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The Translation and Cultural Adaptation of LYMPH-Q Upper Extremity Module to the Indonesian Language

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Background: The LYMPH-Q Upper Extremity module is a patient-reported outcome measurement tool developed by the Q-Portfolio team at McMaster University, Canada, and is widely used to determine the health-related quality of life of patients with upper extremity lymphedema. However, the translation of these patient-reported outcome measurement tools to the Indonesian language has not been attempted by any institution.

Methods: The Indonesian translation of the LYMPH-Q Upper Extremity module was performed according to the International Society of Pharmacoeconomics and Outcomes Research guidelines. The steps included forward translation and reconciliation, back translation and review, and cognitive debriefing with cultural adaptation. The respondents in this study were recruited from Dr. Cipto Mangunkusumo Hospital and the Indonesian LYMPH-Q project community.

Results: A total of 2.94% of the forward-translated items were discordant at the reconciliation meeting. During the back translation review, 4 of 102 items were discordant between the original items and the back translation result. This study also emphasized Indonesian respondents' understanding of the translated items, which were influenced by sociodemographics and religious beliefs tailored specifically to Indonesian characteristics.

Conclusions: The Indonesian translation of the LYMPH-Q Upper Extremity module has already been conducted according to the International Society of Pharmacoeconomics and Outcomes Research guidelines, and future validation studies are necessary. *(Plast Reconstr Surg Glob Open 2025;13:e6608; doi: 10.1097/GOX.0000000000006608; Published online 14 March 2025.)*

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INTRODUCTION

According to the Ministry of Health, Indonesia, breast cancer, which accounts for 30% of all malignancies, is the most common cancer among women in Indonesia in 2013.[1,2] Despite having a 90% five-year survival rate for patients with breast cancer, the development of breast cancer–related lymphedema (BCRL) in the United States occurs in 40% of the population. In Indonesia, approximately 60%–70% of patients with breast cancer have locally advanced disease, which increases their susceptibility to developing lymph obstruction.[3] In a study at the largest oncology center in Indonesia, namely, Dharmais Hospital, BCRL occurred in 27.7% of patients after dissection of the axillary lymph node.[4]

BCRL results from obstruction or disruption of the lymphatic system, which may be associated with management, such as chemotherapy, radiotherapy, or removal of lymph nodes. Several factors also influence the incidence, such as obesity.[3] This incidence is a result of protein-rich fluid overaccumulation in the extracellular space due to insufficient transport capacity of the lymphatic system.[5] This event may influence the psychosocial problems and quality of life of

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breast cancer survivors. Moreover, the sense of arm rigidity, which is derived from BCRL, could lead to productivity loss, with an average of $3325 of out-of-pocket costs per year compared with $2792 for those without lymphedema in the United States.[6] This economic burden could worsen the quality of life of patients with BCRL.

As surgeons, the aspects of patient satisfaction and their own perceptions of quality of life need to be identified as a matter of differences in the perspective of quality of life. To conduct such a holistic approach, a standardized patient-reported outcome measurement (PROM) is needed. Several established PROM tools, such as the LYMQOL-Arm, LLIS, Lymph-ICF-UL, LSIDS-A, ULL-27, ULL-QoL, and LYMPH-Q Upper Extremity module, have been used to help us identify these issues.[7–9]

The LYMPH-Q Upper Extremity module is a recently established tool for assessing the impact of BCRL on patient satisfaction and health-related quality of life (HRQOL).[10] This tool was developed by Klassen et al[10] and McMaster University, Toronto, Canada, to evaluate, support, and compare quality metrics and surgical practices in oncologic breast and plastic surgery. Several systematic reviews and guidelines show that the LYMPH-Q Upper Extremity module has better evidence of methodological quality standards for measuring patients' HRQOL and satisfaction.[7–9] The LYMPH-Q Upper Extremity module consists of several subcategories: HRQOL, experience of care, and satisfaction with the use of arm sleeves.[10]

However, the use of this tool might be a major hindrance due to patient language barriers, as English is not widely spoken in Indonesia. Patients might have a poor understanding of the given questions, which could influence the deviation of the results. Several irrelevant cultural contexts in the questions could be poorly understood for Indonesian women.

Due to the effectiveness of the LYMPH-Q Upper Extremity module in evaluating patient feedback, translation and validation were attempted in many languages, such as German, Dutch, Danish, French, and Portuguese.[11–13] Therefore, we aimed to translate and validate the LYMPH-Q Upper Extremity module to Bahasa Indonesia, in accordance with the protocol of the original author, and to later use it as a standardized tool to assess patients' perceptions of HRQOL and satisfaction.

METHODS

This study, conducted from July 2023 to April 2024, adhered to the protocol established by the Q-Portfolio team and aligned with guidelines from the International Society for Pharmacoeconomics and Outcomes Research (ISPOR)[14] and the World Health Organization.[15] The research methodology comprised the following key stages:

1. Preparation: Ethical approval was obtained from the ethics committee of the Faculty of Medicine, Universitas Indonesia (No. 23-07-1978). Additionally, licenses were acquired from the Q-Portfolio team and McMaster University as the developers of the LYMPH-Q Upper Extremity module.

Takeaways

Question: How to make a translation of a patient-reported outcome measurement tool, namely, the LYMPH-Q Upper Extremity module, which is designated for Indonesian-speaking patients with breast cancer–related lymphedema?

Findings: The translational study is conducted according to the International Society of Pharmacoeconomics and Outcomes Research guidelines, comprising forward translation, back translation, cognitive debriefing, and cultural adaptation.

Meaning: The translation has been conducted according to the International Society of Pharmacoeconomics and Outcomes Research guidelines and ready to use for Indonesian-speaking patients.

2. Forward translation: Two translators who are Indonesian native speakers and proficient in English as a second language (certified by Test of English as a Foreign Language [TOEFL] or International English Language Testing System [IELTS]) translated the questionnaire from English to Standard Indonesian (Bahasa Indonesia). These translators, employed by a medical translation company, subsequently collaborated to harmonize their translation and resolve discrepancies during the forward translation reconciliation meeting, resulting in version 1 of the translated questionnaire.
3. Back translation: A native English speaker who is also fluent in Bahasa Indonesia was selected as the back translator. This translator was also part of the same medical translation company that underwent a thorough recruitment process as a professional translator. This translator was not given the original English version of the questionnaire and was asked to translate the synchronized forward translation (version 1) to English. The final product of this process is version 2.
4. Back translation review: An expert panel meeting, which consisted of bilingual clinicians with expertise in the given patient group as well as translators, was held to review version 2 of the translated questionnaire. The panel reviewed linguistic accuracy, relevance to the Indonesian context, and comprehensibility. This process resulted in version 3 of the translated questionnaire, which was subsequently used for cognitive debriefing.
5. Cognitive debriefing interviews: The interviews using version 3 were conducted with patients with BCRL with the goal of identifying whether the components of the translations were understandable to the patients (ie, the items, instructions, and response options). Any difficulties mentioned by the patients were addressed to make several changes to the translation. All feedback from the patients was gathered, reviewed, and later considered for retranslation and retesting. This was developed into version 4.
6. Proofreading: Version 4 underwent meticulous proofreading by clinicians to ensure minimal errors and establish the final Indonesian LYMPH-Q Upper Extremity module.

Table 1. The Identified Problem Found on the Reconciliation Meeting

Scale	Original Items	Translation by Translator 1	Translation by Translator 2	Description of Differences or Cultural Contexts	The Final Reconciled Result
Symptoms	6. Aching feeling in your arm?	6. *Rasa nyeri di lengan Anda?*	6. *Rasa nyeri di lengan Anda?*	Aching is similar to pain sensation in Indonesian, and this type of pain in vocabulary needs to be different from the type of pain while moving the arm	6. *Rasa nyeri saat lengan Anda tidak disentuh?*
Symptoms	7. Arm feeling numb?	7. *Lengan terasa kebas?*	7. *Lengan terasa baal?*	The Indonesian patients will have different perceptions in feeling numbness. Hence, it needs to be specified as "*mati rasa/kebas/baal*"	7. *Lengan terasa mati rasa?*
Function	10. Holding a bag of groceries?	10. *Menggenggam tas berisi barang belanjaan?*	10. *Memegang sekantung belanjaan?*	There were differences in translator's perception to Indonesian language, whether the translation should be turned into "bags filled with groceries" or "grocery bag" in Indonesian	10. *Menjinjing tas berisi keranjang belanjaan?*

Selection of Cognitive Debriefing Participants

Patients with BCRL from Dr. Cipto Mangunkusumo Hospital and the Indonesian LYMPH-Q project community were selected via consecutive convenience sampling. The inclusion criteria included patients with BCRL who underwent surgical or nonsurgical management of lymphedema with the use of an arm sleeve from June 2022 to July 2023, excluding those with intellectual disabilities that might have impeded questionnaire comprehension.

RESULTS

Translation Process: Version 1

The translation to the Indonesian language was conducted from July to November 2023, which also included the reconciling process of forward translation. The reconciliation process revealed inconsistencies and differences in wording, which amounted to 3 (2.94%) of 102 items. An example of a translation discordance is described in Table 1. This discrepancy arose from the different perceptions of the 2 forward translators while considering the future respondents' language ability. For example, while trying to translate "holding the bag of groceries," one translator translated it into "grocery bag," and another translator emphasized "bags filled with groceries" to be more proper and conceptual in the Indonesian language. With the help of the project manager, the translators were able to predict the characteristics of the patients usually found in clinical settings; hence, the translated items were produced to fit the custom and cultural context of the patient.

After the reconciliation process, version 1 of the translated questionnaire was subsequently produced and used for the next translation process in accordance with ISPOR guidelines.

Translation Process: Versions 2 and 3

Version 2 of the questionnaire was produced after the back translation process for version 1. This step was performed by a native English speaker who understood the Indonesian language. This version was subsequently used in the back translation review process to identify discrepancies between version 2 and the original English questionnaire.

The back translation reviewer session revealed that 4 of 102 items in version 2 were different from those in the original English questionnaire. Most of the discrepancies were a result of limited vocabulary in the target language. The details of the discrepancies are described in Table 2.

The discrepancies were explained and settled by the project manager to the back translation reviewer, who produced the version 3 questionnaire, which was subsequently used for cognitive debriefing.

Cognitive Debriefing and Cultural Adaptations

Five patients from the Indonesian LYMPH-Q community were recruited in the cognitive debriefing session using version 3 of the questionnaire. During the cognitive debriefing session, the respondents produced several comments and recommendations after stumbling upon the difficulties in understanding the questionnaire. The characteristics of the respondents are described in Table 3.

Examples of the responses of the respondents are displayed in Table 4. One of the difficulties in understanding the questionnaire was influenced by socioeconomic background. Patients with higher education levels were more accustomed to using the word *"stocking lengan"* to describe "arm sleeves," whereas others perceived it as *"manset lengan"*. The target language often elicits the double meaning of a certain word, giving different innuendos in the same context of the question, resulting in the project manager changing the items catering to the recommendation of the respondents.

The final results of the cognitive debriefing and cultural adaptations were later reported to the Q-Portfolio team as the owners of the original questionnaire's rights.

DISCUSSION

This study aimed to evaluate the Indonesian translation of a PROM for treating upper extremity lymphedema, especially BCRL. Several considerations took place to justify the LYMPH-Q Upper Extremity module as an appropriate PROM for translation. The development of the LYMPH-Q Upper Extremity module has gone through multiple phases of quality interviews and field study tests in several hospitals in the United States and Canada, which address several aspects of the HRQOL of patients with BCRL holistically. This questionnaire used Rasch

Table 2. Identified Problems During Back Translation Review

Scale	Original Items	Forward Translation Result	Back Translation Result	Description of Differences	Suggested Revision in Bahasa Indonesia
Symptoms	6. Aching feeling in your arm?	6. *Rasa nyeri saat lengan Anda tidak disentuh?*	6. Painful feeling when your arm is not touched?	"Aching" is like a dull pain in English. However, the Indonesian language does not have a variety of adjectives to describe each sensation precisely. Dull pain/ aching feeling could be perceived as "tenderness" in Indonesian women with a certain socioeconomic background. Hence the translator used a different approach	No suggestions were made
Appearance	10. …how your arms looks in a sleeveless shirt?	10. …*bagaimana pakaian terasa pas dengan lengan Anda?*	10. …with how your arm looks when wearing sleeveless clothes?	"Shirts" and "clothes" are different in English. However, the word "*baju*" in Indonesian is a general term to address any kind of clothing on the upper body. So it could mean both "shirt" and "clothes" and be easily understood by women with various socioeconomic backgrounds	No suggestions were made
Psychological	1. Desperate?	1. *Putus asa?*	1. Like giving up?	The original items and the back translation result are different. In the Indonesian native speaker's context, the word "*putus asa*" suits "desperate" better than "giving up." The word "giving up" in Indonesian is "*menyerah*"	No suggestions were made
Psychological	9. Unattractive?	9. *Tidak menarik?*	9. Uninterested?	"Unattractive" in English relates to the appeal of physical appearance. However, the word "*tidak menarik*" could mean both "unattractive" as an adjective, and "not interested" as a verb. But with the context of the instruction, which points out the usage of adjectives, Indonesian native speakers could easily spot the context of the word	No suggestions were made

Table 3. Respondent Characteristics

No.	Age	Diagnosis	Treatment	Religion	Ethnic Group in Indonesia	Hijab/Modesty Status	Dominant Language	Educational Level
1	24	Bilateral arm lymphedema, papilomatosis	LVA	Christian	Bataknese	Absent	Bataknese	High school diploma
2	52	BCRL, right arm, ISL stage I	Radiotherapy, MRM, LVA	Islam	Sundanese	Present	Indonesian	Bachelor degree
3	57	BCRL, left arm, ADB stage V	Radiotherapy, MRM, LVA, debulking liposuction	Islam	West Sumatran	Present	Minangnese	Master degree
4	45	BCRL, right arm	MRM, LVA	Christian	Ambonese	Absent	English and Indonesian	Bachelor degree
5	47	BCRL, left arm	ILR	Islam	Javanese	Absent	Indonesian	Bachelor degree

ADB, arm dermal backflow; ILR, immediate lymphatic reconstruction; ISL, International Society of Lymphology; LVA, lymphaticovenous anastomosis; MRM, modified radical mastectomy.

measurement theory analysis, ensuring the suitability of the scale for use by a wide audience. With this analysis, the answers to the questionnaire have been standardized for subsequent quantification, and several studies have revealed that Rasch measurement theory analysis is the proper PROM tool in healthcare settings. Moreover, the reliability of the original version of the LYMPH-Q Upper Extremity module was tested with the Person Separation Index, which accounts for 0.80%, and Cronbach's alpha, which accounts for 0.89.[10]

During the forward translation process, our translators were instructed not to give a literal translation but rather to be mindful of the conceptual approach of the context of the questionnaire. This approach was also used by the team that performed the Danish translation of the LYMPH-Q Upper Extremity module, which also faced the similar challenge of limited vocabulary to sufficiently represent the original version.[11]

This study followed the instructions of ISPOR to recruit a native English speaker who was fluent in the target language to recruit a professional translator who had experience in translating medical documents. The Dutch translation team had a rather different approach by recruiting 2 residents of plastic and reconstructive surgery who were native target language speakers and fluent in the language of the original version.[13] This might serve as a benefit for the reader to see the conceptual meaning easily rather than perceiving the questionnaire in a literal context because they were native speakers of the target language. However, both this and this study have the same number of inconsistencies between the original version and the back translation result despite having the benefit of understanding.[13]

The Chinese translation team of the LYMPH-Q Upper Extremity module also faced a similar challenge in translating a specific adjective to describe the participants' feelings: "frustrated," which they back translated as "depressed." We also faced a similar situation, with the word "desperate" being back translated as "like giving up" due to the literal context of understanding the word by the

Table 4. The Example of Response and Recommendation From the Respondents During the Cognitive Debriefing

The identified Response	Examples of Difficult Items	Description of the Items and Their Response
Similar adjectives in one subsection	• Original item: "8. Pressure in your arm?" vs "10. Clumsiness (eg, dropping or spilling things)?" vs "11. Tingling in your arm (eg. Pins and needles feeling)?" • Translation: *"8. Tekanan pada lengan Anda?" vs "10. Kecerobohan? (misalnya, menjatuhkan atau menumpahkan sesuatu)?" vs "11. Kesemutan pada lengan Anda (rasa seperti ditusuk-tusuk)?"* • Revised translation: n/a	One respondent commented that there are similar meanings of those three items if translated in Indonesian
The double meaning of an adjective	• Original item: "8. Pressure in your arm?" • Translation: "*8. Tekanan pada lengan Anda?*" • Revised translation: "*Nyeri tekan pada lengan Anda?*"	The word "*tekanan*" could have a double meaning as "things influencing your mental state"
Inconsistency of the given example perceived in the target language	• Original item: "11. Tingling in your arm (eg, pins and needles feeling)?" • Translation: "*11. Kesemutan pada lengan Anda (rasa seperti ditusuk-tusuk)?*" • Revised translation: "*11. Kesemutan pada lengan Anda (misalnya, digigit semut)?*"	Several respondents thought the word "*kesemutan*" is not similar to "*ditusuk-tusuk*." They suggested to remove the example or change the example into the one that represents "tingling" better
Uncommon verb to respondent with specific socioeconomic background	• Original item: "NOTE: If you have lymphedema in both arms, answer each question thinking about the arm that bothers you the most. If you wear an arm sleeve, please answer thinking of how your arm looks without the arm sleeve." • Translation: "*CATATAN: Jika Anda mengalami limfedema pada kedua lengan, jawablah setiap pertanyaan berdasarkan lengan yang paling mengganggu Anda. Jika Anda menggunakan manset lengan, jawablah berdasarkan penampilang lengan Anda tanpa menggunakan manset lengan.*" • Revised translation: "*CATATAN: Jika Anda mengalami limfedema pada kedua lengan, jawablah setiap pertanyaan berdasarkan lengan yang paling mengganggu Anda. Jika Anda menggunakan manset/ stocking lengan, jawablah berdasarkan penampilang lengan Anda tanpa menggunakan manset/ stocking lengan.*"	The word "*manset lengan*" to represent "arm sleeves" confused some respondents as they are more accustomed to describe the arm sleeves as "*stocking*"
Irrelevant to Muslim population/women with specific modesty value	• Original item: "3. …having to dress in a way to hide your arm?" • Translation: "*3. …harus menyesuaikan cara berpakaian untuk menyembunyikan lengan Anda?*" • Revised translation: n/a	The question was inapplicable and irrelevant to Muslim patients with hijab or those with modesty practice because their outfits always cover the whole extremities
The vague wording of the scale	• Original item: "Somewhat dissatisfied," "Somewhat satisfied." • Translation: "*Agak tidak puas,*" "*Agak puas.*" • Revised translation: "*Tidak puas,* "*Puas.*"	The literal translation provided a vague scale to some respondents. The word "somewhat" is necessary to be omitted to give a clearer set point of scale
Awkward phrasing	• Original item: "6. The possibility that you might develop lymphedema after surgery?" • Translation: "*6. Kemungkinan Anda akan mengalami limfedema setelah operasi?*" • Revised translation: "*6. Kemungkinan limfedema Anda kambuh setelah operasi*"	The phrasing is awkward according to several respondents

back translator. Another similar challenge of the Chinese translation team that needs to be addressed is how standard Chinese could differ among Chinese speakers, as it is influenced by geology, degree of literacy, and educational background.[16] Indonesia also has its own variety of ethnic groups who speak different varieties of the local language (not just a dialect), resulting in a variety of understanding of the standard Indonesian language itself. Their team and our team made the translation able to cater to most of our population.[13]

During the cognitive debriefing process, we identified one cultural response that does not normally occur in some parts of the world. As Indonesia has the largest Muslim population in the world, several items of the original questionnaire regarding the choice of clothing were found to be irrelevant. Muslim women with hijab or certain modesty practices have originally used clothes covering both of their arms before lymphedema occurs. Therefore, the choice of clothes cannot be perceived as an indicator of quality of life in most women in this country.

CONCLUSIONS

The attempt to translate the LYMPH-Q Upper Extremity module to the Indonesian language was performed according to the ISPOR guidelines. These translated PROM tools will guide surgeons and health professionals in Indonesia to measure the HRQOL of patients with BCRL to reassess their quality of management and service. However, studies on the validity and reliability of the translated PROM tools need to be conducted in the future to identify the applicability of these tools in a more objective manner.

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ETHICAL APPROVAL

The Ethical Approval of this research was obtained from the Ethics Committee of the Faculty of Medicine, Universitas Indonesia (ethical approval no. 23-07-1378).

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