

## An Evaluation of the Use of the Child and Adolescent Scale of Participation (CASP) to Measure Social Participation After Pediatric ABI in a Specialist Service in East Anglia

Leona Wolters, William F. White, Holly Ellerton, Suzanna Watson, Kate Psaila, Catherine Ford & Fergus Gracey

To cite this article: Leona Wolters, William F. White, Holly Ellerton, Suzanna Watson, Kate Psaila, Catherine Ford & Fergus Gracey (10 Jan 2024): An Evaluation of the Use of the Child and Adolescent Scale of Participation (CASP) to Measure Social Participation After Pediatric ABI in a Specialist Service in East Anglia, *Developmental Neurorehabilitation*, DOI: [10.1080/17518423.2023.2301607](https://doi.org/10.1080/17518423.2023.2301607)

To link to this article: <https://doi.org/10.1080/17518423.2023.2301607>



© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 10 Jan 2024.



Submit your article to this journal [↗](#)



Article views: 142



View related articles [↗](#)



View Crossmark data [↗](#)

# An Evaluation of the Use of the Child and Adolescent Scale of Participation (CASP) to Measure Social Participation After Pediatric ABI in a Specialist Service in East Anglia

Leona Wolters <sup>a</sup>, William F. White<sup>a</sup>, Holly Ellerton<sup>b</sup>, Suzanna Watson<sup>b</sup>, Kate Psaila<sup>b</sup>, Catherine Ford<sup>a</sup>, and Fergus Gracey<sup>a,b</sup>

<sup>a</sup>Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, UK; <sup>b</sup>The Cambridge Centre for Paediatric Neuropsychological Rehabilitation, Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), Cambridge, UK

## ABSTRACT

Pediatric acquired brain injury (ABI) can lead to lifelong challenges restricting social participation, which is an important goal for rehabilitation due to associations with improved wellbeing. This evaluation considered the utility of the Child Adolescent Scale of Participation (CASP) in ABI rehabilitation services. The 20-item measure is rated on a Likert scale with reference to what the rater would expect of their child at that age, including “not applicable” (N/A). It showed high internal consistency ( $\alpha = 0.954\text{--}0.968$ ). Two-step cluster analysis indicated greater difficulties in children with lower participation, including more impairments of executive function and higher staff involvement. Between-group analysis indicated higher rates of N/A answers for younger children and those of ethnic minorities. Overall, the CASP is reliable and clinically useful on an individual level, helping identify people who may need prioritizing for neurorehabilitation; however, group-level analyses were more challenging due to high frequency of N/A responses.

## ARTICLE HISTORY

Received December 4, 2022  
Revised October 4, 2023  
Accepted December 28, 2023

## KEYWORDS

Activities of Daily Living;  
Adolescent; Brain Injuries;  
Child; Patient Outcome  
Assessment

## Introduction

Pediatric acquired brain injury (ABI) can result in life-altering changes to cognitive, behavioral, physical, emotional, and social functioning, leading to challenges in the home, school, and wider community.<sup>4,5</sup> ABI is defined as an injury to the brain arising after birth and sustained through a variety of causes, for example, head injury, stroke, infection, and/or postsurgical damage. In pediatric ABI, several factors have been identified as impacting upon participatory or social outcomes as detailed in the systematic review of Greenham et al.<sup>6</sup> These include the likely influence of injury severity, educational attainment, medical complications, and mental health on participatory outcomes. Possible associations were identified for a supportive environment, provision of rehabilitation, and presence of cognitive or behavioral difficulties. Difficulties might manifest years later, in comparison to functioning in their same-aged peers, since some brain areas mature later in life.<sup>1,7</sup>

Pediatric ABI and its consequences are often conceptualized using the International Classification of Functioning, Disability and Health: children and youth version (ICF-CY)<sup>8</sup>; a biopsychosocial model of disability that integrates social and medical models of disability. Functioning and disability are multi-dimensional concepts that relate to various domains, with arguably the most fundamental domain being social participation.<sup>2</sup> Social participation can be defined as “the nature and extent of a person’s involvement in meaningful life situations” and is influenced by health conditions, body functions and structures, activities, contextual factors, and cultural

background.<sup>8–10</sup> Naturally, social participation will also differ for young people depending on age and possibly other socio-demographic features such as ethnicity. In the ICF-CY, social participation covers nine domains, including communication, domestic life, interpersonal relationships, and community, civic, and social life, among others.<sup>8</sup> Social participation has also been linked to the quality of life in young people with and without disability.<sup>11</sup>

Following childhood ABI, social participation in everyday life is often restricted, and research has shown that 25–80% of children and young people (CYP) with ABI were restricted in at least one area of social participation, with difficulties often increasing over time.<sup>1,9</sup> Social participation in home, community, and school life is crucial for the young person’s development.<sup>12</sup> It provides stimulation and feedback that allow for brain development at the body structure and process level, and opportunities to develop socially and to explore personal interests to contribute to the development of their identity.<sup>8,13</sup> Importantly, social participation in activities across different areas of life has been associated with improved health and wellbeing.<sup>2</sup> Therefore, the ultimate goal of rehabilitation is to improve meaningful participation in daily living of CYP with ABI.<sup>14,15</sup>

Outcome measurement is important to monitor and track the progress of any intervention and the effectiveness of a service, but this is particularly important for complex interventions such as neuropsychological rehabilitation following

ABI.<sup>16</sup> The need for a common set of outcome measures for ABI research had been identified to standardize data acquisition and, therefore, facilitate comparisons between intervention studies.<sup>17,18</sup> Despite the proposal of outcome measures for pediatric brain injury research by the Common Data Elements (CDE) Outcome Workgroup, there is, to date, no consensus on how to measure pediatric ABI outcomes effectively.<sup>17,19</sup>

To assess social participation, the Child and Adolescent Scale of Participation (CASP) has been proposed as a supplementary outcome measure.<sup>3,17</sup> Evidence for high internal consistency of the parent-rated CASP has been gained from a small sample US study of children with ABI ( $\alpha = 0.96$ ), as well as a larger German study including a range of neurological, psychiatric, and developmental conditions (overall  $\alpha = 0.98$ , subscale  $\alpha = 0.92-0.94$ ) and a Canadian study with a similar diverse sample (total  $\alpha$  for parent rated CASP = .95).<sup>3,20,21</sup> A study of consecutive referrals to child ABI services in the Netherlands confirmed the presence of activity restrictions in this population.<sup>22</sup> Their results indicated convergence of child/young person self-ratings on the CASP with parent ratings, although parents rated participation as lower than their children. There was a suggestion that greater restrictions were evident with older children than younger children, with community participation (leisure, friendships, sports, communication) being the most marked area of difficulty.

Given the importance of improving social participation in pediatric rehabilitation, it is critical that it be measured in a reliable, valid, sensitive, and cost-effective way. At the same time, a limited number of brief measures should be used to reduce burden on CYP and families completing them. Whilst the validation studies described above suggest the CASP is promising in this regard, there may be variations in how the measure performs across samples and social and healthcare contexts, warranting further studies to explore reliability, validity, and clinical utility in planning rehabilitation and measuring outcome.

The current Paediatric Neuropsychological Rehabilitation service is a specialist community-based National Health Service (NHS) service in the United Kingdom (UK) offering assessment, formulation, and rehabilitation for CYP and their families after pediatric ABI. Rehabilitation packages are funded by several different Integrated Care Systems across the region based on the young persons' needs. Funding based on individuals' needs highlights the importance of routinely collecting outcome data to evidence to commissioners the funding needed for the service and service users. Families in this service are given outcome measures as part of their routine assessment, consistent with recommendations from the CDE including the CASP, Behavior Rating Inventory of Executive Function (BRIEF), the Strengths and Difficulties Questionnaire (SDQ), and the Pediatric Quality of Life Inventory (PedsQL), among other measures.<sup>17,23-25</sup> Demographic and clinical information, such as gender, age at injury, type of ABI, difficulties in life before ABI, injury severity, and referral information, is also recorded.

While the CASP is routinely used, there has been limited evaluation of its clinical utility in this pediatric ABI

rehabilitation service. Given the paucity of psychometric data, especially in UK-based samples, it is important to understand this further in the current service. Understanding participation and factors potentially linked to this could provide important information for the delivery of the rehabilitation service.

## **Aims and Questions**

The aim of this evaluation was to determine the utility of the CASP for a specialist pediatric neuropsychological rehabilitation service. It falls within a broader service aim to routinely examine service data to ensure measures used support the development of a good understanding of the needs and outcomes across this diverse patient population and minimize burden on CYP and families completing them.

Following the description of sample characteristics, and of any subgroups with missing or partial data, the study will address the following questions:

- (1) What are the levels of social participation as measured using the parent-rated CASP within this service at initial assessment, and what are the clinical or demographic characteristics associated with distinct levels or patterns of participation?
- (2) What are the psychometric properties of the parent-rated CASP for service users. In particular, is the parent-rated CASP reliable for use within this service context?

## **Method**

### **Design**

A cross-sectional design was used. The variable of interest was participation as measured by the CASP. Other variables included gender, type of ABI, age at injury, referral and assessment, time from injury to referral, time from referral to assessment, ethnicity, pre-injury factors, Glasgow Coma Scale (GCS) score, and number of health care professionals (HCPs) involved outside of the service at the time of the referral, scores on the BRIEF, SDQ, and PedsQL.

### **Ethical Considerations**

The evaluation was approved by the local university's Ethics Committee and by the local NHS Research and Development Team. Consent from service users to use anonymized data for service evaluation purposes is routinely obtained on completion of outcome measures. Anonymized data were accessed through secure remote data services. All data was handled in line with the Data Protection Act and GDPR (2016).<sup>26</sup>

### **Participants**

Anonymized data of 152 service users of a pediatric neuropsychological rehabilitation service were available, of whom 91 completed the CASP. Only cases with available CASP score were considered in this service evaluation. All participants met

the inclusion criteria of the service: CYP up to the age of 19, with an ABI sustained after a period of normal development, and complex and enduring neuropsychological needs due to ABI.

### Measures

Data from the initial assessment were used in this evaluation. This included demographic data on age, gender, ethnic background, type of ABI, time of injury, time post-ABI, and pre-injury factors collected as part of routine assessments and the following standardized measures:

#### *The Child and Adolescent Scale of Participation*

The CASP is designed to measure a young person's participation in home, school, and community activities subjectively, compared to a child of the same age, based on a parent/guardian's report.<sup>3,27</sup> It is a part of the Child and Family Follow-up Survey and its development has been informed by the ICF, literature review, and feedback from families, children, clinicians, and researchers.<sup>2,3</sup> According to the family of participation-related constructs (fPRC) framework, participation consists of two main elements: attendance and involvement.<sup>28</sup> A recent review suggested that the CASP is associated with the attendance and involvement constructs of participation and, therefore, assesses the fundamental constructs of participation in line with the fPRC.<sup>15</sup> It was developed to assess the needs and outcomes of CYP with ABI; however, it has also been used for children with other disabilities.<sup>29</sup> To date, it is the only participation measure validated for CYP with ABI, aligned with the fPRC and ICF definitions of participation.<sup>15</sup>

The parent-rated CASP has 20 ordinal items, rated on a 4-point scale ("age expected (full participation)," "somewhat restricted," "very restricted," and "unable"). The rater can tick not applicable (N/A) if the activity is not expected of the child due to their age. As most items are applicable for children aged five and older, it is recommended to administer the CASP for school-aged children. The items are grouped into four subsections: Home Participation (six items), Community Participation (four items), School Participation (five items), and Home and Community Living Activities (five items). Internal consistency has been established as good in a sample of children with ABI in the US ( $\alpha = 0.96$ ) with similar excellent reliability in separate samples of children with chronic conditions or disability in Germany ( $\alpha = 0.98$ ) and Canada ( $\alpha = 0.95$ ).<sup>3,20,21</sup>

#### *Strengths and Difficulties Questionnaire*

The SDQ is a 25-item questionnaire to assess the impact of symptoms and functioning on areas of the young person's everyday life.<sup>24</sup> It can be completed by parents or teachers of 3- to 16-year-old and by 11- to 16-year-old children themselves. It asks about positive and negative attributes and respondents indicate responses on a 3-point Likert scale. The extended version of the questionnaire has an additional five-item impact scale asking about the young person's overall distress and social impairment (e.g., "interfere with home life"). Higher scores indicate a higher impact on the child's

life. This measure shows a satisfactory overall internal consistency (mean  $\alpha = 0.73$ ), good internal consistency of the Impact subscale ( $\alpha = 0.85$ ) and has been widely used in pediatric ABI research.<sup>30,31</sup> The parent report of the SDQ-Impact scale was used in this service evaluation.

#### *Behavioral Rating Inventory for Executive Function*

The BRIEF is an 86-item behavioral measure of executive functions in young people aged 5–18.<sup>23</sup> It can be completed by parents, teachers, or the young person themselves. There are eight subscales, which are summarized in the Behavioral Regulation Index (BRI; including scale scores for inhibition, shifting, and emotional control) and the Metacognition Index (MI; including scale scores for initiation, working memory, planning and organization, organization of materials, and monitoring). The Global Executive Composite (GEC) is the sum of the BRI and MI.

The measure has been used in pediatric ABI research populations, showing good internal consistency for the index scores ( $\alpha$  range = 0.96–0.98).<sup>23</sup> The parent-reported GEC was used in this evaluation.

#### *Paediatric Quality of Life Inventory*

The PedsQL is a questionnaire measuring health-related quality of life in young people aged 2–18.<sup>25</sup> The child-report and parent-proxy versions of the inventory contain 23 questions about the young person's physical, psychosocial, emotional, social, and school functioning; the core dimensions of health as delineated by the WHO.<sup>25</sup> The total score for self-report and proxy-report has shown good internal consistency ( $\alpha$  range = 0.85–0.90 and  $\alpha$  range = 0.89–0.90, respectively).<sup>25</sup> The total score of the PedsQL was used in the current analysis.

### Procedure

In keeping with UK law as implemented within the NHS, parents (for CYP under 16 years) or the young person (if 16 or over) provided consent for their routinely collected clinical data to be used for clinical and service evaluation purposes upon acceptance to the service.<sup>32,33</sup> A selection of demographic and outcome measures are sent out to families in advance of their initial assessment. Data from the questionnaires were added to individual Excel spreadsheets for each service user and collated into a service wide spreadsheet. The information gathered and analyzed was gathered as part of a routine initial clinical assessment for all referrals from 2011 to the time of data analysis in 2021.

#### *Data Analysis*

Data were analyzed using Statistical Package for the Social Sciences (SPSS) Version 27 and G\*Power 3.1. The  $\alpha$ -level was set at 0.05.

Non-parametric tests (Pearson's Chi-squared, Fisher's exact, and Mann-Whitney U tests) were used as data were not normally distributed, to compare young people who did and did not complete the CASP and those who responded to all items of the CASP with those who selected N/A for at least one item. According to G\*Power, there were sufficient participants per group to detect a medium and large effect, respectively.

Descriptive statistics, including medians, interquartile ranges, and frequencies, of the CASP and demographic data were calculated. Cronbach's alpha was used to test the internal consistency of the CASP data. N/A responses affect the ability to calculate Cronbach's alpha. These responses are not equivalent to missing item-values, as they are more meaningful; nevertheless, as N/A does not fit the underlying construct of the response scale, N/A responses cannot be considered in the calculation, as the variance of the measure would increase due to varying numbers of responses given. Therefore, two approaches were used for this calculation. First, Cronbach's alpha was calculated based on a sub-sample of young people who did not select N/A for any item. Second, to calculate Cronbach's alpha based on the full sample, N/A responses were replaced with the participant's respective mean score, as described by Bedell.<sup>3</sup>

A two-step cluster analysis was performed using SPSS to explore differences between participants with different patterns/levels of participation (without N/A responses) according to parent-rated CASP subscale scores. The two-step clustering method identifies clusters by constructing a Cluster Feature (CF) tree first and then grouping leaf nodes of the CF tree using the hierarchical method (i.e., grouping items in a "bottom-up" approach), which produces different cluster solutions. These are then assessed against the Bayes Information Criterion (BIC) to determine the best number of clusters. Two-step analysis is commonly used in psychological and health sciences due to the availability of graphs and its ease of use.<sup>34</sup> The Average Silhouette Coefficient (ASC) was used to measure how tightly grouped all data in the clusters are and, therefore, indicates goodness-of-fit of the clusters. Values above 0.5 indicate a good fit.<sup>35</sup> The Log-Likelihood was used as a similarity measure. The basic conditions for a two-step cluster analysis are 1) to not use a large number of clustering variables; 2) a sample size of at least  $2^m$  ( $m$  is the number of clustering variables); and 3) no high correlation between clustering variables ( $r > 0.90$ ).<sup>35</sup> The ratio between the largest and smallest clusters should be below 2.<sup>36</sup> Statistical analyses were used to establish if cluster membership is associated with different clinical and demographic characteristics.

## Results

### Demographic Variables

The parents of 91 young people completed the CASP compared to parents of 61 young people who did not (CASP non-completers). Descriptive data of the sample with CASP scores are presented below (Tables 1 and 2). No significant differences were found between these groups on demographic variables, except for pre-injury medical issues ( $\chi^2(1) = 7.364$ ,  $p = 0.007$ ) after correcting for multiple comparisons according to Holm-Bonferroni Sequential Correction method. More parents who completed the CASP endorsed that their child had pre-injury medical conditions before ABI (40.7%) than those who did not complete the CASP (19.7%).

In the sample of 91 participants, 7.9% of items were answered with N/A. The count of N/A answers per question

**Table 1.** Frequencies (%) of categorical demographic variables.

	Overall <i>n</i> = 152	CASP completers <i>n</i> = 91	CASP non- completers <i>n</i> = 61
<b>Gender</b>			
Male	86 (56.6)	47 (51.6)	39 (63.9)
Female	66 (43.4)	44 (48.4)	22 (36.1)
<b>Type of Injury</b>			
TBI	74 (48.7)	46 (5.5)	28 (45.9)
Infection	20 (13.2)	10 (11.0)	10 (16.4)
Vascular	18 (11.8)	10 (11.0)	8 (13.1)
Tumour	11 (7.2)	6 (6.6)	5 (8.2)
Multiple	10 (6.6)	6 (6.6)	4 (6.6)
Perinatal	7 (4.6)	4 (4.4)	3 (4.9)
Autoimmune	7 (4.6)	4 (4.4)	3 (4.9)
Other	5 (3.3)	5 (5.5)	0 (0)
<b>Pre-injury Medical Difficulties</b>			
No	103 (78.3)	54 (59.6)	49 (8.3)
Yes	33 (21.7)	37 (4.7)	12 (19.7)
<b>Pre-injury Developmental Difficulties</b>			
No	119 (78.3)	75 (82.4)	44 (72.1)
Yes	33 (21.7)	16 (17.5)	17 (27.9)
<b>Pre-injury Psychiatric Difficulties</b>			
No	131 (86.2)	79 (87.8)	52 (85.2)
Yes	19 (12.5)	11 (12.2)	8 (13.1)

**Table 2.** Median (interquartile range) of continuous demographic variables (in years).

	Overall <i>n</i> = 152	CASP completers <i>n</i> = 91	CASP non- completers <i>n</i> = 61
Age at Injury	9.618 (9.78)	9.306 (9.98)	11.739 (8.39)
Age at Referral	13.183 (6.03)	12.756 (5.69)	14.453 (6.21)
Age at Assessment	13.573 (6.11)	13.233 (5.84)	14.970 (6.35)
Time from Injury to Referral	0.900 (4.01)	1.940 (16.65)	0.750 (2.34)
Time from Referral to Assessment	0.320 (0.46)	0.320 (.50)	0.340 (.44)

is provided in Table 3. Forty-six participants completed all items of the CASP without indicating that an item was N/A. Due to a relatively high frequency of questions not answered, the sample of participants who provided N/A answers to questions was compared to those who did not choose this answer option in order to establish if this was more likely to occur for some participants than others. There was a significant difference between groups, for age at referral ( $U = 685.0$ ,  $p = 0.03$  after Holm-Bonferroni Sequential Correction for multiple comparisons), indicating that the group with N/A answers ( $M = 10.812$ ,  $SD = 3.875$ ) is younger than the other group ( $M = 13.088$ ,  $SD = 3.280$ ). Although younger, the N/A group's mean age is well above 5, and the items have been designed for young people aged 5 and above. Additional analysis showed a negative correlation ( $r = -.266$ ,  $p = 0.011$ ) between age at referral and number of N/A answers, indicating an increase of N/A responses with decreasing age of the participant. A significant difference between groups was also found for ethnic minority groups ( $\chi^2(1) = 9.855$ ,  $p = 0.002$ ). There were proportionally more White participants in the group of

**Table 3.** Count of N/A response (%) per question.

Question	Count of N/A	Question	Count of N/A
1 – Social, play, or leisure activities with family members at home	2 (2.199%)	11 – Educational (academic) activities with other children in his or her classroom at school	7 (7.692%)
2 – Social, play, or leisure activities with friends at home	3 (3.297%)	12 – Social, play, and recreational activities with other children at school	7 (7.692%)
3 – Family chores, responsibilities, and decisions at home	3 (3.297%)	13 – Moving around at school	6 (6.593%)
4 – Self-care activities	2 (2.199%)	14 – Using educational materials and equipment in his or her classroom/s	10 (10.990%)
5 – Moving about in and around the home	2 (2.199%)	15 – Communicating with other children and adults at school	6 (6.593%)
6 – Communicating with other children and adults at home	5 (5.495%)	16 – Household activities	9 (9.890%)
7 – Social, play, or leisure activities with friends in the neighborhood and community	6 (6.593%)	17 – Shopping and managing money	10 (10.990%)
8 – Structured events and activities in the neighborhood and community	10 (10.990%)	18 – Managing daily schedule	11 (12.088%)
9 – Moving around the neighborhood and community	10 (10.990%)	19 – Using transportation to get around in the community	24 (26.374%)
10 – Communicating with other children and adults in the neighborhood and community	5 (5.495%)	20 – Work activities and responsibilities	27 (29.670%)

Note. A brief indication of question content is provided. Please see appendix C for the full questionnaire.

**Table 4.** Descriptive statistics of CASP total and subscale scores.

	N	Min. <sup>a</sup>	Max. <sup>a</sup>	Mean (SD)
CASP Total	91	41	100	80.153 (15.362)
Home Participation	46	41	100	80.364 (18.145)
Community Participation	86	50	100	84.162 (13.986)
School Participation	46	50	100	85.100 (16.136)
Home & Community Living	86	25	100	76.781 (19.192)
	46	25	100	78.261 (21.071)
	86	45	100	82.733 (14.376)
	46	50	100	82.826 (16.352)
	84	25	100	73.306 (23.079)
	46	25	100	73.587 (24.351)

Note. Statistics are presented for the full sample (top row) and for the sub-sample of service users who did not select N/A for any item (bottom row).

<sup>a</sup>The range of possible scores is 25–100 for the total and all subscales, with higher scores indicating higher participation.

people with no N/A answers than participants from an ethnic minority background (97.8% to 2.2%) compared to the group with N/A answers (75.6% to 24.4%, respectively) suggesting that people from an ethnic minority background were more likely to select N/A.

### Levels of Social Participation

Descriptive statistics of total and subscale scores of the CASP are presented in Table 4. The mean total CASP score of 80 (SD = 15.36) is slightly higher than that of the diverse clinical/disability sample in the German validation study of 75/58 (SD = 19.56) but more than 2 SD lower than the population-based sample in this study which showed a high level of appropriate participation (M = 98.16, SD = 5.80).<sup>20</sup> The total and subscale scores we observed are lower than the median scores of the parent rated CASP presented with a child ABI sample presented by Allonsius and colleagues, although our sample broadly fell within the IQR of these median scores.<sup>22</sup>

### Psychometric Properties

The CASP showed high internal consistency for participants who did not indicate N/A to any of the questions (n = 46,  $\alpha$  =

0.968) and in the full sample when N/A answers were replaced by the participants' respective means (n = 90,  $\alpha$  = 0.954).

### Clusters of Participation

For the two-step cluster analysis, the subsample of participants who did not indicate N/A for any questions was used (n = 46) due to limitations in replacing N/A responses in a meaningful way. Basic conditions for the two-step cluster analysis were fulfilled with correlations between the subscale scores ranging (r) from 0.777 to 0.874. Two clusters with sample sizes of 28 (60.9%) and 18 (39.1%) emerged with a ratio of sizes of 1.56. The ASC was 0.7, indicating a good goodness-of-fit of the clusters. The ASC for three or four clusters would have been 0.6 and 0.5, respectively, indicating that the two clusters are the most appropriate fit. Home participation was the strongest predictor of cluster membership, followed by school participation, community participation, and then home and community living. Cluster 1 (low participation) was characterized by lower participation across all sub-domains with the lowest mean score for home and community living. Cluster 2 (average participation) was characterized by higher participation across all domains. Mean scores are presented in Table 5.

Mann–Whitney U tests and chi-square analyses were used to analyze differences in demographic and outcome measure

**Table 5.** Descriptive statistics of the clusters of participation.

	Cluster 1 <i>n</i> = 18 Mean (SD)	Cluster 2 <i>n</i> = 28 Mean (SD)
Home Participation	68.057 (12.210)	96.056 (4.687)
Community Participation	57.292 (15.044)	91.741 (10.765)
School Participation	65.833 (10.182)	93.750 (8.008)
Home & Community Living	48.889 (18.032)	89.464 (10.744)

variables between clusters (Table 6). Mann–Whitney *U* tests and Pearson chi-square  $\chi^2$  tests showed a significant difference between clusters for number of HCPs at the time of referral, PedsQL score, SDQ-Impact score, and BRIEF-GEC score (Table 6). This indicates that participants in cluster 1, had a higher number of HCPs at referral, and a lower PedsQL score as well as higher scores on the SDQ-Impact and BRIEF-GEC.

## Discussion

This service evaluation explored the clinical utility of the parent-rated CASP, as an outcome measure of young people's social participation within a UK NHS community neuropsychological rehabilitation service. Whilst the CASP has been evaluated in this regard in general pediatric and ABI samples in other countries and service contexts, this is the first such evaluation within a UK context, among children with predominantly neuropsychological consequences of ABI.

In summary, CASP completion was more likely to occur where the child had a preexisting medical condition, and elevated levels of N/A responses were found as expected for younger children (where more items will be outside their level of development) and importantly also for those from nonwhite British ethnic background. In relation to question 1, the level of overall participation within this sample was similar to one small study of children with ABI in the US, and a general disability/chronic condition sample in a German study but lower than that found in a larger study sample of children with ABI in the Netherlands.<sup>3,20,22</sup>

A cluster analysis making use of subscale scores identified a 2-cluster solution best accounted for CASP score differences. Scrutiny of the patterns of scores indicated that cluster 1 showed low levels of participation, lower than reported in other studies of ABI and disability.<sup>3,20–22</sup> Cluster 2 represented those with overall higher levels of participation, which corresponded roughly to levels reported in Allonsius and colleagues' study of children with ABI.<sup>22</sup> Across both high and low participation clusters, "home and community living" showed the lowest levels of participation. Items of this subscale include instrumental activities of daily living, which require better executive functioning as they involve sequences of steps over time (and possibly locations) keeping the main goal in mind, being resistant to distraction and may require capacity for flexibility under changing circumstances. Consistent with the impact of EF difficulties on participation, BRIEF general executive composite score was significantly different between the high and low participation clusters. Although not

**Table 6.** Analyses of difference between clusters for demographic and outcome measure variables.

	Median	Cluster 1 Mean rank	Cluster 2 Mean rank	Test statistic	Statistical significance
Age at Injury (years, months)	10.904	18.83	26.5	<i>U</i> = 168.0	<i>p</i> = .059
Age at Referral (years, months)	13.675	19.17	26.29	<i>U</i> = 174.0	<i>p</i> = .079
Age at Assessment (years, months)	13.935	17.74	25.5	<i>U</i> = 148.5	<i>p</i> = .051
Time from Injury to Referral (months)	.920	26.25	21.73	<i>U</i> = 202.5	<i>p</i> = .265
Time from Referral to Assessment (months)	.340	21.97	24.48	<i>U</i> = 224.5	<i>p</i> = .536
PedsQL	54.5	12.82	21.0	<i>U</i> = 75.0	<i>p</i> = .032*
SDQ-Impact	5	26.83	17.5	<i>U</i> = 120.0	<i>p</i> = .014*
BRIEF-GEC	68	30.76	18.29	<i>U</i> = 106.0	<i>p</i> = .002**
Number of HCPs Outside of the Service at Time of Referral	4	30.86	18.77	<i>U</i> = 119.5	<i>p</i> = .002**
		<b>Cluster 1 Frequency</b>	<b>Cluster 2 Frequency</b>		
<b>Gender</b>				$\chi^2 = .056$	<i>p</i> = .811
Male		9 (50%)	15 (53.6%)		
Female		9 (50%)	13 (46.4%)		
<b>Ethnicity</b>					<i>p</i> = 1.000 <sup>a</sup>
White Background		18 (100%)	27 (96.4%)		
Ethnic Minority Background		0 (0%)	1 (3.6%)		
<b>Type of Brain Injury</b>				$\chi^2 = .253$	<i>p</i> = .615
TBI		7 (38.9%)	13 (46.4%)		
Non-TBI		11 (61.1%)	15 (53.6%)		
<b>Pre-injury Medical Difficulties</b>				$\chi^2 = 2.159$	<i>p</i> = .142
No		9 (50%)	20 (71.4%)		
Yes		9 (50%)	8 (26.8%)		
<b>Pre-injury Developmental Difficulties</b>				$\chi^2 = .097$	<i>p</i> = .755
No		16 (88.9%)	24 (85.7%)		
Yes		2 (11.1%)	4 (14.3%)		
<b>Pre-injury Psychiatric Difficulties</b>					<i>p</i> = .199 <sup>a</sup>
No		14 (77.8%)	25 (89.3%)		
Yes		4 (22.2%)	2 (7.1%)		

<sup>a</sup>Fisher's Exact Test; two-sided.\**p* < .05.\*\**p* < .005.

possible to infer direction of effect, quality of life was lower, and SDQ impact of difficulties on the young person greater in the lower participation cluster. This indicates that among children in this service with more significant neuropsychological needs, there are also significantly lower levels of participation and quality of life. Children in cluster 1 were also more likely to have a higher number of health care professionals from outside of the neuropsychological rehabilitation service involved. Although difficult to interpret, we were interested in this in terms of service provision and funding. A greater number of professionals and agencies involved reflects greater rehabilitation costs as well as potential complexity, where care and support must be managed across services which may operate differently, lack expertise in brain injury or neuropsychological problems and have different models and approaches to support. As such, parent-reported CASP scores might help neurorehabilitation service staff identify children who have multiple and complex issues associated with especially low levels of participation. Funders of services would benefit from being aware that there is a subgroup of children with “hidden” neuropsychological disability who might have high care costs and complexity, and risks to mental health and quality of life associated with low levels of participation.

In relation to question 2, the internal consistency found in this sample was high and consistent with the Cronbach’s alpha reported in validation studies.<sup>3,27</sup> Different options were considered in the analysis of reliability to include cases with N/A answers to increase the sample size for a better estimate of internal consistency and avoid deletion of cases without full responses, which might lead to biases if scores are not missing completely at random.<sup>37</sup> A method used by Bedell in one of the validation studies was applied, namely participant mean scores were substituted for N/A answers.<sup>3</sup>

The high percentage of N/A responses, indicating that activities were considered by parents or guardians as not appropriate for their child’s age, reduced the sample size significantly for the cluster analysis. N/A answers could not be treated as missing values, as the “missingness” is intentional and by design, i.e. it is providing a response, namely that the young person is not expected to be able to perform an activity due to their age.<sup>38</sup> As expected, due to the CASP’s scoring guidelines, a significant difference between participants with no N/A answers and participants with some N/A answers for age at referral and/or assessment was found. However, a statistical difference in ethnic background was also found between the two groups of responders (i.e., White vs ethnic minority). This raises the question of whether there are cultural differences in pediatric participation and activities expected of children at different ages and, therefore, if participation measured by the CASP of children from different ethnic backgrounds should be compared.

In determining the potential usefulness of the CASP as a tool in evaluating pediatric neurorehabilitation services, we were interested to find out about the use of the N/A rating and approaches to scoring. Service evaluation requires scores on measures to be aggregated to determine pre-post rehabilitation change, or determination of individual change being reliable and clinically meaningful. As expected, younger age was associated with greater N/A responses. In addition, we took the

approach of replacing N/A responses with mean values for that young person for the purposes of aggregate statistical analysis. An alternative approach might be to band or stratify groups of service users into different age groups (and possibly ethnic groups) and aggregate scores in bands with comparable levels of N/A responses. Further work on the validation of different approaches to handling N/A scoring across age groups and ethnicity is warranted in order to ensure meaningful score aggregation. A further limitation of the measure is the ceiling effect. Mean total scores for this clinical population with known participation restrictions were present was about 80/100, with *SD* of 15. This may make it difficult to determine change at the upper levels of participation. Our study indicates that there is a very low participation cluster among children with ABI with neuropsychological difficulties, where the ceiling effect may be less of an issue for evaluating clinical outcomes in a service context. However, for the ABI sample as a whole (as also indicated by other studies with child ABI) future research should analyze the CASP using item response theory rather than classical test theory, and potentially identify and evaluate new items that are more difficult to endorse and therefore better able to distinguish a person’s ability at the upper end of participation.<sup>3,22</sup> Alternatively, services might consider an alternative measure such as the PEM-CY (child rated) or YC-PEM (parent/caregiver rated).<sup>39,40</sup> While the CASP invites parents to rate the level of their child’s participation on a 4-point scale, the PEM-CY evaluates participation in the home, at school and in the community alongside environmental factors within each of these settings. It invites parents to rate the *frequency* and the *level of involvement* their child has in each activity as well as whether they would like to be able to change their child’s level of participation with each item. Given that goals in Activity and Participation from the ICF-CY were the most frequent for the young people in this service,<sup>41</sup> the PEM-CY may be a more useful rehabilitation tool to help with both assessment of a young person’s level of participation and goal setting for intervention.

## Service Implications and Clinical Recommendations

These findings have valuable implications for clinical practice in this service, and potentially for other services dedicated to working with CYP with ABI.

The CASP showed good internal reliability when used to assess participation in young people in this service. The availability of subscales within the measure can be used to analyze outcomes for specific domains of participation, which might be extremely valuable for clinical implications if future service evaluations with larger sample sizes confirm the clusters found or indicate more distinct clusters.

Nevertheless, given the high percentage of N/A responses, the evaluation highlighted some areas that need to be considered when discussing the utility of the measure for the service. The structure of the measure, allowing parents to indicate N/A if they considered the activity not expected of their child due to their age, might facilitate meaningful responses on an individual clinical level, if selected as expected; however, it creates a challenge when evaluating data on a group level. In addition, the findings highlighted that not only age but also ethnic

background was associated with parents selecting N/A responses. It may be beneficial to provide additional, extended guidelines on when an N/A response should be selected. Alternatively, a member of staff could complete the measure with CYP's parents, which might provide valuable qualitative information on the young persons' participation and might also provide insights into factors contributing to the frequency of N/A responses in the current sample, e.g., cultural factors. It is inherently challenging to measure participation across such a range of developmental stages: A participant outcome measure using response anchors asking about the young person's ability to participate in an activity as well as their actual participation, rather than their ability in relation to what is expected at their age, could provide more meaningful information if compared to normative data for different age groups and cultural backgrounds.

Lower levels of participation were associated with greater executive dysfunction. These young people and their families might benefit from psychoeducation materials specifically about how executive functions play a role in participation and from strategies that could support their participation in daily activities despite having executive function difficulties. A recent review has evaluated prior research into predictors of participation outcome in children post TBI or spinal cord injury.<sup>6</sup> We were unable to include data regarding all possible predictors as identified in this review such as educational level, family functioning, or home or school support. However, taking the findings of Greenham et al., alongside the findings from the present study, attention should be paid to the child's educational level, school, home and community supports as well as mental health and executive functioning when identifying children at risk of poorer participatory outcomes.<sup>6</sup>

In line with the literature, lower levels of participation were also associated with lower quality of life and higher distress due to their difficulties, which emphasizes the importance of monitoring the young persons' psychological wellbeing and providing psychological support following ABI.

### Strengths and Limitations

There are strengths and limitations to this evaluation. The sample size is relatively small due to exclusion of cases with N/A answers and, therefore, the results need to be interpreted with caution. In addition, imputation methods should be used with caution, especially if differences have been found between responders and non-responders. It has been reported that the method of mean substitution overestimates Cronbach's alpha, as the interrelatedness of the items has been manipulated by substituting N/A responses with the person's mean.<sup>42</sup> Furthermore, results of the cluster analysis need to be interpreted with caution, as the analyzed sub-sample has been found to be significantly different from the full sample on two demographic variables, namely age at referral and ethnic background. In addition, the group sizes of the clusters were very small. Finally, service users of pediatric neurorehabilitation services tend to be a very heterogeneous group due to having a variety of injuries at different developmental stages, which should be kept in mind when interpreting these findings.

### Further Outcome Measure Evaluation

There are opportunities for further projects to support the understanding and development of the service with regard to CYP's participation. It could be useful to gain further understanding of when N/A responses are given. This would not only support collecting data as intended by the measure but also provide more data for future analyses. It could be useful to repeat the cluster analysis when more data are available in the service, or combined with data from other services, to be able to conduct more powerful post-hoc analyses and potentially identify more specific clusters and associated characteristics, which may be valuable in informing clinical practice. For example, the service might be able to develop different pathways of care tailored for the different clusters. A further project could evaluate the effectiveness of the service on young people's participation by comparing CASP scores at assessment and discharge and assess what factors might contribute to potential changes in participation. As the results suggest that the content of the CASP might not be fitting across different ethnic or cultural contexts, further research is needed to render measures of participation fully inclusive of all those who might need access to services. Finally, a qualitative study with parents in the service user group could provide an opportunity to learn about parents' experience of the meaningful utility of the CASP, the variables of age and culture, as well as their view on the different participation measures (e.g., PEM-CY vs CASP) available for children with acquired brain injury in the community.

### Conclusion

This evaluation of the CASP provided an understanding of the utility of an outcome measure of participation in a pediatric neurorehabilitation service. The measure has good internal consistency in the service, similar to the Cronbach's alpha reported in validation studies and indicates participation levels of young people in the service at the time of assessment.<sup>3,27</sup> In the sample, two clusters were found: one cluster with young people with lower levels of participation and one cluster with higher levels of participation. More HCPs involved at referral, shorter wait between referral and assessment, as well as higher scores on the BRIEF-GEC and SDQ-Impact were found with lower levels of participations, which provides valuable implications for clinical practice. Results also suggested that higher rates of N/A answers were associated with younger age and being from minoritized ethnic groups.

### Acknowledgments

This work was conducted as part of a Doctorate in Clinical Psychology.

### Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

The author(s) reported that there is no funding associated with the work featured in this article.

## ORCID

Leona Wolters  <http://orcid.org/0000-0002-3151-953X>

## References

- Galvin J, Froude EH, McAleer J. Children's participation in home, school and community life after acquired brain injury. *Aust Occup Ther J*. 2010;57(2):118–126. doi:10.1111/j.1440-1630.2009.00822.x.
- World Health Organization. World Health Organization: international classification of functioning, disability, and health. ICF. Geneva: World Health Organization; 2001.
- Bedell GM, Lash M. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NRE*. 2004;19(3):191–205. doi:10.3233/NRE-2004-19303.
- Fletcher JM, Ewing-Cobbs L, Miner ME, Levin HS, Eisenberg HM. Behavioral changes after closed head injury in children. *J Consult Clin Psych*. 1990;58(1):93–98. doi:10.1037/0022-006X.58.1.93.
- Ross KA, Dorris L, Mcmillan T. A systematic review of psychological interventions to alleviate cognitive and psychosocial problems in children with acquired brain injury. *Dev Med Child Neurol*. 2011;53(8):692–701. doi:10.1111/j.1469-8749.2011.03976.x.
- Greenham M, Botchway E, Knight S, Bonyhady B, Tavender E, Scheinberg A, Anderson V, Muscara F. Predictors of participation and quality of life following major traumatic injuries in childhood: a systematic review. *Disabil Rehabil*. 2022;44(12):2591–607. doi:10.1080/09638288.2020.1849425.
- Watson S, Gracey F. *Assessment in paediatric acquired brain injury*, in *psychological therapy for paediatric acquired brain injury: innovations for children, young people and families*. In J. Jim and E. Cole. Editors. Abingdon, UK: Routledge; 2020pp. 43–69 pp.
- World Health Organization. International classification of functioning, disability, and health: children & youth version: iCF-CY. Geneva: World Health Organization; 2007.
- De Kloet AJ, Berger MAM, Bedell GM, Catsman-Berrevoets CE, van Markus-Doornbosch F, Vliet Vlieland TPM. Psychometric evaluation of the Dutch language version of the child and family follow-up survey. *Dev Neurorehabil*. 2015;18(6):357–64. doi:10.3109/17518423.2013.850749.
- Liebel M, Saadi I. Cultural variations in constructions of children's participation. In: Children's rights from below. Studies in childhood and youth. London: Palgrave Macmillan; 2012.
- Law M, King G, Petrenchik T, Kertoy M, Anaby D. The Assessment of Preschool Children's Participation: internal consistency and construct validity. *Physical & Occupational Therapy In Pediatrics*. 2012;32(3):272–287. doi:10.3109/01942638.2012.662584.
- Van Tol E, Gorter JW, Dematteo C, Meester-Delver A. Participation outcomes for children with acquired brain injury: a narrative review. *Brain Inj*. 2011;25(13–14):1279–1287. doi:10.3109/02699052.2011.613089.
- Thompson M, Elliott C, Willis C, Ward R, Falkmer M, Falkmer T, Gubbay A, Girdler S. Can, want and try: parents' viewpoints regarding the participation of their child with an acquired brain injury. *PloS ONE*. 2016;11(7):e0157951. doi:10.1371/journal.pone.0157951.
- Dunn DS, Ehde DM, Wegener ST. The functional principles as psychological lodestars: theoretical inspiration and empirical direction in rehabilitation psychology. *Rehabil Psychol*. 2016;61(1):1–6. doi:10.1037/rep0000082.
- Resch C, Van Kruijsbergen M, Ketelaar M, Hurks P, Adair B, Imms C, De Kloet A, Piskur B, Van Heugten C. Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties. *Develop Med Child Neuro*. 2020;62(4):434–44. doi:10.1111/dmnc.14465.
- Byard K, Gosling S. *Reflections on outcome measures in child neuropsychological rehabilitation: a child-centred approach*, in *psychological therapy for paediatric acquired brain injury: innovations for children, young people and families*. In J. Jim and E. Cole. Editors. Abingdon, UK: Routledge; 2020pp. 207–25 pp.
- McCauley SR, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, Chapman SB, Ewing-Cobbs L, Gerring JP, Gioia GA. et al. Recommendations for the Use of Common Outcome measures in pediatric traumatic brain injury research. *J Neurotrauma*. 2012;29(4):678–705. doi:10.1089/neu.2011.1838.
- Thompson HJ, Vavilala MS, Rivara FP. Common data elements and Federal Interagency Traumatic Brain Injury Research Informatics System for TBI Research. *Annu Rev Nurs Res*. 2015;33(1):1–11. doi:10.1891/0739-6686.33.1.
- Keetley R, Westwater-Wood S, Manning JC. Exploring participation after paediatric acquired brain injury. *J Child Health Care*. 2020;25(1):81–92. doi:10.1177/1367493520905673.
- De Bock F, Bosle C, Graef C, Oepen J, Philipp H, Urschitz MS. Measuring social participation in children with chronic health conditions: validation and reference values of the child and adolescent scale of participation (CASP) in the German context. *BMC Pediatr*. 2019;19(1):1–13. doi:10.1186/s12887-019-1495-6.
- McDougall J, Bedell G, Wright V. The youth report version of the child and adolescent scale of participation (CASP): assessment of psychometric properties and comparison with parent report. *Child Care Health Dev*. 2013;39(4):512–522. doi:10.1111/cch.12050.
- Allonsius F, de Kloet A, Bedell G, van Markus-Doornbosch F, Rosema S, Meesters J, Vliet Vlieland T, van der Holst M. Participation restrictions among children and young adults with acquired brain injury in a pediatric outpatient rehabilitation cohort: the patients' and parents' perspective. *Int J Environ Res Public Health*. 2021;18(4):1625. doi:10.3390/ijerph18041625.
- Gioia GA, Isquith PK, Guy SC, Kenworthy L. BRIEF: behavior rating inventory of executive function. *Psychological Assessment Resources*; 2000.
- Goodman R. The strengths and difficulties questionnaire: a research note. *J Child Psychol Psychiatry*. 1997;38(5):581–586. doi:10.1111/j.1469-7610.1997.tb01545.x.
- Varni MS, Kurtin P. PedsQL™ 4.0: reliability and validity of the pediatric quality of life inventory™ version 4.0 Generic Core Scales in healthy and patient. In: Varni, Seid Paul. editors. Kurtin. *Lippincott Williams*, in *Medical Care*; 2001. pp. 800–12.
- Data Protection Act. *Data Protection Act 2018*. 2018; Available from: <https://www.gov.uk/government/collections/data-protection-act-2018>.
- Bedell G. *Further validation of the child and adolescent scale of participation (CASP)*. *developmental neurorehabilitation*. *Dev Neurorehabil*. 2009;12(5):342–351. doi:10.3109/17518420903087277.
- Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol*. 2016;59(1):16–25. doi:10.1111/dmnc.13237.
- Weintraub N, Rot I, Shoshani N, Pe'er J, Weintraub M. Participation in daily activities and quality of life in survivors of retinoblastoma. *Pediatric Blood & Cancer*. 2011;56(4):590–594. doi:10.1002/pbc.22790.
- Goodman R. *Psychometric properties of the strengths and difficulties questionnaire*. *Am Acad Child Adolescent Psychiatr*. 2001;40(11):1337–45. doi:10.1097/00004583-200111000-00015.
- Limond J, Adlam ALR, Cormack M. A model for pediatric neurocognitive interventions: considering the role of development and maturation in rehabilitation planning, in *clinical neuropsychologist*. *Clin Neuropsychol*. 2014;28(2):181–198. doi:10.1080/13854046.2013.873083.
- Department of Health and Social Care. Reference guide to consent for examination or treatment. *Second edition* ed. 2009.

33. National Health Service. Children and Young People - Consent To Treatment. London, UK: National Health Service; 2022. [accessed 2023 Nov 1]. <https://www.nhs.uk/conditions/consent-to-treatment/children/>.
34. Marques DR, Gomes AA, Clemente V, Drake CL, Roth T, Morin CM, de Azevedo MHP. Typologies of individuals vulnerable to insomnia: a two-step cluster analysis. *Sleep Biol Rhythms*. 2021;19(1):33–44. doi:10.1007/s41105-020-00285-7.
35. Mooi E, Sarstedt M. A concise guide to market research: the process, data, and methods using IBM SPSS statistics. Berlin: Springer; 2014.
36. Tkaczynski A. Segmentation using two-step cluster analysis. In: Dietrich T, Rundle-Thiele S, Kubacki K, editors. Segmentation in social marketing. Berlin: Springer; 2017. pp. 109–25.
37. Béland S, Pichette F, Jolani S. Impact on Cronbach's alpha of simple treatment methods for missing data. *The Quantitative Methods For Psychology*. 2016;57–73. doi:10.20982/tqmp.12.1.p057.
38. Arifin WN. Calculating the Cronbach's alpha coefficients for measurement scales with "not applicable" option. 2018;1–8.
39. Coster W, BEDELL G, LAW M, KHETANI MA, TEPLICKY R, LILJENQUIST K, GLEASON K, KAO Y-C. Psychometric evaluation of the participation and environment measure for children and youth. *Dev Med Child Neurol*. 2011;53(11):1030–37. doi:10.1111/j.1469-8749.2011.04094.x.
40. Bedell GM. *The child and adolescent scale of participation scoring guidelines*. 2011.
41. McCarron RH, Watson S, Gracey F. What do kids with acquired brain injury want? Mapping neuropsychological rehabilitation goals to the International Classification of Functioning, Disability and Health. *J Int Neuropsychol Soc*. 2019;25(4):403–412. doi:10.1017/S1355617719000213.
42. Huisman M. Imputation of missing item responses: Some simple techniques. *Qual Quant*. 2000;34(4):331–351. doi:10.1023/A:1004782230065.