–9 years [6] and EQ-5D-Y for age 8–15 years [38]—are based on the EQ-5D, the reference case outcome measure for cost-utility analyses in the UK [13].

Another key age-dependent characteristic is the feasibility of child self-report, which is clearly dependent on not only chronological age, but also on children's cognitive capacity and their educational abilities (reading, comprehension and writing skills). Unsurprisingly, only two of 20 measures targeting children aged less than 5 provide for self-report [88, 89], compared to 21 of 29 measures targeting pre-adolescents and all measures targeting adolescents. Where informant reports are used, this review distinguishes between proxy and observer report depending on the extent to which the informant is asked to infer a subjective

Table 5 An overview of country-specific value sets for generic multidimensional childhood PROMs^a

Bibliography/setting	Sampling methods			Preference data collection			Value set statistical features			
	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
16D	Apajasalo [18]	Finland	School children in Helsinki aged 12–15	213	RS	By self	Adolescent's own health	Breathing (most important); physical appearance (least important)	Not reported	0
17D	Apajasalo [67]	Finland	Parents of children in the study: school children, survivors of organ donation and patients with skeletal dysplasia aged 8–11	115	RS	By interviewer	Adult rates on behalf of child	Mobility > breathing > school and hobbies > friends > hearing > vision > eating > elimination > vitality > sleeping > anxiety > discomfort and symptoms > learning and memory > ability to concentrate > depression > speech > physical appearance	Not reported	0
AHUM	Beusterien [78]	UK	UK general population—adults aged ≥ 18	312	TTO	By interviewer	Adult's own health	Not provided	0.419 to 1	0
AQoL-6D Adolescent	Moodie [37]	Australia, Fiji, NZ, Tonga	Students (adolescents) from four countries	279	TTO	Classroom based	Adolescent's own health	Not provided	Australia: 0.072–1; Fiji: 0.094–1; NZ: 0.053–1; Tonga: 0.068–1	0

Table 5 (continued)

Bibliography/setting		Sampling methods		Preference data collection		Value set statistical features				
Acronym ^b	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
CHU9D	Stevens [79]	UK	UK general population (mean age 49)	300	SG	By interviewer	Adult's own health	Pain > activities > daily routine > sleep > sad > work > tired > annoyed > worry	0.337 to 1	0
	Ratcliffe [69]	Australia	Convenient sample of students aged 18–29 (Flinders University, Faculty of Medicine, Nursing and Health Sciences)	38	TTO	By interviewer	Young adult's own health	Sad > pain > annoyed > work > sleep > daily routine > worried > activities > tired [by utility range]	– 0.1059 to 1	0.19
	Ratcliffe [74]		Community based sample of adolescents aged 11–17 (online panel)	1982	BWS	By self; online	Adolescent's own health			
	Chen [66]	China	Students in Nanjing City, China (BWS); undergraduate students from Nanjing Medical University (TTO)	902 (BWS); 38 (TTO)	BWS/TTO	By self (BWS); by interviewer (TTO)	Adolescent's/young adult's own health	Activities > tired > work > sad > sleep > daily routine > pain > annoyed [by utility range]	0.0563 to 1	0
	Rowen [72]	The Netherlands	General adult population in The Netherlands	1276	DCE-TTO	By self; online	Adult's own health	Pain > sleep > activities > daily routine > worry > sad > tired > annoyed > work	– 0.568 to 1	5.17

Table 5 (continued)

Bibliography/setting		Valuation reference		Valuation country		Sampling methods		Preference data collection			Value set statistical features		
Acronym ^b	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
EQ-5D-Y	Craig [68]	US	US general adult population aged ≥ 18	4155	Paired comparisons (DCE)	By self; online	Adult values hypothetical scenario: age of child described (7 or 10); duration of loss in child health	[Based on changes from level 2 to 3] pain/discomfort > anxiety/depression > usual activities > mobility > self-care	Unclear	Unclear	Unclear	Unclear	Unclear
	Rupeš [70]	Slovenia	Online panel adults (aged ≥ 18) across the country (DCE); non-probability purposive non-representative adult sample (aged ≥ 18) in one region (cTTO)	1074 (DCE); 202 (cTTO)	DCE/cTTO	By self (online); By interviewer (face-to-face)	Adult takes perspective of 10-year-old child	Pain/discomfort > anxiety/depression > usual activities > mobility > self-care	-0.691 to 1	20.60			
	Shirowa [71]	Japan	Japanese general adult population (aged 20–79)	1,047	DCE/cTTO	By interviewer; computer	Adult takes perspective of 10-year-old child	Pain/discomfort > worried/sad/unhappy > usual activities > mobility > looking after myself	0.288 to 1	0			

Table 5 (continued)

Bibliography/setting		Sampling methods		Preference data collection		Value set statistical features				
Acronym ^b	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
HUI2	Torrance [75]	Canada	Parents of school-aged children from general population	194	SG/RS	By interviewer	Adult takes perspective of 10-year-old child: imagine living in health state until death at age 70; choose for child, not parent/family	Pain > emotion > mobility > sensation > cognition > self-care > fertility	- 0.025 to 1	0.26
	McCabe [76]	UK	UK general adult population	175	SG/RS	By interviewer	Adult takes perspective of 10-year-old child: imagine living in health state until death at age 70	Pain > sensation > emotion > cognition > self-care > mobility	- 0.08 to 1	0.28

Table 5 (continued)

Bibliography/setting		Valuation reference		Valuation country		Sampling methods		Preference data collection			Value set statistical features		
Acronym ^b	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
HUI3	Feeny [80]	Canada	General adult population aged ≥ 16	256	SG/RS	By interviewer	Adult's own health	[Based on most impaired level per domain] cognition > emotion > pain > dexterity > ambulation > hearing = vision > speech	- 0.359 to 1	77.69 ^e			
	Noto [81]	Japan	General adult population (aged 20–79) from 5 cities	774	SG/RS	By interviewer	Adult's own health	[Based on most impaired level per domain] cognition > emotion > ambulation = vision > dexterity > pain speech > hearing	- 0.002 to 1	0.01			
	Le Galès [82]	France	French general adult population aged 20–65 not suffering from any major chronic/incapacitating illness	365	SG/RS	By interviewer	Adult's own health	Unclear	Unclear whether death is anchored at 0				
QWB	Seiber [83]	USA	US adults (aged 18–85) from primary care and 2 college campuses in San Diego	430	RS	By interviewer	Adult's own health	Calculation taking into account symptoms and activities	0.09–1	0			

Table 5 (continued)

Bibliography/setting		Sampling methods		Preference data collection		Value set statistical features				
Acronym ^b	Valuation reference	Valuation country	Valuation population	Sample size	Elicitation technique	Administration mode	Perspective	Rank order of domains (most to least important) ^c	Value range	Negative values (%) ^d
IQI	Krabbe [77]	China-HK, UK, US	General adult population and primary caregivers of infants and toddlers (0–3 years)	2,638	DCE	By self; online	Adult chooses for infant	Breathing > sleeping > feeding > mood > inter-action > skin > stooling	0.015–1	0

BWS best–worst scaling, *cTTO* composite time trade-off, *DCE* discrete choice experiment, *DCE_{TTO}* DCE anchored with *TTO*, *HK* Hong Kong, *NZ* New Zealand, *PROM* patient-reported outcome measure, *RS* rating scale, *SG* standard gamble, *TTO* time trade-off

^aThere are 19 studies: one study included four value sets [37], and two studies had one value set [69, 74]; thus there are 21 value sets from the 19 studies

^bSee Table 1 for full name of instruments

^cExamined by the authors of this review based on how the value sets were developed and whether sufficient information was reported; it should be noted that there could not be a consistent way to examine all value sets

^dCalculated by authors for all potential health states

^eBased on simulation of publicly available Canadian HUI3 algorithm; however, separate communication with the developers suggests this may be an overestimate

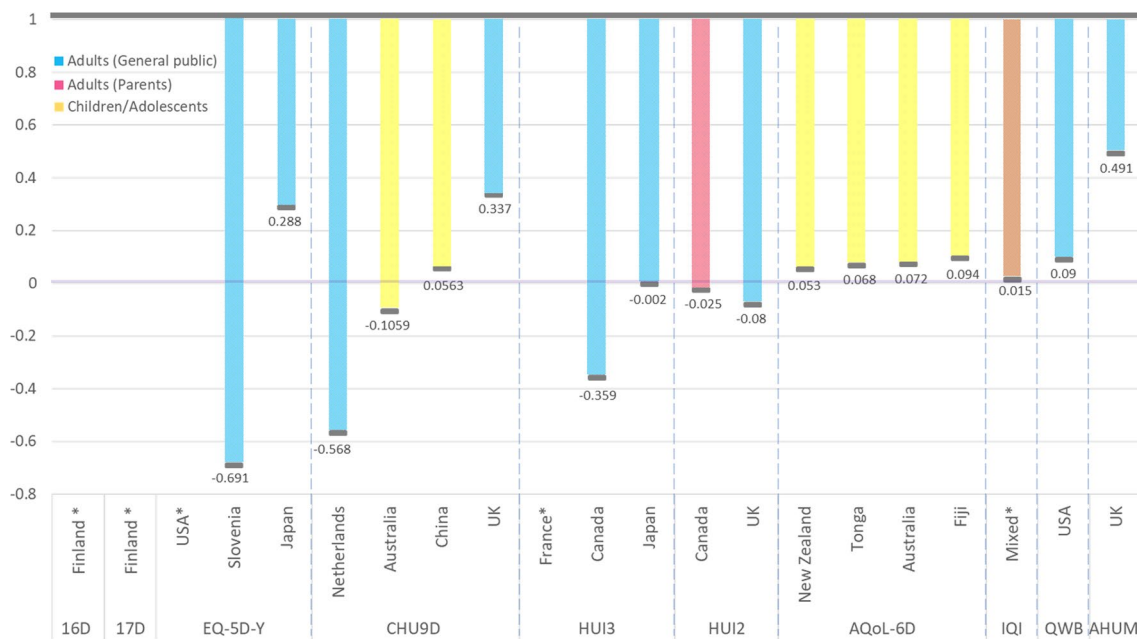


Fig. 4 Preference-based index value range by perspective

perception over health/QoL items for the child. Hence, there is close overlap between the conceptual basis of the measure and informant type. This distinction is recommended by the ISPOR guideline [2], but is yet to be widely implemented. Janssens et al., for example, did not include the observer/proxy distinction in their discussion (p. 325) [4]. Moreover, based on empirical findings that child-informant agreement is poorer for subjective health/QoL constructs (e.g. emotion, pain) than observable ones (e.g. mobility, self-care) [90, 91], the ISPOR guideline recommends instruments involving observer report over those involving proxy report where informant report is found necessary (p. 470) [2]. Of the 61 identified measures compatible with informant report, 19 (31%) involved proxies; of the 33 measures compatible *only* with informant report (i.e. not designed for child self-report), nine (27%) involved proxies. This suggests that many existing measures do not adhere to the ISPOR recommendation, although more recently developed measures for infants and early childhood specifically cite this recommendation as the reason for including only observable domains [39, 87]. A key rationale for incorporating informant (specifically parent) report is that informants often have vital insights into the child's health needs and medical history and hence this facilitates healthcare decision-making [2, 92]. Future research should examine to what extent this decision-making is impaired by limiting the informant focus to observable domains.

Incorporating age-appropriate instrument design is another ISPOR good research practice principle [2]. Electronic data collection is recommended as the preferred administration mode, particularly in pre-adolescent age groups where self-report is possible [2, 21, 93]. Accordingly, three measures specifically targeting pre-adolescents incorporated electronic data collection in self-reports [41, 42, 49] as did another seven with multi-age group coverage including pre-adolescents [43–47, 50, 53]. The ISPOR guideline notes the difficulties children face in comprehending extended periods and recommends a recall period of 24 h or less. A recent systematic review by Coombes et al. on the design of childhood PROMs in primary studies similarly recommends a recall period of 48 h or less for children aged 5–7 years [94]. These recommendations were applied (i.e. recall period of current/today or general) by half of the measures in our review that elicit pre-adolescent self-reports. The other half contains recall periods ranging from the past week to the past 2 months. Concerning instrument length, relatively few instrument developers were concerned about the administrative burden of long instruments and used this as a rationale for development of short forms [53, 55, 58, 95]. In all, the number of instruments adhering to design recommendations is generally low.

For childhood PROMs accompanied by preference-based value sets, a key challenge lies in how to elicit societal preference weights. This review reveals an increasing trend

towards using ordinal approaches (e.g. DCE and BWS) in health state valuation. These approaches (in particular BWS) have different cognitive demands to iterative approaches and may be more suitable for children to self-complete [96]. Given death is normally not included in the hypothetical choice tasks, this also aligns with ethical considerations for children. It enables preferences of children to be directly elicited and has been adopted by the studies that derived value sets for the CHU9D in Australia and China [66, 74]. However, given the raw values from these ordinal tasks are estimated on a latent utility scale, there is a need to have a standalone valuation survey using traditional direct approaches to health state valuation (e.g. TTO or SG) with (normally) a small convenience sample to facilitate the re-scaling exercise. This enables the value sets to produce cardinal health state values compatible with the 0–1 (dead to full health) QALY scale (for a comprehensive overview, see [73, 97]). For the most recently published EQ-5D-Y value sets, a similar approach was used, but instead of using BWS, a DCE was adopted in the main valuation task [70, 71].

This review identified that the majority of value sets (14/21 value sets) were derived using adult samples; in half of these, the adult was asked to take the perspective of a child, and half were from the adult's own perspective. Decisions about the appropriate perspective to adopt when developing value sets for economic evaluation need to consider the preference of health technology assessment (HTA) agencies or decision makers in each country. There are currently notable differences in the approaches taken for each country. For example, CHU9D value sets developed in the UK and The Netherlands are both based on the perspective and preference of the general public (aged ≥ 18 years) [72, 79]. The SG was used for the UK value set [79], whilst a DCE_{TTO} was used for The Netherlands value set [72]. The DCE_{TTO} does not require a separate task or data manipulation for states considered worse than dead [12, 98]; however, this approach was developed for adults, and may not be suitable for children and adolescents given ethical concerns about the inclusion of death. Notably, this issue also applies to the TTO. It will be important for future value set generation that the methods align to decision maker preferences as results will differ depending on approach taken. This also means that caution is required when comparing values generated across country value sets. Comparability of utilities for children with utilities generated for adults will also need to be considered by decision makers. The differences in perspectives used and normative judgments around appropriate perspectives will need to be balanced with considerations of comparability.

The review has also identified a trend over the last decade towards DCE and BWS exercises involving relatively larger samples and a reliance on online surveys. Whilst there are considerable practical advantages with online sampling, care is needed to ensure the quality of responses obtained, with

protocols such as those developed by the EuroQoL Group playing a critical role in quality assurance [99]. Qualitative studies such as 'think aloud' also provide information to understand participant decisions in the absence of a face-to-face interaction [100].

Across all categories of PROMs, regardless of the construct (or concept) being measured or target age(s), a noticeable feature is the scarcity of measures developed in LMIC settings (though this could be partly related to the reviews' sole inclusion of English language studies). Only five LMICs were covered by PROM development and only three by value set development. A previous systematic review of studies applying generic childhood PROMs accompanied by value sets found a similar scarcity, with only 8% of samples coming from LMICs [16] despite the substantially higher childhood disease burdens in these settings [101]. Further development of PROMs and value sets relevant to LMICs is a pressing research need, particularly when many characteristics of PROMs are contingent upon local contexts (e.g. low literacy rates hindering self-administration [36]) and when national HTA agencies demand value sets derived from samples relevant to local decision-making [13].

5.1 Strengths and Limitations

The contributions and strengths of this systematic review relative to previous reviews of childhood PROMs have been discussed under specific themes above (e.g. categorising PROMs by conceptual basis and target age group). There are nonetheless limitations warranting further research as well as caveats that should be borne in mind by readers. First, in contrast to previous reviews [21, 22, 24–26, 102], this review did not assess the psychometric properties of identified PROMs. Assessment of psychometric properties is recommended for PROM selection in research and decision-making [2]. In common with the work conducted by Janssens et al. [85], a separate systematic search and synthesis of the psychometric properties of the PROMs identified by this review is planned. This review provides partial evidence of the content validity of PROMs (Table D, see the electronic supplementary material), which will be combined with evidence of other aspects of content validity such as relevance and comprehensibility, as well as evidence for other psychometric properties [103]. Second, the research is constrained by a lack of consensus surrounding terms that describe the conceptual bases underpinning PROMs [9]. Hence, the methods used in this work to establish the categories of FDH, QoL and HRQoL measures [3], and the cut-off levels for hybrid categories, may be disputed. That said, a sensitivity analysis that changed the cut-off levels required for the proportion of items within measures that captured a child's perception for them to be labelled QoL/HRQoL-FDH hybrid measures (from 25–75% to 33–67%) altered the label of only

one measure (Kiddy-KINDL parent questionnaire [89]), and this had minimal impact on subsequent analyses.

Third, this review covered generic multidimensional childhood PROMs only and did not cover multidimensional childhood PROMs developed for specific conditions. Future research could usefully generate a parallel catalogue of condition-specific multidimensional childhood PROMs to inform research in specific clinical areas [104]. Fourth, the delineation of age and age categories throughout the paper is framed in chronological terms. Consideration of developmental age or markers of reading or educational ability could inform the selection of multidimensional childhood PROMs in some contexts, but this would require analyses of individual-level data from studies that also report developmental or educational outcomes. A final caveat is that this review does not report overall scores on the methodological or reporting quality of included studies through, for example, the Checklist for Reporting Valuation Studies (CREATE) score for valuation studies [105]. This was because CREATE was not developed to encompass values for childhood PROMs and misses key additional elements of the methodological choices required in this context. For PROM development studies, the planned systematic review of psychometric properties of measures will apply the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist to assess their methodological quality [103].

6 Conclusion

The catalogue of generic multidimensional childhood PROMs generated by this systematic review creates a valuable resource for researchers, practitioners and policy makers in selecting the most appropriate measure(s) for application within childhood populations according to their conceptual basis, target age, design and needs of the end user. This information should be viewed in conjunction with evidence surrounding the psychometric performance of measures to be presented in the follow-up systematic review. The description of PROM characteristics should inform decisions about the need to develop measures with alternative features or targeted at particular age groups. Moreover, the identified value sets covering all childhood age groups can be used to inform cost-utility analyses of childhood interventions. However, many methodological questions remain regarding the methods to use in valuing childhood PROMs, and this is currently a very active area of research. The availability of childhood PROMs and the value sets that accompany them have important roles in informing, respectively, individualised care and cost-effectiveness-based decision-making.

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Declarations

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Conflict of interest ND and BM are members of the EuroQol Group, which developed the EQ-5D-Y, one of the measures included in review. Other authors have no conflict of interest to declare.

Ethical approval Not applicable.

Availability of data and material The Excel files of extracted data are available from the corresponding authors on reasonable request.

Code availability The code used in this study is available from the authors upon reasonable request.

Consent for publication The authors, jointly and severally, give the publisher the permission to publish the work.

Consent to participate Not applicable.

Author contributions Conceptualisation and methodology: all co-authors. Database search, study selection and data extraction: SP, JK, EH, MH, KK, SD, NR, CH and SS for identification of patient-reported outcome measures; LF, GC and ND for preference-based value sets. Data synthesis: SP, JK, EH, MH, KK, SD, CH and SS for identification of patient-reported outcome measures; LF, GC, ND, CB, KD, AH, BM and JR for preference-based value sets. Writing original draft: SP, JK, EH, MH, SD, GC, ND, CB, BM and JR. Draft review and editing: all co-authors.

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