


## RESEARCH ARTICLE

WILEY

# A pilot study to develop a participation self-assessment tool for adolescents: The Social Participation Inventory (SPI)

Marie Bernard<sup>1</sup>  | Laura Hoffmann<sup>1,2</sup> | Matthias Richter<sup>1,2</sup> | Carina Völm<sup>3</sup> | Miriam Seyda<sup>4</sup> | Astrid Fink<sup>5</sup> | Britta Dawal<sup>6</sup>

<sup>1</sup>Institute of Medical Sociology (IMS), Interdisciplinary Center for Health Sciences, Medical Faculty, Martin Luther University Halle-Wittenberg, Halle, Germany

<sup>2</sup>Chair of Social Determinants of Health, Department of Sport and Health Sciences, Technical University of Munich, Munich, Germany

<sup>3</sup>Department of Health, Stuttgart, Germany

<sup>4</sup>Chair of School and Teaching (Physical Education), Institute of Sports and Sports Science, Technical University of Dortmund, Dortmund, Germany

<sup>5</sup>Kreis Groß-Gerau, Department of Health, Groß-Gerau, Germany

<sup>6</sup>Department of Educational and Social Sciences, University of Applied Sciences South Westphalia, Iserlohn, Germany

## Correspondence

Marie Bernard, Medical Faculty Martin Luther University Halle-Wittenberg, Magdeburger Str. 8, Halle 06112, Germany.

Email: [marie.bernard@medizin.uni-halle.de](mailto:marie.bernard@medizin.uni-halle.de)

## Funding information

German Research Foundation, Grant/Award Number: 404636197; Publication Fund of the Martin-Luther-University Halle-Wittenberg

## Abstract

**Objective:** Participation is one of the key goals of re/habilitative processes. Since participation impacts adolescents' social-emotional development and overall health, this goal is particularly important for them. However, to date, no German-speaking self-assessment tool for participation among adolescents is available. This study sought therefore to develop such a tool and to test its psychometric properties.

**Methods:** Based on a preliminary qualitative study, we developed 133 items for a pilot version of the Social Participation Inventory (SPI). The SPI assesses the objective dimension (i.e., attendance) and the subjective dimension (i.e., involvement and satisfaction) of participation. To test the psychometric properties of the SPI, we conducted a quantitative cross-sectional survey and applied the SPI to  $n = 151$  adolescents with and without disabilities and/or chronic diseases.

**Results:** By using principal component analyses, we examined the SPI's consistency and verified the theoretical considerations regarding the two components of participation (i.e., objective and subjective dimensions). Items that did not load sufficiently on components were removed after careful theoretical-based consideration. The condensed version of the SPI consists of 39 items that assess participation and 18 items to assess the perceived importance of respective areas of life. The SPI shows very good overall reliability (Cronbach's  $\alpha = .920$ ) and good validity.

**Conclusion:** This study provides a new psychometrically tested participation self-assessment scale for adolescence with and without disabilities and/or chronic diseases. Further research is needed to re-evaluate its psychometric properties and to evaluate the application of the SPI in clinical and scientific contexts.

## KEYWORDS

adolescents, chronic diseases, disabilities, participation, psychometric properties, rehabilitation, self-assessment tool

## 1 | INTRODUCTION

For adolescents, participation is an important driver for developing and improving, for example, social-emotional (Powrie et al., 2015), physical and psychological skills and self-identity and self-concept (Anaby et al., 2022). By introducing the International Classification of Functioning, Disabilities and Health (ICF) (WHO - World Health Organisation, 2001), the importance of participation, which is in this context understood as an unconditional inclusion in social and non-social life situations, was anchored as an ultimate goal of medical care and re/habilitation processes (de Bock et al., 2019). In order to evaluate this goal, assessment instruments to describe, measure and evaluate participation become necessary (Anaby et al., 2022).

To our best knowledge, only a few instruments for measuring generic participation in the re/habilitation context in Germany exist, focusing either on special developmental aspects like communication or specific age groups (FOCUS<sup>®</sup>; Focus on the Outcomes of Communication Under Six) (Neumann et al., 2017) or must be considered as proxy participation measurements (Participation and Environment Measure – Children and Youth, PEM-CY, Krieger et al., 2020; Child and Adolescent Scale of Participation, CASP, de Bock et al., 2019). The CASP is also available as self-rating scale (McDougall et al., 2013) but faces the same short comings as the original version, which were addressed by the authors (Bedell, 2009), as it neither assesses comprehensively socioenvironmental factors nor the subjective relevance of divergent life situations. The authors themselves raise awareness that the CASP focuses merely on body functioning rather on the social aspects of participation (Bedell, 2009). This study aims therefore to develop a self-assessment tool for participation for adolescents with and without physical impairments and chronic diseases and to test its psychometric properties.

So far, the development of appropriate (German) instruments was impeded by limited theoretical concepts of participation. In Germany, the terminology—and thus the theoretical concept—is particularly challenging since there are a couple of terms that describe participation (i.e., *Teilhabe* and *Partizipation*). Both terms differentiate regarding their meaning and needs therefore to be used with caution (Gebhard et al., 2021). To address this issue and to clarify our objective, we decided to refer to participation in life situations as *social participation* (*Soziale Partizipation*). This also includes life situations that a young person spends alone but that are connected to their social life such as autonomous body care as a prerequisite for staying over at a friend's house. However, in the following, we will use the term *participation* when reporting our concept in English. So far, the term *participation* is, however, still a vague concept that needs to be defined in greater detail. Although the family of participation-related constructs (fPRC) developed by Imms et al. (2017) is the most prominent concept, the authors state that the components of participation are not yet fully understood. We thus sought to refine the concept of participation (Bernard et al., n.d.) in a preliminary study based on qualitative results (Bärwalde et al., 2023; Hoffmann et al., 2023). Our findings and the resulting concept of participation (Bernard et al., n.d.) are in line with the fPRC (Imms et al., 2017). Both concepts outline the

### Key Messages

- Participation is crucial for adolescent development and thus a key goal for rehabilitative processes.
- The perception of participation depends particularly on the subjective perspective.
- There is a lack of German comprehensive self-assessment tools for adolescents with and without physical disabilities and/or chronic diseases.
- The Social Participation Inventory (SPI) is an assessment tool for adolescents to self-rate their level of participation in important areas of life in relation to the subjective relevance of these areas.
- The SPI shows very good overall reliability (Cronbach's  $\alpha = .920$ ) and good validity.

importance of attendance (i.e., objective dimension) and involvement (i.e., subjective dimension) as key factors for participation. Apart from this, our findings underline the importance of subjective relevance (Bernard et al., n.d.). That means that participation becomes particularly crucial in life domains that are rated important to the individual whereas life domains that are evaluated to be somewhat irrelevant do not require such a high level of participation. The preceding qualitative surveys (Bärwalde et al., 2023; Hoffmann et al., 2023) indicated the respective domains that play a role in adolescent lives (e.g., familiar interaction, friendships, leisure time, social media, schooling and self-care).

In this paper, we will introduce the Social Participation Inventory (SPI), a participation self-assessment tool for adolescents with and without disabilities and chronic diseases that covers participation in social and non-social life situations.

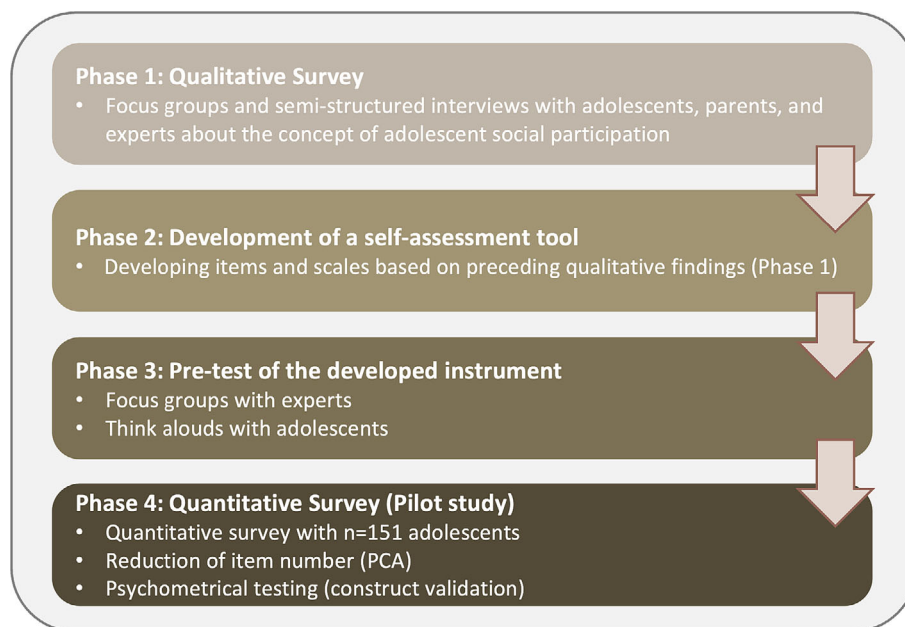
It will be described how the SPI was developed based on our conceptual preliminary considerations, its application within a pilot study and its psychometric properties. By doing so, it was examined whether our theoretical concept of participation can be validated based on empirical data.

## 2 | METHODS

To develop a participation self-assessment for adolescents, we conducted a mixed methods study that comprised four phases (see Figure 1) (Baerwalde et al., 2019).

### 2.1 | Phase 1: Qualitative survey

The qualitative analysis revealed what life domains are relevant in adolescents' lives and how participation was defined by different stakeholders, that is, adolescents, their caretakers and experts in the field of rehabilitation. The importance of attending, functioning and

**FIGURE 1** Phases of the study.

level of involvement in social interaction as well as the subjective perspective of adolescents were emphasized. These findings were used as the foundation to conceptualize participation and to develop a participation self-assessment tool for adolescents, which is outlined in the following. Since the findings of the first phase (i.e., the qualitative survey) were published elsewhere (Baerwalde et al., 2023; Hoffmann et al., 2023), this paper refrains to present the study findings in detail.

## 2.2 | Phase 2: Development of the SPI

Based on qualitative results (Baerwalde et al., 2019) and the derived concept of participation (Bernard et al., n.d.), we developed a pilot version of the SPI, a self-assessment tool for adolescents with and without chronic diseases and/or physical disabilities. Figure 2 displays the structure of the pilot version that was applied in the study.

Our prior qualitative findings (Phase 1) suggested that participation consists of a subjective and objective dimension. The objective dimension assesses attendance, which can be operationalized by functioning in relevant areas, frequency compared to peers and accessible options to participate. The subjective component assesses the level of involvement and satisfaction. Involvement was operated by using only one item (*feeling integrated*), whereas we developed two items (*feeling content* and *feeling comfortable*) to operationalize satisfaction.

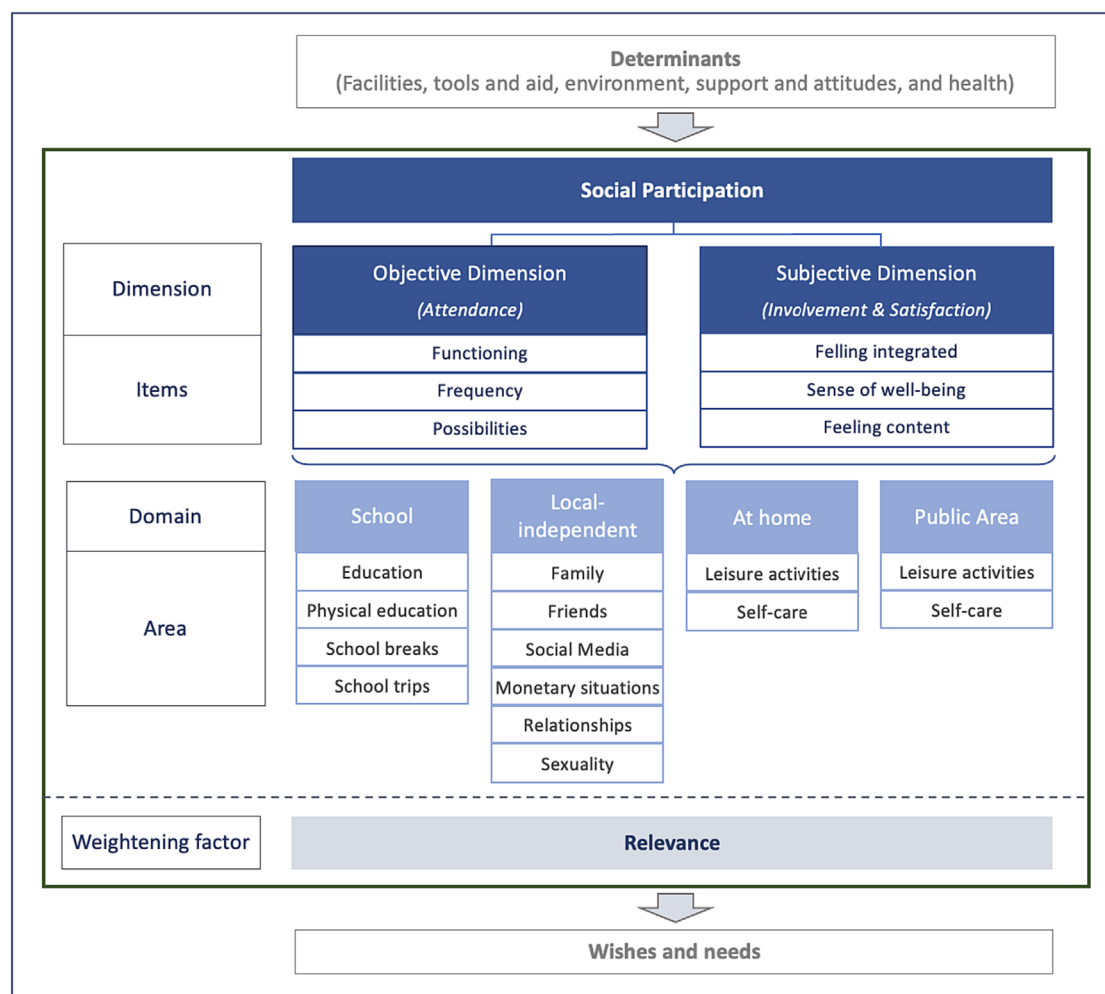
The preceding qualitative study indicated 14 different areas of life (e.g., familiar interaction, friendships, leisure time, social media, schooling and self-care) that are important in adolescent participation, and which can be allocated to four domains (i.e., school, local-independent, at home and public area). To comply with adolescent use of languages, we developed items based on the adolescents' quotes from the qualitative study to assess their attendance (i.e., the objective dimension), involvement and satisfaction (i.e., the subjective dimension) in each area of life.

In addition, we included the subjective relevance of areas as a weighting factor. This follows the idea that participation is particularly important in areas that are rated as relevant for the individual. In contrast, in areas that are perceived as not important, a lack of participation can be considered tolerable.

We developed 104 items to measure participation (i.e., 49 items measuring the objective and 55 items measuring the subjective dimension). In addition, we generated 29 items to assess the subjective relevance that shall be used as the weighing factor by measuring how important the presented areas in life are evaluated. In sum, 133 items were thus developed and tested.

## 2.3 | Phase 3: Pre-test of the developed instrument

Before pretesting the instrument, it was critically evaluated by four experts from social paediatric care content-wise. In addition, two experts in psychometric statistics provided critical methodological feedback. We conducted focus groups with these experts that were video-recorded and content-analytically evaluated by the project team (Mayring, 2022). Concerning the instrument's comprehensiveness, the experts suggested adding additional areas, that is, relationships, sexuality and financial situation. Overall, they evaluated the instrument as comprehensible but long and time-consuming, which might be a problem regarding adolescents' attention span and feasibility in clinical settings. After revising the instrument, we conducted *think aloud* sessions with two adolescents without impairments and two adolescents with disabilities and chronic diseases (Eccles & Aarsal, 2017). Participants are thereby asked to fill out the questionnaire and express their thoughts freely. The *think aloud* sessions were analysed content-wise regarding the items' unambiguousness and comprehensibility, use of language and comprehensiveness. Subsequently, the



**FIGURE 2** Structure of the pilot version of the self-assessment tool for participation.

instrument was revised critically regarding the items' wording (Mayring, 2022).

## 2.4 | Phase 4: Quantitative study (i.e., pilot study)

In this cross-sectional pilot study, we aimed to apply the newly developed SPI and test its psychometric properties.

### 2.4.1 | Pilot study: Recruitment and participants

We aimed to recruit a total of  $n = 150$  adolescents aged between 12 and 17 years. Since the instrument was developed to assess the participation of adolescents with and without physical disabilities/chronic diseases, it was aimed to assess data of  $n = 100$  adolescents with physical disabilities or chronic diseases and  $n = 50$  non-disabled adolescents. Having a cognitive impairment was determined as an exclusion criterion. The recruitment of participants took place between August 2021 and April 2022.

In total, we recruited  $n = 123$  adolescents with physical disabilities/chronic diseases from  $n = 16$  social paediatrics centres (SPCs) and clinics for adolescents and  $n = 1$  school for pupils with special needs in Germany. Adolescents were only included when they and their legal guardians gave their written consent for participation. Adolescents were asked to fill out the questionnaire, which was provided as a paper-pencil version or as an online survey. Five adolescents were excluded since one of them was younger than 12 years and four adolescents were 18 years or older.

Overall, we assessed data of  $n = 30$  adolescents without physical disabilities/chronic diseases through organizations, such as sports and youth clubs. We sent the study information to the corresponding contact persons of these organizations and asked them to forward the call for study participation and the link for the online survey to their adolescent members.

The sociodemographic characteristics of our sample are displayed in Table 1. In our sample, the predominant main diagnoses are infantile cerebral palsy (3.6%), developmental delays (2.7%) and epilepsy (16.5%). A detailed list of participants' diagnoses can be obtained from the [supporting information](#).

**TABLE 1** Participants' sociodemographic characteristics.

Sample size	Total n = 151	Adolescents with disabilities/chronic disease n = 121	Adolescents without Disabilities/chronic disease n = 30
Gender			
Female	66 (43.71%)	42 (34.7%)	24 (8.0%)
Male	83 (54.97%)	77 (63.6%)	6 (2.0%)
Diverse	2 (1.32%)	2 (1.7%)	0 (0.0%)
Age			
12	10 (6.62%)	9 (7.4%)	1 (3.3%)
13	21 (13.91%)	17 (14.1%)	4 (13.3%)
14	37 (24.50%)	34 (28.1%)	3 (1.0%)
15	24 (15.89%)	16 (13.2%)	8 (26.7%)
16	37 (24.50%)	29 (23.9%)	8 (26.7%)
17	22 (14.57%)	16 (13.2%)	6 (2.0%)
Mean (SD)	14.81 (1.49)	14.72 (1.5)	15.2 (1.4)

### 2.4.2 | Pilot study: Instruments

All instruments used are described in the following

#### *The preliminary version of the SPI*

The SPI was developed to assess the participation of adolescents (aged 12–17 years) with and without physical disabilities or chronic diseases. It covers the objective (i.e., attendance) and subjective (involvement and satisfaction) dimension of participation in 14 different areas of life that can be allocated to location-based domains. In total, we developed  $n = 104$  items to assess participation in adolescents. The items contain statements about the objective dimension of participation (addressing functioning, possibilities and frequencies in different areas of life) or rather the subjective dimension (i.e., feeling of involvement and feeling content and sense of well-being). Participants are asked to rate their level of agreement on these statements on a 5-point Likert scale (1 = *strongly disagree*; 2 = *slightly disagree*; 3 = *sometimes agree, sometimes disagree*; 4 = *slightly agree*; and 5 = *totally agree*), whereby higher scores indicate a higher level of participation. Moreover, to measure the subjective relevance of the included areas, we developed  $n = 29$  items containing statements that are rated on the same 5-point Likert scale described above. Higher scores indicate stronger subjective relevance.

#### *Sociodemographic characteristics*

Participating adolescents were asked to provide information regarding general sociodemographic variables (i.e., age, gender and type of school). In addition, practitioners and teachers were asked to state the medical diagnosis based on the ICD-10 (DIMDI D (ICD-10): Band I – Systematisches Verzeichnis, 1994) of adolescents with disabilities and/or chronic diseases (and, if necessary, the degree of severity).

#### *Kidscreen-27*

Because of missing German participation self-assessment tool for adolescents, we used the Kidscreen-27 (Ravens-Sieberer et al., 2007) for the construct validation. Although the Kidscreen-27 addresses the health-related quality of life of children and adolescents and not explicitly participation, both concepts are overlapping. We used the version of the Kidscreen that consists of 27 items, which cover five areas of adolescent life, that is, physical well-being (five items), psychological well-being (seven items), parent relations and autonomy (seven items), social support and peers (four items) and school environment (four items). Adolescents are asked to rate their agreement on a 5-point Likert scale, where higher scores indicate better health-related quality of life.

## 3 | RESULTS

### 3.1 | Data analysis

All data were analysed using Stata (Version 15.1). The analyses aimed to (a) examine the instrument's psychometric properties and (b) substantially shorten it without losing essential information. The latter was done because of the verbal and written feedback of participants, medical staff and teachers, who reported that filling out the questionnaire took too long. Shortening the instrument would thus improve its applicability.

Due to missing values (68–74% missing values), the areas of sexuality, relationships and financial situation were removed. In the preliminary qualitative assessment, these areas were not mentioned by adolescents or their guardians but were retroactively added based on experts' suggestions. Based on the high number of missing values, it can be assumed that these areas might not be relevant to the target group.

## 3.1.1 | Principal component analyses (PCA)

We used principal component analyses (PCAs), to search exploratively for a data-driven structure that aligns also with the theoretical concept (Abdi & Williams, 2010). According to our concept of participation, the PCA with post hoc varimax rotation was separately conducted for both, the objective (attendance) and subjective (involvement and satisfaction) dimensions (Abdi & Williams, 2010). Corresponding to our theoretical considerations, items of the same area should load on one main component (loading  $\geq 0.3$ ), respectively. Items that did not load (loading  $< 0.3$ ) were excluded after careful contextual review.

## 3.1.2 | PCA: Objective dimension (attendance)

We included all items ( $n = 49$ ) assessing the objective dimension of participation in the PCA. Since we aimed to reduce the number of items, we excluded those items that did not load explicitly on one principal component (PC) or did not match our contextual framework. We iterated the PCA seven times until we detected a structure that reconciles the concept of participation and the data. The final PCA, displayed in Table 2, consists of nine PCs, comprises  $n = 20$  items and explained 80.76% of the variance. This final solution can be considered the best match between theoretical arguments, the one dimensionality of the included items as well as their loadings, and their reliability (see also Table 2).

**TABLE 2** PCA objective dimension (attendance).

Area/item	Principle component								
	1	2	3	4	5	6	7	8	9
Family									
Functioning	-.038	.036	.045	.261	.546	-.153	.076	-.082	.042
Possibilities	.007	.004	.020	-.105	.722	.093	-.033	-.014	-.012
Friends									
Functioning	.080	.029	.692	-.139	.070	-.183	.083	-.038	.064
Possibilities	-.138	-.084	.608	.201	-.038	.209	-.121	.062	-.132
Leisure time									
Functioning	-.004	.086	-.056	-.045	.076	.699	.071	-.017	-.140
Possibilities	.071	.069	.279	-.078	-.045	.389	-.048	-.045	.109
Social media									
Frequency	-.030	.051	.023	-.015	-.108	-.039	.018	.788	-.036
Possibilities	.032	-.078	-.067	.035	.241	.075	-.018	.557	.067
Self-care									
Possibilities	.431	.072	-.079	-.033	.056	.019	-.054	.041	.098
Functioning (body care)	.533	-.023	.017	.009	.057	.046	.038	-.084	-.021
Functioning (dressing)	.575	-.010	-.036	.054	-.079	.015	-.033	-.048	-.125
Functioning (meals)	.402	-.036	.155	.004	-.021	-.119	.033	.172	.062
Education									
Functioning	.032	.081	.072	.627	-.132	-.046	.053	.037	-.032
Possibilities	.010	-.042	-.087	.653	.096	.019	-.044	-.034	.016
Physical education									
Functioning	-.019	.646	.055	-.029	.074	-.013	.004	.052	.060
Possibilities	.010	.697	-.068	.047	-.042	.067	-.028	-.006	-.035
School break									
Functioning	-.024	.117	.075	.062	-.157	-.052	.659	-.064	.097
Possibilities	.011	-.113	-.058	-.044	.115	.095	.719	.066	-.089
School trips									
Functioning	-.023	.013	-.005	-.011	.010	-.040	-.008	-.009	.878
Possibilities	.026	-.158	-.043	.134	-.107	.454	.002	.009	.340

Note:  $n = 119$ , number of components 9, explained variance  $Rho = .8076$ . The items of the same areas would load on the same principle component. The best match of loadings was highlighted in black letters. Greyed letters indicate weak and thus irrelevant loadings.

**TABLE 3** Bivariate analysis items addressing self-care at home and outside home.

		Self-care at home			
		Possibilities	Functioning body care	Functioning dressing	Functioning meals
Self-care outside home	Possibilities	.553	.503	.515	.475
	Functioning Body care	.585	.709	.654	.506
	Functioning dressing	.567	.675	.804	.582
	Functioning Meals	.478	.603	.620	.728

Note: Correlation coefficients are displayed. All coefficients were significant ( $p \leq .001$ ). The items of the same areas would load on the same principle component. The best match of loadings was highlighted in black letters. Greyed letters indicate weak and thus irrelevant loadings.

**TABLE 4** PCA subjective dimension (satisfaction and involvement).

Area/item	Principle component								
	1	2	3	4	5	6	7	8	9
Family									
Feeling comfortable	-.067	.052	.007	-.043	.710	.047	-.021	.043	.007
Feeling involved	.108	-.071	-.001	.100	.649	-.042	-.004	-.058	-.009
Friends									
Feeling comfortable (quantity friendships)	.007	.662	-.051	.038	-.031	.002	-.056	.010	.002
Feeling comfortable (quality friendships)	-.080	.592	.046	-.110	.038	.045	.092	.141	.095
Feeling involved	.285	.381	.061	.206	.009	-.115	-.011	-.153	-.118
Leisure time									
Feeling comfortable	-.141	-.000	-.034	.680	.062	.025	.035	-.026	.113
Feeling involved	.348	.063	.013	.413	-.112	.075	-.028	-.144	-.089
Social media									
Feeling comfortable	-.112	.049	.025	.105	.082	.744	-.074	-.063	-.020
Feeling involved	.175	-.064	-.016	-.124	-.112	.636	.059	.087	.052
Self-care									
Feeling comfortable	.006	.048	-.045	-.001	.019	.030	.086	-.066	.806
Feeling involved	.047	-.118	.128	.257	-.097	-.103	-.249	.201	.474
Education									
Feeling comfortable	.494	-.035	-.014	-.204	.139	-.009	-.044	.161	.119
Feeling involved	.608	-.017	-.013	-.067	-.027	-.018	-.072	-.012	-.004
Physical education									
Feeling comfortable	-.001	-.062	.683	-.067	.057	-.009	.084	-.021	.057
Feeling involved	-.007	.051	.709	.035	-.044	.025	-.053	.010	-.082
School break									
Feeling comfortable	.001	.078	-.002	-.070	-.005	-.011	-.006	.781	.005
Feeling involved	.049	-.114	-.023	.383	.018	.019	.094	.483	-.230
School trips									
Feeling comfortable	-.076	.014	.016	.015	-.022	-.038	.812	.026	.040
Feeling involved	.297	-.067	.004	.056	.014	.033	.471	-.052	.027

Note:  $n = 115$ , number of components 9, explained variance  $Rho = .8506$ . The items of the same areas would load on the same principle component. The best match of loadings was highlighted in black letters. Greyed letters indicate weak and thus irrelevant loadings.



We removed the items that assess 'frequency compared with peers' since they turned out to be difficult to interpret. We had to note that participation is not quantifiable by asking about the mere frequency of doing things since it does not allow any conclusion about whether the frequency is experienced as sufficient. The structure of PCs was not affected by this removal.

The PCA also showed that the area of 'leisure time' split up into two PCs: 'leisure time alone' and 'leisure time with others'. Since we did not assess involvement (subjective dimension) for leisure time that is spent alone separately, we decided based on theoretical and empirical reasons to remove respective items. We also shortened the instrument by removing the items that assessed 'self-care at home' since these items were loaded on the same PC as 'self-care outside the home' and an additional bivariate analysis showed that these items correlate strongly with each other (see Table 3).

### 3.1.3 | PCA: Subjective dimension (involvement and satisfaction)

We started the PCA with  $n = 55$  items. Again, we aimed to reduce the number of items and to search for a reasonable structure in alignment with our concept. After seven iterations and respective adjustments, we found the final structure with nine PC and  $n = 19$  items. This final PCA is presented in Table 4, explaining 85.06% of the overall variance. The subjective dimension included one item that assessed the level of involvement and two items that assessed the individual's subjective level of satisfaction with participation in each area (i.e., 'being content' and 'feeling comfortable'). To avoid redundancies and to shorten the instrument, we decided to just keep the item that assesses if adolescents feel comfortable in certain areas of life.

### 3.1.4 | Synthesizing the objective and subjective dimension

According to our preliminary theoretical consideration, participation in certain areas comprises objective and subjective components. The objective component, that is, the possibility to attend, is required for participation but not sufficient. Participation is only reached when also subjective criteria are met. In other words, it is not enough to attend; the individual needs to feel integrated and comfortable in social interactions. Against this consideration, the objective and subjective dimensions should be displayed by the same number of PCs that should also be content-wise congruent. We found this balance with nine PCs.

We also conducted an overall PCA model in order to check whether the final items of both dimensions would load on the same PC according to the respective area. The former structure could also be found in the full PCA model, which reinforces the theoretical concept statistically.

The items of each PC were put to a reliability check (Table 5). In general, the items in each area showed a (very) good reliability. Only the items that addressed participation in social media had

below-average reliability (Cronbach's  $\alpha = .51$ ). Therefore, we calculated additionally the H-coefficient, which has less strict preconditions compared to Chronbach's  $\alpha$  but was rated to be equally informative (McNeish, 2018). The H-coefficient indicates a satisfactory reliability of 0.64 for these items.

According to the results of the PCA, the developed instrument, the SPI, follows the scheme displayed in Figure 3. The SPI was shortened substantially from the former 104 items to 39 items measuring participation in nine areas of life (four school-related areas and five non-school-related areas). Therefore, also the items assessing the subjective importance of certain areas of life could be reduced from the former 29 items to 18 items.

## 3.2 | Construct validation of the SPI

For construct validation (Grimm & Widaman, 2012), we used the Kidscreen-27, a validated self-assessment tool for children and adolescents. We calculated index variables (mean scores) based on the items of all respective areas of the Kidscreen-27 and the newly developed SPI. Thereafter, we conducted a correlation analysis using these index variables (Table 6).

The areas of the Kidscreen-27 and the SPI are not congruent. For example, the SPI does not consider physical well-being as an area of participation but rather as a determinant for participation. Furthermore, the SPI does not contain the area of psychological well-being. In the SPI, psycho-emotional factors are integrated as items of the subjective dimension in every area. On the other hand, the Kidscreen-27 does not display self-care, which is a crucial area of the SPI.

Despite different focuses, the correlation analysis shows medium to high associations and therefore a good validity (Cohen, 2013). Only the area 'school trip' (SPI) showed stronger correlations with the area 'social support and peers' (Kidscreen-27), which might be counterintuitive at first sight. However, this might be traced back to the fact that the area 'school environment' (Kidscreen-27) does not cover the area 'school breaks', which are merely spent with peers.

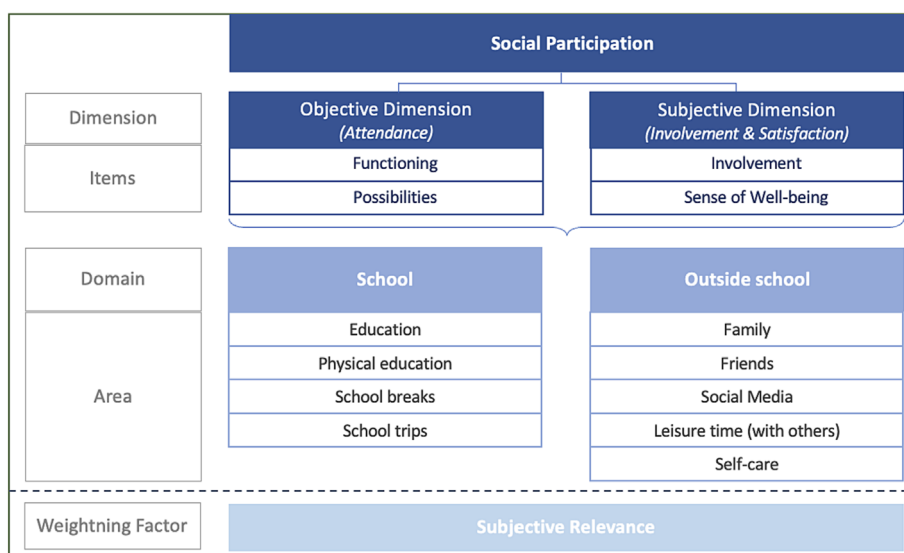
## 4 | DISCUSSION

The aim of this study was to develop a participation self-assessment tool for adolescents and to examine its psychometric properties. Based on qualitative preliminary work, we developed the SPI and applied it in a pilot study using data from adolescents with and without disabilities and/or chronic diseases. We sought to test whether the preliminary theoretical consideration of participation can also be found in the data's structure. For this reason, we conducted PCA that indeed reinforced the idea of two complementary dimensions of participation. The objective dimension assesses whether individuals have access to participation. It can thus be considered a requirement for participation, whereas the subjective dimension describes whether individuals feel involved and overall satisfied with the level of participation.



**TABLE 5** Principal components of the objective and subjective dimensions, respective item descriptions and Cronbach's  $\alpha$ .

Principal components	$\alpha$	Subjective dimension (involvement & satisfaction) Items	$\alpha$	Objective dimension (attendance) Items	$\alpha$
Family	.791	<ul style="list-style-type: none"> <li>Feeling comfortable with familiar interactions</li> <li>Feeling involved in familiar interactions</li> </ul>	.846	<ul style="list-style-type: none"> <li>Functional capability of doing things with family</li> <li>Possibilities for familiar activities</li> </ul>	.705
Friends	.764	<ul style="list-style-type: none"> <li>Satisfaction with the number of friends</li> <li>Satisfaction with the quality of friendships</li> <li>Feeling involved in activities with friends</li> </ul>	.758	<ul style="list-style-type: none"> <li>Functional capability of doing things with friends</li> <li>Possibilities to meet friends or stay in contact with them</li> </ul>	.676
Social media	.816	<ul style="list-style-type: none"> <li>Feeling comfortable on social media</li> <li>Feeling involved through social media</li> </ul>	.776	<ul style="list-style-type: none"> <li>I spend as much time on social media compared to my peers</li> <li>Possibilities to use social media</li> </ul>	.509
Leisure time	.643	<ul style="list-style-type: none"> <li>Feeling comfortable with leisure time spent with others outside the home</li> <li>Feeling involved during leisure time with others outside the home</li> </ul>	.757	<ul style="list-style-type: none"> <li>Functional capability of spending leisure time outside the home</li> <li>Possibilities to spend leisure time outside the home</li> </ul>	.748
Self-care	.856	<ul style="list-style-type: none"> <li>Feeling comfortable with self-care outside the home</li> <li>Feeling involved through self-care outside the home</li> </ul>	.783	<ul style="list-style-type: none"> <li>Possibilities for self-care outside the home</li> <li>Functional capability of self-care outside the home</li> <li>Functional capability of (un-)dressing outside the home</li> <li>Functional capability of eating outside the home</li> </ul>	.871
Education	.752	<ul style="list-style-type: none"> <li>Feeling comfortable in class</li> <li>Feeling involved in class</li> </ul>	.806	<ul style="list-style-type: none"> <li>Functional capability in class</li> <li>Possibilities to participate in class</li> </ul>	.675
Physical education	.860	<ul style="list-style-type: none"> <li>Feeling comfortable in physical education classes</li> <li>Feeling involved in physical education classes</li> </ul>	.895	<ul style="list-style-type: none"> <li>Functional capability in physical education</li> <li>Possibilities to participate in physical education classes</li> </ul>	.890
School breaks	.784	<ul style="list-style-type: none"> <li>Feeling comfortable during school breaks</li> <li>Feeling involved during school breaks</li> </ul>	.688	<ul style="list-style-type: none"> <li>Functional capability during school breaks</li> <li>Possibilities to spend school breaks as wanted</li> </ul>	.665
School trips	.767	<ul style="list-style-type: none"> <li>Feeling comfortable on school trips</li> <li>Feeling involved in school trips</li> </ul>	.716	<ul style="list-style-type: none"> <li>Functional capability on school trips</li> <li>Possibilities to participate during school trips</li> </ul>	.644
Total	.920		.862		.881

**FIGURE 3** Scheme of the Social Participation Inventory (SPI).

**TABLE 6** Partial correlation analysis ( $r$  [p]).

	Areas	Kidscreen-27				
		Physical well-being	Psychological well-being	Parent relations & autonomy	Social support & peers	School environment
SPI	Family	-.107 (.187)	-.065 (.418)	.685 (.000)	.205 (.011)	.345 (.000)
	Friends	-.080 (.318)	-.047 (.558)	.229 (.004)	.469 (.000)	.204 (.011)
	Leisure time (with others)	-.036 (.653)	-.023 (.773)	.414 (.000)	.469 (.000)	.235 (.003)
	Social media	-.129 (.109)	-.094 (.243)	.407 (.000)	.285 (.000)	.197 (.015)
	Self-care	-.006 (.945)	-.019 (.811)	.311 (.000)	.224 (.005)	.060 (.462)
	Education	-.015 (.853)	.022 (.790)	.495 (.000)	.440 (.000)	.647 (.000)
	Physical education	-.079 (.340)	-.097 (.238)	.302 (.000)	.318 (.000)	.303 (.000)
	School breaks	-.062 (.440)	-.022 (.782)	.319 (.000)	.490 (.000)	.302 (.000)
	School trips	.019 (.813)	-.084 (.299)	.180 (.027)	.321 (.000)	.383 (.000)

The SPI differs from existing instruments in several important ways. While the PEM-CY (Krieger et al., 2020) assesses the parents' perspective on participation, it excludes the crucial adolescents' insider perspective. Another instrument, the *Child and Adolescent Scale of Participation* (CAPS) (de Bock et al., 2019), captures the adolescent perspectives; it focuses on the mere frequency of certain activities but neglects how partaking in activities is perceived by adolescents. The methodological and theoretical shortcoming of solely addressing the matter of 'being there' in the context of participation has been previously pointed out (Schlebusch et al., 2020). By contrast, the SPI is a self-assessment tool for adolescents, which measures participation by the possibilities and functionality as determinants of attendance (i.e., objective dimension) as well as the sense of well-being and level of involvement (i.e., subjective dimension), separately. As Adair et al. (2015) state the separate assessment of the objective and subjective dimensions results in more reliable measurement. Apart from that, the SPI also takes the subjective relevance of areas of life into account, which is a real enhancement compared to previous instruments. In that way, adolescents are enabled to indicate their wishes and needs and therefore to advocate for themselves. By including the adolescent's subjective perception of how important they rate major areas of life, the SPI and its underlying concept differentiate from the fPRC (Imms et al., 2017). Therefore, The SPI steps in where former instruments have fallen short. Furthermore, we were able to reduce the initial number of items substantially in order to create a theory-driven and practicable instrument that can be implemented in a rehabilitation context. Reducing the number of items and shorting redundancies,

the SPI should also address the adolescent needs in terms of concentration and motivation span. This meets the need for briefer and more feasible measurements, an issue that was raised before.

Moreover, besides items that assess the current level of participation, it contains items that assess the subjective importance of relevant areas of life. This allows a comparison between the status quo and the desired status, which is necessary to derive the respective need for action in single areas of life.

After careful implementation into clinical settings, the SPI could potentially be used to make rehabilitative processes evaluable concerning its main goal, that is, improving participation. Therefore, it is important to assess not only participation but also potential determining factors. However, the final version of the SPI has not yet been applied and tested. This is therefore an important issue for future research.

Following the experts' advice, we developed items to assess participation in the areas of sexuality, relationships and financial situation. Because of the high number of missing values within these areas, they were removed. Future studies might investigate in what sense adolescents perceive sexuality, relationships and financial resources as relevant areas of participation.

Although a current study showed the longitudinal importance of frequency for adolescents mental well-being (Hwang et al., 2020), we identified problems regarding the wording of these respective items that were supposed to assess the frequency of doing things compared to peers. This item was classified as an objective component but was excluded because of its limited meaning. Instead, this item should

have rather been assigned to the subjective dimension and asked if the individual is content with the frequency of doing certain things. Although it can be argued that the item assessing the overall satisfaction with participation in certain areas might already cover this component, this must be an objective for future research. Also, we must address the shortcomings regarding the incomplete item development for leisure time that is spent alone. We did not generate items assessing whether individuals feel involved by spending leisure time by themselves. For example, by reading books and playing single-player video games, adolescents might also feel included, as they can share their thoughts and progress with peers. In future studies, the shortcomings of the current version of the SPI should be addressed by developing or rephrasing items to test them in a PCA.

#### 4.1 | Limitations

The recruitment of adolescents was impeded due to the Covid-19 pandemic, which hampered access to institutions (e.g., schools and SPCs). Although we reached our initial goal to recruit at least  $n = 150$  adolescents, instead of the planned  $n = 50$ , we could only recruit  $n = 30$  adolescents without physical disabilities or chronic diseases. Since our data indicate that participation between adolescents with and without physical disabilities or chronic diseases did only differ significantly in three of nine areas (i.e., self-care, leisure time outside the home and physical education), this can be considered a minor limitation.

It can also be discussed that the validated instrument that was used for construct validation might not be the perfect fit. The Kidscreen-27 aims to assess health-related quality of life in children and adolescents and not explicitly participation. Considering that the urgent need to develop a German participation self-assessment tool for adolescence was based on the fact that no such instrument has been implemented before indicates that there is no better-suited (German) self-assessment tool that could have been used for construct validation. Moreover, the content-related overlap between the Kidscreen-27 and the SPI can be considered adequate.

#### 4.2 | Implications for clinical and scientific application

The SPI can be applied in clinical and scientific settings. The level of participation can be determined by calculating the respective mean scores of the objective and subjective dimensions for each area of life. These mean scores can be interpreted when putting them into relation with the weighing factor (i.e., the subjective relevance of the respective area). When the participation score is equal to or higher than the subjective relevance, the level of participation can be interpreted as sufficient. In turn, when the subjective relevance of an area is higher rated than the respective participation mean score, the level of participation must be considered inadequate.

In re/habilitation settings, clinicians should frame the application of the SPI thoughtfully. The SPI was not developed to compare the individual's level of participation with others. It was rather developed to assess it under the lens of subjective preferences and needs and to detect individual deficits. In areas in which the level of participation is evaluated as inadequate, clinicians, adolescents and parents can evaluate what barriers exist and/or what could improve the adolescent's participation.

### CONCLUSION

The newly developed SPI shows good psychometric properties. The overall Cronbach's  $\alpha$  of .920 indicates very good reliability and thus internal consistency. Furthermore, the SPI could be conceptually validated by using the Kidscreen-27. However, we only applied the pilot version of the participation self-assessment tool. The shortened version of the SPI was not tested again in an independent sample. Further work should thus be done to evaluate the applicability of the SPI in the clinical and scientific context and to validate its psychometric properties.

### AUTHOR CONTRIBUTIONS

Astrid Fink, Britta Dawal and Matthias Richter outlined and specified the research question. Marie Bernard, Laura Hoffmann and Britta Dawal compiled all study documents and contacted social paediatrics centres, schools and organizations, which were asked to recruit participants. Marie Bernard and Miriam Seyda conducted statistical analyses. Marie Bernard wrote the first draft of the manuscript. Laura Hoffmann, Britta Dawal, Astrid Fink and Matthias Richter edited and revised it critically for important intellectual content. All authors contributed to and have approved the final manuscript.

### ACKNOWLEDGEMENTS

Open Access funding enabled and organized by Projekt DEAL.

### CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interest.

### DATA AVAILABILITY STATEMENT

The datasets generated during and/or analysed during the current study are available from the corresponding author upon reasonable request.

### ETHICS STATEMENT

The study was approved by the Medical Ethics Review Board of the Medical Faculty at Martin Luther University Halle-Wittenberg (2017-67). Informed consent was obtained from all individual participants included in the study.

### ORCID

Marie Bernard  <https://orcid.org/0000-0003-4208-4057>

## REFERENCES

- Abdi, H., & Williams, L. J. (2010). Principal component analysis. *WIREs Computational Statistics*, 2(4), 433–459. <https://doi.org/10.1002/wics.101>
- Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015). The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Developmental Medicine and Child Neurology*, 57(12), 1093–1104. <https://doi.org/10.1111/dmcn.12809>
- Anaby, D., Khetani, M., Piskur, B., van der Holst, M., Bedell, G., Schakel, F., de Kloet, A., Simeonsson, R., & Imms, C. (2022). Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and Rehabilitation*, 44(9), 1746–1757. <https://doi.org/10.1080/09638288.2021.1903102> [published Online First: 8 April 2021].
- Baerwalde, T., Gebhard, B., Hoffmann, L., Roick, J., Martin, O., Neurath, A. L., & Fink, A. (2019). Development and psychometric testing of an instrument for measuring social participation of adolescents: Study protocol of a prospective mixed-methods study. *BMJ Open*, 9(2), e028529. <https://doi.org/10.1136/bmjopen-2018-028529>
- Bedell, G. (2009). Further validation of the child and adolescent scale of participation (CASP). *Developmental Neurorehabilitation*, 12(5), 342–351. <https://doi.org/10.3109/17518420903087277>
- Bernard, M., Hoffmann, L., Richter, M., Völm, C., Fink, A., & Dawal, B. Participation of adolescents with and without physical disabilities and chronic diseases: A comprehensive conceptualizing.
- Cohen, J. (2013). *Statistical power analysis for the behavioral sciences*. Routledge. <https://doi.org/10.4324/9780203771587>
- de Bock, F., Bosle, C., Graef, C., Oepen, J., Philippi, H., & Urschitz, M. S. (2019). 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 Pediatrics*, 19(1), 125. <https://doi.org/10.1186/s12887-019-1495-6>
- DIMDI D (ICD-10): Band I – Systematisches Verzeichnis. (1994). Version 1. 0, Stand August 1994. Springer Berlin/Heidelberg.
- Eccles, D. W., & Arsal, G. (2017). The think aloud method: What is it and how do I use it? *Qualitative Research in Sport, Exercise and Health*, 9(4), 514–531. <https://doi.org/10.1080/2159676X.2017.1331501>
- Gebhard, B., Völm, C., & Fink, A. (2021). Partizipation in der Frühpädagogik—Die ICF als disziplinverbindendes Element. *ZfG*, 14(2), 199–214. <https://doi.org/10.1007/s42278-021-00106-x>
- Grimm, K. J., & Widaman, K. F. (2012). Construct validity. In H. Cooper, P. M. Camic, D. L. Long, et al. (Eds.), *APA handbook of research methods in psychology, Vol 1: Foundations, planning, measures, and psychometrics* (pp. 621–642). American Psychological Association. <https://doi.org/10.1037/13619-033>
- Hwang, A.-W., Chang, C.-H., Granlund, M., Imms, C., Chen, C. L., & Kang, L. J. (2020). Longitudinal trends of participation in relation to mental health in children with and without physical difficulties. *International Journal of Environmental Research and Public Health*, 17(22), 8551. <https://doi.org/10.3390/ijerph17228551>
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology*, 59(1), 16–25. <https://doi.org/10.1111/dmcn.13237>
- Krieger, B., Schulze, C., Boyd, J., Amann, R., Piškur, B., Beurskens, A., Teplicky, R., & Moser, A. (2020). Cross-cultural adaptation of the Participation and Environment Measure for Children and Youth (PEM-CY) into German: A qualitative study in three countries. *BMC Pediatrics*, 20(1), 1, 492–15. <https://doi.org/10.1186/s12887-020-02343-y>
- Mayring, P. (2022). *Qualitative content analysis: A step-by-step guide*. Sage.
- McDougall, J., Bedell, G., & Wright, V. (2013). 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 and Development*, 39(4), 512–522. <https://doi.org/10.1111/cch.12050>
- McNeish, D. (2018). Thanks coefficient alpha, we'll take it from here. *Psychological Methods*, 23(3), 412–433. <https://doi.org/10.1037/met0000144>
- Neumann, S., Salm, S., Rietz, C., & Stenneken, P. (2017). The German Focus on the Outcomes of Communication Under Six (FOCUS-G): Reliability and validity of a novel assessment of communicative participation. *Journal of Speech, Language, and Hearing Research*, 60(3), 675–681. [https://doi.org/10.1044/2016\\_JSLHR-L-15-0219](https://doi.org/10.1044/2016_JSLHR-L-15-0219)
- Powrie, B., Kolehmainen, N., Turpin, M., Ziviani, J., & Copley, J. (2015). The meaning of leisure for children and young people with physical disabilities: A systematic evidence synthesis. *Developmental Medicine and Child Neurology*, 57(11), 993–1010. <https://doi.org/10.1111/dmcn.12788> [published Online First: 4 May 2015].
- Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., Power, M., Duer, W., Cloetta, B., Czemy, L., Mazur, J., Czimbalmo, A., Tountas, Y., Hagquist, C., Kilroe, J., & European KIDSCREEN Group. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research*, 16(8), 1347–1356. <https://doi.org/10.1007/s11136-007-9240-2>
- Schlebusch, L., Huus, K., Samuels, A., Granlund, M., & Dada, S. (2020). Participation of young people with disabilities and/or chronic conditions in low- and middle-income countries: A scoping review. *Developmental Medicine and Child Neurology*, 62, 1259–1265. <https://doi.org/10.1111/dmcn.14609>
- WHO - World Health Organisation. (2001). International classification of functioning, disability and health (ICF). Geneva.
- Bärwalde, T., Hoffmann, L., Fink, A., Völm, C., Martin, O., Bernard, M., Gebhard, B., & Richter, M. (2023). The adolescent concept of social participation—A qualitative study on the concept of social participation from adolescents with and without physical disabilities. *Qualitative Health Research*, 33(3), 143–153. <https://doi.org/10.1177/10497323221146414>
- Hoffmann, L., Völm, C., Bernard, M., Fink, A., Richter, M., & Dawal, B. (2023). What does social participation mean? A qualitative study exploring the concept of participation from the perspectives of experts and parents. *BMJ Open*, 13, e072684. <https://doi.org/10.1136/bmjopen-2023-072684>

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Bernard, M., Hoffmann, L., Richter, M., Völm, C., Seyda, M., Fink, A., & Dawal, B. (2023). A pilot study to develop a participation self-assessment tool for adolescents: The Social Participation Inventory (SPI). *Child: Care, Health and Development*, 1–12. <https://doi.org/10.1111/cch.13164>