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Development and validation of a patient knowledge questionnaire for rheumatoid arthritis (PKQ-RA-11) in Danish and German

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Objective: Patient education is a cornerstone of rheumatology care, enabling patients to effectively and safely manage their condition. Standardized patient knowledge assessments are essential for benchmarking care quality and tailoring education to individual needs. This study aimed to develop and validate Danish and German versions of a patient knowledge questionnaire (PKQ) for rheumatoid arthritis (RA).

Method: Danish and German adaptations from the English version involved a forward-and-backward translation process. Face validity was assessed with patients with RA in Denmark and Germany. Subsequently, the generated PKQ-RA-11 versions were tested in Danish and German RA patients.

Results: The face-validity assessment included 20 patients (10 Danish, 10 German). Adjustments in the Danish version included rephrasing options and aligning with digital patient education content. The German version followed the refined Danish version with necessary cultural adjustments. PKQ-RA-11 comprises 11 multiple-choice questions with a scoring system to minimize guessing. The final PKQ-RA-11 was completed by 175 Danish and 174 German patients; mean completion time was 7.5 and 7.4 minutes, respectively. Mean \pm sd baseline PKQ-RA-11 scores were 7.9 ± 1.6 for Danish and 6.2 ± 2.5 for German participants. Longitudinal data from Denmark indicated an increase in knowledge scores following patient education, shown by a mean score of 8.6 ± 1.5 , demonstrating the tool's responsiveness to changes in patient understanding of RA.

Conclusion: PKQ-RA-11 is a standardized tool for assessing disease-related knowledge in individuals with RA. It can be used to provide objective and transparent measures of patient understanding in educational programmes, clinical practice, or research.

Patient education in inflammatory arthritis can be defined as 'a planned interactive learning process designed to support and enable people to manage their life with inflammatory arthritis and optimize their health and well-being' (1). Recommendations for effective patient education in inflammatory arthritis emphasize the evaluation of outcomes aligned with programme objectives (1), such as

participants' knowledge following an intervention (2). While knowledge of the disease and medical treatments alone may not guarantee appropriate actions or coping responses (3, 4), it is generally considered a foundational step towards behavioural changes and self-management. Therefore, knowledge scores can serve as valuable indicators of a patient's comprehension of the disease and its medical treatments (2, 5).

Telehealth and digital patient education programmes supporting self-management have increasingly become more common in rheumatology (6). In both Denmark (7) and Germany (8), these interventions, which measure patient knowledge as an outcome following self-management support, are being actively explored. In the context of patient education, we define patient knowledge

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as the information and understanding that patients have about their condition, treatment options, and self-care practices. We acknowledge that experiential knowledge is also valid, especially in supporting self-management (9) however, that construct is not something that can be standardized and measured in a questionnaire.

A few questionnaires exist for measuring knowledge of rheumatoid arthritis (RA), including the Hill Patient Knowledge Questionnaire (PKQ) (5), the Arthritis Community Research and Evaluation Unit (ACREU) RA Knowledge Questionnaire (10), and the PKQ specifically designed for patients with early RA (2). All of these instruments have undergone validation to evaluate patients' knowledge of RA. In addition, the PKQ has been modified and adapted in English and Spanish for the assessment of multimedia patient education tools for RA patients (11). The current study aimed to translate and adapt the original English version of the PKQ (5) and its modified versions (2, 11), and validate it in a Danish and German context.

Method

Design

This research adheres to established standards for assessing validity evidence, following the COSMIN taxonomy (12, 13). We focused on specific aspects of the validation process: namely, establishing content validity, including face validity of the instrument in both Denmark and Germany, and testing its responsiveness in the Danish sample.

The first section of this study outlines the translation and content validation process of the PKQ into Danish and German. Modifications to the existing PKQ instruments were required to ensure alignment with current practice, treatment guidelines, and language conventions

specific to Denmark and Germany. In addition, specific adjustments were made to the Danish version to align with the content of a digital patient education self-management programme, wherein the PKQ served as an outcome measure (7). The second part of this process focused on refining the scoring system following the testing of the PKQ-RA-11 in two samples, including incident RA patients in Denmark and prevalent RA patients in Germany. The overarching development and adaptation of the PKQ are illustrated in Figure 1.

Part I: Translation and content validation

Setting and patients. The study took place between November 2020 and April 2023 in an outpatient rheumatology clinic at Aarhus University Hospital, Denmark, and between June and December 2022 in an outpatient rheumatology clinic at Erlangen University Hospital, Germany. Inclusion criteria for establishing the content validity were a diagnosis of RA according to the American College of Rheumatology/European Alliance of Associations for Rheumatology 2010 (ACR/EULAR 2010) criteria (14), age >18 years, and the ability to speak, read, and understand Danish or German. Ten patients were included in each clinic in connection with a visit to the outpatient clinic. Participants were selected among patients attending the outpatient clinic over 2 weeks in September 2020 (Danish sample) and June 2022 (German sample). A purposive selection strategy (15) was used to achieve demographic variety among participants, i.e. we aimed to achieve diversity by including participants from both genders with various ages and disease duration.

The PKQ instrument. The PKQ was developed to assess knowledge in patients with RA following

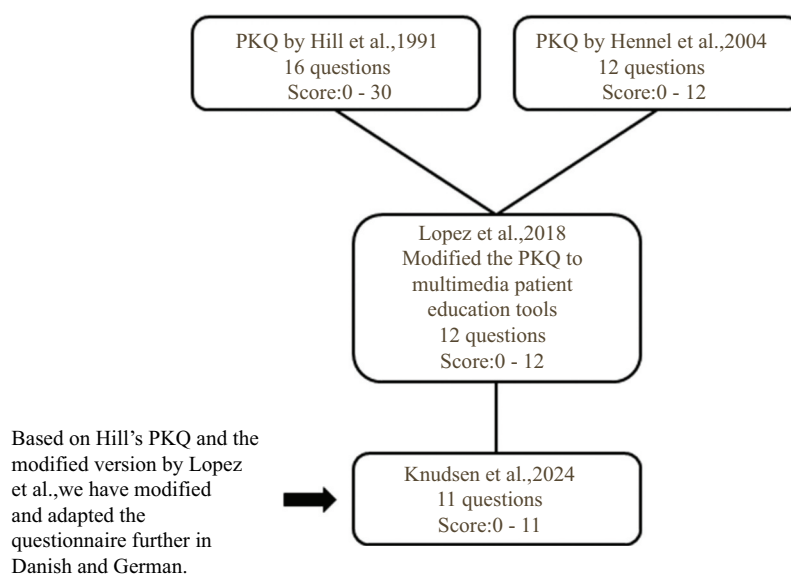


Figure 1. Part I: Translation and face-validity assessment. PKQ, Patient Knowledge Questionnaire.

patient education (2, 5). The different versions of the PKQ consist of multiple-choice questions covering disease aetiology, signs and symptoms, drug therapy and monitoring, joint protection, and exercise and energy conversation (2, 5, 11). The original PKQ has 16 questions and the scores range from 0 to 30, corresponding to the sum of possible correct options in each question (5). Higher scores indicate a higher level of knowledge. In the later versions, scores range from 0 to 12, corresponding to the sum of possible correct questions in total (2, 11).

Translation. The translation of the PKQ was based on methods of the International Quality of Life Assessment (IQOLA), and implies forward-and-backward translations (16, 17).

The adaptation of the PKQ to a Danish and German version, the 11-item Patient Knowledge Questionnaire for Rheumatoid Arthritis (PKQ-RA-11), comprised the following steps: (i) Selection of questions for translation and adaptation to the content of our patient education programmes; (ii) translation of the PKQ from English to Danish/German by two independent translators with proficiency in translation within healthcare services; (iii) synthesizing the translations, to achieve coherence; (iv) assessing the face validity of this version in patients with RA and establishing its feasibility; and (v) back-translation of the consensus version by two other independent translators with proficiency in translation

within healthcare services. To ensure that the intended meaning of the PKQ was retained and that changes and additions of options were operational and meaningful, modifications and adaptations were discussed with the person responsible for the questionnaire permission of the original PKQ (MN). Figure 2 illustrates the translation and validation process.

Content validity. Assessment of the face validity was based on the principles of cognitive interviewing, which is a method ‘for identifying and correcting problems with survey questions’ (18). Methodologically, the practice of cognitive interviewing falls into two general techniques: ‘think aloud’ and verbal probing following intensive interviewing (18, 19). Through the ‘think aloud’ technique, informant-initiated rather than interviewer-initiated data are promoted, as the technique allows examination of the informant’s perceptions with minimal interference from the interviewer (18). In our study, this technique was used, for example, by asking the participants: ‘What comes into your mind when you read this?’, ‘What did you notice when answering this question?’, or ‘Did you find it easy or difficult to answer this question?’ (19). Thus, participants were asked to go through the questionnaire while thinking aloud and commenting on questions and options along the way. They were asked to comment on their understanding of the introduction section of the questionnaire, items, and response options, including phrasing, relevance of items, and suggestions for

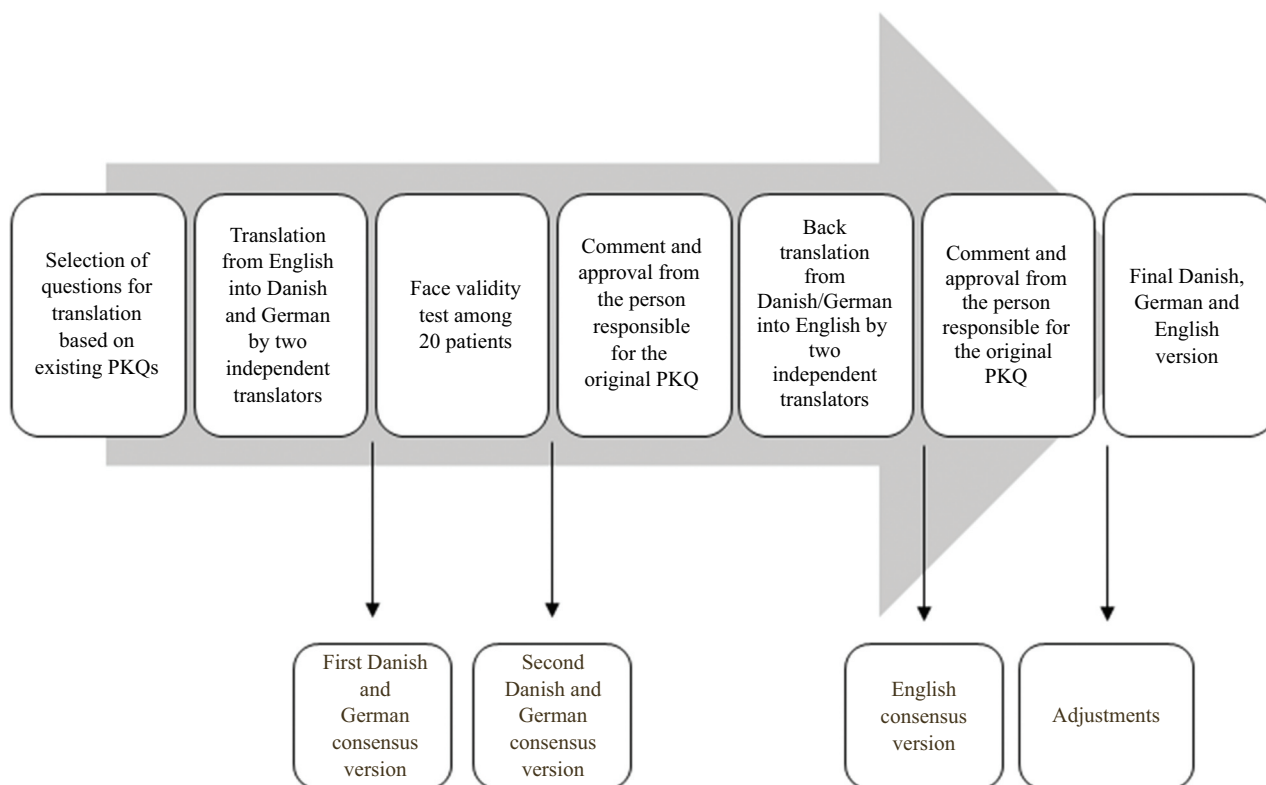


Figure 2. Content validation: assessing face validity. PKQ, Patient Knowledge Questionnaire.

improvements to make the questionnaire easy to understand. In Denmark, a study nurse, and in Germany, a rheumatologist, conducted the face-validity evaluation by providing instructions to patients and observing and noting their behaviour during the completion of the questionnaire. This involved documenting details such as time spent, any hesitations, and expressions of confusion.

Part II: Testing of the final PKQ-RA-11

Setting and patients. The final PKQ-RA-11 was tested in a larger sample of participants in a Danish and German context to evaluate differences between the two cohorts. This included evaluating how accurately they identified the correct answers and the challenges that they faced with the questions. This also included testing its responsiveness based on longitudinal PKQ-RA-11 data from the Danish cohort of incident RA patients. These patients, from five rheumatology outpatient clinics, participated in a randomized controlled trial that tested the effectiveness of digital patient education in improving self-management (7), using the initial scoring system from the original instruments. Subsequently, the PKQ-RA-11 was piloted in consecutive RA patients in a German university hospital outpatient clinic. The final scoring system was refined to accommodate missing responses, additional answers, and other potential scenarios. This ensured the accuracy and reliability of the scoring.

Results

Participants

The translation and assessment of face validity included 20 participants: 10 in the Danish sample and 10 in the German sample. Quantitative validation was conducted in two large samples: 175 participants from Denmark and 174 participants from Germany. Participant characteristics are summarized in Table 1.

Translation and content validation

Danish version. The forward translation from English to Danish showed that some linguistic adjustments were needed to establish the face validity. In particular, the phrasing of options did not appear fluent as the choice of words seemed inconsistent regarding grammar. Hence, the use of action words such as ‘can’, ‘will’, ‘may’, or combination words such as ‘you’ or ‘it’ were either inconsistent or absent in several cases. Thus, for the Danish translation to become idiomatic, rephrasing and achieving a common trend in the tone was necessary. This process was carried out while synthesizing the translations to the first Danish consensus version. Subsequently, evaluation of face validity was conducted by a study nurse trained and guided by AdT, an experienced scientist in questionnaire research. The mean time taken to complete the questionnaire was 7.5 min [range 4.5–13 min].

The PKQ intends to reflect the respondents’ general knowledge about RA disease and treatment, and this is emphasized in the introduction section of the questionnaire. However, participants often based their answers on their own previous experiences instead. Therefore, this was further clarified in the introduction section (Appendix 1).

All participants expressed confusion about items 10 and 12 (Appendix 1), as they found the wording unclear or ambiguous. Furthermore, several participants found it challenging to answer item 12 (‘suitable activities to choose in a busy day marked by fatigue’). Participants expressed that this was particularly difficult to answer without drawing on their own experience, and they did not see one option as more correct than another. Thus, as predefined options seemed pointless, item 12 was removed from the questionnaire. Other observations from participants pointed towards minor adjustments in the choice of words, and adaptations were made to reflect the contents of the digital patient education programme and current guidelines.

Table 1. Participants’ characteristics.

	Danish sample (N = 10)	German sample (N = 10)
Face validity assessment		
Age (years), mean [range]	58 [24–84]	46.5 [32–65]
Female sex, n (%)	6 (60)	7 (70.0)
Disease duration (years), mean [range]	10 [1–42]	n/a
Testing of final PKQ-RA-11		
	(N = 175)	(N = 174)
Age (years), mean ± sd	57.6 ± 14.1	59.9 ± 13.3
Female sex, n (%)	111 (61.3)	125 (71.8)
Disease duration* (days/years), mean ± sd	15.4 [18.7] days	9.6 [9.4] years

PKQ-RA-11, 11-item Patient Knowledge Questionnaire for Rheumatoid Arthritis.

*The Danish sample comprised incident cases, whereas the German sample included prevalent cases.

Regarding items about medical treatment, we chose to replace ‘DMARDs’ (disease-modifying anti-rheumatic drugs) with ‘methotrexate’ and to remove ‘NSAIDs’ (non-steroidal anti-inflammatory drugs), as these abbreviations and terms are not necessarily known among Danish patients. All adjustments were made following discussion by the research group.

German version. After the improvements to the PKQ had been implemented in the Danish version, the German translation and validation process followed. Therefore, the German translation was derived from the English consensus version that was developed during the Danish translation and face-validity evaluation.

The translation from English to German also showed that some adjustments were needed before the face-validity evaluation. ‘Fatigue’ was changed to ‘tired’ and ‘(cortisone)’ was added after glucocorticoids. ‘Infection count’ in question 4 was changed to ‘inflammation marker’. The ‘decrease’ in liver count was changed to ‘increase’ and ‘headache’ was changed to ‘malaise’ in question 7. To aid in answering question 10, ‘most strongly’ was added to the two reasons. The mean time used to complete the questionnaire was 7.4 min [range 5–15 min].

An overview of changes in the PKQ in the Danish and German versions is presented in English in Appendix 1.

Final PKQ-RA-11 (Danish and German)

Regarding response structure, we decided to decrease the chance of purely guessing the correct answer by assigning items with one correct answer six possible options (including ‘don’t know’), questions with two correct answers eight possible options, and so forth. By doing so, we reduced the chance of guessing correctly to 20%.

This modified version is named the PKQ-RA-11. This questionnaire consists of 11 multiple-choice questions covering disease aetiology, signs and symptoms, medical treatment, monitoring, and prevention. In this modified version, each question has one, two, or three correct options, and the total score ranges from 0 to 11; higher scores indicate a higher level of knowledge. The scoring system is inspired by the modified PKQ by Lopez-Olivo et al. (20), but has been significantly adjusted to address different scenarios where patients select too few or too many statements. The final scoring system is presented in Appendix 2.

Test results

The mean \pm sd Danish and German PKQ-RA-11 baseline scores were 7.9 ± 1.6 and 6.2 ± 2.5 , respectively. Furthermore, longitudinal data on the Danish version demonstrated that the PKQ-RA-11 effectively detected changes following both digital and face-to-face patient education in the hospital. This was evidenced by an increase in the

mean score to 8.6 ± 1.5 immediately after patient education, with this improvement remaining stable across three additional assessments over a 12 month period (7).

Table 2 shows the percentages of correctly answered PKQ-RA-11 questions for German and Danish participants. In the German test, the statement that RA ‘can occur after a viral or bacterial infection’ was the least correctly answered, by 19.0%, while the statement that ‘morning stiffness in the joints is a characteristic symptom of RA’ had the highest correct response rate at 89.7%. In the Danish test, the least correctly answered statement was that RA ‘sometimes affects the eyes and can cause heart disease’, by 22.3%, whereas the statement that untreated RA can cause ‘damage to the joints’ had the highest rate at 97.7%. Overall, German patients identified true and false statements correctly 55.0% and 89.9% of the time, respectively, while Danish patients scored 69% for true statements and 91% for false ones.

The PKQ-RA-11 has 23 correct options, and the tests showed some discrepancies between the German and Danish results. For 15 of the 23 options, the difference in correct answers was more than 10%, with the Danish cohort generally scoring higher overall. The remaining eight options had differences of less than 10%.

Hence, the cohorts differed considerably on several statements. For question 2, a higher percentage of German participants (44.3%) correctly answered that RA ‘sometimes affects the eyes and can cause heart disease’, compared to 22.3% of the Danish participants. In question 3, 90.3% of Danish participants identified fatigue as a characteristic of RA, versus 67.8% in the German cohort. For questions about methotrexate (questions 6 and 7), correct response rates ranged from 73.7% to 91.4% among Danish participants, compared to 38.5–61.5% for Germans. Similarly, in question 8 about joint injection, over 80% of Danish participants answered correctly, while around 47% of German participants did. Conversely, German participants were more knowledgeable about the effects of influenza vaccination (question 9). For treatment changes (question 10), 65.1% and 72.6% of Danish participants answered correctly, compared to 51.7% and 44.8% in the German cohort. Finally, 84.5% of Danish participants knew to contact the clinic if symptoms lasted for more than a week, while 67.2% of German participants knew this.

Discussion

This study aimed to develop and validate Danish and German versions of the PKQ for individuals with RA. The successful adaptation from English versions into Danish and German demonstrates the tool’s adaptability to different cultural contexts. The updating of the items to reflect current management and the response structure to prevent the likelihood of guessing ensures that the tool remains relevant and valid. The PKQ-RA-11 represents the first validated tool for the standardized assessment of

Table 2. Percentage of appropriately answered questions on the 11-item Patient Knowledge Questionnaire for Rheumatoid Arthritis (PKQ-RA-11) in the prevalent German and incident Danish rheumatoid arthritis patient populations.

PKQ questions and options	Classification	Answered appropriately	
		German (n=174)	Danish (n=175)
1. Please choose three correct statements from the following options: Rheumatoid arthritis...			
a. Can be hereditary	correct	69.5%	74.9%
b. Can occur after a damage in the joint	false	87.4%	90.9%
c. Can be caused by cold and damp weather	false	70.7%	91.4%
d. Can occur due to reduced kidney function	false	93.7%	98.9%
e. Is of unknown cause	correct	33.3%	41.7%
f. Can occur after a viral or bacterial infection	correct	19.0%	30.9%
g. Can be caused by stress	false	73.0%	93.7%
h. Can be caused by excessive load of joints and muscles*	false	71.8%	-
i. Don't know	insufficient	23.0%	23.4%
2. Please choose two correct statements from the following options: Rheumatoid arthritis...			
a. Only affects the bone	false	61.5%	67.4%
b. Sometimes affects the eyes and can cause heart disease	correct	44.3%	22.3%
c. Is most common among elderly people	false	89.1%	69.1%
d. Affects the memory	false	93.7%	98.3%
e. Can cause diabetes	false	97.1%	97.7%
f. Is a chronic disease	correct	74.7%	86.9%
g. Can be cured	false	95.4%	96.6%
h. Don't know	insufficient	16.1%	18.9%
3. Choose two characteristics of rheumatoid arthritis:			
a. Morning stiffness in the joints	correct	89.7%	96.0%
b. Overweight	false	95.4%	97.1%
c. Hair loss	false	93.7%	99.4%
d. High blood pressure	false	91.4%	98.9%
e. Fatigue	correct	67.8%	90.3%
f. Rash	false	97.7%	98.9%
g. Constipation	false	98.9%	99.4%
h. Don't know	insufficient	7.5%	5.7%
4. Choose one blood test, which can be used to determine how active the arthritis is:			
a. Cholesterol level	false	97.7%	100%
b. C-reactive protein (CRP, infection count)	correct	75.9%	75.7%
c. Vitamin D status	false	97.1%	96.5%
d. Liver count	false	94.8%	95.9%
e. Blood sugar	false	98.3%	98.8%
f. Don't know	insufficient	20.1%	15.6%
5. Choose two correct statements: If untreated, rheumatoid arthritis can lead to...			
a. Problems keeping your balance	false	81.0%	62.9%
b. Damage to the joints	correct	87.9%	97.7%
c. Persistent headache	false	94.8%	96.6%
d. Eye, blood vessel, and heart disease	correct	42.0%	34.9%
e. The symptoms disappearing by themselves after a while	false	97.7%	96.6%
f. Stronger bones	false	97.7%	100%
g. Persistent constipation	false	98.9%	99.4%
h. Don't know	insufficient	11.5%	-

(Continued)

Table2. (Continued).

6. Choose three correct statements about Methotrexate:			
a. It must be taken together with folic acid	false	37.4%	69.7%
b. It can slow down the progression of the disease	correct	61.5%	77.7%
c. It can take many weeks. before it starts showing effect	correct	38.5%	73.7%
d. It should be taken daily	false	89.7%	97.7%
e. It can be taken in case of severe infections. requiring treatment (e.g. pneumonia. dental abscess etc.)	false	97.7%	100%
f. It should only be taken for severe pain	false	96.6%	100%
g. It should be taken once a week	correct	55.7%	91.4%
h. It should be taken on an empty stomach	false	98.3%	97.1%
i. Don't know	insufficient	16.7%	6.9%
7. Choose three common side-effects of Methotrexate:			
a. Constipation	false	93.1%	88.0%
b. Slightly decrease of liver count	correct	56.3%	77.7%
c. Nausea	correct	39.1%	85.7%
d. Headache	correct	31.0%	30.3%
e. Dry mouth	false	70.7%	66.3%
f. Loss of the sense of taste	false	96.0%	98.3%
g. High blood pressure	false	86.8%	93.7%
h. Depression	false	93.7%	96.0%
i. Don't know	insufficient	33.3%	30.9%
8. Choose two correct statements about injection of glucocorticoids in the joints:			
a. Can cause shivering	false	98.3%	98.9%
b. It has a local effect in the joint	correct	46.6%	82.3%
c. Can be given regularly once a month	false	96.0%	96.6%
d. Is always the right choice for pain	false	91.4%	96.0%
e. Is fast-acting	correct	47.1%	85.7%
f. Causes hair loss	false	90.8%	100%
g. Causes damage to the joint	false	87.9%	99.4%
h. Don't know	insufficient	31.0%	16%
9. Choose two correct statements about vaccination against influenza:			
a. It is necessary	false	76.4%	88.0%
b. Causes influenza symptoms	false	93.7%	72.0%
c. It can prevent infections	correct	52.3%	32.6%
d. Should be given once a year	correct	69.0%	72.0%
e. Can be given at all times of the year	false	94.8%	94.3%
f. Can aggravate rheumatoid arthritis	false	98.3%	95.4%
g. Lowers the risk of damage to the joints	false	98.3%	98.3%
h. Don't know	insufficient	18.4%	30.9%
10. Choose two reasons for changing the treatment for rheumatoid arthritis:			
a. The current treatment is not sufficiently effective	correct	51.7%	72.6%
b. You have received the current treatment for over 5 years	false	88.5%	99.4%
c. The current treatment has side-effects	correct	44.8%	65.1%
d. The rheumatoid arthritis is dormant	false	88.5%	86.3%
e. Blood tests are normal	false	90.8%	92.0%
f. You have developed osteoporosis	false	94.3%	91.4%
g. Don't know	insufficient	28.2%	22.9%
11. Choose one correct statement that fits with how you should react if you have pain and swelling of one or more joints:			
a. You should contact the clinic if the symptoms have not disappeared after a week	correct	67.2%	84.5%
b. Do everything you had planned to do	false	92.5%	97.1%
c. Take a short rest and do all the things you had planned (German) / You must exercise intensely (Danish)	false	85.1%	100%
d. Do essentials and leave the rest	false	98.9%	-
e. Spend the day resting in bed	false	81.0%	96.5%
f. Don't know	insufficient	0.0%	9.2%

*These items were not included in the first Danish version: PKQ1, 'h. Can be caused by excessive load of joints and muscles'; PKQ5, 'h. Don't know'; and PKQ11, 'd. Do essentials and leave the rest'.

disease knowledge among Danish- and German-speaking patients with RA. Implementing this questionnaire enables the identification of specific knowledge gaps, customization of educational materials, and empowerment of patients to manage their RA more effectively. A pragmatically translated version had been used to evaluate the efficacy of a complex national German education programme (21). The validation of the PKQ-RA-11 now provides a robust tool for these assessments, enabling more precise and meaningful evaluations of patient knowledge across both languages and enhancing the quality of patient education programmes.

Hennel et al. (2), who previously revised the PKQ following the original version by Hill et al. (5), emphasized the importance of reducing the complexity of the PKQ. However, in our revision, we chose to add more options for each question. This decision was made to capture the nuances of patient education and document what patients learn, as well as to reduce the likelihood of random guessing. Nevertheless, this approach may inadvertently increase the instrument's complexity by presenting patients with more options from which to choose. Further revision and refinements will be necessary in the future to reflect the increase in our understanding of the disease processes and new treatments. For example, during the German face-validity evaluation, patients wondered why methotrexate was mentioned as the only medication. To maintain the relevance of the PKQ-RA-11, ongoing updates are essential. As healthcare practices and patient education strategies evolve, the questionnaire should be periodically reviewed and revised to reflect new information and emerging patient needs. Expanding the tool's applicability to other languages and cultural contexts will broaden its utility, fostering a more inclusive approach to patient education in rheumatology.

The mean \pm sd PKQ-RA-11 scores revealed notable differences between the Danish (7.9 ± 1.6) and German (6.2 ± 2.5) participants. Several factors may contribute to this disparity, including variations in the baseline knowledge levels, the effectiveness of existing patient education programmes, and cultural differences in healthcare communication. The Danish version's alignment with digital patient education content may have positively influenced the Danish participants' scores, highlighting the potential benefits of integrating digital resources into patient education. The Danish patients, being newly diagnosed, may have been more up to date with information regarding RA and methotrexate as the primary conventional DMARD anchor drug. In contrast, the German patients, with a mean disease duration of 10 years, were likely to have transitioned to other treatments. This underscores the importance of tailoring medication-related questions based on disease duration and the patient's current treatment regimen.

The rigorous process of translation and adaptation represent strengths of this study, ensuring that the PKQ-RA-11 is culturally relevant and linguistically appropriate for both Danish and German RA patients. This study undertook

a cross-cultural adaptation, and the next steps would be to undertake a cross-cultural invariance test to evaluate its measurement equivalence across the studied cultures. We considered conducting a reliability test, but it was ultimately deemed inappropriate and irrelevant since the instrument focuses on knowledge. First, among participants with stable conditions, which is a prerequisite for a reliability test, knowledge is unlikely to change within the short time frame of a reliability test. In addition, a general risk with reliability tests is that participants may remember their previous answers, a concern that is especially pronounced when assessing knowledge on a specific topic.

Conclusion

The Danish and German PKQ-RA-11 represents a ready-to-use validated disease-specific knowledge questionnaire for RA patients. The questionnaire not only facilitates objective knowledge assessments but also supports the customization of educational programmes, ultimately contributing to better patient outcomes. Future efforts should focus on expanding its reach and continuously refining its content to meet the evolving needs of RA patients globally.

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Supplementary material

Supplemental data for this article can be accessed online at <https://doi.org/10.1080/03009742.2025.2463734>.

Authors' contributions

LRK and AdT conceived the study conception and design. LRK and AdT initially modified the PKQ to align with the content provided in the Danish digital patient education programme before translation. A study nurse conducted the data collection for the face-validity test. LRK, AdT, and the study nurse worked together on refining the Danish questionnaire based on the results of the face-validity test, closely

collaborating with MN, who is responsible for the original PKQ-RA. JK, JH, FM, and AH collaborated on the adaptation of the German questionnaire based on the face-validity test in close collaboration with MN, being responsible for the original PKQ-RA. LRK and JK drafted the manuscript in collaboration with AdT, MN, FM, JH, and AH, who critically revised the article regarding content, methods, and design. All authors read and approved the final manuscript.

Data availability statement

The PKQ-RA-11, Danish and German version, is freely available with appropriate citing of this paper. The questionnaires can be found in Appendix 3 and Appendix 4. The English consensus version, which forms the basis of the Danish and German PKQ-RA-11 versions, is presented in Appendix 1. However, it should be noted that this English version has not undergone face validation with an English-speaking population.

Ethics approval and consent to participate

The Danish part of this study is part of a major project approved by the Danish Data Protection Agency (no. 1-16-02-52-19). The German part was approved by the Ethics Committee of the University of Tübingen (vote no. 869/2021BO2). According to Danish Law and German Law and the Central Denmark Region Committee of Health Research Ethics, this study did not require ethical approval. Participants were contacted in connection with a consultation in the outpatient clinic. Written information about the purpose and content of the study was given along with verbal information. Eligible participants were informed about the voluntariness of participation and the possibility of withdrawing at any time without consequences for their care and treatment. Further, their confidentiality and anonymity were ensured. Permission to translate and adapt the original PKQ was obtained before this study.

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References

- Zangi HA, Ndosi M, Adams J, Andersen L, Bode C, Boström C, et al. EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis* 2015;74:954–62.
- Hennell SL, Brownsell C, Dawson JK. Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. *Rheumatology (Oxford)* 2004;43:467–71.
- Holman HR, Lorig K. Perceived self-efficacy in self-management of chronic disease. In: Schwarzer R, editor. *Self-efficacy: thought control of action*. Washington: Hemisphere, 1992:305–23.
- Coulter A. *Engaging patients in healthcare*. Maidenhead: Open University Press, 2011.
- Hill J, Bird HA, Hopkins R, Lawton C, Wright V. The development and use of Patient Knowledge Questionnaire in rheumatoid arthritis. *Br J Rheumatol* 1991;30:45–9.
- de Thurah A, Bosch P, Marques A, Meer Y, Mukhtyar CB, Knitza J, et al. EULAR points to consider for remote care in rheumatic and musculoskeletal diseases. *Ann Rheum Dis* 2022;81:1065–71.
- Knudsen LR, Ndosi M, Hauge EM, Lomborg K, Dreyer L, Aaboe S, et al. Effectiveness of a novel digital patient education programme to support self-management of early rheumatoid arthritis: a randomised controlled trial. *Rheumatology (Oxford)* 2024;63:2547–56.
- Becker C, Diener M, Hueber AJ, Henes J, Krusche M, Ignatyev Y, et al. Unmet information needs of patients with rheumatic diseases: results of a cross-sectional online survey study in Germany. *Int J Environ Res Public Health* 2022;19:7071.
- Dumez V, L'Espérance A. Beyond experiential knowledge: a classification of patient knowledge. *Soc Theory & Health* 2024;22:173–86.
- Lineker SC, Badley EM, Hughes EA, Bell MJ. Development of an instrument to measure knowledge in individuals with rheumatoid arthritis: the ACREU rheumatoid arthritis knowledge questionnaire. *J Rheumatol* 1997;24:647–53.
- Lopez-Olivo MA, Ingleshwar A, Volk RJ, Jibaja-Weiss M, Barbo A, Saag K, et al. Development and pilot testing of multimedia patient education tools for patients with knee osteoarthritis, osteoporosis, and rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2018;70:213–20.
- Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol* 2010;63:737–45.
- de Vet HCW. *Measurement in medicine: a practical guide*. Cambridge: Cambridge University Press, 2011.
- Aletaha D, Neogi T, Silman AJ, Funovits J, Felson DT, Bingham CO, et al. 2010 Rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Arthritis Rheum* 2010;62:2569–81.
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016;26:1753–60.
- Bullinger M, Alonso J, Apolone G, Leplège A, Sullivan M, Wood-Dauphinee S, et al. Translating health status questionnaires and evaluating their quality: the IQOLA Project approach. *Int Qual Life Assess J Clin Epidemiol* 1998;51:913–23.
- Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993;46:1417–32.
- Beatty PC, Willis GB. Research synthesis: the practice of cognitive interviewing. *Public Opin Q* 2007;71:287–311.
- Collins D. Pretesting survey instruments: an overview of cognitive methods. *Qual Life Res* 2003;12:229–38.
- Lopez-Olivo MA, Lin H, Rizvi T, Barbo A, Ingleshwar A, Des Bordes JKA, et al. Randomized controlled trial of patient education tools for patients with rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2020.
- Schwarze M, Fieguth V, Schuch F, Sandner P, Edelmann E, Händel A, et al. Disease-related knowledge acquisition through structured patient information in rheumatoid arthritis (StruPI-RA): first results of the StruPI-RA study in Germany. *Z Rheumatol* 2021;80:364–72.