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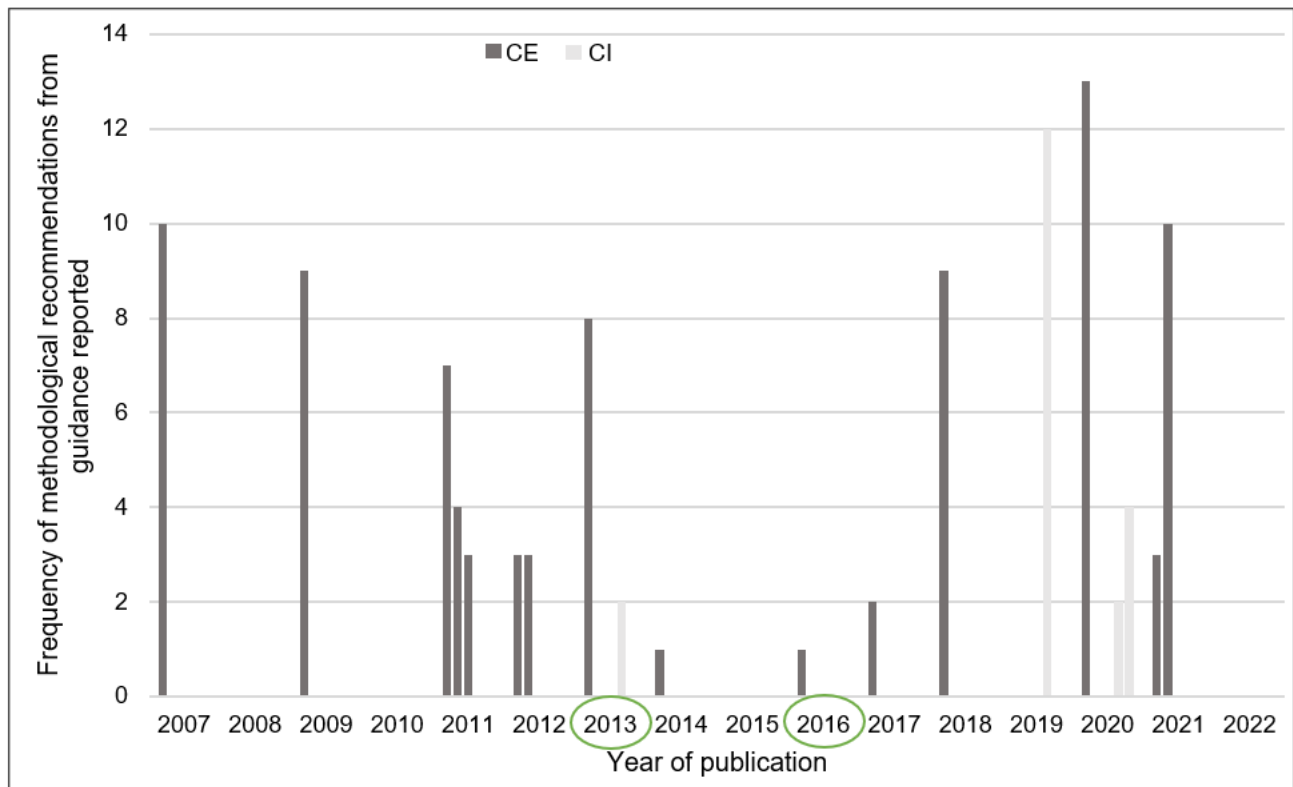
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Online resource 4 – Publication dates of included studies and guidance papers and PROM characteristics

Publication dates of included studies and guidance documents [1-3] and frequency of reported methodological recommendations.



Frequency of methodological recommendations reported by each included study (listed by year of publication). Guidance documents published in 2013 [1, 2] and 2016 [3] indicated by green circles.

Characteristics of PROMs identified from included studies (where developed)

Author (Year)	Paper title	Instrument name	Intended concept	Intended context of use	Intended target population	Versions available	Recall period	Domains	No. of items	Response options	Mode of administration
Carlton (2013) [4]	Identifying potential themes for the child amblyopia treatment questionnaire	Child Amblyopia Treatment Questionnaire (CAT-QoL)	HRQoL related to amblyopia treatment	Research or clinical practice	Children with amblyopia aged 4-7 years	7 treatment-specific versions available (glasses, patch, drops, patch and drops, patch and glasses, glasses and drops, glasses, patch and drops)	Past week	Physical, psychological, and social aspects of daily life	8 (sad, feeling, hurt, doing work at school, other children laughing/calling names, doing things (colouring, tv etc.), worried, playing with friends)	3-point Likert scale with tick boxes (not, a bit, very/a lot)	Self-complete or adult can read the questionnaire aloud to the child
Carlton (2013) [5]	Developing the draft descriptive system for the child amblyopia treatment questionnaire (CAT-QoL): a mixed methods study										
Christie et al (2011) [6]	Exploring views on satisfaction with life in young children with chronic illness: An innovative approach to the collection of self-report data from children under 11	No information available – corresponding author emailed									
Connor et al (2008) [7]	Attitudes of children with dysphonia	No information available – corresponding author emailed									
Follansbee-Junger et al (2016) [8]	Development of the PedsQL epilepsy module: focus group and cognitive interviews	PedsQL epilepsy module	HRQoL in epilepsy	Not available	Children with epilepsy 2-18 years	Child self-report (5-7, 8-12, 13-18 years) and proxy report	Not available	5 scales - impact, cognitive, executive function,	28 items	3-point Likert scale response - not at all,	Not available

									forgetting, feeling tired, mouth sores etc.		
Krenz et al (2021) [14]	Health-related quality of life after pediatric traumatic brain injury: a qualitative comparison between children's and parents' perspectives	Quality of life after traumatic brain injury (QOLIBRI) - Kiddy	HRQoL after traumatic brain injury	Not reported for the children's version. Adult version for clinical practice and research	Children and adolescents after traumatic brain injury	Intentions to adapt the adult version (QOLIBRI) for 3 ages: Kiddy (6-7), Kid (8-12) and Ado (13-17)	Not available – emailed corresponding author				
Markham et al (2009) [15]	Children with speech, language, and communication needs: their perceptions of their quality of life	Paediatric Speech and Language Quality of Life Scale (Ped Sal QoL)	Quality of Life related to speech, language, and communication needs	One example reported is to involve children in the management decisions of their SLCN	Children and young people with SLCN	Intended to be self-report where possible. Proxy versions not reported explicitly	Not available – emailed corresponding author				Interview administered (children have SLCN)
Morris et al (2007) [16]	Development of the Oxford ankle foot questionnaire: finding out how children are affected by foot and ankle problems	The Oxford Ankle Foot Questionnaire	Subjective wellbeing	Clinical settings or applied research	Child patients (aged 5-16 years) affected by foot and ankle conditions	Child self-report (child and teenager) or proxy report	The last week	3 - physical (6 items), school and play (4 items), emotional (4 items)	15 items - 14 are used to calculate domain scores (15th reflects concern by many)	5-point Likert scale (tick box) never, rarely, sometimes, very often, always	Pen and paper completion

									children that they can/cannot wear footwear they prefer)		
Nutakki et al (2017) [17]	Development of the pediatric quality of life inventory neurofibromatosis type 1 module items for children, adolescents and young adults: qualitative methods	PedsQL NF1 module	HRQoL in NF1	Not reported	Children and young people with NF1 2-25 years	Child self-report (5-7, 8-12, 13-18, 18-25 years) and proxy report (2-4, 5-7, 8-12, 13-18, 18-25 years)	Not reported	18 dimensions - skin itch bother, skin sensations, pain, pain impact, pain management, cognitive functioning, speech, fine motor, balance, vision, perceived physical appearance, communication, worry, treatment, medicines, stomach discomfort, constipation, diarrhoea	104 items	3-point Likert scale response - not at all, sometimes, a lot	Not reported
Paneinto et al (2012) [18]	Development of the PedsQL sickle cell disease module items: qualitative methods	PedsQL sickle cell disease module	HRQoL in sickle cell disease	Not reported	Children and young people with sickle cell disease 2-25 years	Child self-report (5-7, 8-12, 13-18, 18-25 years) and proxy report (2-4, 5-7, 8-12, 13-18, 18-25 years)	Not reported	9 dimensions - pain and hurt, pain impact, pain management, worry 1, worry 2 (not in child self-report), emotions, treatment, communication 1,	40 items for young child self-report and 42 items for proxy report for young children	3-point Likert scale response - not at all, sometimes, a lot	Not reported

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