



# Dutch translation and cultural adaptation of new LYMPH-Q- scales measuring impact on work and lymphedema worry

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## Abstract

**Background** Breast cancer-related lymphedema (BCRL) is a significant complication of breast cancer treatment that can impact patients' quality of life. This study focuses on the translation and cultural adaptation of two new LYMPH-Q scales 'Impact on Work' and 'Lymphedema worry' into Dutch to assess the work-related challenges and worries experienced by patients with BCRL in the Netherlands.

**Methods** The translation process followed established guidelines from the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the World Health Organization (WHO). Forward and back translations, expert panel reviews, cognitive debriefing interviews with patients with BCRL, and proofreading were conducted to refine the Dutch translation of the scales. The translation aimed to ensure conceptual equivalence and cultural relevance.

**Results** The translation process resulted in the Dutch versions of the LYMPH-Q 'Impact on Work' and 'Lymphedema worry' scales. The forward translation revealed discrepancies in meaning, word order and synonyms. The back translation and review resulted in changes in item formulation. The expert panel meeting and cognitive debriefing interviews provided valuable input for further refinement.

**Conclusion** The translated LYMPH-Q 'Impact on Work' and 'Lymphedema worry' scales provide healthcare professionals with an instrument to assess and monitor the impact of BCRL on work-related challenges and on worries. This comprehensive translation process, involving patients with BCRL and experts, ensured the linguistic accuracy, cultural relevance, and clarity of the Dutch versions. The translated scales will contribute to a better understanding of the multifaceted impact of BCRL and facilitate the development of tailored interventions to improve patients' well-being and functional outcomes.

**Level of Evidence:** Not ratable

**Keywords** LYMPH-Q upper extremity module · Patient-reported outcome · Translation and cultural adaptation · Quality of life · Breast cancer · Lymphedema

## Introduction

One of the complications that can arise from the treatment of breast cancer is breast cancer-related lymphedema (BCRL), characterized by the abnormal accumulation of fluid and proteins in body tissue [1]. Patients with BCRL commonly experience symptoms such as swelling, infection, pain, and a negative impact on their quality of life (QoL) [2, 3]. These symptoms combined with the demanding treatment regimen for BCRL (e.g., massage, exercise, compression bandages) have a considerable impact on patient's daily lives.

Previous research shows that patients with BCRL not only experience physical symptoms but also encounter

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**Table 1** The new LYMPH-Q upper extremity module scales

Concept	Scale	No. of items	Summary of subjects
Quality of Life	Impact on Work	17	Changed work content; need for help; need for breaks; challenges at work; changed workload; altered quality; job loss; lymphedema symptoms at work; changed work hours; accommodations.
	Lymphedema worry	21	Lymphedema symptoms; circumference; activities; infections; injury; outdoor factors; selfcare; exercise; esthetics; mental health; social life.

psycho-social challenges. Compared to breast cancer patients without lymphedema, they report significantly decreased psychological and social well-being [4]. Work-related challenges and lymphedema worry, in particular, emerge as critical themes that influence the overall well-being and functioning of patients with BCRL. Maintaining employment, productivity and career prospects can be profoundly affected by the physical limitations and symptoms of BCRL. Additionally, the fear and anxiety surrounding the progression of the condition, self-management strategies, and potential complications can contribute to heightened worry among patients [5, 6].

Previous studies on BCRL have focused only on the circumference or volume of the arm. More recently, studies have emphasized the importance of using patient-reported outcome measures (PROMs) to assess the well-being of patients with BCRL [7, 8]. Research has shown that it is not only the size of the arm, but also the pain and other lymphedema-related symptoms that significantly impact QoL. As a result, the use of PROMS provides a better understanding of the burden experienced by patients with BCRL [9].

To measure the impact of BCRL on patients, the LYMPH-Q Upper Extremity Module was developed [10]. This PROM consists of eight independently functioning scales that measure health-related quality of life

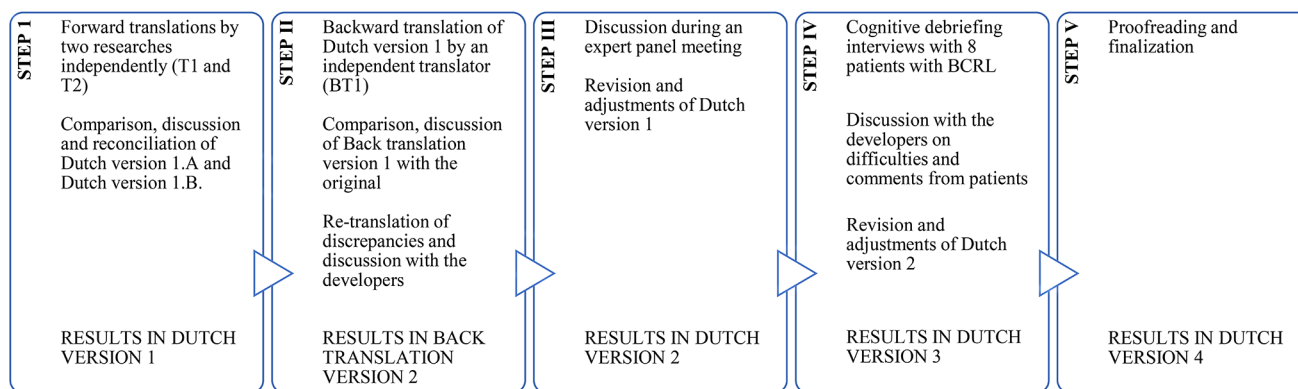
(HRQoL), experience of care, and treatment. Previously, the first six LYMPH-Q scales were translated into Dutch by our team [11]. With input from patient interviews, two new scales were recently developed to measure the impact of lymphedema on work and lymphedema-related worry. The aim of this study was to perform a Dutch translation and cultural adaptation of the field-test version of the new LYMPH-Q scales. With the translation of these scales, we will be able to assess the work-related challenges and worries experienced by Dutch-speaking patients with BCRL in the future.

## Methods

We requested permission from the developers prior to the Dutch translation and cultural adaptation of the two new LYMPH-Q Upper Extremity Module scales [10]. Through an addendum to the ethics review of the previous LYMPH-Q scales translation, exemption from full ethics review was obtained from the Medical Ethics Committee of the Erasmus Medical Center (Rotterdam, the Netherlands) (MEC-2019-0386).

The field-test version of the new LYMPH-Q scales ‘Impact on Work’ and ‘Lymphedema worry’ consist of 17 and 21 items, respectively (Table 1). Each scale includes a title, three introductory sentences, and five response options on a 5-point Likert scale. Consequently, a total of 51 items needed translation into Dutch.

The translation was performed following guidelines from the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the World Health Organization (WHO) [12, 13]. This resulted in a five-step translation process including forward translation, backward translation, an expert panel meeting, cognitive debriefing interviews, and proofreading and finalization (Fig. 1).

**Fig. 1** Steps in the Dutch translation and cultural adaptation of the new LYMPH-Q upper extremity module scales

### Step 1.1: forward translation

The forward translations were performed independently by two native Dutch speakers fluent in English (T1: LM Beelen, expert on BCRL and T2: AM van Dishoeck, language expert). This step resulted in two individual translations (Dutch version 1.A and Dutch version 1.B) of the scales.

### Step 1.2: reconciliation

The two individual translations (Dutch version 1.A and Dutch version 1.B) were combined into a single reconciled version (Dutch version 1) by one researcher (JS Mos). If there were any inconsistencies, they were discussed by the translators and the researcher until consensus was reached. This step included a written report on discrepancies and how they were resolved.

### Step 2: back translation and review

The back translation from Dutch version 1 (Back translation version 1) was performed by an independent sworn translator whose native language is Dutch and who is fluent in English. This translator was a language expert who did not have expertise in BCRL. The translator was blinded to the original English version of the scales. The translation (Back translation version 1) was compared to the original English version for discrepancies. If there was a change in the meaning of the items or instructions, it was re-translated and discussed with the developers until a correct translation was achieved. This step resulted in the back translation of the two new scales (Back translation version 2).

### Step 3: expert panel meeting

An expert panel meeting was conducted, consisting of the forward translators, the researcher, two plastic surgeons, a surgeon, and a physical therapist and physician assistant who both specialize in BCRL. The panel reviewed and discussed the forward and backward translations to identify and resolve any discrepancies, linguistic issues, or cultural nuances. The expert panel was asked if any questions were ambiguously worded or could be misinterpreted. There was also room for the experts to indicate whether any concepts were missing that could be formed into new items for the scales. The feedback provided by the expert panel was used to revise and refine the Dutch translation, resulting in the second version of the translation of the two scales (Dutch version 2).

### Step 4: cognitive debriefing interviews and review

The second version of the translation (Dutch version 2) was presented to Dutch-speaking patients with BCRL (aged  $\geq 18$  years) at the Erasmus Medical Center. Informed consent was obtained from all participants prior to their inclusion in the study. The interviews were conducted by one researcher (JS Mos) and took place at the Plastic and Reconstructive Surgery outpatient clinic of the Erasmus Medical Center. The interviews were scheduled before or after the participants' check-up appointments. Using the "thinking-out loud" method, special attention was paid to the item-interpretation of the respondents and whether their responses aligned with the developers' intentions. In case of ambiguities or misinterpretations, the researcher clarified the purpose of each item. Participants were then asked for suggestions on how to improve the question's formulation to enhance its comprehensibility among patients. All interviews were recorded and transcribed verbatim.

The transcripts were examined to identify aspects of each scale (items, instructions, response options) that participants identified as problematic. After the interviews, final adjustments were made, resulting in the pre-final version of the two new LYMPH-Q scales (Dutch version 3).

### Step 5: proofreading and finalization

The pre-final version of the translation (Dutch version 3) was proofread, including checks for spelling, grammar, and other errors. This resulted in the final version (Dutch version 4) of the LYMPH-Q 'Impact on Work' and 'Lymphedema worry' scales.

## Results

### Step 1: forward translation

Comparison of the two individual translations revealed six discrepancies out of the total 51 items (12%). These discrepancies resulted from different translations that slightly altered the meanings. Additionally, there were instances where the word order was different (8%), or where other synonyms were used (57%). It is important to note that none of the translations completely altered the meaning of the items. Within the 51 items, multiple Dutch words could accurately represent several English words. For example, the word 'big' can be translated as "groot" (English: large) or "dik" (English: thick). Certain words ( $n=3$ ) posed challenges during translation because their

literal translations did not accurately capture the intended meaning of the original item. For example, the item ‘that involved my arm’ was literally translated as “waar mijn arm bij betrokken is” in Dutch, but the word ‘betrokken’ in Dutch is commonly used to mean ‘committed’ rather than ‘involved’. Therefore, the translators decided to use the phrase “waarbij ik mijn arm nodig had” (English: where I needed my arm) to convey the intended meaning. Table 2 provides examples of the problems encountered and the revisions made throughout the forward translation process. Through discussion between the researcher and the translator, a consensus was reached on the most appropriate translation.

### Step 2: back translation and review

When the back translation was compared to the original English version seven items (14%) required revision. The back translation differed from the original such that their meaning changed. Moreover, in four items (8%) there were differences in formulation between the original and the back translation. However, the Dutch translation was maintained in agreement with the developers, as it accurately captured the intended meaning. For example, the item ‘I worried when I was not seen regularly by someone for lymphedema treatment’ was back translated as ‘I worried when I didn’t have frequent appointments for lymphedema treatment’. The correct translation of ‘not seen’ is ‘geen afspraak hebben’ (English: have no appointment), which created a discrepancy between the original and the back translation. Examples of the issues and revisions encountered during the back translation review process are provided in Table 2.

### Step 3: expert panel meeting

During the expert panel, all items were thoroughly discussed. Any questions or feedback from the experts were addressed within the panel until a consensus was reached. As a result, some minor adjustments were made to the Dutch translation (31%). To make sure that the developer also agreed to these changes, we contacted the developers after the meeting to discuss the adjustments. Other examples of the adjustments made during the expert panel meeting can be found in Table 2.

During the expert meeting we decided to present some of these adjustments to the patients in the subsequent step, the cognitive debriefing interviews. For example, in Dutch there is a significant difference between ‘verwonden’ (English: injure) and ‘beschadigen’ (English: damage). To account for this variation in interpretation, we initially used the item ‘ik was extra voorzichtig om

te voorkomen dat ik mijn arm zou verwonden op werk’ (English: I took extra care to prevent injuring my arm at work), and then asked patients if they would interpret the question differently if it was ‘ik was extra voorzichtig om te voorkomen dat ik mijn arm zou beschadigen op werk’. Given the diverse interpretations of ‘verwonden’ (English: injure) and ‘beschadigen’ (English: damage), we included both words in the Dutch translation.

### Step 4: cognitive debriefing interviews and review

We conducted interviews with eight patients with BCRL (Table 3). The patients had varying educational levels, ranging from further education to bachelor’s degree. Five of the patients were employed at the time of BCRL diagnosis. Both scales were discussed with these patients, while the other three patients only reviewed the ‘Lymphedema worry’ scale. None of the patients reduced their work hours due to the BCRL diagnosis. One patient initially worked fewer hours but had returned to full working hours at the time of the interview.

During the cognitive interviews, we discovered that some Dutch words were too complex for the participants. We asked the participants to suggest alternatives and collaboratively searched for simplified synonyms (B1 language level). For example, the word ‘weerhouden’ (English: withhold) was deemed too complex and was changed to ‘hielden mij tegen’ (English: kept me from). Table 2 presents examples of the issues and revisions during this step.

### Step 5: proofreading and finalization

After proofreading, minor revisions were made to punctuation, typography, and grammar. These adjustments enhanced the clarity and readability of the items, instructions, and response options, ensuring an accurate and equivalent Dutch translation of the LYMPH-Q ‘Impact on Work’ and ‘Lymphedema worry’ scales.

## Discussion

The translation and cultural adaptation process successfully resulted in the Dutch version of the new LYMPH-Q scales ‘Impact on work’ and ‘Lymphedema worry’. Through a rigorous five-step translation process, these scales were carefully translated and evaluated to create a Dutch PROM that maintains the original meaning of the LYMPH-Q scales while being easily understood by patients.

**Table 2** Examples of the problems and revisions throughout the LYMPH-Q Dutch translation process

LYMPH-Q Scale	Item no	Item	Forward translation	Back translation	Expert panel	Cognitive debriefing interviews
Impact on work	2	Translation of 'self-conscious'	Translated to 'voortdurend bewust van' (English: constantly aware of)	Back translated as 'constantly aware of' but no better Dutch translation possible	No change	No change
Impact on work	7	Interpretation of 'keep up with'	Translated to 'bijhouden' (English: keep up)	No change	No change	Changed to het werktempo bijhouden (English: keep up the work pace) / bij blijven met werk (English: Keep up with work)
Impact on work	11	Translation of 'my arm'	Translated to 'de symptomen van mijn arm'	No change	Changed to 'mijn arm' (English: my arm)	No change
Impact on work	16	Examples given for 'accommodations'	Kept the original examples	No change	No change	Expanded the examples with 'aanpassingen aan werkplek' (English: workplace modifications)
Impact on work	17	Translation of 'less capable'	Translated to 'minder capabel' (English: less capable)	No change	Uncertain whether 'minder capabel' will be understood correctly by patients.	Changed to 'minder goed mijn werk kon doen' (English: less able to do my job)
Lymphedema worry	2	Translation of 'big'	Translated to 'groot' (English: big)	No change	Changed to 'dik' (English: thick)	No change
Lymphedema worry	3	Translation of 'involved'	Translated to 'nodig heb' (English: need)	No change	Changed to 'gebruik' (English: use)	No change
Lymphedema worry	9	Translation of 'incorrectly'	Translated to 'niet goed' (not right)	No change	Changed to 'niet juist' (English: incorrect)	No change
Lymphedema worry	13	Translation of 'impact'	Translated to 'impact' (English: impact)	No change	No change	Changed to 'de gevolgen' (English: the consequences)
Lymphedema worry	16	Translation of 'Worrying'	Translated to 'de zorgen' (English: the concerns)	Changed to 'mijn zorgen' (English: my worries)	No change	No change
Lymphedema worry	18	Translation of 'mental health'	Translated to 'geestelijke gezondheid' (English: mental health)	No change	Changed to 'mentaal welbevinden' (English: mental well-being)	Changed to 'geestelijke gezondheid' (English: mental health)
Lymphedema worry	20	Translation of 'fit'	Translated to 'eromheen past' (English: fits around)	No change	Changed to 'passend' (English: fitting)	No change

To ensure a systematic approach, we followed the guidelines provided by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the World Health Organization (WHO) [12, 13]. These guidelines were instrumental in translating the introduction, questions, and answer options into Dutch. The Dutch translation underwent a thorough review during an expert panel meeting, involving experts from all relevant fields in BCRL care. This multidisciplinary approach ensured that the translated scales align with the language and terminology used in current Dutch healthcare practices. The cognitive debriefing interviews with patients with BCRL provided valuable insights, ensuring that the scales are easily understood by Dutch patients.

BCRL is a recognized complication of breast cancer treatment, and previous research has demonstrated its negative impact on patients' quality of life (QoL) [4, 9]. The decline in QoL is not solely attributed to physical characteristics and symptoms but is also influenced by psychosocial factors such as worries about lymphedema and work-related difficulties. Previous studies showed that patients with BCRL had to modify their workplace, had to reduce the number of work hours per week, and some described feeling disabled at the workplace due to BCRL [6, 14]. The translation of the newly developed scales, 'Impact on work' and 'Lymphedema worry', provides healthcare professionals with a novel means to

**Table 3** Patient characteristics

		<i>N</i>
Age	30–39	1
	40–49	1
	50–59	3
	60–69	2
	70–79	1
Gender	Female	8
	Male	0
Currently working	Yes	5
	No	3
Adjusted work hours related to lymphedema	Yes	0
	No	5
Retirement related to breast cancer or lymphedema	Yes	1
	No	2
Highest level of education	Primary school	0
	High school	0
	MBO	5
	HBO	3
	University	0

assess and monitor the impact of BCRL on worry and work during the course of patient care.

One limitation of this study is that the professional translator involved in the back translation step was not a native English speaker. However, to mitigate this limitation, regular contact was maintained with the developers of the LYMPH-Q scales. This approach ensured that any discrepancies or ambiguities in the translation were addressed and discussed with the original scale developers, who had a thorough understanding of the intended meanings and concepts. By maintaining this close collaboration and communication and adherence to best practice guidelines, we ensured the Dutch translation of the new LYMPH-Q scales was done to the highest standard.

## Conclusions

In conclusion, this study successfully translated and culturally adapted the LYMPH-Q scales measuring impact on work and lymphedema worry into Dutch. Our rigorous translation process ensured a conceptually equivalent translation of the two new scales, which will be available for use in both clinical care and research settings. The availability of these translated scales will contribute

to better measurement and monitoring of the impact of BCRL on patient's daily lives, improving patient care and outcomes.

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## Declarations

**Ethics approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. According to the Dutch Medical Research with Human Subjects Law (WMO), the present study did not have to undergo full ethics review because participants are not subject to procedures and are not required to follow rules of behavior. A Non-WMO declaration was provided by the Medical Ethics Committee of the Erasmus Medical Center.

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent to publish** All participants gave their consent.

**Competing interests** Anne F. Klassen and Andrea L. Pusic are co-developers of the LYMPH-Q. As such, they receive royalties when this PROM is used in for-profit clinical trials. The other authors have no relevant financial or non-financial interests to disclose.

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