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### Participation Restriction Questionnaire: A New Tool to Evaluate Participation in Children

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#### ABSTRACT

**Objective:** This study was planned to develop the Participation Restriction Questionnaire for children based on the International Classification of Functioning, Disability and Health: Children and Youth (ICF-CY). **Materials and Methods:** A total of 242 children; 209 typically developing (mean age:6.82±4.22 years) and 33 with chronic diseases (mean age:74±4.98 years) and their parents were included in the study. The processes followed were literature review, item pooling based on ICF-CY, eliciting and evaluating expert opinion, scoring the scale, collecting data (with google forms), and analyzing the data. Exploratory and confirmatory factor analysis was performed for scale validity, and Cronbach  $\alpha$  and Intraclass Correlation Coefficients (ICC) were used for scale reliability. The re-test was applied to 33 volunteer families two weeks after the first test. **Results:** The final version of the scale was constituted of 23 items (after removing 7 items out of 30 items) and three subscales as body structures and functions, activity and participation, and environmental factors. The model fit was found acceptable (The Root Mean Square Error of Approximation=0.084, Goodness of Fit Index=0.779, Adjusted Goodness of Fit Index=0.732, Chi-Square/degrees of freedom=2.696,  $p<0.001$ ). For internal consistency Cronbach's  $\alpha$  ( $\alpha=0.884-0.959$ ) and for test-retest reliability ICC values (ICC=0.625-0.895) were found moderate to high ( $p<0.05$ ). **Conclusion:** These findings show that the Participation Restriction Questionnaire, developed as a new tool is a valid and reliable scale for children with typically developing and chronic diseases for evaluating participation. The questionnaire is recommended for use in further studies to identify the factors which restrict participation.

**Keywords:** Child, Parental Perspective, Participation, ICF-CY.

#### Katılımda Kısıtlılık Anketi: Çocuklarda Katılımı Değerlendirmek için Yeni Bir Araç

##### ÖZ

**Amaç:** Bu çalışma, Uluslararası İşlevsellik, Engellilik ve Sağlık Sınıflandırması: Çocukluk ve Gençlik (ICF-CY) temelli çocuklar için bir Katılımda Kısıtlılık Anketi geliştirmek için planlandı. **Gereç ve Yöntem:** İki yüz dokuz tipik gelişen (ortalama yaş:6.82±4.22 yıl) ve 33 kronik hastalığı olan (ortalama yaş:74±4.98 yıl) toplam 242 çocuk ve ebeveynleri çalışmaya dahil edildi. İzlenen süreçler; literatür taraması, ICF-CY'ye dayalı madde havuzu oluşturma, uzman görüşünün alınması ve değerlendirilmesi, ölçeğin puanlanması, veri toplanması (Google formlar ile) ve verilerin analizidir. Ölçek geçerliliği için açıklayıcı ve doğrulayıcı faktör analizi, ölçek güvenilirliği için Cronbach  $\alpha$  ve Sınıf İçi Korelasyon Katsayısı (ICC) kullanıldı. İlk testten iki hafta sonra 33 gönüllü aileye tekrar test uygulandı. **Bulgular:** Ölçeğin son halini vücut yapısı ve fonksiyonları, aktivite ve katılım ve çevresel faktörler olmak üzere 23 madde (30 maddeden 7 madde çıkarıldıktan sonra) ve üç alt boyuttan oluştu. Model uyumu kabul edilebilir bulundu (Yaklaşık Hataların Ortalama Karekökü=0.084, Uyum İyiği İndeksi=0.779, Düzeltilmiş Uyum İyiği İndeksi=0.732, Ki Kare/Serbestlik Derecesi=2.696,  $p<0.001$ ). İç tutarlılık için Cronbach's  $\alpha$  ( $\alpha=0.884-0.959$ ) ve test-tekrar test güvenilirliği için ICC değerleri (ICC=0.625-0.895) orta-yüksek ( $p<0.05$ ) bulundu. **Sonuç:** Bu bulgular, yeni bir araç olarak geliştirilen Katılımda Kısıtlılık Anketinin tipik gelişen ve kronik hastalığı olan çocuklarda katılımı değerlendirmek için geçerli ve güvenilir bir ölçek olduğunu göstermektedir. Anketin, katılımı kısıtlayan faktörleri belirlemek için daha sonraki çalışmalarda kullanılması önerilir.

**Anahtar Kelimeler:** Çocuk, Ebeveyn Perspektifi, Katılım, ICF-CY.

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## INTRODUCTION

The Children and Youth version of the International Classification of Functioning, Disability and Health (ICF-CY) recommends a multidimensional assessment approach embodying body functions, activity and participation, individual and environmental factors for the assessment of children (Björck-Åkesson et al., 2010; World Health Organization, 2007). The World Health Organization (WHO) defines the concept of participation as involvement in life by accomplishing social roles (Rosenbaum & Stewart, 2004).

Participation consists of various parts such as individual participation in an activity, participation in an activity within a group, frequency of activity participation, and enjoyment of participation (Michelsen et al., 2014; Noonan et al., 2009). Participation has diverse contexts such as participation in indoor and outdoor activities, social activities, leisure activities, daily life activities, and school activities (Kang et al., 2012; Law et al., 2015). Participation in various leisure activities provides essential benefits for the general health and development of children and youth (Shikako-Thomas et al., 2013).

While preschool children mostly engage in indoor and outdoor play activities, school-age children and the youth interact with their peers at school and in social spaces (Sandberg & Eriksson, 2010). Child participation is when the child can go to the playground, start and maintain playing a game with their friends, share with their peers and familiar and unfamiliar people. In this way, the child learns and develops their abilities and a sense of personal identity (Law et al., 2012; Sandberg & Eriksson, 2010). King et al. (2003) developed a theoretical model for the determinants of participation consisting of child, family and environmental factors, which can affect the level of participation in leisure activities. Subsequent studies revealed that child-related factors such as the gross motor function, gender, socio-economic status, and parental education level of a child predict participation in leisure activities (Law et al., 2006). Although health conditions (body structures and functions) have an important role in children's participation, environmental factors are also a dimension that should be considered (Rosenberg, et al., 2012). Participation is a complex structure and is affected by diverse factors (Shikako-Thomas et al., 2013). Determining the factors that can affect the participation of children in daily life is essential and necessary in order to develop the interventions to take place in this regard (Fauconnier et al., 2009; Hammal et al., 2004; King et al., 2006; Law et al., 2012). Numerous scales are available to evaluate participation in children with motor development difficulties (Adair et al., 2018; Noonan et al., 2009). Lots of them were translated in to Turkish but there were some usage problems such as license or special course needing, only hard copy

version, only for special illnesses, too long and not easy to understand.

However, to the best of our knowledge, there is no scale to assess participation restriction in terms of all components of the ICF-CY intrinsic to children with chronic diseases. For this reason, the purpose of this study is to develop a Participation Restriction Questionnaire to evaluate participation within the framework of ICF, which can be applied to typically developing children and children with chronic diseases.

## MATERIALS AND METHODS

### Study type

This observational prospective study was conducted as an online survey with parents of children from June 2021-March 2022.

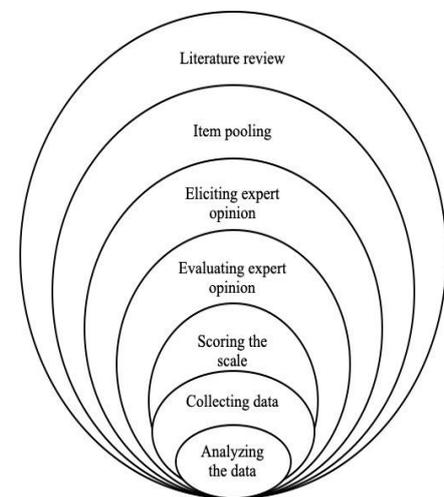
### Study group

The population of the study consisted of volunteer parents of children between the ages of 2-18 years, and residents in various provinces of Turkey. Parents of children with both typically developing and chronic conditions (this includes neurodevelopmental disorders, allergic asthma, chromosomal abnormalities, and various metabolic diseases) were included.

Non-Turkish-speaking and illiterate parents were excluded from the study.

### Procedures

Scale developing stages were given in figure 1 according to the guidelines (DeVellis, 2016; Polat et al., 2017).



**Figure 1. Scale developing stages.**

### Item Pooling

A literature review was performed to generate the item pool, and the questionnaire studies and questionnaire items in the literature developed to evaluate participation were examined. An item pool composed of 30 questions falling into the subscales of body structures and functions, activity and participation and environmental factors was constructed based on the ICF-CY manual.

*Eliciting Expert Opinion*

The items were forwarded to the field 10 specialists (pediatric physical therapists) who are working with pediatric population between 5-15 years in Physiotherapy and Rehabilitation Departments for revisions of language, meaning and expression and content. The subjects of opinions elicited from the specialists are as follows;

- 1) Are the expressions clear and understandable?
- 2) Is the content coherent to the subject?
- 3) Is the item proper to measure the factor?

Furthermore, the experts were enabled to make additions by means of an inserted field of opinions and suggestions.

*Expert Opinion Evaluation*

The Lawshe technique was used to analyze the expert opinions. This technique was utilized to elicit the opinions of the experts on an item and obtain the content validity ratios (Yurdugül, 2005). Content validity ratios (CVR) were calculated by means of the method applying the sum of all the experts who delivered an opinion on an item minus one to the number of experts indicating "Essential" regarding the item. Consequent to the expert opinions evaluated by employing this method, the items in the negative and 0 range were removed from the question pool. After expert opinions evaluated in this way, 4 of the 30 items were found to be negative and in the range of 0 and were excluded from the scale.

*Scale Scoring*

The scale was scored in a 5-point Likert type as follows:

- 0: My child doesn't have such a problem,
- 1: Doesn't restrict at all,
- 2: Restricts slightly,
- 3: Restricts moderately,
- 4: Restricts extremely

**Data collection**

The study data were collected from April 2021 to June 2021 through an online questionnaire. It took 5 to 10 minutes to complete the online assessments for each individual. It was planned to recruit 5-10 participants for each item in the scale (Nunnally & Wilson, 1975). A two-stage evaluation form was used in the study. In the first stage, the sociodemographic information form developed by the researchers investigated the age, gender, diagnoses of the physician, if any, and the sociodemographic information of the parents of the children.

The ICF-CY-based Participation Restriction Questionnaire scale items were presented in the second stage. The scale was prepared in a digital environment on "Google forms", and the questionnaire link was delivered to the parents by means of the online inquiry method via social media (e-mail, WhatsApp, Instagram and such). Only the data of the parents who accepted the written informed consent form explained in detail at the beginning of the inquiry form were used in the analysis. Re-test was sent to volunteer parents two weeks after the first

test. When the minimum acceptable reliability is set to 0.50, expected reliability set to 0.80, significance level set to 0.005, and power is fixed at 80% the sample size needs to be recruit was calculated as 28 individuals. Considering that there may be data loss, the forms were re-sent to 40 parents for retest.

**Statistical analysis**

Data were analyzed using SPSS 23.0 (SPSS Inc., Chicago, IL, USA) and AMOS package program. Kolmogorov Smirnov test were employed to analyze the normal distribution of numeric variables. As descriptive statistics, the number was expressed as a percentage (%) in the mean±standard deviation (Mean±SD) or median (minimum-maximum) categorical variables according to whether the numeric variables exhibited a normal distribution.

The Kaiser-Meyer Olkin (KMO) value was calculated first in order to examine the adequacy of the sample size in the analysis of the data (Polat et al. 2017). Exploratory factor analysis was performed to determine the factor distribution of the items, and item subtraction or substitution was performed for items with a factor load below 0.40. Finally, AMOS was employed to conduct confirmatory factor analysis in order to examine the construct validity of all the items.

The sufficient KMO value was established as >0.70. The Root Mean Square Error of Approximation (RMSEA<0.080), Goodness of Fit Index (GFI>0.90), Adjusted Goodness of Fit Index (AGFI>0.90), Chi-Square/degrees of freedom (CMIN/df<4.0) were tested for model fit. The interpretation of the specified values alone is insufficient, and it is important that all of them comply with the cut-off values for a good model fit. Cronbach  $\alpha$  and Intraclass Correlation Coefficients (ICC) were used for scale reliability. If the Cronbach alpha coefficient is over 0.80, it is interpreted as having high reliability (Uzunsakal & Yıldız, 2018). Values greater than 0.5 have been interpreted as acceptable for ICC values (Koo & Li, 2016). Type 1 error was accepted as  $p<0.05$ .

**Ethical considerations**

The approval to conduct the study was obtained from the Cumhuriyet University Non-Invasive Clinical Studies Ethics Committee (Decision no: 2021-03/06). The study was performed according to the Declaration of Helsinki.

**RESULTS**

The expert opinion determined that 26 items are essential. Parents of 250 children were contacted for study participation. Eight children who didn't complete the questionnaire entirely or didn't give consent were excluded from the study. In conclusion, this study included parents of 209 children with typically developing aged  $6.82\pm 4.22$  years and 33 children with chronic diseases aged  $9.74\pm 4.98$  years (Table 1).

**Table 1. Demographic characteristics of the children (n=242).**

	Typical Developing Children (n=209)	Children with Chronic Conditions (n=33)
	(X±SD)	(X±SD)
<b>Age (Year)</b>	6.82±4.22	9.74±4.98
<b>Gender</b>	<b>n (%)</b>	<b>n (%)</b>
Female	108 (51.67)	14 (42.42)
Male	101 (48.32)	19 (57.57)
<b>Living Place</b>		
Rural	-	1 (3.03)
District	24 (11.48)	8 (24.24)
Province	185 (88.51)	24 (72.72)

X=Mean, SD=Standard deviation.

The Kaiser-Meyer-Olkin value yielded a sufficient sample size sufficient (KMO=0.920,  $p<0.05$ ). The total variance revealed that the scale items were grouped in 3 factors (Table 2). Based on the factor load (factor load $<0.4$ ), two items were removed from the body structures and functions subscale, one item

was transferred to the activity and participation subscale, and one item was removed from the subscale of environmental factors in the exploratory factor analysis (Table 3). Thus, the final version of the scale consisted of 23 items under three subscales.

**Table 2. Total variance explained (n=242).**

Component	Rotation Sums of Squared Loadings		
	Total	Percent (%) of Variance	Cumulative Percent (%)
<b>1</b>	5.703	24.797	24.797
<b>2</b>	5.609	24.385	49.182
<b>3</b>	4.696	20.416	69.598
<b>4</b>	-	-	-

**Table 3. Rotated component matrix (n=242).**

Items	Component		
	1	2	3
<b>Environmental 6</b>	0.823		
<b>Environmental 8</b>	0.813		
<b>Environmental 7</b>	0.801		
<b>Environmental 5</b>	0.796		
<b>Environmental 4</b>	0.770		
<b>Environmental 2</b>	0.708		
<b>Environmental 9</b>	0.639	0.411	
<b>Environmental 3</b>	0.619		
<b>Environmental 10</b>	0.591		
<b>Activity &amp; Participation 3</b>		0.838	
<b>Activity &amp; Participation 5</b>		0.812	
<b>Activity &amp; Participation 7</b>		0.790	
<b>Activity &amp; Participation 6</b>		0.786	
<b>Body structures &amp; Functions 2</b>		0.763	
<b>Activity &amp; Participation 4</b>		0.760	
<b>Activity &amp; Participation 2</b>		0.565	0.517

Table 3 (Continued). Rotated component matrix.

Activity & Participation 1	0.401	0.552	0.404
Body structures & Functions 4			0.861
Body structures & Functions 5			0.856
Body structures & Functions 6			0.846
Body structures & Functions 7			0.794
Body structures & Functions 8		0.422	0.613
Body structures & Functions 1			0.532

The confirmatory factor analysis indicated an acceptable model fit CMIN/df= 2.696, GFI= 0.779, AGFI= 0.732, RMSEA= 0.084, p<0.001). All of the

path coefficients were 0.7 and above (p>0.05). Figure 2 demonstrates the distribution of the items based on the subscales and their factor loads.

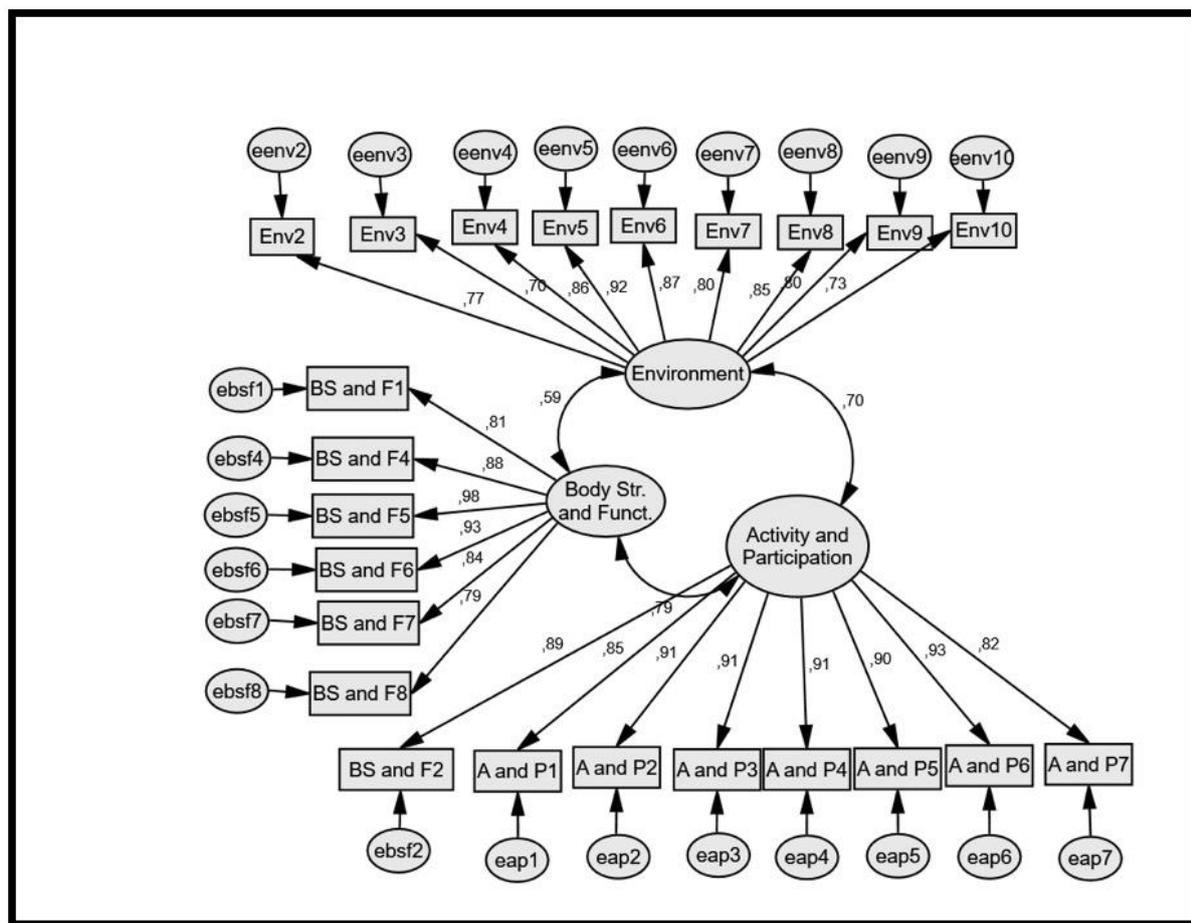


Figure 2. Path diagram.

Internal consistency of the scale (Cronbach  $\alpha_{\text{body structures and functions}}$ : 0.884, Cronbach  $\alpha_{\text{activity and participation}}$ : 0.955, Cronbach  $\alpha_{\text{environment}}$ : 0.919, Cronbach  $\alpha_{\text{total}}$ : 0.959) and test-retest reliability (ICC for  $\text{body structures and functions}$ : 0.625, ICC for  $\text{activity and participation}$ : 0.895, ICC

for  $\text{environment}$ : 0.802, ICC for  $\text{total}$ : 0.851) was determined to be high. Cronbach  $\alpha$  and ICC values of the Participation Restriction Questionnaire subscales and the total are exhibited in table 4.

**Table 4. Results for Internal consistency and test-retest reliability (n=242).**

PRQ subscales	Cronbach alpha	ICC (95% CI)	p	df
Body structures & Functions	0.884	0.625 (0.054-0.852)	<0.001	19
Activity & Participation	0.955	0.895 (0.736-0.959)	<0.001	19
Environmental	0.919	0.802 (0.512-0.924)	<0.001	19
Total	0.959	0.851 (0.624-0.941)	<0.001	19

PRQ= Participation Restriction Questionnaire, ICC=Intraclass Correlation Coefficients, CI=Confidence Interval, df=Degrees of Freedom, p<0.05.

## DISCUSSION

This study presents a new scale to assess the restriction in child participation in daily life from the perspective of parents pursuant to the ICF aspects. Determining the factors that cause the participation restriction in children provides guidance to develop the intervention plan. The study findings reveal that the scale is applicable, valid and reliable in children with typical development and chronic diseases.

Internal consistency of the Participation Restriction Questionnaire was found to be moderate to excellent (Cronbach  $\alpha$ >0.80). Test-retest reliability of the Participation Restriction Questionnaire was found to be acceptable (ICC>0.50) in the subscales of the Body Structures and Functions, Activity and Participation, Environmental and the total.

Exploratory and confirmatory factor analyses were employed to assess the construct validity of the scale. The results of the exploratory factor analysis concluded that the three subscales of the scale explained the total variance by a 69.5%, and the three subscales explained the variance at nearly similar rates (24.7%, 24.3% and 20.4%). The subscale explaining the participation restriction at the highest level was environmental factors while the subscale explaining it at the lowest level was the impairment in body structures and functions. The findings revealed that impairment in body structures and functions, limitation of activity, and environmental barriers are potential factors restricting child participation. In the scale constituted by 26 items, 2 items with a factor load below 0.40 were excluded from the body structures and functions subscale, and 1 item from the subscale of environmental factors. One item was transferred from the body structures and functions subscale to the activity subscale. The confirmatory factor analysis determined the total model fit of the scale to be at an acceptable level.

Our scale evaluates the participation restriction of a child in daily life from the perspective of the parents in accordance with the ICF aspects. The approaches focusing mainly on body structures and functions have been abandoned in planning physiotherapy interventions for children with chronic diseases. The current ICF-based approaches in the 21st century prioritize the activity and participation of children in life apart from their body structures and functions. It is aimed to minimize the negative effects of environmental factors in order to enhance child

participation. The attempts to change the environmental conditions in order to support and promote the manifestation of motor developmental stages are progressing rapidly. In this regard, our scale, evaluating the restrictions of child participation in life in terms of not only body structures and functions but also activity and participation and environmental factors, can determine the factors causing restrictions to the greatest extent in the life of a child.

Various tools are available in the literature to assess child participation. The Assessment of Life Habits (Noreau et al., 2007), Children's Assessment of Participation and Enjoyment (King et al., 2004), Participation and Environment Measure-Children and Youth (Coster et al., 2011) can be cited among them. An ICF core set was developed specific to childhood chronic diseases such as ADHD (Bolte et al., 2018) and CP (Schiariti et al., 2018). However, a great number of other chronic diseases affect the participation of children. The Turkish validity and reliability study of the first of the scales was conducted by a team of which we are also a member. The Turkish version of the latest scale is in use. The fact that both scales are subject to a fee and the implementation period is long limits their use. Contrary to these scales, the ICF-CY-based Participation Restriction Questionnaire focuses on measuring the participation restriction and can be applied in a short time since it contains 23 items in total. Therefore, the use of our scale in clinical practice will provide convenience to clinicians. If a difficulty is determined related to a particular area in the restriction of a child, more detailed scales can be used for further investigation. The Environmental Restriction Questionnaire also assesses environmental restrictions regarding the participation of young children with mild developmental disabilities. Rosenberg et al. (Rosenberg et al., 2010) revealed that parents perceived physical and human environmental factors as slightly restrictive to the participation of their children, and the home factor affected the child participation dimension of independence. The ERQ scale assesses the physical properties of the home and outdoor environment and the attitudes of other individuals in the social environment of parents and the child. Our scale, on the other hand, contains additional questions about the body structures and functions of a child.

There are two strong aspects of this study;

- 1) It is the first Turkish scale developed for the assessment of participation within the framework of ICF.
- 2) It is not specific to a single disease; thus, it can be used as a comprehensive scale to examine participation restriction in the general pediatric population.

### Limitation of study

One of the limitations of our study is that individuals with similar socioeconomic conditions participated in our study. In addition, the scale is organized according to the ICF structure, and in this respect, it is not designed to question the frequency and intensity of participation and the type of activity.

### CONCLUSION

Based on the ICF-CY in children with typical development and chronic diseases, the Participation Restriction Questionnaire is valid and reliable. The questionnaire is recommended for use in further studies to identify the factors which restrict participation.

### Acknowledgement

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### Conflict of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

### Author Contributions

**Plan, design:** OC, ANA; **Material, methods and data collection:** OC, ANA; **Data analysis and comments:** OC, ANA; **Writing and corrections:** OC, ANA.

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