Translation and Cultural Adaptation of the Pectus Excavatum Evaluation Questionnaire From English to Catalan and Spanish

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Research

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Abstract

Background:

Pectus excavatum is the most common congenital chest wall deformity. It can have a negative effect in exercise tolerance. However, cosmetic features are the most frequent concerns in these patients. The pectus excavatum evaluation questionnaire is a patient-reported outcome (PRO) tool to measure the physical and psychosocial quality of life changes after surgical repair of pectus excavatum. No specific tool has been developed in our languages to evaluate PRO in pectus excavatum patients. Our aim is to translate and culturally adapt the pectus excavatum evaluation questionnaire to European Spanish and Catalan.

Methods:

Guidelines for translation of PRO were followed. The pectus excavatum evaluation questionnaire, consisting of 34 items, was translated from English to Spanish and to Catalan. Three forward translations and one back translation were performed for each language. Cognitive debriefing interviews were developed.

Results:

The reconciliation of the forward translations revealed a 14.7% of inconsistencies for each language. The Spanish back translation showed a 64.7% of disagreement with the source, the Catalan 58.8%. Changes in each reconciled version were made to amend the diverting items. 10 patients and their parents participate in the cognitive debriefing for each language, 5 patients had been operated and 5 had not. 4 patients out of 10, for each language, showed difficulties for understanding one of the pectus excavatum evaluation questionnaire items, thus also resulted in a modification of the reconciled version.

Conclusion:

The translation and cultural adaptation process resulted in the development of a European Spanish and a Catalan version of the pectus excavatum evaluation questionnaire for application in Spanish and Catalan pectus excavatum patients.

Background

_Pectus excavatum_ (PE) is the most common congenital chest wall deformity. It is defined by a depression of the sternal body and the lower costal cartilages at the xiphisternal junction. It is observed between one and eight in every 1000 children [1] and it is more frequent in boys (male:female ratio of 4:1 approximately) [2]. The sternal depression may restrict thoracic volume and therefore vital capacity; it can have a negative effect in tolerance to physical exercise. PE may also cause cardiac compression reducing cardiac output and further contributing to exercise intolerance [3]. However, these symptoms are rarely disabling and cosmetic features are the most frequent concerns of children with PE [4, 5]. Several studies have shown the repercussion of the defect in the psychological wellbeing of children and adolescents with PE [6].

The PE evaluation questionnaire (PEEQ) was developed and validated by Lawson et al. [7] as a patient reported outcome (PRO) tool to measure the physical and psychosocial changes of quality of life (QoL) after surgical repair of PE. The global use of PRO instruments should lead the professionals to a better understanding of health conditions and how these affect patients. However, although the use of PROs has been largely applied in research, it has not an effective clinical application yet [8]. So far, no specific tool has been developed in our languages to evaluate PRO in children with PE.

The aim of our study is to translate and culturally adapt the PEEQ to Catalan and European Spanish.

Material And Methods

Ethics
The study was evaluated and approved by the Research Ethics Board at our center (reference PIC-82-19) complying with the local laws on Biomedical Research (**Ley 14/2007, de 3 de julio, de Investigación Biomédica**). All legal guardians or patients older than 18 years provided written informed consent according to our center’s policy. Children aged 12 to 17 years also provided written assent.

**PEEQ**

The PEEQ is a tool designed by a psychologist and a group of PE clinical experts [7] in Norfolk, Virginia. It consists of both preoperative and postoperative telephone questionnaires, with versions for patients and parents. It includes questions related to body image and also to physical activities. Answers are given using a Likert-type scale from 1 to 4, reflecting the extent or frequency of a particular experience. Higher values on the response scale indicate a less desirable experience (e.g., 4 very unhappy and 1 very happy).

The questionnaire is divided in two parts: the first part is for patients and the second one for parents. The patient’s preoperative part of the questionnaire consists of 15 items; the postoperative part consists of 17 items. Items 1-14 are equal in both pre-surgical and post-surgical; the other items differ. There are a total of 18 different questions in the patient’s part. The parents’ part consists of 16 items; there is only a slight difference in one item (item 13) that was considered irrelevant for the analysis.

**Process of adaptation of the PEEQ into Catalan and European Spanish**

Principles of good practice for the translation and cultural adaptation process for PRO were followed according to the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) recommendations [9].

- **Step 1: Preparation.**

  Permission was obtained from Dr. RE Kelly, one of the PEEQ developers. He provided the original version of PEEQ and allowed us to transform the telephonic original version into a written questionnaire.

- **Step 2: Forward translation.**

  Selected forward translators were native speakers of both target languages and had an advanced knowledge of English. One of them is a professional translator; the other two are pediatric surgeons—one has special dedication to PE patients and the other is a senior pediatric surgeon with previous experience in PRO translation [10].

  A document including our written adaptation of the PEEQ original version and an explanation of the tool and the goals of our study was prepared and delivered to translators. Following the ISPOR recommendations, we stressed that the translation should be conceptual rather than literal. Common language was also recommended, so that patients and parents having diverse educational level could easily understand the questions and responses.

  Each translator developed a Catalan and a European Spanish version of the PEEQ.

- **Step 3: Reconciliation.**

  Reconciliation of the three forward translations into a single one in each language was performed in a meeting between the forward translators and the thoracic pediatric surgeon of our department. Agreement of the main word and sentence construction was recorded for each item of the questionnaire. An item was considered discordant if all the 3 versions were different in any of both parts of the translation (key-word or sentence construction).

- **Step 4: Back translation.**
A native English speaker was the back translator for each target language (Catalan and European Spanish). They are both medical doctors. A document including the reconciled version, an explanation of the tool and the goals of the study, was delivered to each translator. Again, we stressed that the translation should be conceptual rather than literal and that common language was recommended.

- Step 5: Back translation review.

A revision of the back translations against the original English version was performed in a meeting of two of the forward translators and the thoracic pediatric surgeon of the department. For each item, we recorded changes in the wording or in sentence construction in the back translations compared to the original source. Discrepancies between the original version and the back translations were identified and an improved version was developed for each language. Despite differences with the original source were detected; we only changed the forward version in case of significant meaning alteration.

- Step 6: Harmonization.

Comparison between our new Catalan and European Spanish versions and the original English version was performed to guarantee conceptual equivalence between the source language and the target language versions. Formulation of questions was also unified at this point. The forward translators and the thoracic pediatric surgeon of the department amended this issue in the back-translation review meeting.

- Step 7: Cognitive debriefing.

In order to ensure that the translation was comprehensible to the patient population, a cognitive debriefing was performed on 10 patients for each language. Patients aged 8 to 21 years were selected from the thoracic outpatient agenda between April and September 2019. Five patients who had undergone Nuss procedure and five untreated patients were selected for each language. The main researcher approached potential participants, explained them and their parents the purpose of the study and invited them to participate. After informed consent, patients and parents were asked to answer the questionnaires and express for each item whether they understood the entire sentence and every word. Sentences in which patients or parents required any clarification were considered difficult to understand, age, gender and treatment of PE of the participants were recorded.

- Step 8: Review of the results of cognitive debriefing and finalization.

The results of the cognitive debriefing were reviewed and sentences that were not easily understood by the patients or their parents were checked in a meeting between two of the forward translators and the thoracic pediatric surgeon of the department. The necessary modifications were done to improve the final versions.

- Step 9: Proofreading.

Two other pediatric surgeons of our department proofread the final versions.

- Step 10: Final report.

A final report was done including a description of all translation and cultural adaptation decisions.

**Results**

Translation and cultural adaptation of the PEEQ resulted in the development of a Catalan and a European Spanish version of the questionnaire.
Results of the forward translation process of PEEQ into Catalan and Spanish

An evaluation of the degree of discordance between the three forward versions for each language showed:

- Catalan version: 14.7% of the items were discordant (5 out of 34).
- Spanish version: 14.7% of the items were discordant (5 out of 34).

For each item, the best translation or a new one, using words from any of the forward versions, was chosen. In case two translations were equal and different, the equal ones were often selected for the reconciled version.

For example, item 8 of the child questionnaire (How often does your chest make you feel shy or self-conscious?) of the Spanish version had a discordant translation: translator 1 translated the item as “¿El pecho te hace sentir tímido o tenso?”, translator 2 as “¿Avergüenzas del aspecto de tu torso?” and translator 3 as “¿Cuánta frecuencia te sientes tímido o acomplejado/a por la forma de tu pecho?”. Translator 1 and 3 use the same key-word “tímido”, however the construction of the 3 sentences was different. In this case, we chose a new translation using items of the three versions “¿Te sientes acomplejado/a por la forma de tu pecho?”.

Results of the back translation process of PEEQ into Catalan and Spanish

After the back translation review, some items of the forward translation were changed in order to make the target language version more similar to the original source. In other cases, despite detected differences, our forward translation was considered more accurate to the original source than the back translation; therefore, we didn’t change it.

- Catalan version: wording or sentence construction changed in 58.8% of the items (20 out of 34). However, we only changed the forward version in 41.2% of the cases (14 out of 34).
- Spanish version: wording or sentence construction changed in 64.7% of the items (21 out of 34). However, we only changed the forward version in 41.2% of the cases (14 out of 34).

Harmonization

No major differences were found comparing Catalan and European Spanish versions.

In both languages, the word “forma” (equivalent of shape) was changed for “aspecte” or “aspecto” (equivalent of appearance) in items 8 to match items 5, 7 and 9.

Participants and results of cognitive debriefing

Participants in the cognitive debriefing answered the questionnaire and expressed for each item whether they understood the sentence and the wording. For each item, we recorded if any difficulty was present.

- Catalan version:

Mean age of the 10 participants was 14.8 years, 50% male. Parents did not show any difficulties for understanding whether patients showed: Item 1 was difficult for 2 out of 10, item 7 for 2 out of 10 and item 8 for 4 out of 10. We reviewed each of these items. Finally, we add a clarification in item 1, 7 and 8.

- Spanish version:

Mean age of the 10 participants was 16.4 years; all of them were males (100%). Parents did not show any difficulties for understanding whether patients showed: item 7 was difficult for 2 out of 10, item 8 was difficult for 4 out of 10 and item 11
for 1 out of 10. We reviewed each of these items. Finally, we added only a clarification in item 8.

**Adaptation and translation process**

Tables 1–4 show the discordances found in the forward and the back translations and the changes and solutions made in order to get a translation equivalent to the source.
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|-------------------------|----------------------------------------------------------------------|----------------------------------------|--------------------------|---------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 1. Patient              | How do you feel about the way you look in general?                   | No                                     | -                        | Yes                                   | (your general appearance?)                                                | 2/10                                   | Add the Catalan equivalent for “physical appearance”? |
| 2. Patient              | How do you feel about the way you look with your shirt or your top off? | No                                     | -                        | Yes                                   | (when you aren’t wearing a T-shirt?)                                     | Change for Catalan equivalent for “when you are with your shirt or your top off” | No       | -                                  |
| 3. Patient              | If you had to spend the rest of your life with your chest as it looks now, how would you feel? | No                                     | -                        | No                                    | (How would you feel if you had to live the rest of your life with your chest as it is now?) | -                                      | No       | -                                  |
| 4. Patient              | How often do other kids do fun about you because of your chest?      | No                                     | -                        | Yes (laugh at you)                    | Change for Catalan equivalent for “be made fun of” or “be mocked” and omit the “appearance of your chest” | No                                    | -        |
| 5. Patient              | How often do you avoid doing things, like spending the night at a friend’s house, because of the way your chest looks? | No                                     | -                        | Yes                                   | (Do you stop making plans with your friends, like a sleepover, because of your chest?) | Change for Catalan equivalent for “doing things” | No       | -                                  |
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|-------------------------|----------------------------------------------------------------------|----------------------------------------|--------------------------|----------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 6. Patient              | How often do you try to hide your chest to keep people from knowing about it? | No                                     | -                        | Yes                                    | (Do you try to hide your chest so that people don't know what it looks like?) | Change for Catalan equivalent for “the chest” | No       |
|                         |                                                                       |                                        |                          |                                        | Keep Catalan equivalent for “how it is”                                  |                                        |          |
| 7. Patient              | How often are you bothered because of the way your chest looks?      | No                                     | -                        | Yes                                    | (Do you worry about how your chest looks?)                                | Change for the Catalan equivalent for “are you bothered because of the appearance of your chest” | 2/10     |
|                         |                                                                       |                                        |                          |                                        |                                                                          | Add the Catalan equivalent for “by other people”                       |          |
| 8. Patient              | How often does your chest make you feel shy or self-conscious?       | No                                     | Exclude "shy" from Catalan version | Yes                                    | (Do you have a complex about your chest?)                                 | Keep the Catalan equivalent for “self-conscious” | 4/10     |
|                         |                                                                       |                                        |                          |                                        |                                                                          | Add again the Catalan equivalent for “shy”                               |          |
| 9. Patient              | How often do you feel bad about yourself because of the way your chest looks? | No                                     | -                        | No                                     | (Does the look of your chest make you feel bad?)                         |                                        | No       |
| 10. Patient             | Have trouble running around or exercising because it made your chest hurt? | No                                     | -                        | No                                     | (Problems during running or exercising because your chest hurt)           |                                        | No       |
| 11. Patient             | Have shortness of breath                                             | No                                     | Use the Catalan equivalent for “feeling shortness of breath” | No                                    | (Shortness of breath)                                                    | Omit the Catalan equivalent for “feeling” | No       |
| 12. Patient             | Be tired                                                             | No                                     | -                        | No                                     | (Tiredness)                                                              |                                        | No       |
| Type and number of item | Item | 3 discrepancies in forward translation | Translation explanation | Changed meaning post back translation | Solution | Difficulties for patient to understand | Solution |
|-------------------------|------|---------------------------------------|--------------------------|--------------------------------------|----------|--------------------------------------|----------|
| 13. Patient             | Not be able to participate in gym class | No                      | Change "participate" for the Catalan equivalent for "do" | Yes (to follow the Physical Education class at school) | Keep the Catalan equivalent for "do" | No | - |
| 14. Patient             | Miss school                           | No                      | -                               | No (Missing school)                  | -        | No | - |
| 15. Patient pre surgery | How much do you want the surgery to make your chest look different? | No                      | Use the Catalan equivalent for "would you like to undergo surgery to change how your chest looks?" | Yes (Would you like to be operated on so that your chest looks different?) | Keep the Catalan equivalent for "would you like to undergo surgery to change how your chest looks?" | No | - |
| 15. Patient post surgery| How did the surgery change how your chest looks? | No                      | Use the Catalan equivalent for "do you think that the surgery changed the appearance of your chest?" | Yes (Do you think surgery has changed the appearance of your chest?) | Change for the Catalan equivalent for "how has the surgery changed the appearance of your chest?" | No | - |
| 16. Patient post surgery| How did the surgery change how you feel about your chest? | No                      | Use the Catalan equivalent for "After the surgery, how do you feel about your chest?" | Yes (After surgery, how do you feel about your chest?) | Keep the Catalan equivalent for "After the surgery, how do you feel about your chest?" | No | - |
| 17. Patient post surgery| How happy are you that you had the surgery? | No                      | Use the Catalan equivalent for "Are you happy that you had the surgery?" | Yes (Are you happy that you were operated on?) | Keep the Catalan equivalent for "Are you happy that you had the surgery?" | No | - |
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|-------------------------|----------------------------------------------------------------------|----------------------------------------|---------------------------------|---------------------------------------|--------------------------------------------------------------------------|---------------------------------------|----------|
| 1. Parents              | How often has your child’s pectus excavatum caused him/her to have trouble being physically active? | Yes                                    | Change for Catalan equivalent for “difficulties to do physical activity” | Yes (Difficulties for exercising)   | Change for the Catalan equivalent for “trouble”                           | No                                    | -        |
| 2. Parents              | How often has your child’s pectus excavatum caused him/her to have chest pain when physically active, such as running or playing sports? | No                                     | -                               | Yes (Chest pain during exercise (running...)) | Keep the Catalan equivalent for “chest pain during physical activity” | No                                    | -        |
| 3. Parents              | How often has your child’s pectus excavatum caused him/her to have shortness of breath? | Yes                                    | Use Catalan equivalent for “feeling shortness of breath” | No (Shortness of breath)           | Omit the equivalent for “feeling” in the Catalan version                | No                                    | -        |
| 4. Parents              | How often has your child’s pectus excavatum caused him/her to become tired? | Yes                                    | Use the Catalan equivalent for “tiredness” | No (tiredness)                      | Keep the Catalan equivalent for “tiredness”                              | No                                    | -        |
| 5. Parents              | How often has your child’s pectus excavatum caused him/her to have problems gaining weight? | No                                     | -                               | Yes (Difficulties to gain weight)   | Keep the Catalan equivalent for “problems to gain weight”               | No                                    | -        |
| 6. Parents              | How often has your child’s pectus excavatum caused him/her to be irritable? | No                                     | Use the Catalan equivalent for “feeling of irritability” | No (Irritability)                  | Omit the equivalent for “feeling” in the Catalan version               | No                                    | -        |
| 7. Parents              | How often has your child’s pectus excavatum caused him/her to be frustrated? | No                                     | Use the Catalan equivalent for “feeling of frustration” | No (Frustration)                   | Omit the equivalent for “feeling” in the Catalan version               | No                                    | -        |
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|------------------------|----------------------------------------------------------------------|----------------------------------------|---------------------------------|--------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 8. Parents             | How often has your child’s pectus excavatum caused him/her to be sad or depressed? | No                                     | Use the Catalan equivalent for “feeling sadness or depression” | No (Sadness or depression) | Omit the equivalent for “feeling” in the Catalan version | No | - |
| 9. Parents             | How often has your child’s pectus excavatum caused him/her to be restless? | No                                     | -                               | Yes (Worry)                         | Keep the Catalan equivalent for “restlessness”                           | No | - |
| 10. Parents            | How often has your child’s pectus excavatum caused him/her to be isolated? | No                                     | Use the Catalan equivalent for “feeling of isolation” | Yes (feeling of isolation) | Omit the equivalent for “feeling” in the Catalan version | No | - |
| 11. Parents            | How often has your child’s pectus excavatum caused him/her to be made fun of? | No                                     | Use the Catalan equivalent for “other children laugh at him/her” | Yes (Other children to laugh at him/her) | Change for the Catalan equivalent for “be made fun of” or “be mocked” | No | - |
| 12. Parents            | How often has your child’s pectus excavatum caused him/her to limit him/her playing sports? | No                                     | -                               | Yes (Limitation to practice sport) | Keep the Catalan equivalent for “limitation to practice sports” | No | - |
| 13. Parents            | How often has your child’s pectus excavatum caused him/her to miss school. | No                                     | Use the Catalan equivalent for “missing class” | Yes (Missing class) | Change “class” for the Catalan equivalent for “school” | No | - |
| 14. Parents            | How often has your child’s pectus excavatum caused him/her to be reluctant to wear a bathing suit? | Yes (reluctant) | Keep the Catalan equivalent for reluctant | No (To be reluctant to use a swimsuit) | - | No | - |
| 15. Parents            | How often has your child’s pectus excavatum caused him/her to be reluctant to change clothes in front of others? | Yes (reluctant) | Keep the Catalan equivalent for reluctant | No (To be reluctant to change clothes in front of other people) | - | No | - |
| Type and number of item | Item | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution | Difficulties for patient to understand | Solution |
|-------------------------|------|---------------------------------------|---------------------------------|--------------------------------------|----------|---------------------------------------|----------|
| 16. Parents             | How often have you been concerned about the effects pectus excavatum has on your child's life? | No | - | No | - | No | - |

(Are you concerned about the effects of pectus excavatum on your child's life?)
### Table 3
Translation and adaptation process from English to Spanish. Patient part.

| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|-------------------------|----------------------------------------------------------------------|---------------------------------------|---------------------------------|---------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 1. Patient              | How do you feel about the way you look in general?                   | No                                    | -                               | Yes                                   | Keep the Spanish equivalent for “about your appearance in general?”      | No                                     | -        |
| 2. Patient              | How do you feel about the way you look with your shirt or your top off? | No                                    | -                               | Yes                                   | Change for Spanish equivalent for “when you are with your shirt or your top off” | No                                     | -        |
| 3. Patient              | If you had to spend the rest of your life with your chest as it looks now, how would you feel? | No                                    | -                               | No                                    | -                                                                        | No                                     | -        |
| 4. Patient              | How often do other kids do fun about you because of your chest?      | No                                    | Change for Spanish equivalent for “laugh at you” | Yes                                   | Change again for Spanish equivalent for “do fun about you” and omit “the shape” | No                                     | -        |
| 5. Patient              | How often do you avoid doing things, like spending the night at a friend’s house, because of the way your chest looks? | No                                    | Change “doing things” for Spanish equivalent for “making plans” | Yes                                   | Change again for Spanish equivalent for “doing things”                   | No                                     | -        |
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|--------------------------|----------------------------------------------------------------------|----------------------------------------|----------------------------------|---------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 6. Patient               | How often do you try to hide your chest to keep people from knowing about it? | No                                     | -                               | Yes                                   | Change for Spanish equivalent for “the chest”                           | No                                     | -        |
|                          |                                                                                     |                                        |                                  | (so that people do not know how you have it?) |                                                                                     |                                        |          |
| 7. Patient               | How often are you bothered because of the way your chest looks?                   | No                                     | Use the Spanish equivalence for “worried” instead of “bothered” | Yes                                   | Change again for the Spanish equivalent for “are you bothered by other people” | 2/10                                  | -        |
|                          |                                                                                     |                                        |                                  | (Are you worried about the appearance of your chest?) |                                                                                     |                                        |          |
| 8. Patient               | How often does your chest make you feel shy or self-conscious?                   | Yes (shy)                              | Exclude “shy” from Spanish version | Yes                                   | Keep the Spanish equivalent for “self-conscious”                           | 4/10                                  | Add again the Spanish equivalent for “shy” |
|                          |                                                                                     |                                        |                                  | (Do you feel ashamed about the shape of your chest?) |                                                                                     |                                        |          |
| 9. Patient               | How often do you feel bad about yourself because of the way your chest looks?    | No                                     | -                               | Yes                                   | -                                                                        | No                                     | -        |
|                          |                                                                                     |                                        |                                  | (Does the appearance of your chest make you feel bad?) | -                                                                        |                                        |          |
| 10. Patient              | Have trouble running around or exercising because it made your chest hurt?       | No                                     | -                               | No                                    | -                                                                        | No                                     | -        |
|                          |                                                                                     |                                        |                                  | (Problems when running or exercising because your chest hurt) | -                                                                        |                                        |          |
| 11. Patient              | Have shortness of breath                                                           | Yes                                    | Use the Spanish equivalent for “feeling shortness of breath” | Yes                                   | Remove the Spanish equivalent for “feeling”                              | 1/10                                  | -        |
|                          |                                                                                     |                                        |                                  | (Feeling short of breath)             |                                                                                     |                                        |          |
| 12. Patient              | Be tired                                                                            | No                                     | -                               | No                                    | -                                                                        | No                                     | -        |
| Type and number of item | Item | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution | Difficulties for patient to understand | Solution |
|-------------------------|------|---------------------------------------|---------------------------------|--------------------------------------|----------|--------------------------------------|----------|
| 13. Patient             | Not be able to participate in gym class | No | Change for the Spanish equivalent for “to do physical education class” | Yes | Change for the Spanish equivalent for “participate” | No | - |
| 14. Patient             | Miss school | No | - | No | - | No | - |
| 15. Patient presurg     | How much do you want the surgery to make your chest look different? | Yes | Use the Spanish equivalent for “would you like to undergo surgery to change how your chest looks?” | Yes | (Would you like to operate to have a different breast?) | Keep the Spanish equivalent for “would you like to undergo surgery to change how your chest looks?” | No | - |
| 15. Patient postsurg    | How did the surgery change how your chest looks? | No | - | Yes | (Do you think the operation has changed the appearance of your chest?) | Keep the Spanish equivalent for “Do you think the operation has changed the appearance of your chest?” | No | - |
| 16. Patient postsurg    | How did the surgery change how you feel about your chest? | No | - | Yes | (After the operation, how do you feel about your chest?) | Keep the Spanish equivalent for “After the operation, how do you feel about your chest?” | No | - |
| 17. Patient postsurg    | How happy are you that you had the surgery? | No | - | No | (Are you happy to have gone through the surgery?) | - | No | - |
| Type and number of item | Item                                                                 | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution                                                                 | Difficulties for patient to understand | Solution |
|-------------------------|----------------------------------------------------------------------|----------------------------------------|---------------------------------|--------------------------------------|--------------------------------------------------------------------------|----------------------------------------|----------|
| 1. Parents              | How often has your child’s pectus excavatum caused him/her to have trouble being physically active? | No                                     | Change for the Spanish equivalent for “difficulties in physical activity” | Yes                                  | Change for the Spanish equivalent for “trouble”                           | No                                     | -        |
| 2. Parents              | How often has your child’s pectus excavatum caused him/her to have chest pain when physically active, such as running or playing sports? | No                                     | -                                | No                                   | -                                                                        | No                                     | -        |
| 3. Parents              | How often has your child’s pectus excavatum caused him/her to have shortness of breath? | No                                     | Add the Spanish equivalent for “feeling” | Yes                                  | Omit the Spanish equivalent for “feeling”                                | No                                     | -        |
| 4. Parents              | How often has your child’s pectus excavatum caused him/her to become tired? | No                                     | -                                | No                                   | -                                                                        | No                                     | -        |
| 5. Parents              | How often has your child’s pectus excavatum caused him/her to have problems gaining weight? | No                                     | -                                | No                                   | -                                                                        | No                                     | -        |
| 6. Parents              | How often has your child’s pectus excavatum caused him/her to be irritable? | No                                     | Change for the Spanish equivalent for “Irritability” | No                                  | -                                                                        | No                                     | -        |
| 7. Parents              | How often has your child’s pectus excavatum caused him/her to be frustrated? | No                                     | Add the Spanish equivalent for “feeling” | Yes                                  | Omit the Spanish equivalent for “feeling”                                | No                                     | -        |
| Type and number of item | Item | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution | Difficulties for patient to understand | Solution |
|------------------------|------|---------------------------------------|---------------------------------|--------------------------------------|----------|--------------------------------------|----------|
| 8. Parents             | How often has your child’s pectus excavatum caused him/her to be sad or depressed? | No                               | Add the Spanish equivalent for “feeling” | Yes (Feeling sad or depressed) | Omit the Spanish equivalent for “feeling” | No       | -                                   |
| 9. Parents             | How often has your child’s pectus excavatum caused him/her to be restless? | No                               | Add the Spanish equivalent for “sensation” | Yes (Sensation of anxiety) | Omit the Spanish equivalent for “sensation” and keep the equivalent for “restlessness” | No       | -                                   |
| 10. Parents            | How often has your child’s pectus excavatum caused him/her to be isolated? | No                               | Add the Spanish equivalent for “sensation” | Yes (Sensation of isolation) | Omit the Spanish equivalent for “sensation” | No       | -                                   |
| 11. Parents            | How often has your child’s pectus excavatum caused him/her to be made fun of? | No                               | Change for the Spanish equivalent for “be the object of jokes” | Yes (Be the object of jokes) | Change for the Spanish equivalent for “be made fun of” or “be mocked” | No       | -                                   |
| 12. Parents            | How often has your child’s pectus excavatum caused him/her to limit him/her playing sports? | No                               | - | Yes (Limitation to practice sport) | Keep the Spanish equivalent for “limitation to practice sport” | No       | -                                   |
| 13. Parents            | How often has your child’s pectus excavatum caused him/her to miss school. | No                               | Change for the Spanish equivalent for “class” | Yes (Missing class) | Change “class” for the Spanish equivalent for “school” | No       | -                                   |
| 14. Parents            | How often has your child’s pectus excavatum caused him/her to be reluctant to wear a bathing suit? | Yes (reluctant) | Keep the Spanish equivalent for reluctant | No (Show reluctance to use a swimsuit) | - | No | - |
| 15. Parents            | How often has your child’s pectus excavatum caused him/her to be reluctant to change clothes in front of others? | Yes (reluctant) | Keep the Spanish equivalent for reluctant | No (Show reluctance to change clothes in front of others) | - | No | - |
Type and number of item | Item | 3 discrepancies in forward translation | Forward translation explanation | Changed meaning post back translation | Solution | Difficulties for patient to understand | Solution
---|---|---|---|---|---|---|---
16. Parents | How often have you been concerned about the effects pectus excavatum has on your child’s life? | No | - | No | - | No | -

### Discussion

Patients with PE are frequently considered to have only a cosmetic problem, being often denied the opportunity for surgical correction. However, previous work on this subject has brought to light that surgical repair of PE can significantly improve body image and physical activity of these patients. Furthermore, scientific evidence has failed to prove a correlation between the anatomic severity of the chest depression and the PEEQ score, suggesting that the sole presence of the deformity produces body image and psychosocial concerns. Therefore, it is more than obvious that the exclusive use of anatomic severity criteria to discern which patients should undergo surgical repair is insufficient [11]. This fact stresses the need of having a validated tool in our language that allows us to adequately evaluate the body image and physical difficulties that concern patients with PE.

The process of translation and cultural adaptation of the PEEQ resulted in the development of a Catalan and a European Spanish version for use in Spain and in Catalonia that are likely to be highly comparable to the original English version.

In 1999, the QoL Special Interest group—Translation and Cultural Adaptation group was created to discuss and establish standards for the translation and cultural adaptation of PROs. After identifying a lack of consistency in previously existing methods and publications, they developed a document of consensus that synthesized the previous methods and could serve as a guide to homogenize future translation and adaptation processes: The Principles of Good Practice for the Translation and Cultural Adaptation Process for PRO Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation [9].

In order to obtain an equivalent to the source and an adequate translation of PEEQ, all the steps of the ISPOR guidelines were followed. We also followed the recommendations for the selection of the translators, using a professional translator and medical doctors with an extensive knowledge of the source language for the forward translations; and medical doctors native in the source language and with a high knowledge in the target language for the back translations.

We found around 15% discordances comparing the three forward translations. These discrepancies were easily amended in the reconciliation process leading to a single reconciled version. The back-translation review revealed that in both versions (Catalan and European Spanish), the sentence construction or wording used by the back translators were different to the original source in more than half of the items. However, in spite of a differing wording, the meaning of the translation was not always altered. To comply with the principle of giving prevalence to conceptual over literal translation, not every discordant translation resulted in a modification of the reconciled version.

Most publications addressing translation and cultural adaptation of PRO instruments show a high variability in the number of discordances in forward and back translations [10, 12–16]. Despite discordances in the translation process, this exhaustive translation method guarantees that the translation achieved is equivalent to the original source [9].
There is no agreement in which should be the preferred method for harmonization. As we described previously, we amended this issue in the back-translation review meeting. There was a high equivalence between both translations, probably due to the fact that the same translators developed forward translations in both languages. At this moment, we detected the use of different words for expressing the same concept in two different items. Harmonization allowed us to use the same words making both language versions more homogeneous.

A potential limitation of the present study is that the small patients sample needed for cognitive interviews may not be representative of our PE population. Therefore, responses to the questionnaire have been overlooked in this work. We believe that the fact that all participants in the Spanish version were males is unlikely to have a real impact on the quality of the translations. Moreover, the gender proportion in the whole sample of patients that participated in cognitive interviews approaches that of PE population (25% of girls) (2).

As far as we know, there is no other translation of the PEEQ following the ISPOR recommendations. Furthermore, until now there isn’t any other PRO tool in our languages (Catalan and European Spanish) for the evaluation of patients with PE.

**Conclusion**

After a thorough process of translation and cultural adaptation, we reached a Catalan and a European Spanish version of PEEQ for use in Spanish and Catalan patients. These versions will allow us to better understand and evaluate the psychological and physical difficulties that PE patients suffer, to better establish the indication for surgery and to compare our outcomes with series of patients from other countries.

**List Of Abbreviations**

PE  
Pectus excavatum  
PEEQ  
Pectus excavatum evaluation questionnaire  
PRO  
Patient reported outcome  
QoL  
Quality of life  
e.g.  
exempli gratia  
ISPOR  
International Society for Pharmacoeconomics and Outcomes Research

**Declarations**

**Ethics approval and consent to participate**: The study was evaluated and approved by the Research Ethics Board at our center (reference PIC-82-19) complying with the local laws on Biomedical Research (Ley 14/2007, de 3 de julio, de Investigación Biomédica). All legal guardians or patients older than 18 years provided written informed consent according to our center’s policy. Children aged 12 to 17 years also provided written assent.

**Consent for publication**: Not applicable.

**Availability of data and materials**: The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

**Competing interests**: The authors declare that they have no competing interests.
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Authors' contributions:

IHJ designed the study, participated in the translation and cultural adaptation process: selecting the translators, preparing the documents for the translators and also developed one of the forward translations. Performed the cognitive debriefing interviews, analyzed the data and participated in writing the final PEEQ versions for each language. Wrote the manuscript and participated in its critical review.

XT participated in the study design, asked permission to the developer to translate the questionnaire, contributed in the translation process (reconciliation, back translation review and review of the cognitive debriefing and finalization) and participated recruiting participants for the cognitive debriefing. Critically reviewed the manuscript.

AAC participated in the translation and cultural adaptation process developing one of the forward translations and participating in the reconciliation meeting, back translation review and review of the cognitive debriefing and finalization. Critically reviewed the manuscript.

NGS participated in the translation and cultural adaptation process developing one of the back translations and critically reviewed the manuscript.

AFC participated in the translation and cultural adaptation process developing one of the forward translations and participated also in the reconciliation meeting. Critically reviewed the manuscript.

CSG participated in the translation and cultural adaptation process developing one of the back translations and critically reviewed the manuscript.

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