



# Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties

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## PUBLICATION DATA

Accepted for publication 12th December 2019.

Published online 23rd January 2020.

## ABBREVIATIONS

ABI	Acquired brain injury
APCP	Assessment of Preschool Children's Participation
CAPE	Children's Assessment of Participation and Enjoyment
CASP	Child and Adolescent Scale of Participation
CEDL	Child Engagement in Daily Life Measure
COSMIN	Consensus-based Standards for the selection of health Measurement Instruments
CPQ	Children Participation Questionnaire
FPQ	Frequency of Participation Questionnaire
fPRC	Family of participation-related constructs
ICF	International Classification of Functioning, Disability and Health
QYPP	Questionnaire of Young Peoples Participation

**AIM** To examine which instruments used to assess participation of children with acquired brain injury (ABI) or cerebral palsy (CP) align with attendance and/or involvement constructs of participation; and to systematically review measurement properties of these instruments in children with ABI or CP, to guide instrument selection.

**METHOD** Five databases were searched. Instruments that quantified 'attendance' and/or 'involvement' aspects of participation according to the family of participation-related constructs were selected. Data on measurement properties were extracted and methodological quality of the studies assessed.

**RESULTS** Thirty-seven instruments were used to assess participation in children with ABI or CP. Of those, 12 measured attendance and/or involvement. The reliability, validity, and responsiveness of eight of these instruments were examined in 14 studies with children with ABI or CP. Sufficient measurement properties were reported for most of the measures, but no instrument had been assessed on all relevant properties. Moreover, most psychometric studies have marked methodological limitations.

**INTERPRETATION** Instruments to assess participation of children with ABI or CP should be selected carefully, as many available measures do not align with attendance and/or involvement. Evidence for measurement properties is limited, mainly caused by low methodological study quality. Future studies should follow recommended methodological guidelines.

Acquired brain injury (ABI) and cerebral palsy (CP) are two of the most frequently occurring neurological conditions in paediatric rehabilitation, and are the leading causes of disability in children worldwide.<sup>1,2</sup> Common negative consequences of paediatric ABI and CP include motor, cognitive, and behavioural problems that affect children's activity performance. In addition, children with ABI and

CP experience restricted participation across home, community, and school settings.<sup>3-9</sup>

Over the last two decades, participation has received increasing attention as the ultimate outcome of rehabilitation. Participation is one of the key components of the International Classification of Functioning, Disability and Health (ICF).<sup>10,11</sup> According to the ICF, participation

represents the societal perspective of functioning and is defined as ‘involvement in a life situation’. However, within the ICF, a uniform operationalization of the term participation has not been provided.<sup>12,13</sup> Moreover, given that there is no core set of ‘life situations’ for children and adolescents, instruments aiming to measure participation may include different content at varying levels of specificity. When assessing participation, it is essential to focus on individually meaningful and culturally relevant life situations. To do so, a range of tools is needed to address the varying life situations that may constitute participation.

To improve collective agreement of what participation is and how it can be defined across the various possible life situations, the family of participation-related constructs (fPRC) was developed.<sup>13,14</sup> Within this framework, participation is defined as comprising two essential elements: attendance and involvement. Attendance is defined as ‘being there’ (in the participatory context) and can be quantified by measuring the frequency or the diversity of activities in which a child takes part.<sup>13</sup> Involvement is the subjective experience of participation in the moment and includes affect, motivation, persistence, and perhaps social connection.<sup>13</sup> Results of previous systematic reviews have indicated that instruments used to assess participation in children with a broad range of disabilities sometimes do not measure attendance and/or involvement, but rather assess participation-related constructs such as activity competence, sense of self, preferences, or environmental context.<sup>13,15</sup> For instruments specifically used to assess participation of children with ABI or CP, alignment with the fPRC attendance and involvement constructs remains to be investigated. Being clear about the construct of interest is essential to facilitate understanding and comparability of outcomes.

In addition to the conceptualization of participation, measurement properties are important to consider when selecting instruments for use in research and clinical practice. Providing information about prognosis, as well as decision-making regarding treatment and evaluation of interventions, requires reliable and valid tools.<sup>16,17</sup> Measurement properties can differ substantially between populations.<sup>18</sup> Therefore, to assist researchers and clinicians in selecting instruments, their measurement properties should be known in the specific population of interest.<sup>18,19</sup>

Two previous systematic reviews aimed to identify instruments to assess participation specifically of children with ABI<sup>20</sup> or CP<sup>21</sup> and to describe their measurement properties. Note that, in both previous reviews, the selection of the instruments did not consider alignment with attendance and/or involvement. For children with ABI, five instruments were identified, but as most of them had only recently been developed, studies into their measurement properties were rare and more extensive evaluations were recommended.<sup>20</sup> For children with CP, seven instruments were identified, three of which had also been used in children with ABI;<sup>21</sup> some evidence was available regarding reliability and validity. However, studies into measurement properties of the included instruments were not

### What this paper adds

- Twelve instruments used to assess participation of children with acquired brain injury (ABI) or cerebral palsy (CP) aligned with attendance/involvement.
- Seven instruments have some psychometric evidence supporting their use with children with CP.
- For children with ABI, only the Child and Adolescent Scale of Participation has shown preliminary evidence of measurement properties.

systematically searched. Moreover, in both previous reviews, methodological quality of the studies evaluating measurement properties was not assessed. Evaluating the quality of studies is necessary, as inadequate study quality may bias results and lead to an incorrect approximation of the measurement properties of the instrument.<sup>22</sup> Therefore, the aims of this review were twofold: (1) to examine which instruments have been used to assess participation of children with ABI or CP and their alignment with the concepts of attendance and/or involvement; and (2) to examine what is known about the measurement properties of these instruments in children with ABI or CP.

### METHOD

A systematic review was designed and reported in accordance with the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) guidelines for systematic reviews of patient-reported outcome measures.<sup>19,23</sup>

### Information sources

We conducted one literature search to address both our research aims. The initial literature search was conducted on 12th April 2018 and included the following electronic databases: MEDLINE (1966–present), CINAHL (1982–present), Embase (1974–present), and PsycINFO (1967–present). The search was updated to include articles published before 1st May 2019. In addition to the database searches, instrument manuals, reference lists of all articles included in the present review, as well as of relevant reviews and meta-analyses known to the authors, were examined.

### Search

The search consisted of a combination of key terms and medical subject headings or thesaurus terms. The terms specifying the construct (i.e. participation) and the population of interest (i.e. children with ABI or CP) were based on previous systematic reviews of these topics,<sup>4,24–26</sup> COSMIN guidelines,<sup>27</sup> suggestions from experts in the field, and search blocks (as formulated on <https://blocks.bmi-online.nl/>). The search was limited to studies of children (aged 0–18y). No date or language restriction was employed. The full electronic search for the MEDLINE database may be found in Appendix S1 (online supporting information).

### Eligibility criteria

For our first aim, regarding which instruments have been used to assess participation of children with ABI or CP, the following criteria were set: (1) the instrument (or a

subscale or section) was explicitly used according to the study authors to measure participation, attendance, or involvement;<sup>8,28,29</sup> (2) the instrument used to assess participation was a quantitative measure that was clearly named and/or was accompanied by the original reference; (3) the instrument was used in a study with children diagnosed with ABI or CP; (4) the instrument was used in a study including children (age <19y); (5) the instrument was used in an article reporting on an empirical study; (6) the instrument was used in an article that was published in a peer-reviewed journal.

Counts of frequencies of observed participation behaviour were excluded if they did not concern a named/published instrument. If the study included patients with other diagnoses than ABI or CP, or typically developing children, data for children with ABI or CP had to be presented separately, or at least 50% of the participants had to be diagnosed with ABI or CP.<sup>27</sup> If the sample also included adults, data for children and adults had to be presented separately, at least 50% of the participants had to be children, or the mean or median age of the sample had to be between 0 and 18 years,<sup>27</sup> for the paper to be included.

The same criteria for the first aim were also applied to address the second aim, regarding the measurement properties of the participation instruments in children with ABI or CP, with one additional eligibility criterion: one aim of the study using the instrument was to evaluate at least one measurement property of the participation instrument.<sup>27</sup> Measurement properties of interest in the present review were determined using the COSMIN guidelines, and included initial instrument development, reliability (i.e. internal consistency, reliability, and measurement error), validity (i.e. content validity, structural validity, construct validity, and cross-cultural validity), and responsiveness.<sup>19,22,27</sup> Definitions of these terms are provided in Table S1 (online supporting information).

### Instrument and study selection

Two of the authors (CR and MvK) independently screened titles and abstracts of studies based on the eligibility criteria. Full texts were read by the first author (CR). Screening the articles to determine which instruments had been used to assess participation of children and adolescent with ABI or CP (relating to the first aim of the present review) was mainly directed at the *instrument* and in which population it was used. In contrast, for our second aim of examining measurement properties, the *study* itself was screened.

### Alignment with attendance and/or involvement

All instruments that had been used to measure participation of children with ABI or CP were mapped to the fPRC. Some instruments had been previously mapped by two of the authors of the present review (BA and CI);<sup>15</sup> if this was the case, results of the previous mapping were recorded. Instruments not yet mapped to the fPRC were evaluated independently by the two authors who contributed to the development of the fPRC and who

conducted the previous mapping (BA and CI). To be considered aligned with the attendance and/or involvement constructs, the instrument, or at least one of its subscales or subscores, had to align exclusively with the attendance and/or involvement constructs of the fPRC. More specifically, if an instrument's total scale or a subscale aligned with attendance and/or involvement, but also with another construct of the fPRC (e.g. activity competence), this instrument or subscale was excluded from further consideration.

### Extraction and synthesis of measurement properties

Measurement properties of participation instruments were extracted from the included studies as per the COSMIN guidelines, and evaluated based on the COSMIN criteria for good measurement properties by the first author (CR).<sup>19,22,27</sup> Results were rated sufficient (+), insufficient (-), or indeterminate (?).<sup>27</sup> It should be noted that, according to the COSMIN standards, content validity studies are those that include a new sample, independent from the sample that was included in the study of the initial development of the instrument.<sup>27</sup>

### Methodological quality of studies into measurement properties

To assess the methodological quality of studies examining measurement properties, we used the COSMIN Risk of Bias checklist. Methodological quality of the study was rated on a four-point rating scale from 'very good' to 'inadequate'.<sup>19</sup> A previous version of the checklist had good interrater reliability and agreement.<sup>30</sup> The new version, as used in the present systematic review, is highly comparable to the previous version.<sup>27</sup> Two authors (CR and PH) independently determined which items of the COSMIN Risk of Bias checklist were appropriate for each study reviewed. Two independent reviewers (pairs including CR plus AdK, BP, CvH, ES, or MvK) independently evaluated the methodological quality of the included studies. Disagreement was resolved through discussion or consultation with another author (PH).

## RESULTS

Details concerning the instrument and study selection for our two research aims are illustrated in Figure S1 (online supporting information). Our search yielded 18 119 unique records. Screening of titles ( $n=18\ 119$ ), abstracts ( $n=3809$ ), and full-texts ( $n=1237$ ) yielded 37 instruments used to quantify participation in our populations of interest (Table S2, online supporting information). Of these instruments, 24 had exclusively been used for children with CP. Seven were exclusively used to measure participation of children with ABI. Six instruments had been used both for children with CP and ABI.

### Alignment with attendance and/or involvement

Twelve instruments (i.e. the complete instrument or one or more of the subscales) aligned exclusively with the

attendance and/or involvement constructs of the fPRC. Detailed characteristics of the instruments are shown in Table S3 (online supporting information). For two other instruments (the Canadian Occupational Performance Measure and the Goal Attainment Scale),<sup>31,32</sup> the content of the items is determined by the individual participant. Therefore, whether the items align with the attendance and/or involvement construct, or something else,<sup>15</sup> depends on the goals set by the participant. Three instruments could not be mapped to the fPRC because we were not able to acquire the measure for mapping (the Pediatric Injury Functional Outcome Scale and the Child Health Questionnaire)<sup>33,34</sup> or because they were only available in Chinese (the Caregiver Questionnaire for Health-Related Quality of Life in children with Cerebral Palsy).<sup>35</sup> Two were excluded because they did not exclusively align with the attendance and/or involvement constructs (the School Function Assessment and the Caregiver Information and Support Link).<sup>36,37</sup> The resulting scores may therefore not be a clear reflection of attendance and/or involvement.

### **Measurement properties of instruments and methodological quality of their studies**

Of the 12 instruments or scales that aligned exclusively with the attendance and/or involvement constructs of the fPRC, eight (in different phases of instrument development and language versions) had undergone testing of measurement properties in children with ABI and/or CP. These instruments are the Assessment of Preschool Children's Participation (APCP),<sup>38</sup> the Children's Assessment of Participation and Enjoyment (CAPE),<sup>39</sup> the Child and Adolescent Scale of Participation (CASP),<sup>40</sup> the Child Engagement in Daily Life Measure (CEDL),<sup>41</sup> the Children Helping Out: Responsibilities, Expectations and Supports,<sup>42</sup> the Children Participation Questionnaire (CPQ),<sup>43</sup> the Frequency of Participation Questionnaire (FPQ),<sup>44</sup> and the Questionnaire of Young People's Participation (QYPP).<sup>45</sup> The CAPE, the CEDL, the Children Helping Out: Responsibilities, Expectations and Supports, and the CPQ consist of multiple subscales/scores of which only some align with the attendance and/or involvement constructs, while other scales align with other fPRC components. Only the subscales/scores that align with the attendance and/or involvement constructs were considered for the evaluation of measurement properties.

We identified 14 studies that examined measurement properties of these eight instruments in children with ABI or CP. Characteristics of these studies are reported in Table S4 (online supporting information). Measurement properties of participation instruments included from these studies are shown in Table S5 (online supporting information). The methodological quality of the included studies is reported in Table 1. Below, we report on the available evidence for each participation instrument, both regarding measurement properties and methodological quality of the study examining these properties. Of the studies included in the present review, none examined content validity

according to COSMIN criteria. Therefore, no information on the content validity of the instruments could be provided.

### **APCP**

The APCP was examined in its English version in children with CP in two studies: one conducted in Canada and one in Taiwan.<sup>46,47</sup> Instrument development, internal consistency, measurement error, construct validity, and responsiveness were examined. Owing to the lack of evidence of cross-cultural validity, it remains to be determined to what extent results from the studies are comparable, given the potential cultural differences between Canada and Taiwan.

During its initial development in Canada, the APCP was shown to include relevant items for children with CP, but comprehensiveness and comprehensibility are indeterminate. Unfortunately, instrument development was of inadequate methodological quality. To confirm the relevance (and comprehensiveness and comprehensibility) of the items of the APCP, additional content validity studies are needed. Internal consistency was sufficient for all diversity subscales, but only for one of four intensity subscales; however, methodological study quality was doubtful. Methodological quality of the assessment of measurement error was adequate, with results showing that the minimal detectable change was smaller than the minimal clinically important difference for all diversity and intensity scores except for the social subscale. In terms of construct validity, positive associations were found between APCP scores and assessment of daily activities, gross motor functioning, and functional independence. In contrast, APCP scores correlated negatively with the number of additional health conditions. However, as the APCP and these other measures assess different constructs (i.e. only the APCP measures attendance/involvement), the methodological quality of these assessments of construct validity is doubtful. Other evidence for construct validity comes from findings of differences in APCP scores between children of different age groups, sex, gross motor functioning level, and income level; methodological quality of this evaluation was adequate. Finally, the APCP was found to be responsive to change over time, but methodological quality of the study was inadequate.

### **CAPE**

The Spanish version of the CAPE had been studied for its measurement properties in children with CP in Spain. Note that for other language versions of the CAPE, no studies into measurement properties had been conducted with samples where data were available specifically for children with ABI or CP. The Spanish CAPE was shown to include relevant items for children with CP in Spain; assessment of comprehensiveness and comprehensibility was not described. Overall, the methodological quality of the instrument development was inadequate. Methodological quality of the evaluations of reliability, measurement error, and construct validity was adequate. The results of

**Table 1:** Methodological quality of the studies investigating measurement properties of the instruments tested in acquired brain injury or cerebral palsy samples

Study	Instrument	Development	Reliability			Validity			Responsiveness
			Internal consistency	Reliability	Measurement error	Structural validity	Construct validity	Cross-cultural validity	
Law et al. <sup>46</sup>	APCP	Inadequate	Doubtful				Doubtful – adequate		
Chen et al. <sup>47</sup>	APCP				Adequate		Doubtful		Inadequate
Longo et al. <sup>64</sup>	CAPE	Inadequate		Adequate	Adequate		Adequate		
Bedell <sup>40</sup>	CASP phase 2	Doubtful	Doubtful	Doubtful		Inadequate	Doubtful		
Bedell <sup>49</sup>	CASP		Doubtful			Adequate	Inadequate		
Golos and Bedell <sup>50</sup>	CASP		Very good			Adequate	Doubtful		
Golos and Bedell <sup>17</sup>	CASP						Doubtful		Inadequate – doubtful
de Kloet et al. <sup>51</sup>	CASP	Doubtful	Doubtful	Adequate			Doubtful – adequate		
Chiarello et al. <sup>41</sup>	CEDL		Very good	Adequate		Very good	Doubtful		
Palisano et al. <sup>60</sup>	CEDL				Inadequate				Adequate
Amaral et al. <sup>65</sup>	CHORES	Doubtful		Adequate					
Amini et al. <sup>66</sup>	CPQ		Very good	Adequate		Inadequate	Doubtful		
Michelsen et al. <sup>44</sup>	FPO	Inadequate					Adequate	Doubtful	
Tuffrey et al. <sup>45</sup>	QYPP	Doubtful	Doubtful	Doubtful		Inadequate	Doubtful		

APCP, Assessment of Preschool Children’s Participation; CAPE, Children’s Assessment of Participation and Enjoyment; CASP, Child and Adolescent Scale of Participation; CEDL, Child Engagement in Daily Life Measure; CHORES, Children Helping Out: Responsibilities, Expectations and Supports; CPQ, Children Participation Questionnaire; FPO, Frequency of Participation Questionnaire; QYPP, Questionnaire of Young Peoples Participation.

these evaluations indicate that test–retest reliability was sufficient for four out of five subscales. The smallest detectable change was reported but not compared to the minimally important change, leaving the rating for the measurement error indeterminate. The methodological quality of the assessment of construct validity was adequate when assessing differences between children with and without CP; differences were found, but the size of the differences is unknown. Construct validity assessment with the KIDSCREEN<sup>48</sup> was of doubtful methodological quality owing to the difference in construct assessed with the CAPE (participation) and the KIDSCREEN (quality of life); varying correlations were found between different subscales of these measures, leaving the validity indeterminate.

### CASP

The CASP was examined in five studies. One study examined the English CASP in an early phase of the development, after which it went through another round of (minor) adaptations.<sup>40</sup> Items were found to be relevant for children with ABI, but comprehensiveness and comprehensibility are unknown. Moreover, description of the development of the instrument was of doubtful methodological

quality. Internal consistency and test–retest reliability is sufficient, but both evaluations were of doubtful methodological quality. Structural validity remains indeterminate. Positive correlations were found with daily functioning and negative correlations with medical and environmental restrictions, providing preliminary indications for sufficient construct validity. However, methodological quality of these assessments is doubtful, as all instruments assessed different constructs.

Similar to the results of the phase 2 version, the final version of the CASP shows sufficient internal consistency (although examined in a methodologically doubtful study),<sup>49</sup> but indeterminate structural validity. Negative correlations with medical and environmental restrictions were found, as well as differences in scores between children with different disabilities, but methodological quality of these assessments was inadequate.

Two other studies examined the final version of the CASP, but combined data from the English and the Spanish versions.<sup>17,50</sup> Given the lack of evidence of cross-cultural validity of the CASP, it remains to be determined to what extent these versions are comparable. Internal consistency was sufficient (and examined in a high-quality study), structural validity could not be determined. Positive

correlations with quality of life and behavioural assessment, as well as subgroup differences in some disability groups, indicate preliminary evidence for construct validity, but the methodological quality of these assessments was doubtful. The CASP was found to be responsive to changes in some, but not all, disability groups; however, methodological quality was doubtful at best.

Finally, one study developed and examined the Dutch version of the CASP in the Netherlands.<sup>51</sup> Items of the scale were found to be relevant for children with ABI; comprehensiveness and comprehensibility are still to be determined. However, the development was methodologically doubtful. Internal consistency was sufficient, but the evidence is based on a study of doubtful methodological quality. The evaluation of test–retest reliability was of adequate methodological quality, indicating sufficient test–retest reliability. Evidence for construct validity is mixed, with some associations found between medical and environmental restrictions (negative) and quality of life (positive), but no associations with the Dutch version of the CAPE. Methodological quality of evaluations of construct validity was adequate (for associations with the CAPE), but doubtful for the associations with the measures of other constructs.

### **CEDL**

The CEDL showed sufficient internal consistency, examined in a high-quality study. Evaluation of reliability was adequate, indicating sufficient test–retest reliability. Rating of measurement error remains indeterminate as the minimal important change is unknown. Structural validity remains indeterminate. Differences between subgroups (e.g. depending on level of gross motor functioning or age) provide evidence for construct validity, but the methodological quality of the evaluations was doubtful. Differences in change over time between subgroups provide preliminary evidence for responsiveness, examined in a study of adequate methodological quality.

### **Children Helping Out: Responsibilities, Expectations and Supports**

The Brazilian–Portuguese translation of the Children Helping Out: Responsibilities, Expectations and Supports included relevant items but did not capture all relevant activities for children with CP in Brazil. Comprehensibility could not be determined. Moreover, methodological quality of the initial development was doubtful. The methodological quality of reliability was adequate, indicating sufficient test–retest reliability. Other measurement properties were not investigated.

### **CPQ**

The CPQ Persian language version, evaluated in children with CP in Iran, showed sufficient internal consistency for 13 of 18 subscales, as evaluated in a very good methodological study. Test–retest reliability was sufficient. Structural validity was found to be sufficient, but inadequate methodological approaches/reports were used to evaluate this. Inconsistent

evidence for construct validity is found due to varying correlations with behavioural assessment. Moreover, methodological quality of the evaluation of construct validity was doubtful, given that the measure used to assess construct validity measured a different construct than the CPQ.

### **FPQ**

For the FPQ, the English, Swedish, French, Danish, and Italian versions were used during psychometric analysis in the specific countries. Cross-cultural validity remains indeterminate. The combined results from these different language versions and countries should therefore only cautiously be used as evidence for measurement properties in one of these countries or versions. There was an inadequate description/evaluation of the development, leaving ratings of relevance, comprehensiveness, and comprehensibility for children with CP indeterminate. Differences between subgroups of participants were only partly in line with the original study authors' expectations, thus providing mixed results for construct validity, although the methodological quality of the study was adequate.

### **QYPP**

Finally, the study into the QYPP combined data from a self-report and a proxy-report version, even though agreement between these two versions is not clear. Relevance of the questionnaires' items for children with CP was sufficient, while comprehensiveness and comprehensibility were indeterminate. However, methodological quality of the (description of the) instrument development was doubtful. Internal consistency was sufficient for four of the seven subscales, but the methodological quality of the evaluation was doubtful. Test–retest reliability was sufficient, but the evaluation was of doubtful methodological quality. Structural validity remains indeterminate. Subgroup testing revealed mixed results and the evaluation was of doubtful quality.

## **DISCUSSION**

In the present review, we investigated instruments that have been used to assess participation in children with ABI or CP, their alignment with the attendance and/or involvement constructs of the fPRC, and what evidence exists for the measurement properties of these instruments in our population of interest.

We identified 37 instruments that had been used to assess participation of children with ABI or CP. When mapped to the fPRC, only 12 of these instruments were found to align with attendance and/or involvement and are therefore thought to assess the essential elements of 'participation' according to the recent fPRC conceptualization.<sup>13</sup> Participation is an evolving concept, and the fPRC framework was not available when most of the studies screened for the present review were conducted. Selection of the instruments to assess participation in many previous studies is therefore likely to have been guided by the understanding of the concept at that time (e.g. by using the ICF).<sup>10</sup> For example, before the development of the fPRC, a previous review from

2005 on participation instruments for children with CP recommended the use of the Activities Scale for Kids and the condition-specific Lifestyle Assessment Questionnaire for CP.<sup>52</sup> According to the fPRC, only a subscale of the Activities Scale for Kids quantifies attendance, while the Lifestyle Assessment Questionnaire for CP does not align with either attendance or involvement (Table S2). Thus, while these two instruments are both categorized as measures of Activities and Participation according to the ICF, they assess different constructs according to the fPRC. When comparing results on participation outcomes across different studies, it is therefore essential to critically examine the instruments used and the underlying constructs assessed by these instruments. Mapping instruments to the fPRC can help clarify which constructs underlie the scores of the instruments, which, in turn, can facilitate comparability of results across studies. Future studies may consider alignment with the fPRC when selecting instruments. The overview of instruments used to assess participation of children with ABI or CP and their alignment with attendance and/or involvement presented in the present review (Table S2) may provide a useful aid in this regard.

Fourteen studies were identified that assessed measurement properties of eight (out of 12) participation instruments aligning with the attendance and/or involvement constructs. As described previously, we only included studies that examined measurement properties in children with ABI or CP. This is consistent with the recommendation to examine measurement properties of instruments for health-related outcomes, such as participation, in the specific population of interest.<sup>18,19</sup> Compared to previous reviews investigating measurement properties of participation instruments for children with ABI or CP,<sup>20,21</sup> we identified five additional measures for which information on measurement properties was available (APCP, CEDL, CPQ, FPQ, and QYPP). While this indicates that the evidence has increased, the limited number of studies included still highlights the lack of evidence of measurement properties in the specific population of children with ABI or CP. Herein, we provide a comprehensive overview of the current evidence of measurement properties of participation instruments in children with ABI or CP, which may provide a useful starting point to determine which measurement properties still need further investigation.

For most instruments, sufficient measurement properties were found for at least one aspect (i.e. reliability, validity, or responsiveness). However, no instrument had been investigated for all measurement properties nor demonstrated sufficient properties for all psychometrics. Most noticeably, measurement error and responsiveness have rarely been investigated. Currently, the CEDL is the only instrument that has been shown to have sufficient responsiveness in children with CP, as examined in a study of adequate methodological quality. No instrument has received a sufficient rating for measurement error combined with a study of at least adequate quality. Sufficient measurement error and responsiveness are essential to

determine intervention effectiveness, both in research and in clinical settings. Future studies should therefore consider investigating (existing) instruments to confirm these measurement properties.

With the development of the COSMIN guidelines, significant progress was made in establishing standards for instrument development and assessment of measurement properties.<sup>22,27,53</sup> According to these guidelines, few studies included in the present review were of good methodological quality. Low methodological study quality does not necessarily indicate that participation instruments themselves are of low quality. For example, indeterminate ratings of measurement properties resulted if a certain measurement property had been examined, but not all information needed for adequate comparison against the quality criteria for good measurement properties was presented. Most studies included in the present review were conducted and published before the development of the COSMIN guidelines, which made it impossible for the authors to have followed them. With progressive insight and understanding of what is essential in terms of measurement properties, how they should be evaluated, and how these evaluations should be reported, measurement properties that have previously been established in low quality studies may need to be confirmed in new, higher-quality studies.

There are several reasons why the methodological quality of the included studies was rated low. We present them here and include suggestions for future research on how to improve the methodological quality. Structural validity determined through confirmatory factor analysis, analyses based on item response theory, or Rasch analyses were frequently examined in small samples, thereby decreasing the quality rating of the study. Consequentially, the rating of the evidence for internal consistency is also downgraded, as this requires clarity about the (uni-)dimensionality of the scale. For future studies, it is important to consider statistical guidelines when evaluating measurement properties to increase methodological quality. Construct validity was mostly examined by correlating scores from the participation instrument of interest with another instrument that was not aimed at assessing participation but, for example, quality of life or behavioural functioning. As participation measures are still emerging and measurement properties of many of these instruments are still unknown, it is understandable that other valid and reliable instruments measuring related constructs are chosen as comparison tools. However, as mentioned above, results from correlations with instruments that assess different constructs may not be comparable. To determine construct validity of a participation instrument in relation to another instrument, it is essential that validation occurs also with instruments proposing to assess the same construct (in this case, participation). Future studies could consider computing associations between different participation instruments to assess construct validity, provided that these participation instruments measure the same construct (attendance and/or involvement) in a comparable manner (i.e. comparing frequency and diversity of participation to

participation restrictions may yield very different results). Finally, many of the studies included in the present review had small study samples. While we are aware of the challenges of studies into measurement properties in a specific clinical population, it may be essential for future studies to aim to include larger samples to increase the quality of evidence of measurement properties.<sup>19</sup>

Five instruments that aligned with the attendance and/or involvement constructs, had not undergone testing of measurement properties in a sample comprising at least 50% of children with ABI or CP: the Activities Scale for Kids,<sup>54</sup> the Physical Activity Questionnaire for Adolescents,<sup>55</sup> the Physical Activity Questionnaire for Children,<sup>55</sup> the Participation and Environment Measure for Children and Youth,<sup>56</sup> and the Exercise Questionnaire.<sup>57</sup> Future studies are needed to determine validity, reliability, and responsiveness of these instruments for children with ABI or CP.

### **Strengths and limitations of the present review**

The present review was aimed at investigating participation instruments and their measurement properties in children with two frequently occurring neurological conditions: ABI and CP. Surprisingly, only a fraction of the instruments discovered had been used to assess participation in both groups. While measurement properties should be examined in the specific population of interest, the instruments themselves may not need to be diagnosis specific, depending on the purpose of the assessment. As participation is an important outcome of interest for both ABI and CP, generic instruments enabling comparison in outcome across these patient groups may be preferred.<sup>58,59</sup> Future research may want to determine which of the instruments aligning with attendance and/or involvement show good measurement properties for both children with ABI and CP or for either of these groups.

In line with our aim to examine measurement properties of participation instruments for children with ABI or CP, we only included studies that investigated measurement properties in this population. This is a strength in the light of recommendations to investigate measurement properties in the specific population of interest.<sup>18,19</sup> The limited number of studies examining measurement properties of participation instruments in samples of children with ABI or CP may be a surprising finding for many researchers and clinicians. Frequently, information on measurement properties of instruments is combined across multiple populations (e.g. children with various and diverse conditions and disabilities) without analysing subgroups of different diagnostic groups.<sup>25</sup> This can provide a broad overview of available and examined measures. However, it cannot assist researchers or clinicians in selecting instruments with good measurement properties for their specific population of interest. More studies are needed to clarify the measurement properties of instrument to assess participation in children with ABI or CP.

It is possible that some relevant studies for the present review were not discovered during our search. For example, the studies focusing on a broader population such as 'children with physical disabilities' may not have been

identified, while meeting our inclusion criterion of examining at least 50% of children with ABI or CP. Given our extensive search in databases, manuals, and reference lists, we expect that we did not miss many relevant studies and that the main conclusions of our review would not change.

In the present review, we separated different instrument versions to assess their measurement properties. Instruments in different phases of development, different language versions of instruments, and different reporter versions should be considered separate measures, as measurement properties documented for one of the versions may not be transferable to all other versions.<sup>19</sup> Moreover, measurement properties determined simultaneously in multiple countries may be confounded and therefore not necessarily applicable to only one of these countries. However, some studies reported combined data from different instrument versions, making separate assessment impossible. For example, three studies combined data from different language versions of the same instrument, i.e. English and Spanish versions of the CASP,<sup>17,50</sup> and English, Swedish, French, Danish, and Italian versions of the FPQ.<sup>44</sup> One study combined data from a self-report and a proxy-report of the QYPP.<sup>45</sup> Two studies combined data on the measurement properties of the CEDL collected in the USA and Canada.<sup>41,60</sup> Particularly striking in this context is the lack of evidence of cross-cultural validity for all these measures. When researchers or clinicians want to assess participation, it is essential for them to consider that evidence for measurement properties of an instrument found in different languages or countries are not necessarily transferable to another country or population.

### **Clinical and research implications**

Participation is essential to consider when assessing outcomes for children with ABI or CP. Children should be assessed and monitored using a recommended set of outcome measures that are specific to the life situation in focus, have good measurement properties, and are culturally adapted. To do so, the construct of interest should be clearly defined, and selected instruments should align with these constructs. With the overview of instruments aligning with attendance and/or involvement provided in the present review (Table S2) we aim to facilitate the selection of instruments with a comparable construct for future research and clinical practice. The alignment with attendance and involvement provides an important step towards a clear conceptualization of participation. However, none of the studies in the present review examined content validity of the participation instruments following standardized evaluation guidelines. While there are instruments with known content validity for children with ABI or CP, researchers and clinicians are advised to carefully consider the content of the available measures to select the one that is most appropriate for the population or patient and question at hand. For example, in clinical practice, there are likely to be differences between individuals regarding life situations of interest. Therefore, it is important to have



instruments that cover the various life situations, so the appropriate instrument can be selected.

In the research reviewed for the present review, participation instruments were used for varying purposes: to describe (sub)groups of clinical populations; to compare clinical populations with typically developing children; to determine predictors of participation outcomes; or to evaluate effectiveness of interventions. Selection of participation instruments should be guided by the aim of the assessment. Participation instruments used as best practice in clinical settings may not necessarily be the same as the instruments used in research settings.<sup>61</sup> For example, when an instrument is used to set individual therapy goals or to support conversations with the child and/or the parents, participation instruments reviewed in the present review may be of use. In this context, measurement properties such as internal consistency may be of less interest, while content validity or responsiveness may be essential to consider.

Researchers and clinicians should also consider that, depending on a child's neurological (health) condition or developmental phase, both the time for participation changes to be evident and the amount of change that might be expected may differ. Rapid change may be more likely to occur in children in the early phase after ABI than in children with CP.

When evaluating the outcome of an intervention, researchers and clinicians should consider alignment between the content of the intervention and the content of the instrument. Participation is an important outcome of interventions for children with ABI or CP, but not all interventions may lead to changes in participation. A memory strategy training for a child with ABI will most likely not lead to (immediate) better participation, but rather has a much more limited effect that may not be captured with a participation instrument. In contrast, the Pathways and Resources for Engagement and Participation intervention was found to be effective in improving participation of children in leisure activities chosen by the participating child and/or his therapist or parent when assessed using the Canadian Occupational Performance Measure.<sup>61–63</sup> Importantly, outcomes were assessed in the same areas as addressed by the intervention, thereby ensuring alignment between content of assessment and intervention.

For valid and reliable assessment of participation, measurement properties of existing or novel instruments need further evaluation. With the present review, we provide a comprehensive overview of the available evidence for

measurement properties of eight instruments to assess participation of children with ABI or CP. As no instrument had sufficient ratings for all measurement properties, researchers and clinicians may consider selecting the instrument based on the aim of the assessment. For example, if a researcher or clinician aims to examine changes in participation of a young child with CP after a certain intervention or treatment, the CEDL may be the instrument of choice, as sufficient responsiveness and test-retest reliability have been determined in studies of adequate methodological quality. For researchers and clinicians working with children with ABI, the CASP may be the instrument of choice as it is the only participation instrument for which preliminary evidence of measurement properties is available in this population. Nevertheless, we cannot yet draw final conclusions about the quality of any of these instruments for use with children with ABI or CP, as the amount of available evidence is limited, and the current overall quality of evidence is mostly low. Future studies should consider including the specific population of interest, and, importantly, follow the COSMIN guidelines to improve methodological study quality.

## ACKNOWLEDGEMENTS

We would like to thank Eline Scholten (Center of Excellence for Rehabilitation Medicine; University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, the Netherlands) for her assistance with the COSMIN Risk of Bias ratings. Mette van Kruijsbergen and Marjolijn Ketelaar have been financially supported by HandicapNL as part of the project 'Impact op Meedoen'.

## SUPPORTING INFORMATION

The following additional material may be found online:

**Appendix S1:** Full search strategy (MEDLINE/PubMed).

**Table S1:** COSMIN definitions of measurement properties, adapted from Mokkink et al.

**Table S2:** List of instruments used to quantify participation and alignment with the attendance and/or involvement constructs

**Table S3:** Characteristics of identified participation instruments

**Table S4:** Characteristics of the studies investigating measurement properties of eight of the included instruments in children with ABI or CP

**Table S5:** Measurement properties of the eight instruments tested in ABI or CP populations

**Figure S1:** Flowchart for the literature search and study selection.

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**RESUMEN**

Evaluación de la participación de niños con lesión cerebral adquirida y parálisis cerebral: una revisión sistemática de las propiedades de escalas de medición

**OBJETIVO**

Examinar qué instrumentos utilizados para evaluar la participación de niños con lesión cerebral adquirida (ABI) o parálisis cerebral (PC) se alinean con los constructos de participación de concurrencia y / o participación directa (involucramiento); y para revisar sistemáticamente las propiedades de medición de estos instrumentos en niños con ABI o CP, para guiar la selección de instrumentos.

**MÉTODO**

Se realizaron búsquedas en cinco bases de datos. Se seleccionaron los instrumentos que cuantificaron los aspectos de 'concurrencia' y / o 'participación directa' según la familia de construcciones relacionadas con la participación. Se extrajeron los datos sobre las propiedades de medición y se evaluó la calidad metodológica de los estudios.

**RESULTADOS**

Se utilizaron 37 instrumentos para evaluar la participación en niños con ABI o PC. De ellos, 12 midieron concurrencia y / o participación directa. La fiabilidad, validez y capacidad de respuesta de ocho de estos instrumentos se examinaron en 14 estudios con niños con ABI o PC. Se informaron propiedades de medición suficientes para la mayoría de los dominios, pero no se evaluó ningún instrumento en todas las propiedades relevantes. Además, la mayoría de los estudios psicométricos tienen marcadas limitaciones metodológicas.

**INTERPRETACIÓN**

Los instrumentos para evaluar la participación de niños con ABI o PC deben seleccionarse cuidadosamente, ya que muchas medidas disponibles no se alinean con la concurrencia y / o participación directa (involucramiento). La evidencia de las propiedades de medición es limitada, causada principalmente por la baja calidad del estudio metodológico. Los estudios futuros deben seguir las pautas metodológicas recomendadas.

**RESUMO**

Avaliando participação de crianças com lesão cerebral adquirida e paralisia cerebral: uma revisão sistemática de propriedades de medida

**OBJETIVO**

Examinar quais instrumentos usados para avaliar participação de crianças com lesão cerebral adquirida (LCA) ou paralisia cerebral (PC) se alinham com os constructos de comparecimento e/ou envolvimento da participação; e revisar sistematicamente as propriedades de medida destes instrumentos em crianças com LCA ou PC, para guiar a seleção de instrumentos.

**MÉTODO**

Cinco bases de dados foram pesquisadas. Os instrumentos que quantificaram aspectos da participação de "comparecimento" e/ou "envolvimento" segundo a família de construtos relacionados à participação foram selecionados. Os dados das propriedades de medida foram extraídos, e a qualidade metodológica dos estudos foi avaliada.

**RESULTADOS**

Trinta e sete instrumentos foram usados para avaliar a participação em crianças com LCA ou PC. Destas, 12 mediram comparecimento e/ou envolvimento. A confiabilidade, validade, e responsividade de oito destes instrumentos foram examinados em 14 estudos com crianças com ABI ou PC. Propriedades de medidas suficientes foram reportadas para a maioria das medidas, mas nenhum instrumento teve todas as propriedades relevantes avaliadas. A maioria dos estudos psicométricos teve limitações metodológicas importantes.

**INTERPRETAÇÃO**

Instrumentos para avaliar a participação de crianças com LCA ou PC devem ser selecionados cuidadosamente, já que muitas medidas disponíveis não se alinham com o comparecimento/envolvimento. Evidências das propriedades de medida são limitadas, principalmente devido à baixa qualidade metodológica dos estudos. Futuros estudos devem seguir diretrizes metodológicas recomendadas.