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CULTURAL ADAPTATION OF PATIENT-REPORTED INDICATOR SURVEYS (PaRIS) PATIENT AND PRIMARY CARE PRACTICE QUESTIONNAIRES TO THE SLOVENIAN CONTEXT

KULTURNA PRILAGODITEV VPRAŠALNIKOV O KAZALNIKIH, O KATERIH POROČAJO PACIENTI (PATIENT-REPORTED INDICATOR SURVEYS – PaRIS), ZA PACIENTE IN AMBULANTE PRIMARNEGA ZDRAVSTVENEGA VARSTVA SLOVENSKIM RAZMERAM

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ABSTRACT

Introduction: The objective of the study is to describe the adaptation process (with emphasis on cognitive testing) of the Slovenian version of the PaRIS international survey, including two questionnaires to assess patient-reported health outcomes and the experiences of adults living with one or more chronic conditions managed in primary care settings: (1) Patient questionnaire (targets patients aged 45 and older) and (2) Provider questionnaire (targets health care providers working in primary care).

Methods: The translation process of both PaRIS questionnaires followed a team-based double translation and reconciliation approach. Cognitive interviewing with 29 participants was performed. An analysis grid and debriefing were implemented, and the cognitive testing rating was assessed for each tested question. Cross-national error source typology (CNEST) was used.

Results: The results of cognitive interviewing revealed difficulties in 30 questions / segments (out of a total of 44 tested) in the Patient questionnaire and difficulties in 23 questions / segments (out of a total of 24 tested) in the Provider questionnaire. In both questionnaires most difficulties were identified as poor source question design.

Conclusions: Our study showed that cognitive interviewing is a crucial step in questionnaire adaptation, especially while transferring internationally developed questionnaires on Patient Reported Experience Measures and Patient Reported Outcome Measures into different national contexts. Through a rigorous process of translation and cognitive testing, we obtained better quality PREMs and PROMs measures in the Slovenian language. However, the measurement tools need to be piloted, and psychometrically evaluated in future to test reliability and validity.

Keywords:
Primary care
Patient Reported Outcome Measure
Cognitive testing

IZVLEČEK

Uvod: *Cilj raziskave je opisati proces prilagoditve (s poudarkom na kognitivnem testiranju) slovenske različice mednarodne ankete PaRIS, ki vključuje dva vprašalnika za oceno pacientovih poročanih zdravstvenih izidov in izkušenj pacientov, ki živijo z enim ali več kroničnimi stanji, obravnavanimi v okviru osnovne zdravstvene oskrbe: (1) vprašalnik za paciente (cilja na paciente, stare 45 let in več) in (2) vprašalnik za zdravstvene delavce (osredotočen na zdravstvene delavce, ki delajo v osnovni zdravstveni oskrbi).*

Metode: *Postopek prevajanja obeh vprašalnikov PaRIS je sledil pristopu dvojnika in usklajevanja, ki temelji na timskem pristopu. Izvedeno je bilo kognitivno intervjuvanje z 29 udeleženci. Uporabljena sta bila analiza in povratni pregled, ter ocenjena ocena kognitivnega testiranja za vsako testirano vprašanje. Za zmanjšanje in izogibanje napakam pri merjenju ter zagotavljanje mednarodne primerljivosti je bila uporabljena tipologija virov napak v presečnih raziskavah (CNEST).*

Rezultati: *Rezultati kognitivnega intervjuvanja so razkrili težave v 30 vprašanjih/segmentih (od skupno 44 testiranih) v vprašalniku za paciente in težave v 23 vprašanjih/segmentih (od skupno 24 testiranih) v vprašalniku za zdravstvene delavce. Pri obeh vprašalnikih so bile večinoma težave povezane s slabim izhodiščnim oblikovanjem vprašanj.*

Zaključki: *Naša raziskava je pokazala, da je kognitivno testiranje ključni korak pri prilagajanju vprašalnikov, zlasti pri prenosu mednarodno razvitih vprašalnikov o pacientovih poročanih izkušnjah in zdravstvenih izidih v različne nacionalne kontekste. S strogim postopkom prevajanja in kognitivnega testiranja smo pridobili bolj kakovostna orodja za merjenje izidov zdravstvene oskrbe in izkušenj z zdravstveno oskrbo na osnovni zdravstveni ravni. Omenjena orodja pa je treba v prihodnosti pilotno preizkusiti in psihometrično ovrednotiti, da se preveri njihova zanesljivost in veljavnost.*

Ključne besede:
osnovno zdravstvo
izidi zdravstvene oskrbe
kognitivno testiranje

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1 INTRODUCTION

Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) are crucial in evaluating healthcare quality from the patient's perspective, particularly in chronic care management within primary care settings. PROMs provide insights into the patient's health status, treatment outcomes and quality of life, while PREMs focus on patient experiences with healthcare services and healthcare professionals (1). Primary care has a significant place in the management of people with chronic conditions as it offers continuous, coordinated, people-centred and comprehensive care. Yet PROMs and PREMs data in primary care are scarce.

In large-scale international studies, ensuring international comparability is essential, through using the same survey design and instruments. However, adaptation of the survey and tools to the national context is important to address contextual issues (4). Structured and rigorous translation processes are key in international studies where the source instruments are developed in a foreign language, and ensure the validity and reliability of data collection. While using existing instruments has the advantage of established validity, a previously validated instrument may not be valid in a different time, culture, or context (2). Self-report scales can show variations due to culturally determined factors such as social desirability and response styles (3). Therefore, cultural adaptation, in addition to translation, becomes important to ensure content equivalence between source and target versions (3). There is no consensus on how to adapt instruments for different cultural settings, but simple translation is insufficient, as it can result in multiple, inconsistent translations, losing the original intent (4). Rigorous translation and cognitive testing are two important steps in ensuring that instruments such as PROMs and PREMs are appropriately adapted to different cultural contexts, preserving their original intent (7, 8).

The OECD's Patient-Reported Indicator Survey (PaRIS) (5) aims to measure the performance of health systems in delivering high quality safe primary care by collecting PROMs and PREMs. It assesses the outcomes and experiences of the healthcare of people living with chronic conditions aged 45 and above through a patient questionnaire (PaRIS-PQ) (2) and through a primary care practice questionnaire (PaRIS-PCPQ) (3) which collects information on the characteristics of care such as delivery design and type of practice (e.g., group practice). Based on the PaRIS conceptual framework, PaRIS-PQ and PaRIS-PCPQ were developed in English and French through a rigorous process of review of literature, modified Delphi process and stakeholder consultations from existing validated instruments (10-13).

The aim of this study was to adapt the PaRIS-PQ and PaRIS-PCPQ to the Slovenian setting and language. The study focused on cognitive testing to ensure the questionnaires' comprehensibility, relevance and effectiveness in the national context.

2 METHODS

2.1 Study type and settings

This was a qualitative study based on the translation and cultural adaptation of the PaRIS-PQ and PaRIS-PCPQ. It was performed among Slovenian family medicine providers and patients as part of the OECD's PaRIS survey (5, 6).
The OECD led the development and implementation of the PaRIS survey, with support from the PaRIS-SUR consortium, an international team highly experienced in primary care research and survey development (5). The development of the PaRIS questionnaires was an iterative co-development process (3), including countries, academics, primary care professionals and patient organisations (10).

The study was approved by the National Ethical Committee of Slovenia (approval number 0120-260/2021/3).

2.2 Participants

We involved primary care providers and their patients; a purposive sampling technique was used. For providers, interested family physicians were contacted by the researchers, with the aim of including a range of providers (age, gender, area of work and work experiences).

In Slovenia, the family medicine practice team consists of a family physician, registered nurse and practice nurse (7). Therefore, the inclusion criterion for the providers' sample was that the participant needed to be a family physician, registered nurse, or practice nurse. We contacted 10 providers.

The inclusion criteria for patients were: 1) adults aged 45 years or older, 2) living in a private household in the community, and 3) have had one or more consultations with a primary/outpatient healthcare provider in the past six months.

To get the patient contact information, we asked the providers to find interested patients and obtain their consent to send their contact data to the research team. Through this process, 20 patients were contacted to participate in the study.

2.3 Measurement tools

The English version of the PaRIS-PQ (2) and PaRIS-PCPQ (3) source questionnaire were used as the measurement tools.

2.4 Procedures

The entire adaptation process followed the following phases: 1) translation of source questionnaires into Slovenian; 2) First round of cognitive testing; 3) Second round of cognitive testing; 4) Field trial of survey design and instruments and 5) Final questionnaires for the main survey implementation.

2.4.1 Translation of source questionnaires into Slovenian

The translation process followed a team-based double translation and reconciliation approach (TRAP-D - Translation, Review, Adjudication, Pretesting and Documentation) (5). The team approach to translating and adapting questionnaires is a well-established practice in international research and is recommended by the guidelines for intercultural research (8). Using a collaborative and iterative approach ensures that translated versions accurately reflect the local context while maintaining the integrity of the original source.

The process began with a translatability assessment to verify the suitability of the source version for translation. This assessment identified potential translation issues and offered alternative phrasings or translation/adaptation notes to clarify terms or expressions and guide the translators on necessary adaptations. The PaRIS-SUR consortium reviewed this translatability report to finalise the source version.

Following this, two translations were produced: a local translator appointed by the national research team, and an external translator, provided by cApStAn (a specialist linguistic quality control agency). An external adjudicator (also provided by cApStAn) then reconciled these translations into a single version. This merged translation was discussed in an adjudication meeting, involving both translators, the adjudicator, the Slovenian national project manager and a PaRIS-SUR member. The purpose of these meetings was to resolve any controversial or difficult translation choices to finalise the questionnaire wording. Once the translation had been finalised by adjudicators, a final proof check of each national version was carried out by a proof-reader.

Throughout the translation, adaptation and reconciliation/adjudication process, all steps were documented in an Excel monitoring tool called the Questionnaire Translation and Adaptation Workbook (QTAW). The entire translation, adaptation and proofreading process utilised the open-source software OmegaT (9). To support the translations, a glossary was created, which provided descriptions, translation notes and examples for unclear terms identified during the translatability assessment. This glossary aimed to enhance the comprehensibility of terms and ensure consistent translations.

2.4.2 Cognitive testing

Cognitive interviews were implemented in two rounds of semi-structured interviewing using the think aloud technique, verbal probing (pre-prepared probes and spontaneous probes) and observation (hesitation, confusion, request for clarification etc.). We used the four-stage model of cognitive interviewing (4), focusing on the process of understanding, recall, judgement and response while people are answering questionnaires. Researchers took detailed notes and completed a structured analysis grid to ensure evidence was available to support the need for any changes throughout the two rounds of testing. Each round led to recommendations for changes to the questionnaires. Changes that were considered were either source changes (changes or revisions to the source questionnaires to be implemented in all countries) or localisations (issues that were identified in the national context, allowing adaptation of the questions or response options to support comprehension, as well as to correct translation errors).

All participants received the following materials in advance (via regular mail or e-mail): 1) Information sheet (with all the information about the study and our contacts), 2) Consent form, and 3) Privacy notice. All participants received a small thank you for taking part (a small first aid kit package), which was not offered in advance. Due to COVID-related restrictions the interviews were conducted in two modes: 1) online (GoToMeeting (video)conference), and 2) by telephone.

2.4.2.1 First round of cognitive testing

The first round of cognitive interviewing took place between 8 and 19 July 2021. We aimed to include 15 participants (5 healthcare providers and 10 patients). Cognitive testing only included items that the PaRIS consortium had previously identified as necessary for testing (3). Researchers documented their observations and utilised a structured analysis grid to substantiate the need for any modifications during the second round of testing. These changes were categorised as either recommendations for source changes, which involved alterations or revisions to the original questionnaires to be implemented across all countries, or localisations, which addressed issues identified within the national context. This allowed the national research team to adapt questions or response options to enhance comprehension and correct translation errors.

2.4.2.2 Second round of cognitive testing

This took place between 25 October and 2 November 2021. Again, we aimed to include 15 participants (5 healthcare providers and 10 patients), all different to those included in the first round. We tested only the items that needed adaptation based on the results of the first round, and

an additional two questions (in which issues appeared spontaneously during the first round of testing).

2.4.3 Data analysis

According to the results of the cognitive testing (based on observed problems), the researchers (NR, EM) assessed each question independently, rating them as: Not problematic; Somewhat problematic; or Very problematic. The researchers (NR, EM) assigned a quantitative number to each descriptive assessment: Not problematic = 0 points; Somewhat problematic = 1 point; Very problematic = 2 points. For each question, total difficulty points (sum of all points over all tests) were calculated, separately for round 1 and round 2 of cognitive interviewing. Where there was disagreement between the researchers (NR, EM), a consensus meeting with ZKK took place.

For an easier assessment of the actual cognitive complexity, a ratio was also calculated of Total difficulty points / Number of tests for each question in each round of cognitive testing. A higher ratio indicated greater cognitive difficulty of the question, and a greater need to change or modify the question, response options or introductory text. A ratio of 0.5 or higher per question was decided as the cut-off point for further detailed consideration. Since this was an international project, including many countries each with different healthcare systems, the cross-national error source typology (CNEST) (10) was used with the intention to reduce and avoid measurement error, and to provide international comparability. CNEST error source typology focused on three types of errors: 1) poor source question design, 2) translation error, and 3) difficulties resulting from cultural portability (10).

2.4.4 Finalisation of the questionnaires

We analysed cognitive testing results using the Cross-National Error Source Typology (3) to identify and categorise errors related to source question design, translation and cultural adaptation (3). This analysis allowed researchers to pinpoint issues and recommend solutions for each question tested.

3 RESULTS

3.1 PaRIS-PQ

The patient sample comprised 20 participants: 11 females and nine males. All participants were aged 45 years or older at the time of sampling and lived in a private household in the community (i.e. not in a long-term care facility, healthcare or other residential institution). The age of participants varied between 47 years old and 95 years old (mean 67 years, standard deviation 12 years). Of the participants, 11 had a chronic condition.

The results of cognitive testing revealed difficulties in 30 questions or segments (out of a total of 44 tested, and out of total 120 items in the questionnaire), where changes would be beneficial.

The table below lists question codes, number of tests, total difficulty points, ratio and identified error types.

In addition to the CNEST error typology (poor source question design, translation error, cultural portability) we also added Poor introduction to a section or sequence of questions (Table 1).

Table 1. Error types revealed after cognitive testing of the PaRIS-PQ.

	Round 1			Round 2			
Question content	**N of tests**	**Tot. diff. score**	**Ratio**	**N of tests**	**Tot. diff. score**	**Ratio**	**Error Type**
Difficulties in breathing	9	4	0.4	10	5	0.5	Poor source question design.
Emotional problems (anxiety, depression, irritability)	7	4	0.6	9	3	0.3	Poor source question design.
Care for health and healthcare	7	4	0.6	10	5	0.5	Poor source question design.
Health professionals spoken about healthy eating	8	4	0.5	10	5	0.5	Poor source question design.
Information about health issues	8	11	1.4	/	/	/	Translation error.
Experience with healthcare	9	6	0.7	9	5	0.6	Cultural portability.
Consulted with a doctor	8	4	0.5	9	5	0.6	Poor source question design, Translation error.
Diagnosed with disease by a doctor	7	4	0.6	/	/	/	Poor source question design, Poor introduction / section design (text after diagnosed with disease by doctor).
Healthcare professional coordinating health services	9	11	1.2	10	7	0.7	Translation error / Cultural portability, Poor introduction / section design (Experience in family medicine practice, text after Diagnosed by doctor with disease).
Same health professional for most problems	7	7	1.0	/	/	/	Poor introduction / section design (Single healthcare professional for coordination, Experience with family medicine practice, text after Diagnosed with disease by doctor).
Who is this health worker?	7	10	1.4	9	5	0.6	Poor introduction / section design (Experience with care in family medicine practice, text after Diagnosed with disease by doctor, questions Is there a single professional responsible for coordinating care, Is it the same professional as for most health problems), Translation error (response option 3).
Health professional for most health problems	8	4	0.5	10	6	0.6	Cultural portability, Poor introduction / section design (Realationship with care in your family medicine practice, Diagnosed by doctor with any disease).
Setting health goals with health professionals	8	7	0.9	10	6	0.6	Poor section design, Poor source question design. * Firstly, question was without introduction.

	Round 1			Round 2			
Question content	N of tests	Tot. diff. score	Ratio	N of tests	Tot. diff. score	Ratio	Error Type
Questions relate to treatment plan/ Treatment plan for health needs	8	10	1.3	10	10	1.0	Poor introduction design, Poor source question design, Cultural portability.
Health care involves family, friends, caregivers	8	1	0.1	8	7	0.9	Poor source question design, Poor introduction / section design.
Reviewing all the medications	7	4	0.6	10	2	0.2	Poor source question design, Poor introduction / section design.
Last consultation/main purpose of consultation	9	11	1.2	9	11	1.2	Poor introduction design (Relate to last consultation in medical clinic), Poor source question design, Translation error, Cultural portability.
Most time spent with healthcare professionals	9	5	0.6	7	8	1.1	Poor introduction / section design, Cultural portability.
Employment of a health worker	9	13	1.4	5	3	0.6	Poor introduction /section design, Cultural portability.
Best describes the type of medical care	8	6	0.8	6	4	0.7	Poor introduction / section design, poor source question design.
How quickly you got the appointment for consultation	8	2	0.3	7	6	0.9	Poor introduction / section design, poor source question design.
Symptoms of COVID-19 in last two months	8	2	0.3	8	7	0.9	Translation error / Cultural portability.
Highest level of education	10	6	0.6	/	/	/	Translation error / Cultural portability.
Your sex	7	7	1.0	/	/	/	Cultural portability.
Your gender	9	8	0.9	/	/	/	Cultural portability.
Current employment status	4	5	1.3	/	/	/	Translation error / Cultural portability.
Enough money for healthy food	8	5	0.6	4	1	0.3	Poor source question design.
Need for emotional care	9	7	0.8	/	/	/	Poor source question design.
Agree or disagree that healthcare system can be trusted	8	1	0.1	8	5	0.6	Poor source question design.
Best describes the live in place	/	/	/	6	5	0.8	Poor source question design (difficult international comparability).

Legend: *= questions which were additionally tested only in Slovenia. N of test = Number of tests, Tot. diff. score = Total difficulty score, Ratio = Total difficulty score / Number of tests.

The terms "Ni ustrezno" (English: Not relevant) were not understood correctly by some participants, therefore these terms were substituted everywhere in the questionnaire with "Vprašanje ni ustrezno zame" (English: Question is not relevant to me). In the paper version of the Patient questionnaire some problems were detected with the routing markings (identifying which question people should answer next when skipping questions). Some problems were detected also due to the length of the questionnaire, especially long, complex introductory text (which was even longer in the Slovenian language due to usage of both grammatical genders). As a result, to reduce cognitive complexity, the wording in the Patient questionnaire was changed to use the male grammatical gender only. In the web version it was noticed that the information buttons (which included some additional description of terms) were often overlooked. To resolve this, it was suggested the important text be included directly in the wording of the main questions.

3.2 PaRIS-PCPQ

The sample included nine participants: five females and four males. Five worked as nurses in family medicine and four as family physicians. Seven worked in a solo practice (as part of a healthcare centre) and two in a group practice as part of a private clinic.

The results of cognitive testing revealed difficulties in 23 questions or segments (out of a total of 24 tested, and out of a total 34 in the questionnaire). The following error types were revealed after the cognitive testing of the PaRIS-PCPQ: Poor source question design, Translation error and Cultural portability (Table 2).

Cognitive testing revealed the need to clarify in the PaRIS-PCPQ that the survey refers to primary care, including model family medicine practices. This clarification was added because some participants were unsure whether model family medicine practices should be included. Similarly to the PaRIS-PQ, it was observed that in the web version, the information buttons (containing additional descriptions of certain terms) were frequently overlooked. Consequently, it was recommended that essential information be included directly in the main questions.

4 DISCUSSION

Cognitive testing of the PaRIS-PQ and PaRIS-PCPQ have significantly improved the clarity and user experience of the PaRIS questionnaires in the Slovenian context. The assessment identified beneficial changes for 30 out of 120 PaRIS-PQ items and for 23 out of 34 PaRIS-PCPQ items, improving comprehension of the questionnaires through changes including question design, translation accuracy, cultural relevance and sequence design. Clearer terminology was introduced, replacing terms that were not well understood, and adjustments were made to simplify wording and reduce complexity in the questionnaire.

Cognitive testing identified "Poor source question design" as a significant issue. Despite using validated questions, cognitive testing highlighted issues with how these questions functioned in the context of the Slovenian survey. These problems suggest that even validated instruments can fail in new cultural or linguistic contexts. This finding is very important since cognitive practice often focused more on checking specific question understanding, rather than how a question plays out in the context of an entire questionnaire. This indicates that some questions were not effectively constructed, leading to confusion among respondents. This was also shown in other participating countries and was the most prevalent type of error in PaRIS-PCPQ international cognitive testing (3). In Slovenia, most issues associated with poor source question design were linked to cultural and contextual differences. Such issues can lead to biased results. The report notes the importance of cultural adaptation beyond mere translation. Poor design was often linked to a lack of cultural portability, underscoring that validated instruments require contextual refinement to maintain their integrity across diverse populations. The issues identified during cognitive interviews (e.g., confusion or misunderstanding) were pivotal in refining the questions. This indicates that validation in prior studies does not guarantee flawless application in all scenarios, particularly in multilingual and multicultural studies. Maintaining international comparability while addressing local context is a complex challenge. Some of the poor design elements may have persisted because questions were developed with an international audience in mind, which can dilute their relevance or clarity in specific national settings. It is essential to adapt questions to fit the cultural context of the target population. This includes considering local terminologies, customs and healthcare practices. Misunderstandings due to cultural discrepancies can significantly impact the validity of the data collected (11).

Both questionnaires encountered translation errors, which can distort the intended meaning of questions. Similar issues were observed in international cognitive testing (3). Ensuring accurate translations that preserve the original meaning is essential, as well as consultation with native speakers (12, 13).

Some questions did not translate well across different cultural contexts, an issue known as cultural portability which was found as a prevalent issue in the international cognitive testing (3). This underscores the utmost importance of culturally sensitive adaptations that respect local contexts and terminologies (12, 13).

Table 2. Error types revealed after cognitive testing of the PaRIS-PCPQ.

	Round 1			Round 2			
Question content	N of tests	Tot. diff. score	Ratio	N of tests	Tot. diff. score	Ratio	Error Type
Type of practice	3	5	1.7	5	7	1.4	Cultural portability.
Practice offers services without an appointment/ Which type of patients can come without an appointment	3	2	0.7	5	6	1.2	Poor source question design, Translation error, Cultural portability.
Which of the following out-of-hours options does your practice provide	3	3	1.0	5	9	1.8	Poor source question design, Cultural portability, Translation error.
Roles and functions of the nurses	3	3	1.0	5	5	1.0	Poor source question design, Cultural portability.
Scheduled time in practice	3	3	1.0	5	5	1.0	Poor source question design, Translation error, Cultural portability.
How prepared is a practice to manage care?	3	3	1.0	5	7	1.4	Poor source question design, Translation error, Cultural portability.
Access to equipment for managing chronic patients	4	5	1.3	/	/	/	Poor source question design.
Physicians paid in practice	4	6	1.5	/	/	/	Poor source question design, Cultural portability.
Practice receives dedicated payments	4	5	1.3	5	10	2.0	Cultural portability.
Types of medical record kept	4	4	1.0	5	4	0.8	Poor source question design, Translation error.
How are individual patient care plans developed at your practice?	4	6	1.5	5	5	1.0	Poor source question design, Cultural portability.
Practice produces information using computer system	4	3	0.8	5	7	1.4	Poor source question design, Translation error, Cultural portability.
Tasks routinely performed using computer system	3	3	1.0	5	5	1.0	Cultural portability, Translation error.
Review indicators	3	4	1.3	5	6	1.2	Poor source question design, Translation error, Cultural portability.
In charge of coordinating with chronic conditions	3	5	1.7	5	10	2.0	Poor source question design, Translation error.
Self-management support for patients with chronic conditions	3	1	0.3	4	2	0.5	Cultural portability.
Care in practice following chronic conditions	3	4	1.3	/	/	/	Poor source question design, Translation error.
Info about COVID-19	3	2	0.7	/	/	/	Translation error.
Changes in practice due to COVID-19	2	1	0.5	3	2	0.7	Poor source question design.
Salary in COVID-19	2	1	0.5	/	/	/	Poor source question design.
Stressed when managing patients with covid-19	2	1	0.5	2	1	0.5	Poor source question design.
Professional background	4	5	1.3	3	2	0.7	Cultural portability.
Does your practice offer video, phone, or other online techniques for consultations to patients?	3	0	0.0	5	1	0.2	No major difficulties detected in Slovenia.

Legend: N of test = Number of tests, Tot. diff. score = Total difficulty score, Ratio = Total difficulty score / Number of tests.

The cognitive testing highlighted issues with the design of introductions and the sequence of questions. Long and complex introductions were particularly problematic, especially in languages such as Slovenian that require gender-specific language. On the contrary, at the international level, this was the least prevalent issue (3). This finding underlines the importance of continuous testing and refinement of the terminology used in large-scale surveys as well as adaptation to national contexts while ensuring international comparability of results (12). The findings of this study confirm that cognitive interviewing in addition to translation is a crucial step in the development of questionnaires and the adaptation process, especially for developing PROMs and PREMs (14, 15). In large-scale initiatives, it is even more important to do cognitive testing in local languages, since even if the survey instruments used are validated in other contexts, it does not necessarily mean that they have the same face validity in all participating countries. This is why by design, PaRIS ensured that all countries followed a rigorous translation and cognitive testing process, meaning that the final questionnaires were understood by all participating patients, providing comparable data.

Cognitive testing is the most direct way of finding out whether respondents understand questions consistently, have the information needed to answer the questions and can use the response alternatives provided to describe their experiences or their opinions accurately. It does not directly assess the validity of the answers, but cognitive problems will seriously compromise validity and reliability (16, 17). Therefore, we can conclude that cognitive interviewing ensured that the Slovenian version of both PaRIS questionnaires had much better face validity.

Our study has some limitations that must be addressed. Cognitive testing was performed only on specific questions - those questions that were identified and pre-selected for testing in Slovenia by the PaRIS consortium. However, the cognitive complexity of sentences may be different in different languages (e.g. some wording in English sounds less complex than in Slovenian). Also, the testing was adapted to the conditions of the individual interview (time duration, fatigue etc.), therefore not all questions were tested on all participants.

Additionally, during cognitive testing, some participants had difficulty developing rich metacognitive thinking (awareness of their own thoughts and mental processes), which is an important factor in effective cognitive interviewing. Despite encouragement, some participants could not consistently think aloud and were unable to reflect much despite verbal probing. Furthermore, cognitive interviewing was not performed face-to face, but online (GoToMeeting (video) conference) and by telephone due to COVID-related restrictions, which limits the ability to observe non-verbal communication.

Finally and importantly, cooperating in this international cognitive interviewing study was beneficial since it ensured that the questions which were further tested in the PaRIS survey Field Trial were similar in different countries, which ensures good final data comparability.

5 CONCLUSION

This study describes the cognitive testing of the international PaRIS-PQ and PaRIS-PCPQ in the Slovenian language and in a sample of Slovenian primary care providers and patients. To our knowledge, this is the first time PREMs or PROMs for primary care have undergone cognitive testing in Slovenia, marking a critical step toward better aligning healthcare evaluation tools with local cultural and linguistic contexts. Identified errors enabled the questionnaires to be adapted to the Slovenian context, while keeping consistency with international standards for cross-country comparisons. Through a rigorous process of translation and cognitive testing, we obtained culturally adapted PREMs and PROMs measures in the Slovenian language for family medicine practices, ensuring better validity for any future studies that also use them.

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ETHICAL APPROVAL

The study in Slovenia was approved by the National Ethics Committee (No. 0120-260/2021/3).

CONFLICTS OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from OECD. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of OECD.

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