

## *Participation and Environment Measure for Children and Youth (PEM-CY): cross-cultural adaptation for use in Brazil*

### *Medida da Participação e do Ambiente – Crianças e Jovens (PEM-CY): adaptação transcultural para o uso no Brasil*

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**ABSTRACT:** *Introduction:* The Participation and Environment Measure for Children and Youth (PEM-CY) is a tool that assesses the participation and environment of these individuals in the home, school and community contexts through the perception of their parents and/or guardians. *Objective:* To adapt the PEM-CY culturally to Brazilian Portuguese. *Method:* The process of cross-cultural adaptation was composed of five stages: (I) Initial adaptation to Brazilian Portuguese; (II) Synthesis of the versions; (III) Back-translation; (IV) Committee of experts; (V) Understanding by parents and back-translation for final approval. *Results:* The adaptations made aimed to promote the fluency when reading as well as to facilitate the interpretation and understanding of the questionnaire. The title undergone alteration and some terms were replaced in the survey instructions. More examples were added to some activities of the participation and environment sections, and some words were replaced with expressions more equivalent to the language of the people. *Conclusion:* The version adapted to Brazilian Portuguese provides an innovative tool for evaluation of participation and environment of children and young people, which can be used in different contexts of practice and research.

**Keywords:** Child; Adolescent; Surveys and questionnaires; Activities of daily living, International Classification of Functioning, Disability and Health.

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**RESUMO:** *Introdução:* A Medida da Participação e do Ambiente – Crianças e Jovens (PEM-CY) é um instrumento que avalia a participação desses indivíduos nos ambientes da casa, da escola e da comunidade, a partir da percepção de seus pais e/ou responsáveis. *Objetivo:* Adaptar culturalmente a PEM-CY para o português do Brasil. *Método:* O processo de adaptação transcultural foi composto por cinco estágios: (I) Adaptação inicial para o português do Brasil; (II) Síntese das versões; (III) Retrotradução; (IV) Comitê de especialistas; (V) Compreensão pelos pais e retrotradução para aprovação final. *Resultados:* As adaptações implementadas visaram favorecer a fluência na leitura, bem como facilitar a interpretação e compreensão do questionário. O título sofreu alteração e alguns termos foram substituídos nas instruções para pesquisa. Mais exemplos foram adicionados a algumas atividades das seções de participação e ambiente dos três ambientes, e algumas palavras foram alteradas para expressões mais equivalentes à linguagem popular. *Conclusão:* A versão adaptada para o português do Brasil disponibiliza um instrumento inovador de avaliação da participação e do ambiente de crianças e jovens que poderá ser utilizado em diferentes cenários de prática e pesquisa.

**Descritores:** Criança; Adolescente; Inquéritos e questionários; Atividades cotidianas; Classificação Internacional de Funcionalidade; Incapacidade e saúde.

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## INTRODUCTION

The International Classification of Functioning, Disability and Health (ICF), proposed by the World Health Organization (WHO)<sup>1</sup>, defines participation as the individual's involvement in life situations, which could mean for children and young people participate in activities at home, school and community. Participation involves the person's day-to-day experiences and may be determined by personal factors such as health condition, and environment factors<sup>1,2</sup>, including aspects of the physical environment and social values. Similarly, the ICF considers that disability results from the interaction between the individuals and their surroundings, highlighting the environment factors that influence their life. Thus, the environment where people with disabilities live significantly influences their extent of participation<sup>1,3</sup>.

Children and young people with and without disabilities have the same aspirations, wishes and expectations regarding participating in the socialization activities. However, studies show the opportunities are not the same, mainly due to barriers related to the physical, social or attitudinal environment<sup>4-9</sup>. Consequently, the identification of barriers and facilitators of the environment are required to know the aspects that may worsen the levels of disability and dependence, as well as those that can increase the conditions of participation at home, school and community, favoring the development of interventions aimed at this purpose<sup>10</sup>.

Involvement in activities at home, school and community is an important part of childhood and health indicator, as it improves children's health and quality of life and is associated with social and recreational development, in addition to being an important goal of rehabilitation for children with cerebral palsy and other disabilities<sup>11,12</sup>. Considering the importance of the quality of life of these children, social participation and environment have been topics of interest in various investigations, which has sparked interest in specific instrument for these assessments in different contexts. Some of these measures have already been translated and adapted to the Brazilian Portuguese<sup>13-17</sup>; however, none of them enables evaluating the environments of home, school and community and

the impact of their aspects on youth's public participation simultaneously<sup>18</sup>.

PEM-CY (*Participation and Environment Measure for Children and Youth*) – translated as *Medida da Participação e do Ambiente – Crianças e Jovens*) was developed in Canada in 2010 by researchers at the *Center for Childhood Disability Research* (CanChild) aiming at being an innovative tool for simultaneous measurement of participation and environment of children and adolescents with and without disabilities, based on ICF<sup>11</sup>. This tool has been translated into 14 languages, including European Portuguese. Nonetheless, validation studies are available only for the English (original) and Korean versions<sup>11,18,19</sup>. Its use favors the incorporation into intervention therapies focused on the context and on the participation of children and young people, benefiting this population, as well as professionals, rehabilitation programs, researchers and their families.

Although WHO recognizes the influence of the environment (physical, social and attitudinal) on the functionality and inability, the lack of standardized assessment tools to identify such factors, especially in children, hinders the identification of barriers and facilitators associated with the social participation of people with disability<sup>1</sup>.

To be applied to the Brazilian population, the version of PEM-CY in European Portuguese needed to undergo the stage of cross-cultural adaptation due to linguistic and cultural differences between both countries (Portugal and Brazil). Thus, this study aimed at the cross-cultural adaptation of the PEM-CY for use in Brazil.

## METHOD

This is a methodological study that involved the cross-cultural adaptation of the Participation and Environment Measure for Children and Youth (PEM-CY) for use in Brazil.

### **Participation and Environment Measure for Children and Youth (PEM-CY)**

The Participation and Environment Measure

for Children and Youth (PEM-CY) evaluates, through the perception of parents/guardians of children and young people from 5 to 17 years, participation and environmental factors in three sections: home, school, and community. Each section is divided into “participation” and “environment”. In the part related to participation, the items evaluated consist of typical activities that children generally perform in those scenarios (home, school or community), and in the part related to the environment, the items relate to the environmental characteristics (barriers or facilitators present at home, school or community) that influence on participation. The questions are distributed as follows: in the section home, 10 items on the participation and 12 items on the environment; in the section school, 5 items on the participation and 17 items on the environment; and in the section community, 10 items on the participation and 16 items on the environment<sup>21</sup>. Each environment also has a space for the guardian to list things that he/she or family members do to help on the child participation.

Each item on the participation is evaluated in three dimensions: frequency (seven-point scale), involvement (five-point scale) and desire for change (scores from 0 to 100%). The environment, in turn, is assessed through its characteristics, as well as through the availability of services and resources (scores from 0 to 100%).

The PEM-CY allows knowing what types of activities the parents understand as important to children and young people, identifying what types of factors that support or hinder a child’s participation in important life situations, in addition to assessing the frequency of participation of their children and the facilitators and environmental barriers influencing on the participation<sup>18</sup>.

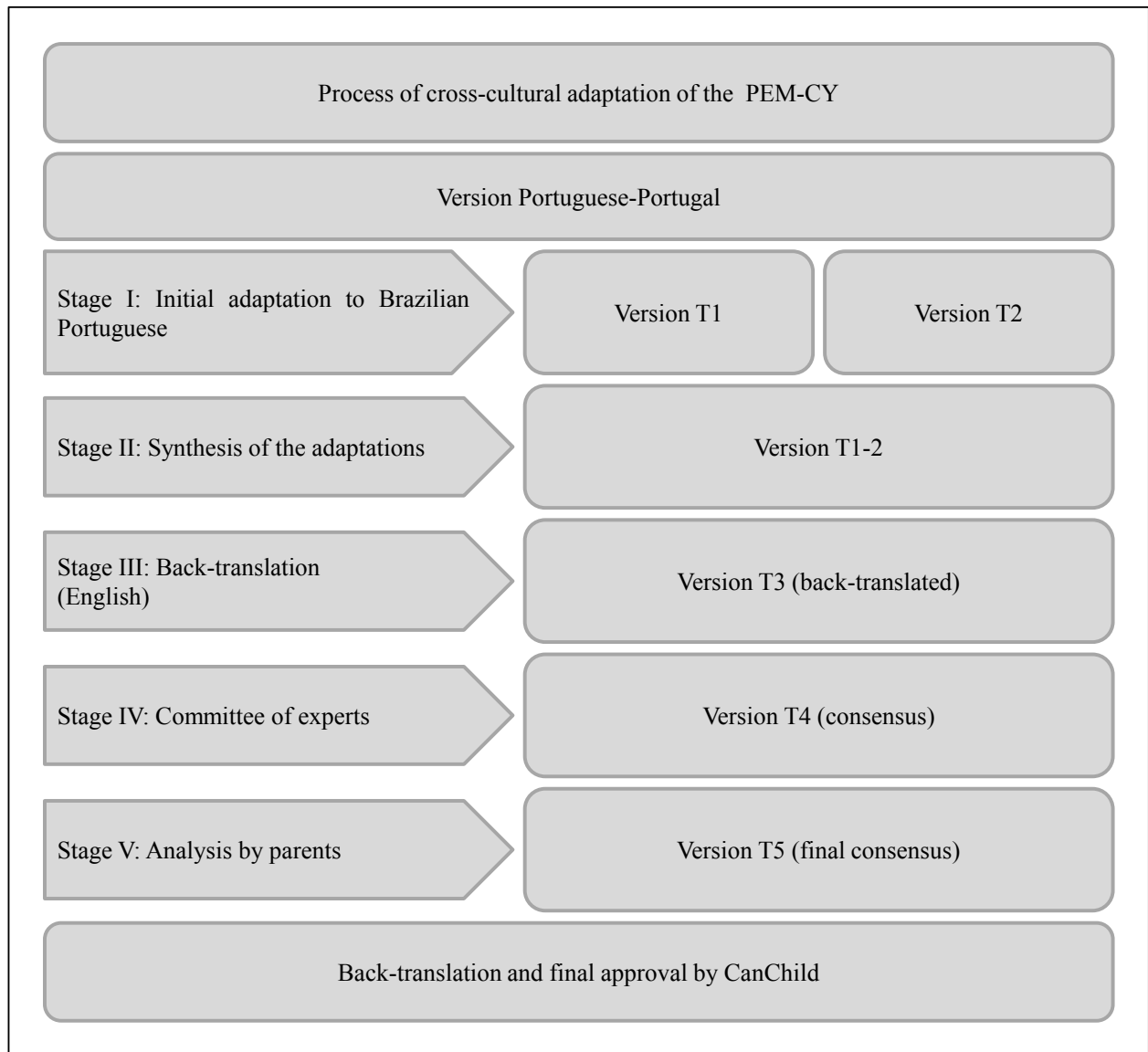
## Procedures

Interested in using the PEM-CY, a group of researchers from three Brazilian universities were allowed by the authors of the tool (*CanChild/Canada*) to adapt the questionnaire from the European Portuguese to the Brazilian Portuguese. The protocol for cross-cultural adaptation followed the procedures suggested by Beaton et al.<sup>22</sup>, and this study was approved by the Research Ethics Committee of the School of Health Sciences (FACISA),

at Trairi, of the Universidade Federal do Rio Grande do Norte (UFRN), its center of origin, under the opinion 2.388.525/2017 and CAAE 79628017.0.0000.5568.

In stage I, two adaptations (version T1 and version T2) to Brazilian Portuguese were performed by two university teachers (one physical therapist and one occupational therapist) with knowledge and understanding of the questionnaire. Stage II integrated the synthesis of the versions adapted, resulting in a consensus version (version T1-2). From this version, a back-translation (stage III) into the original language of the tool (English) was done by a third professor who did not know it, and the version generated obtained approval by the group of authors (version T3). Stage IV corresponded to the analysis of the committee of experts, composed of other five professionals or university teachers of five different Brazilian states (RN, PB, MA, RJ and SP). This committee examined the clarity, pertinence and equivalence of the consensus version (version T1-2) and suggested alterations. After the alterations recommended by the committee were made, a new consensus version (version T4) was obtained and used for consultation and analysis by 16 parents and guardians of children and youths with and without disabilities, aged between 5 and 17 years (at whom the PEM-CY is aimed), in two Brazilian states from different regions.

This stage (stage V) occurred in the cities of Natal (RN) and São Carlos (SP), with eight parents for each municipality, recruited by convenience and according to their availability, to assess the degree of understanding of the tool. This stage aimed to identify whether the guardians understood the instructions in the PEM-CY, as well as its items. The participants from São Carlos analyzed the questionnaire individually, but they could consult a member of the research group in case of doubts; in relation to Natal, six guardians analyzed the tool in group and two individually, without consultation. The different types of analysis were performed according to the families’ preference and availability. After their suggestions of alterations, a new consensus was reached and the last version (version T5) was back-translated for obtaining the final approval by *CanChild*. Figure 1 shows a synthesis of the steps performed in this study.



**Figure 1** – Synthesis of the methodology used in the adaptation of the PEM-CY tool for Brazil

## RESULTS

After permission by the group responsible (*CanChild*), two researchers compared the Portuguese-Portugal version with the original version, in English, identifying the necessary changes for the version in Brazilian Portuguese. In addition to general changes in the text to promote fluency when reading, some terms were also replaced.

In the first consensus version (stage II), the modifications were initiated in the title of the questionnaire.

In the survey instructions, the term “commitment” gave way to the word “involvement” and the options of answers related to it were modified. The questions related to participation were altered to become the Brazilian version similar to the original version (in English), as well as to become its reading and interpretation easier. Modifications were also undergone in the options of activities and items on the environment of the three contexts (Chart 1).

**Chart 1** – The items altered in stage II of the process of cross-cultural adaptation of the PEM-CY for Brazil (consensus version)

Section	Portugal Version	Item modification*	English Version
Title	Medida da Participação e do <b>Contexto</b> - Crianças e Jovens.	Medida da Participação e do <b>Ambiente</b> - Crianças e Jovens.	Participation and <b>Environment</b> Measure for Children and Youth
Survey instructions	Quando selecionar a sua resposta, por favor pense <b>acerca do</b> nível de atenção, concentração, <b>empenho</b> emocional, ou satisfação da sua criança (considerando o uso de suportes ou ajudas que estão geralmente disponíveis). <b>Algo envolvido.</b> <b>Minimamente envolvido.</b>	Quando selecionar a sua resposta, por favor pense <b>sobre</b> o nível de atenção, concentração, <b>envolvimento</b> emocional, ou satisfação da sua criança (considerando o uso de suportes ou ajudas que estão geralmente disponíveis). <b>Mais ou menos envolvida.</b> <b>Pouco envolvida.</b>	When you select your answer, please think <b>about</b> your child's level of attention, concentration, emotional <b>engagement</b> , or satisfaction (considering using the supports or aids generally available). <b>Somewhat involved.</b> <b>Minimally involved.</b>
Home participation	1. Jogos de computador e <b>consolas</b> . 2. Jogos e brincadeiras <b>no interior</b> (ex. brincar com brinquedos, <b>puzzles</b> , jogos de tabuleiro). 3. Artes, <b>trabalhos manuais</b> , música e passatempos. 7. Tarefas domésticas (ex. <b>pôr/tirar louça da máquina de lavar louça</b> , limpar o quarto ou outras áreas da casa...).	1. Jogos de computador e <b>vídeo games</b> . 2. Jogos e brincadeiras <b>dentro de casa</b> (ex. brincar com brinquedos, <b>quebra-cabeças</b> , jogos de tabuleiro). 3. Artes, <b>artesanato</b> , música e passatempos. 7. Tarefas domésticas (ex. <b>Ajudar a lavar ou guardar a louça</b> , limpar o quarto ou outras áreas da casa...).	1. Computer and <b>video games</b> . 2. <b>Indoor</b> play and games (e.g. playing with toys, puzzles, board games). 3. Arts, <b>crafts</b> , music and hobbies. 7. Household chores (eg. put/get the dishes in/out of the <b>dishwasher</b> , clean the bedroom or other areas of the house...).
Home environment	2. As <b>qualidades</b> sensoriais do <b>contexto doméstico</b> . 4. As exigências <b>cognitivas</b> das atividades típicas do <b>contexto doméstico</b> .	2. As <b>características</b> sensoriais do <b>ambiente de casa</b> . 4. As exigências <b>mentais</b> das atividades típicas <b>de casa</b> .	2. The sensory <b>qualities</b> of the <b>home environment</b> . 4. The <b>cognitive</b> demands of typical <b>activities in the home</b> .
School participation	2. <b>Visitas de estudo</b> e eventos na escola.	2. <b>Passeios</b> e eventos na escola.	2. <b>Field trips</b> and school events.
School environment	2. As <b>qualidades</b> sensoriais do <b>contexto</b> escolar. 3. Condições <b>atmosféricas exteriores</b> . 5. As exigências <b>cognitivas</b> das atividades típicas do <b>contexto escolar</b> .	2. As <b>características</b> sensoriais do <b>ambiente</b> escolar. 3. Condições <b>do tempo nas áreas abertas</b> . 5. As exigências <b>mentais</b> das atividades típicas <b>da escola</b> .	2. The sensory <b>qualities</b> of the school environment. 3. <b>Outdoor weather</b> conditions. 5. The <b>cognitive</b> demands of typical activities <b>in the school</b> .
Community participation	1. Saídas <b>na vizinhança</b> . 4. Atividades físicas <b>organizadas</b> .	1. <b>Passeios no bairro</b> . 4. Atividades físicas <b>livres</b> .	1. <b>Neighborhood</b> outings 4. <b>Unstructured</b> physical activities
Community environment	2. As <b>qualidades</b> sensoriais dos <b>contextos</b> comunitários. 4. As exigências <b>cognitivas</b> das atividades típicas. 8. Condições <b>atmosféricas exteriores</b> .	1. As <b>características</b> sensoriais dos <b>ambientes</b> comunitários. 4. As exigências <b>mentais</b> das atividades típicas. 8. Condições <b>do tempo em áreas abertas</b> .	2. The sensory <b>qualities</b> of community <b>settings</b> . 4. The <b>cognitive</b> demands of typical activities in the community. 8. <b>Outside weather</b> conditions.

\*The words altered in each item are in bold.



After these alterations, the back-translation of the tool into English was performed (stage III) and, then, the adaptation process was carried on with the analysis of the committee of experts to conclude the stage IV. After analysis, in general, in the section of participation of the three environments (home, school and community), adding examples to improve the identification of the type of activity was suggested: “tablet” and “cell phone” were terms added to the examples of technologies; “tests”, “parties”, “snack” and “playground” were terms added to the school activities and “Programa Jovem Aprendiz” was included in the examples of paid work activity in the community. In the environment section, the most relevant alteration was that of the item 1 of the three environments, “A disposição física ou a quantidade de espaço e mobília

em sua casa” (“the physical layout or the amount of space and furniture in the home”) to “A maneira como os móveis estão organizados e o espaço disponível” (“the way the furniture is arranged and the space available”); and the replacement the item 2 of the sensory “As características sensoriais do ambiente” (“the sensory qualities of the environment”) with “As características dos estímulos do ambiente” (“the characteristics of the stimuli of the environment”). The term “typical activities” was replaced with “habitual activities”, and examples were added to the items 8 (home environment) and 12 (school environment).

Stage V was composed of some parents/guardians of children with and without disabilities, considering that this questionnaire is intended for the former. Table 1 shows the characteristics of participants

**Table 1** – Characteristics of participants

Participant	State	Degree of relatedness	Respondent Education	Child's age	Diagnostic condition
1	SP	Mother	High School	9	CP GMFCS III
2	SP	Mother	High School	11	CP GMFCS I
3	SP	Mother	College Degree	5	CP GMFCS I
4	SP	Mother	Primary School	9	CP GMFCS II/Down syndrome
5	SP	Mother	High School	12	Motor delay and Mild Autism
6	SP	Mother	High School	5	CP GMFCS IV
7	SP	Mother	Primary School	13	CP GMFCS II
8	SP	Mother	College Degree	5	CP GMFCS IV
9	RN	Mother	College Degree	6	CP GMFCS V
10	RN	Mother	Graduate degree	8	Meningoencephalitis Sequelae
11	RN	Mother	Graduate degree	7	Myelomeningocele and hydrocephaly
12	RN	Mother	College Degree	6	Spinal Cord Injury
13	RN	Mother	High School	7	Myelomeningocele and hydrocephaly
14	RN	Mother	High School	13	Myelomeningocele and hydrocephaly
15	RN	Mother	Graduate degree	12	Child Typical
16	RN	Father	Graduate degree	9	Child Typical

Legend: CP - Cerebral Palsy; GMFCS - Gross Motor Function Classification System.

As a result of this analysis, it was suggested adding information about for whom the questionnaire is intended in the instructions. Regarding the content, the main problems identified are related to some terms used in the environment sections. The parents pointed that some terms were difficult to understand. Therefore, after

discussion in the group of researchers responsible for the adaptation process, the decision was to modify them. Adding more examples to the item on “information” of the three contexts was also suggested and, in a specific manner, adding examples to the item 13 of the school environment (Chart 2).

**Chart 2** – Items modified in stage V of the cross-cultural adaptation of PEM-CY for Brazil, after parents’ analysis

Section	Version before parents’ analysis	Item modification*
Survey instructions		<b>This questionnaire is intended for parents or caregivers of children and young people, aged between 5 and 17 years.</b>
Home environment	2. The characteristics of the stimuli of the home (e.g. amount and/or type of sound, light, temperature, texture of objects). 3. The physical demands of habitual activities in the home (e.g. strength, endurance, coordination). 10. Information (e.g. about activities, services, programs).	2. The sensory qualities of the home environment (e.g. noise, lighting, temperature, texture of objects)**. 3. The physical demands of typical activities in the home (e.g. amount of muscle strength, physical exertion, coordination of movements, fatigue)**. 10. Information (i.e. receive information and/or orientations on how to perform daily activities, on resources and adaptations, on services and programs available for child’s participation at home, such as recreational activities or health services).
School environment	13. Policies and procedures related to the school (e.g. eligibility criteria for services, rules of behavior). 15. Information (e.g. about activities, services, programs).	13. School-related policies and procedures (e.g. rules of the school, eligibility criteria for services, rules of behavior). 15. Information (i.e. receive information and/or orientations on how to perform daily activities, on resources and adaptations, on services and programs available for child’s participation at home, on rights and benefits).
Community environment	13. Information (e.g. about activities, services, programs).	13. Information (i.e. receive information and/or orientations on how to perform daily activities, on resources and adaptations, on services and programs available for child’s participation at home, such as recreational or cultural activities, health services, training programs, information on rights and benefits).

\*The words altered in each item are in bold.

\*\* Regarding these items, similar modifications in school and community environments were made.

This process of adaptation triggered reflection on how to apply this questionnaire, and this investigation was also suggested by some respondents. Considering that the parents performed the analysis in three different ways (individually with and without consultation, and in group), the evaluation of the best way to use the PEM-CY with the Brazilian population was included in the design of the study of tool validation.

## DISCUSSION

To translate and adapt a tool, a set of techniques and procedures previously defined and standardized are required, aiming at systematizing the actions for the production of reliable measure with valid content<sup>18</sup>. The methodology used for translating and adapting the Participation and Environment Measure for Children and Youth (PEM-CY) for Brazil was recommended by experts

in the field<sup>22</sup> to obtain a version with proper translation, being culturally adapted to Brazilians and corresponding to the original version, allowing broad understanding of the environment of children and young people, with and without disabilities, in the activities performed at home, school and community.

The cross-cultural adaptation of this tool was not difficult. Probably, this occurred due to the method adopted and the fact that the original version (in English) was structurally well formulated. The initial adaptation was carried out by selecting the words and phrases that best reflect the cultural reality of most of the Brazilian population, considering the proposals of the tool, through a simple and representative language, which could preserve the semantic, conceptual, cultural and idiomatic equivalences, corresponding to the transcultural adaptation<sup>22,23</sup>.

Initially, some modifications were suggested. One

of them was related to the title, replacing the word “context” with “environment”, since their meanings are different and the contextual factors encompass environmental and personal factors. Personal factors are related to individual characteristics and to the particular history of each person, while environmental factors include the physical, social and attitudinal environment. Thus, the contextual factors comprise all the individual’s history of life and lifestyle<sup>1</sup>, not relating to the objective of assessment proposed by the tool. Hence, the title was changed to facilitate the understanding by the target audience and enable greater similarity to the ICF concepts.

The observations inserted in the PEM-CY instructions aimed at a greater clarification on for whom the questionnaire is intended and who should answer it, as well as at an improved understanding of the answer options regarding the level of involvement in the activities. Regarding the sections participation and environment of the three contexts, the modifications sought to ensure the inclusion of terms that best corresponded to the tasks performed at home, school and community. The need for provision and change of examples in a few items was also evaluated to adapt the terms to the Brazilian context, simplifying the language and adjusting the tool to the socioeconomic reality of the country. Some modifications were also carried out aiming at becoming the Brazilian version similar to the original version in English and facilitating the reading and interpretation of the questionnaire.

As Brazil has a great cultural diversity and marked regional differences, these characteristics were considered in this study. However, despite having involved centers and researchers from different regions, the analysis by the parents, for whom the questionnaire is intended, was performed only in two states of different regions. Thus, cultural particularities, amidst the many existing in our country, may influence on the understanding of any item of the questionnaire and generate differences in its interpretation. On the other hand, when applying the questionnaire to the parents or guardians, one suggests that professionals or researchers reinforce that the activities listed in each section of the tool are only examples of activities carried out in that environment, so that other

similar activities can be considered when answering each question. This characteristic of the tool allows a greater similarity between the answers and the local and individual reality of the family.

Another aspect that deserves attention of professionals or researchers is that the PEM-CY seeks to evaluate the participation, which is measured by the frequency, involvement and desire for change. In this sense, involvement cannot be confused with performance capacity; that is, the aim is not to measure the child’s degree of independence or ability to perform the activity, but rather to analyze how the parents notice their involvement in the activities, which can be identified through the child’s non-verbal behavior and focus of attention, even if he/she needs help to perform them<sup>12</sup>.

Originally, the PEM-CY was conceived to be self answered by parents/guardians of children and youths<sup>11,18</sup>. However, considering the Brazilian reality, some parents/guardians have difficulty in reading and interpreting the items of the questionnaire. In view of this, the final version of the tool will be tested both for the definition of the way to apply it and for the identification of possible cultural differences between the population.

The study of the psychometric properties of the tool will be conducted using the data collected, consisting of its validation for use in Brazil. This process is relevant to become the PEM-CY a consistent and reliable measure to be used with the Brazilian population, as well as to encourage other researchers to develop similar studies.

## CONCLUSION

The process of cross-cultural adaptation of the PEM-CY was conducted satisfactorily. The stages for this procedure followed the criteria set and the linguistic and experiential conflicts were solved, aiming at the cultural adaptation of the questionnaire. The version adapted to Brazilian Portuguese offers an innovative tool of assessment of the participation and environment for the use of professionals in the fields of health, education and rehabilitation of the country, as well as of relatives of children and young people with and without disability.

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