## RESEARCH



# The spanish and catalan versions of the kidney patient reported experience measure (PREM) for chronic kidney disease (CKD): cultural adaptation and face validity



M. Moharra<sup>1,2\*</sup>, A. Llupià<sup>3,4,5</sup>, B. Bayés<sup>4,6</sup>, C. Almazán<sup>1,2</sup>, A. Busby<sup>7</sup> and M. Herdman<sup>8</sup>

## Abstract

**Background** Chronic kidney disease (CKD) is a progressive condition affecting more than 800 million individuals worldwide. Patient Reported Experience Measures (PREMs) are questionnaires aimed at evaluating patients' experiences with healthcare received. Given that CKD management often involves continuous treatments, capturing patient experiences can guide improvements in care that align with patients' preferences, making PREMS a relevant tool in CKD management. The Kidney PREM questionnaire was developed in the United Kingdom to measure patient experience across entire service provisions in patients with chronic kidney disease (CKD). This study aimed to adapt the English version to Spanish and Catalan and assess the face validity of the new language versions.

**Methods** The translation process was guided by the International Society of Pharmacoeconomics and Outcome Research (ISPOR) Principles of Good Practice for the Translation and Cultural Adaptation of Patient-Reported Outcomes Measures and included forward and back translation, cognitive debriefing, and harmonisation between the Spanish and Catalan versions. Face validity was assessed in a sample of Spanish- and Catalan-speaking health professionals.

**Results** In the cognitive debriefing, 9 patients with CKD (4 in Catalan and 5 in Spanish) participated. Fourteen healthcare professionals (2 nurses and 12 nephrologists) assessed the face validity of the Catalan and Spanish versions. Overall, the language used in the original version of the questionnaire did not cause substantial problems for translation into Catalan or Spanish. Patients generally found the questionnaire to be relevant and relatively easy to complete but reported some difficulties with questionnaire design, including the use of 'skip' questions. Clinicians and nurses highly rated the questionnaire in terms of relevance (mean score of 8.7 on a 0–10 scale) and acceptability, indicating good face validity, but considered some elements to be lacking, such as the absence of an open-ended question or any queries regarding lifestyle.

\*Correspondence: M. Moharra mmoharra@gencat.cat

Full list of author information is available at the end of the article



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

Page 2 of 9

**Conclusions** It was feasible to produce culturally adapted Spanish and Catalan versions of the Kidney PREM questionnaire, and they showed acceptable face validity. They will be useful tools for furthering research and clinical practice in CKD patients in Spain.

Keywords Chronic kidney disease, Cognitive debriefing, Cross-cultural translation, Content validity

## Introduction

Chronic kidney disease (CKD) is a progressive condition that affects>10% of the general population worldwide and affects>800 million individuals [1]. The high number of affected individuals and the significant adverse impact of CKD on patient quality of life require a constant focus on improving prevention and treatment.

Studies of patient experience in recent years have focused on a new element of value in the quality of healthcare [2, 3]. Patient experience is defined as the sum of all interactions that occur between the patient and the healthcare system within the framework of a specific organisational culture that influences the perception of the person being treated [4]. Patient experience can be measured in different ways, including with qualitative studies and surveys [5]. Patient Reported Experience Measures (PREMs) are questionnaires developed to assess patient experience, thereby supporting the provision of person-centered and value-based health care [5, 7, 8] by providing large numbers of reports from individual patients regarding their care encounters [3, 9, 10].

The OECD Health Committee launched the Patient-Reported Indicators Surveys (PARIS) [11] initiative in January 2017. In that month, OECD Health Ministers met in Paris to discuss the next generation of health reforms. These discussions revealed clear political momentum to pay greater attention to what matters to patients. PREMs differ from patient satisfaction measures [12, 13] because they ask patients to provide feedback on their care experience. PREMs also differ from patient-reported outcome measures (PROMs) in that they aim to provide feedback on the care experience rather than focusing on patients' views of their health status or health-related quality of life.

PREMS are becoming internationally recognised as a means of measuring the quality of health services from the patient's perspective [14]. As with any such measurement instrument, PREMs need to be developed following rigorous procedures and carefully tested and validated. Although some generic PREMs exist [8], i.e., instruments that can be applied across a range of patient populations, there are also an increasing number of PREMs aimed at specific patient populations. Such tools focus on the needs and interests of specific groups of patients or patients undergoing a specific clinical process or intervention. Recent studies have indicated that PREMs are likely to have the most potential in patients with chronic conditions, where it is important to guarantee certain standards of social and health care [15]. Given that CKD management often involves long-term treatment such as dialysis or transplantation, capturing patient experience can guide improvements in care that align with the preferences and values of patients. This, in turn, can enhance treatment adherence, patient satisfaction, and overall quality of life, making PREMs an indispensable tool in CKD care, supporting better patient-centered care [16].

There are relatively few tools available to capture the patient experience of healthcare for CKD patients. The UK Kidney Association (UKKA) and Kidney Care UK commissioned the development of the Kidney PREM patient-reported experience measure [17], an instrument that can measure patient experience across entire renal service provisions, aiming to support evaluations of renal services and inform national and local quality improvement initiatives. The Kidney PREM aims to measure patients' experiences with renal services in secondary care for any CKD stage or treatment modality, and initial studies have demonstrated that it is reliable and valid [17]. Given that no such tool is available to assess the experience of CKD patients in Spain or Catalonia, it was considered of considerable interest to translate and adapt the questionnaire previously developed [17], see Supplementary material file. However, as the concepts relevant to patients and the organisation of healthcare can vary between countries, it is important to ensure that a rigorous process of cross-cultural adaptation is followed when planning to use a questionnaire such as the Kidney PREM in another country and language. Additionally, face validity and harmonisation were two aspects incorporated into the study that are not always included in the standard process of cultural adaptation. This manuscript presents the outcomes of cross-culturally adapting the Kidney PREM into Spanish and Catalan.

## Materials and methods

## The kidney PREM questionnaire

The Kidney PREM questionnaire, which was developed in the UK, is an instrument for evaluating CKD patient experience. The questionnaire consists of 38 questions carefully developed and tested by patients, researchers and healthcare professionals (HCPs) in the UK. Patients were involved and included during the production process of the questionnaire, particularly during content generation.

There are two versions of the questionnaire, the original "long" version of 38 questions and a short version of

15 questions, which may be more practical when applied in clinical practice and could be used to support local quality improvement initiatives. The English Kidney PREM has shown good content validity, internal consistency and test-retest reliability in different studies carried out in the United Kingdom [17]. Work is underway to establish the reliability and validity of the Short Form PREM, with results due later in 2024. The structure and content of the Kidney PREM questionnaire are shown in Table 1.

Translation and cross-cultural adaptation of the Kidney PREM questionnaire into Spanish and Catalan were conducted according to International Society for Pharmacoeconomic and Outcomes Research guidelines. The author of the original questionnaire gave permission to adapt the Kidney PREM into Catalan and Spanish.

This process included the following principal phases: forward and back translation, cognitive debriefing, and harmonisation.

## Forward and back translation

Four translators who were native speakers of the target languages independently prepared a translated version of the questionnaire, two in Catalan and two in Spanish. Translators were requested to produce Spanish and Catalan versions that were as faithful as possible to the original English version but which, as far as possible, used natural and understandable wording in the target languages. The two independent translations in each language were reviewed and compared by the research team until, following discussion, a first consensus version was agreed upon for both Catalan and Spanish.

In the back translation phase, the first consensus Catalan and Spanish versions were each translated back into English by two native English speakers who were fluent in Catalan or Spanish. The back-translations for each version were reviewed and compared, both with each other and with the original UK English source version by the research team, which included members who were bilingual in English and Catalan and/or Spanish. Any discrepancies between the back-translated versions and/or the original versions were identified and discussed by the research team, and modifications were made to the Catalan or Spanish versions if necessary to better convey the meaning of the original version. The results of this phase gave rise to the second consensus Catalan and Spanish versions.

## **Cognitive debriefing**

Cognitive debriefing is a standardised procedure to test the suitability and ease of understanding of translated versions of a questionnaire and to identify inadequate wording or culturally inappropriate items. Semi-structured online interviews were conducted with members

otal kidney prem sco	ores (38 ITEMS)										
vccess to Support	Communication	Patient	Fluid	Needling	Tests	Sharing	Privacy and	Scheduling	How the	Transport	The Environment Over-
(idney		Information	intake			Decisions	Dignity	and planning	kidney		all
eam			and						team		-sche-
			Diet						treats		ri-
									Nou		ence

 Table 1
 Structure and content of the Kidney PREM questionnaire

each item uses a 7-point Likert scale (never to always in Access to the Kidney Team-Transport, poor to excellent in The Environment, Worst it can be to Best it can be in Overall Experience)

litem

5 items

3 items

3 items

2 items

2 items

3 items

3 items

1 item

2 items

2 items

5 items

3 items

3 items

of the target population, specifically Catalan- or Spanish-speaking CKD patients. In this phase, the second consensus version of the questionnaire was tested in a convenience sample of nine patients with CKD (4 in Catalan and 5 in Spanish). A range of patient characteristics was sought in terms of sex and educational level. Patients to be interviewed were identified by staff at the Hospital Clinic de Barcelona. The inclusion criteria comprised patients who were either Spanish or Catalan native speakers and who were in any of the following situations regarding their CKD: peritoneal dialysis, haemodialysis, outpatient visits to the dialysis unit or who had successfully undergone transplantation. After explaining the objectives of the study to the patients and the implications of their participation, the staff asked them for verbal consent to (a) participate in the interviews and (b) provide their contact details so that the interviewer could contact them. For the interview, questions or prompts were used to assess patients' comprehension of the questionnaire. These includes questions such as: Did you find this item/word/sentence easy/difficult to understand? Were there any words/phrases in that section/sentence that you found difficult to understand or which sounded strange or unusual? "Did you have difficulty deciding which answer to give for {that} question? If so, why? 'What do you think this word/item means/is asking?'

## Face validity and harmonisation

Face validity refers to whether, on the surface, a questionnaire appears to measure what it is intended to measure, covers all relevant questions, and uses appropriate language [18]. The research team reached out to clinical contacts actively working in various roles and settings (such as urban and rural) with CKD patients, asking if they were willing to participate in the face validity exercise. Those who agreed to participate (i.e., those who selfnominated) were included. A total of fourteen HCPS (2 nurses and 12 nephrologists) currently attending patients in the nephrology department completed a short survey on adapted versions of the Kidney PREM. The online questionnaire consisted of five questions eliciting their opinions about different aspects of the translated Kidney PREM. The questionnaire asked about the relevance of Kidney PREM content for their patients, whether they considered any important aspect to be missing, and whether they thought the patients they saw on a daily basis would have difficulty completing the questionnaire. The questions on relevance were rated on a scale from 0 to 10, while the remaining three questions were openended. In addition to these questions, professionals were also asked to provide any comments they thought were relevant to any aspect of the questionnaire.

The harmonization phase was conducted by a bilingual panel consisting of the researchers involved in the study, whereby the Catalan and Spanish versions of the questionnaire were compared to align them as much as possible. Each part of the questionnaire was reviewed, and changes were introduced, as necessary to ensure that the terminology used and the way items were formulated were as similar as possible.

## **Data Availability**

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

## Ethics and consent to participate

The questionnaire did not involve any invasive procedure or data collection beyond standard clinical practices. Therefore, ethical approval from an ethics committee was deemed unnecessary according to "Law 14/2007 of July 3 on Biomedical Research". Participants gave fully informed written consent to participate.

## Results

## Forward translation (FT) and back translation (BT)

In general, the language employed in the initial version of the questionnaire did not pose significant challenges for translation to Spanish and Catalan. However, occasional difficulties did arise. For instance, finding a suitable translation of the concept of an 'in-satellite' centre was problematic in part because the meaning of the original English was not entirely clear and in part because the system for receiving dialysis is somewhat different in Catalonia, where patients can receive dialysis in outpatient clinics or in public or private dialysis centres. For clarity's sake, the translation used was 'centro de diálisis' (dialysis centre), which was found to be well understood by patients. Other issues arising included the translation of the 'kidney unit'; although a direct translation exists ('unidad renal'), it was considered to not be widely used, so the more common 'Servei de Nefrologia' (Nephrology Service) was used. In addition to trying to find the most widely used term when different options for translation were presented in Catalan and Spanish, the translators and research team also made sure to try to select the most easily understandable option. For example, 'kidney disease' can be correctly translated to Spanish as 'enfermedad renal', which is a somewhat lower register, or 'nefropatía' (nephropathy), which is a higher register. In such cases, the lower register option was always chosen to facilitate understanding.

During the back translation stage, given that several members of the research and translation team were bilingual in English and Catalan and/or Spanish and that most issues were resolved at the forward translation stage, relatively few errors in the translations were revealed. However, comparing back translations with the original English version was found to be useful for making final adjustments to the translated versions, as it provided an opportunity for additional discussion of problematic items and terms.

## **Cognitive debriefing**

In total, nine patients (5 men, 4 women) with CKD participated in a face-to-face interview and were able to complete the questionnaire and answer the interviewer's questions without assistance. A range of patient characteristics was sought in terms of sex and educational level. In line with the patients generally seen in CKD services in Catalonia, the patients interviewed tended to be elderly and of a relatively low level of education [19]. Five patients were admitted to the nephrology department for reasons other than dialysis and had not undergone transplantation, three were on dialysis, and 1 had undergone transplantation.

The time needed to complete the questionnaire ranged between 10 and 18 min. Most patients completed the

survey in approximately 15 min. The questionnaire content was generally considered relevant by participants, and in general, the translated versions of the questionnaire were well understood, although some difficulties did arise. Several patients mentioned that they sometimes had difficulty following the text on the first two pages, given that it was quite long and repetitive at times. To ameliorate this, the Spanish and Catalan instructions were shortened as much as possible while retaining the essential information, and some of the questions were reformatted (Fig. 1). Additionally, the use of the question 'skipping' (where respondents jump to another question based on their previous answers) was deemed problematic. This was particularly challenging since the instructions to skip certain questions were not always clear, especially given that patients often only skim item instructions.

Given that most items in the Kidney PREM include a 'Not applicable' response option, after discussion, the research team decided that it would omit the 'skip'

If you are currently <u>attending a kidney clinic and are not on dialysis or with a functioning transplant</u>, which below best describes your current care?

(Please leave blank unless you are currently attending kidney clinic and are not on dialysis or transplantation)

I attend regularly for monitoring of my kidney function only

☐ I have been advised that my kidneys will fail and I have chosen Haemodialysis in a unit / Haemodialysis at home / Peritoneal Dialysis □ I have been advised that my kidneys will fail and I have chosen conservative/supportive/ medical management □ I have been □ I don't know advised that my kidneys will fail and have not yet decided a treatment option

Si en la actualidad <u>está acudiendo a una consulta de Nefrología y no está haciendo diálisis ni está</u> <u>trasplantado</u>, ¿cuál de las siguientes opciones describe mejor la atención que recibe ahora? *(Si ya recibe diálisis o ya le han hecho un trasplante, deje la respuesta en blanco)* 

Me han dicho que tengo insuficiencia renal y	
me he decidido por la hemodiálisis en una unidad o en casa, o por diálisis	
peritoneal	
me he decidido por un tratamiento médico conservador/paliativo	
todavía no me he decidido por ninguna opción de tratamiento	
estoy en estudio para un trasplante de riñón	
acudo periódicamente solo para el seguimiento de mi función renal	
No lo sé	

Fig. 1 Original question in the Kidney PREM questionnaire and the reformulated question in Spanish

instructions from the Catalan and Spanish versions and that it would emphasise that patients should use the 'not applicable' response option instead. The appropriate use of the not applicable response option will be checked in a large-scale validation study, which is currently ongoing.

Of the 38 items in the original questionnaire, only one was omitted entirely from the Spanish and Catalan versions. This was an item on shard care that was found to be poorly understood by the majority of patients in cognitive debriefing, possibly because the idea of shared care is less well established within the Spanish healthcare system at present, although there are efforts to further strengthen and promote it.

## Patient views on questionnaire content and coverage of relevant issues

Patients emphasised that the questionnaire should ask about their situation regarding the waiting list for a transplant. They explained feelings of being tied down and limited by uncertainty about timing of their potential transplant. They worried about not being close to home if an organ becomes available and that they might miss their opportunity when it arises. For that reason, they give up trips and limit their lives without knowing how

Table 2	Results	of face va	alidity	testing	at the	<b>HCPS</b>
---------	---------	------------	---------	---------	--------	-------------

Face Que	e validity estions	Example comments	Mean score (0– 10)
Q1	Rate the relevance of the questionnaire	"In general, the questionnaire provides a complete vision of the care process of the nephrology patient"	8.7
Q2	Is there any ques- tion in the ques- tionnaire that is not relevant?	<b>Q16</b> : [How often do the renal team insert your needles with as little pain as possible?] "It seems irrelevant or poorly formulated. The concept that the insertion of needles hurts more or less to the patient (it always hurts) is more related to their general pain perception rather than the care provided by health-care professionals when performing the procedure".	
Q3	Are any relevant aspects miss- ing from the questionnaire?	"Some open-ended questions might be included to expand patient experience."	
Q4	Rate the ease of filling out the questionnaire	<b>Q27</b> : [Are the arrangements for your blood tests convenient for you? ]. <i>"I don't understand what it refers to: programming? Frequency?"</i>	7.3
Q5	Would you change any aspect of the questionnaire?	<b>Q16</b> : [How often do the renal team insert your needles with as little pain as possible?]. "I would improve the wording or modify it to avoid leading the patient to respond affirmatively that they always feel pain. For example: How many times do you experience pain?"	

long that situation will last. Additionally, several patients noted a common issue for kidney patients: the feeling of being "in no-man's land" when their kidneys are failing but they have not yet started dialysis. Contrary to how they feel when they begin dialysis, this transitional period is marked by uncertainty and it is a crucial moment when many important decisions must be made, but they often feel they do not have enough support and that the questionnaire should reflect this situation.

## Face validity and harmonisation

Table 2 summarises the feedback from the HCPs in face validity testing. In response to the request to rate the questionnaire in terms of its relevance for CKD patients, the mean score was 8.7 on a scale from 0 to 10, indicating that clinicians and nurses considered the questionnaire to be of considerable relevance. Comments received on this point included the idea that "the questionnaire provides a complete vision of the care process of the nephrology patient, in our case in the CKD consultation" and that "All areas and points of interest for patients are covered". No negative comments were received on this point, although one of the clinicians did note that "the issue of transportation might be somewhat complicated to deal with because it does not fall under our remit. However, we can transfer the results [obtained from administering the questionnaire] to the ambulance services involved, as it might help them to improve their service".

When asked whether they considered any of the individual items in the questionnaire to be irrelevant, only one of the clinicians mentioned that he thought the item on pain experienced from needling during dialysis was either poorly worded or possibly irrelevant. However, as none of the other professionals consulted considered the item irrelevant, it was retained. Regarding whether the professionals considered any items to be missing, the general consensus from their comments suggested that they found the questionnaire to adequately cover all relevant aspects of CKD. However, some additional items noted for consideration included aspects such as physical activity, smoking habits, and whether patients used any type of treatment for the pain associated with needling. Two professionals also suggested that an open question could be included in which patients could comment on any aspects not covered currently by the questionnaire.

In terms of the ease with which their patients were likely to be able to complete the questionnaire, the general impression among the health professionals was that, primarily due to their age, at least some of their patients would probably require help to complete the questionnaire. While the questionnaire's length was considered a potential drawback, there were also comments suggesting that the majority of patients would likely find it acceptable. Several of the HCPs also noted that there was potential for confusion among patients, as it was not always clear which department or unit they should be thinking about when they answered. As one of the HCPs noted, "There may be confusion about what is considered the Nephrology Department, and it needs to be clearer what the patient is expected to evaluate. In our setting, the Nephrology Service is located in the reference hospital and manages outpatient consultations, ambulatory haemodialysis, and home dialysis. However, there are also the out-of-hospital haemodialysis units known as "Dialysis Centres", which manage the treatment in a semiautonomous fashion, carrying out a large part of the analytical controls necessary for dialysis in the centre itself without the patient having to go to the hospital. These concepts are often confused during the questionnaire, so it's not always clear which of the two centres, the hospital or the dialysis centre, the patient will be giving their opinion on". The mean HCP score for ease of completion was 7.3 on a scale of 0-10, with a range from 5 to 8 points, which presumably reflects the concerns noted above, given that this score was lower than that for questionnaire relevance.

## Discussion

This study successfully produced cross-culturally adapted Spanish and Catalan versions of the Kidney PREM, following international guidelines. To the authors' knowledge, this is the first PREM instrument for use in CKD patients that is available in Spanish and Catalan.

Overall, the cognitive debriefing interviews with patients showed that they were able to complete the questionnaire without assistance and considered the content relevant and acceptable. One interesting aspect of the cognitive debriefing process was that patients indicated areas of concern that are not currently covered by the questionnaire, which could lead to the inclusion of new questions in the future. In this regard, patients noted that Kidney PREM places more emphasis on haemodialysis than other treatment modalities, while transplant waiting lists and pre-dialysis were highlighted as factors that need to be explored further. This finding supports anecdotal feedback from the UK Kidney PREM, and given the length of the Kidney PREM, it is possible that modality-specific tools could be developed to be used alongside the all-CKD Kidney PREM.

Interestingly, the views on Needling held by the clinicians in this study mirrored feedback from clinicians in the UK. As a result of that UK feedback, a needlingspecific measure has been developed to reliably assess patients' experiences of needling for haemodialysis [20]. Although it was developed and tested in the UK, it could benefit renal patients in Catalonia and Spain in parallel with the all-CKD Kidney PREM.

A key strength of our study was the inclusion of HCPs in the face validity phase, which is not always performed during the linguistic validation of PREM questionnaires. This was a useful addition, with clinician views complementing those of patients obtained in the cognitive debriefing phase. Although some suggestions were made, no additional items were included for validity testing at this stage to maintain comparability with the original English version. However, additional items or changes could be included in later iterations of the questionnaire. In particular, clinicians' views of transportation mirror those held in the UK Kidney PREM since they are often beyond the control of renal centres. During validation, items from the transport theme were found to have suboptimal response profiles but were retained due to their significance in patients' experience of renal care. This highlights the importance of patient involvement when developing such measures. Additionally, an open question is included at the end of the UK Kidney PREM, asking participants to comment on any other aspects of their care which could be included in a future Catalan or Spanish translation.

Harmonisation was a crucial stage of the translation process because it allowed the research team to pull together the best elements of the Catalan and Spanish versions and use them to optimise and align the wording in both. This was considered important because both language versions might frequently be used in the same study in Catalonia, making it necessary to compare and potentially pool the data obtained with them.

Regarding the implications for practice of using the questionnaire at the micro-, meso- or macro-level, it is noteworthy that most of the published studies about the use of PREMs in health systems refer to evidence at the micro level [10, 21], focusing on initiatives aimed at improving the quality of front-line care. In that sense, the Kidney PREM questionnaire in Spain and Catalonia could be useful for comparing patient experience [22] across different treatment modalities: receiving haemodialysis, receiving peritoneal dialysis, living with a kidney transplant, being on the waiting list for transplantations or receiving conservative management. Additionally, the Kidney PREM questionnaire has demonstrated sufficient response variance across UK renal centres [23, 24], identifying areas where patient experience varies within and between centres. Consequently, the Spanish and Catalan versions of the questionnaire might also have potential meso- and macro-level impacts for comparing patient experience across renal centres in Spain and Catalonia, where patient experience in the context of person-centred care is a key element in the Health Action Plan at the government level [25, 26].

One possible study limitation was that the number of patients involved in the cognitive debriefing of the two language versions could be considered low (4 for Catalan and 5 for Spanish). However, the exact number of patients participating in the cognitive debriefing phase may vary depending on several factors, including the cultural context. In this case, as both Catalan and Spanish are romance languages that are directly descended from Vulgar Latin, and as both are widely spoken in Cataloniaand have significant similarities, we considered that with 4–5 participants for each language we would obtain sufficient feedback on linguistic aspects as well as on any challenges related to completing the questionnaire, which would likely be common to both languages.

Finally, satisfactory cross-cultural adaptation was achieved through various stages, including initial translation, back translation, cognitive debriefing, face validity and harmonisation. These stages were crucial for ensuring the quality of the cross-cultural adaptation process. Furthermore, a future study is currently underway to assess reliability and construct validity to ensure that the questionnaire accurately measures the intended concepts related to patient experience in renal care. These validation steps will be essential for ensuring the clinical and research applications of the Kidney PREM.

## Conclusions

By following a rigorous, multiphase process of cultural adaptation, the Catalan and Spanish versions of the Kidney PREM questionnaire were developed to meet the acceptance criteria of both patients and healthcare professionals. The Catalan and Spanish versions of the Kidney PREM for CKD patients achieved cultural adaptation and face validity. Following further and future psychometric and feasibility testing in large samples to ensure that they will produce valid and reliable results, these questionnaires can be made available for research on patients with CKD as well as in clinical practice.

## Acknowledgements

The authors extend their gratitude to the healthcare professionals from the Hospital Clínic, Hospital de Bellvitge, Hospital Son Espases, Hospital del Mar and Fundació Puigvert, as well as to the patients and staff who were involved in the study.

## Author contributions

Authors' contributions: MMF, CA, MH, ALL are responsible for the conception, methodology and design of the study. MMF, MH, BB contributed to the acquisition of data and data analysis. MMF, MH, ALL, BB, AB are responsible for investigation and validation. MMF is responsible for writing the first draft of the article. All authors contributed significantly to the intellectual content of the article and gave approval for publication of the final version.

## Funding

Not applicable.

## Data availability

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

## Declarations

## Ethics approval and consent to participate

The questionnaire did not involve any invasive procedure or data collection beyond standard clinical practices. Therefore, ethical approval from an ethics committee was deemed unnecessary according to "Law 14/2007 of July 3 on Biomedical Research". All participants gave fully informed written consent to participate.

### Consent to publish

Not applicable.

#### Conflict of interest

The authors report no conflicts of interest.

#### Author details

<sup>1</sup>Departament de Salut de Catalunya, Agència de Qualitat i Avaluació Sanitàries de Catalunya (AQuAS), Barcelona, Spain

<sup>2</sup>CIBER de Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain <sup>3</sup>Preventive Medicine and Epidemiology Department, Hospital Clínic, Barcelona, Spain

<sup>4</sup>Faculty of Medicine and Health Sciences, University of Barcelona, Barcelona, Spain

<sup>5</sup>Institute for Global Health (ISGlobal), Barcelona, Spain

<sup>6</sup>Hospital General de Granollers, Barcelona, Spain

<sup>7</sup>Health Research Methods Unit, University of Hertfordshire, Hatfield, UK <sup>8</sup>Saw Swee Hock School of Public Health, National University of

Singapore, Kent Ridge, Singapore

## Received: 21 April 2024 / Accepted: 9 December 2024 Published online: 18 December 2024

## References

- 1. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022. Kidney International Supplements; 2022.
- Stewart M. Towards a global definition of patient centred care: The patient should be the judge of patient centred care. BMJ. 2001.
- Gilmore KJ, Pennucci F, De Rosis S, Passino C. Value in healthcare and the role of the patient voice. Healthc Pap. 2019.
- Wolf JA, Niederhauser V, Marshburn DLS. Operationalizing and defining the patient experience. Patient Exp J. 2014;1(1):17–9.
- De Silva D. Evidence scan: Measuring the patient experience. Heal Found. 2013.
- Bull C, Teede H, Watson D, Callander EJ. Selecting and Implementing Patient-Reported Outcome and Experience Measures to Assess Health System Performance. JAMA Health Forum; 2022.
- OECD., Informe d'estat. Indicadors notificats pel pacient per avaluar el rendiment del sistema sanitari. Mesurar el que importa: les enquestes d'indicadors reportades pel pacient [Internet]. 2019. http://www.oecd.org/health/health-s ystems/Measuring-what-matters-the-Patient-Reported-Indicator-Surveys.pdf
- Https://www.oecd.org/health/paris/. Economic. Organisation for Development, Co-operation and Development.
- Jenkinson C, Coulter A, Bruster S. The picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries. Int J Qual Heal Care. 2002.
- 10. De Rosis S, Cerasuolo D, Nuti S. Using patient-reported measures to drive change in healthcare: The experience of the digital, continuous and systematic PREMs observatory in Italy. BMC Health Serv Res. 2020.
- Slawomirski L, van den Berg M. Patient-Reported indicator survey (Paris): aligning practice and policy for better health outcomes. World Med J. 2018;64(3):8–14.
- Beattie M, Murphy DJ, Atherton I, Lauder W. Instruments to measure patient experience of healthcare quality in hospitals: A systematic review. Syst Rev. 2015.
- 13. Coulter A. Can patients assess the guality of health care? BMJ. 2006.
- Black N. Patient reported outcome measures could help transform healthcare. BMJ. 2013.
- Bertran MJ, Viñarás M, Salamero M, Garcia F, Graham C, McCulloch A et al. Spanish and Catalan translation, cultural adaptation and validation of the Picker Patient Experience Questionnaire-15. J Healthc Qual Res. 2018.

- Munro H et al. Patient-Reported Experience Measures to Evaluate and Improve the Quality of Care in Nephrology. Semin Nephrol. 2024;44(3).
- Hawkins J, Wellsted D, Corps C, Fluck R, Gair R, Hall N et al. Measuring patients' experience with renal services in the UK: development and validation of the Kidney PREM. Nephrol Dial Transpl. 2022;37(8).
- DeVellis RF. Scale Development-Theory and Applications: Chap. 1&2. In: Scale Development-Theory and Applications. 2012.
- 19. Organització Catalana de Trasplantaments (OCATT). Registre de malalts renals de Catalunya, informe estadístic 2022. Barcelona. Departament de Salut, Generalitat de Catalunya abril de, 2024. Informe estadístic del Registre de malalts Renals de Catalunya; 2022.
- 20. Wellsted D. Development of an arteriovenous fistula and graft cannulation patient reported experience measure for adults with chronic kidney disease on haemodialysis. National Institute for Health and Care Research; 2023.
- 21. Jamieson Gilmore K, Corazza I, Coletta L, Allin S. The uses of Patient Reported Experience Measures in health systems: A systematic narrative review. Vol. 128, Health Policy. 2023.
- 22. Cirillo L, et al. Association between Satisfaction with Dialysis Treatment and Quality of Life: A Cross-Sectional Study. Blood Purif. 2021;50(1):188–95.

- Hawkins J, Smeeton N, Busby A, Wellsted D, Rider B, Jones J et al. Contributions of treatment centre and patient characteristics to patient-reported experience of haemodialysis: A national cross-sectional study. BMJ Open. 2021.
- 24. Patient Reported Experience of Kidney Care in the UK 2022. Patient Reported Experience of Kidney Care in the UK 2022. 2022.
- Health M. of. The Catalan Health Plan 2021–2025 [Internet]. 2021. https://salut web.gencat.cat/ca/departament/pla-salut/index.html#googtrans(ca%7Cen).
- Encuesta de Resultados en Salud. Patient-Reported Indicators Surveys (PaRIS). Subdirección General de Información Sanitaria; Ministerio de Sanidad. Madrid. España. 2023.

## **Publisher's note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.