

# Development of a self-administrated quality of life questionnaire for sarcopenia in elderly subjects: the SarQoL

CHARLOTTE BEAUDART<sup>1</sup>, EMMANUEL BIVER<sup>2</sup>, JEAN-YVES REGINSTER<sup>1</sup>, RENÉ RIZZOLI<sup>2</sup>, YVES ROLLAND<sup>3</sup>,  
IVAN BAUTMANS<sup>4</sup>, JEAN PETERMANS<sup>5</sup>, SOPHIE GILLAIN<sup>5</sup>, FANNY BUCKINX<sup>1</sup>, JULIEN VAN BEVEREN<sup>6</sup>,  
MARC JACQUEMAIN<sup>7</sup>, PATRICK ITALIANO<sup>7</sup>, NADIA DARDENNE<sup>1</sup>, OLIVIER BRUYERE<sup>1</sup>

<sup>1</sup>Public Health, Epidemiology and Health Economics, University of Liège, Liège 4000, Belgium

<sup>2</sup>Division of Bone Diseases, Faculty of Medicine, Geneva University Hospitals, Geneva, Switzerland

<sup>3</sup>Clinical Gerontology, CHU Toulouse, Toulouse, France

<sup>4</sup>Frailty in Ageing Research Department, Vrije Universiteit Brussel, Brussels, Belgium

<sup>5</sup>Geriatric Department, CHU Liège, Liège, Belgium

<sup>6</sup>Department of French and Romance Languages and Literatures, Faculty of Philosophy and Letters, University of Liège, Liège, Belgium

<sup>7</sup>Institute of Human and Social Sciences, University of Liège, Liège, Belgium

Address correspondence to: C. Beaudart. Tel: +32 436 64933; Fax: +32 436 62812. Email: [c.beaudart@ulg.ac.be](mailto:c.beaudart@ulg.ac.be)

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## Abstract

**Background:** the impact of sarcopenia on quality of life is currently assessed by generic tools. However, these tools may not detect subtle effects of this specific condition on quality of life.

**Objective:** the aim of this study was to develop a sarcopenia-specific quality of life questionnaire (SarQoL, Sarcopenia Quality of Life) designed for community-dwelling elderly subjects aged 65 years and older.

**Settings:** participants were recruited in an outpatient clinic in Liège, Belgium.

**Subjects:** sarcopenic subjects aged 65 years or older.

**Methods:** the study was articulated in the following four stages: (i) Item generation—based on literature review, sarcopenic subjects' opinion, experts' opinion, focus groups; (ii) Item reduction—based on sarcopenic subjects' and experts' preferences; (iii) Questionnaire generation—developed during an expert meeting; (iv) Pretest of the questionnaire—based on sarcopenic subjects' opinion.

**Results:** the final version of the questionnaire consists of 55 items translated into 22 questions rated on a 4-point Likert scale. These items are organised into seven domains of dysfunction: Physical and mental health, Locomotion, Body composition, Functionality, Activities of daily living, Leisure activities and Fears. In view of the pretest, the SarQoL is easy to complete, independently, in ~10 min.

**Conclusions:** the first version of the SarQoL, a specific quality of life questionnaire for sarcopenic subjects, has been developed and has been shown to be comprehensible by the target population. Investigations are now required to test the psychometric properties (internal consistency, test–retest reliability, divergent and convergent validity, discriminant validity, floor and ceiling effects) of this questionnaire.

**Keywords:** *sarcopenia, quality of life, questionnaire, older people*

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## Introduction

Sarcopenia is defined by a progressive and generalised loss of muscle mass and function with advancing age [1, 2]. This geriatric syndrome, now recognised as a major clinical problem for older people, is an increasing public health issue in

our society [3]. Indeed, sarcopenia is associated with some adverse clinical outcomes such as physical impairment, limitation of mobility, increased risk of falls, hospitalisation and mortality [4–8] but also with major co-morbidities such as type 2 diabetes, obesity and osteoporosis [9].

As of today, the association between sarcopenia and altered quality of life (QoL) has been little studied. Health-related QoL is defined by the World Health Organization (WHO) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Although the decline in HR-QoL is intuitively evident for sarcopenic subjects, it is only supported by a few studies showing a significant association between, on one side, decreased grip strength and, on the other side, decreased physical and general health [10–12]. Moreover, QoL in these studies has only been measured through generic QoL questionnaires. However, generic tools may not be able to detect subtle effects of a specific condition on QoL. Consequently, a specific tool would be necessary to assess the impact of sarcopenia on QoL. Even if a large number of disease-specific QoL questionnaires currently exist, none are specific to sarcopenia. In the absence of such a specific tool, the ability to clinically characterise QoL in subjects with sarcopenia, as well as the capacity to assess changes over time in the QoL of these subjects seems compromised. Complete assessment of the benefits of a therapeutic

intervention should provide evidence of an impact on patients' HR-QoL.

The aim of this study was to develop a sarcopenia-specific QoL questionnaire, called SarQoL (Sarcopenia Quality of Life), designed for community-dwelling elderly subjects aged 65 years and older. In this paper, we describe the four stages of the development of this specific QoL questionnaire.

### Methods

Based on different procedures on how to develop a HR-QoL questionnaire [13–15], but also on experts' recommendations and on many successful studies [16–20], we applied the following four steps to develop our questionnaire (Figure 1):

Step 1. Item generation—based on literature review, sarcopenic subjects' opinion, experts' opinion, focus groups.

Step 2. Item reduction—based on sarcopenic subjects' and experts' relevance ranking.

Step 3. Questionnaire generation—developed during an expert meeting.

Step 4. Pretest of the questionnaire—based on sarcopenic subjects' opinion.

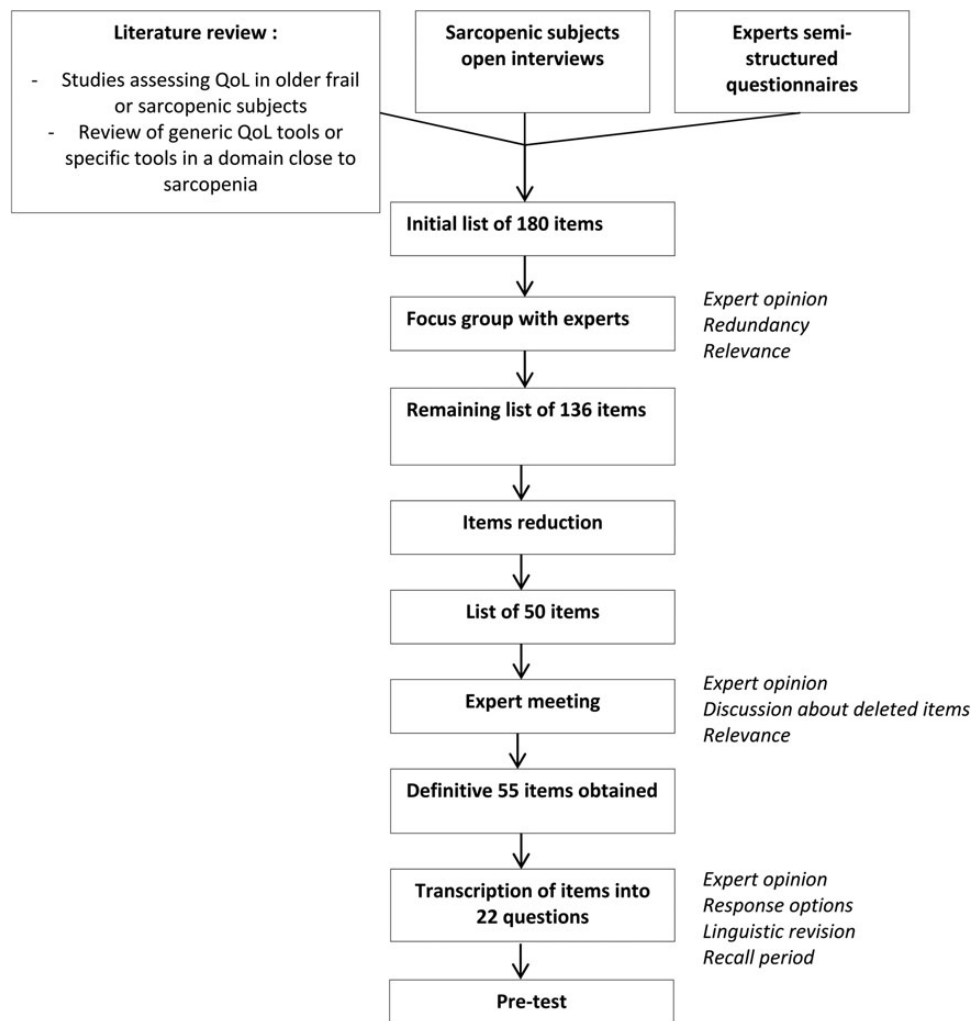


Figure 1. Overview of study procedures.

## Language

The SarQoL questionnaire has been developed in French.

## Identification of experts

Different experts (eight from Belgium, one from France and two from Switzerland) were included in the development of this questionnaire: three geriatricians (S.G., J.P., Y.R.), three rheumatologist experts in the field of bone and muscle (E.B., J.Y.R., R.R.), one physiotherapist and Professor in Bio-Gerontology and Geriatric Rehabilitation (I.B.), one linguist expert in the French language (J.V.B.), two experts in methodology of questionnaires (M.J., P.I.) and, at last, one statistician (N.D.).

## Identification of patient population

We used the definition of the European Working Group on Sarcopenia in Older People (EWGSOP) [21] as criteria for diagnosing sarcopenic subjects. Subjects, aged 65 years and older, were recruited in an outpatient clinic in Liège, Belgium. They are currently enrolled in a 5-year prospective Belgian cohort called SarcoPhAge [22]. Sarcopenia was defined as follows:

- An appendicular lean muscle mass/height<sup>2</sup> (SMI) <5.5 kg/m<sup>2</sup> for women and <7.26 kg/m<sup>2</sup> for men assessed by Dual-energy X-ray absorptiometry.
- A muscle strength <20 kg for women and <30 kg for men assessed by a hydraulic hand dynamometer OR physical performance: ≤8 points for the Short Physical Performance Battery (SPPB) test.

Forty-six community-dwelling sarcopenic subjects were recruited in an outpatient clinic in Liège, Belgium. Inclusion criteria included age ≥65 years, French maternal language and written informed consent obtained. Exclusion criteria were amputated limb and BMI above 30 kg/m<sup>2</sup>.

Subjects had to read and sign an informed consent after having been informed of the objectives and methods of the research. The study was approved by the Ethics Committee of the University Teaching Hospital of Liège (number 2013/6).

## Step 1: Item generation

Items for the SarQoL were generated in a three-step process. The first step was to draw up, from an exhaustive review of the literature, a comprehensive list of items about QoL in sarcopenia. This list of items was drawn up not only from generic QoL questionnaires intended to either a general population or a population of similar age but also from different studies having assessed the QoL of frail and sarcopenic subjects. This list was then amended after having interviewed five subjects with sarcopenia, in a face-to-face discussion, about how sarcopenia impacts their QoL. All interviews, using open discussion and open-ended questions, were performed by the same clinical researcher (C.B.). During these interviews, sarcopenic subjects described all problems related to sarcopenia that affected their QoL.

Answers were transcribed, and a qualitative content analysis of the responses was carried out according to the published methodology [23, 24]. Finally, this list was completed by feedbacks of experts who had received a semi-structured questionnaire, which allowed them to discuss about sarcopenia and its impact on QoL.

Then, the list of items was discussed with the experts in a meeting to reformulate some of them, delete or subdivide others, and, finally, organise them into domains of dysfunction.

## Step 2: Item reduction

The aim of this step was to select the most pertinent items to include in the final questionnaire.

To perform this stage, the list of items identified in the generation phase was submitted to 21 sarcopenic subjects, different from those included in Phase 1, and to the experts. They had to grade the relevance of each item on a 4-point Likert scale ranging from '1, not relevant' to '4, extremely relevant'. Then, for each item, we examined its 'frequency' (the proportion of subjects or experts who identified the item as 'extremely relevant') and its importance (the mean importance score based on the Likert scale for this item) and selected items on the basis of the product: frequency × importance. Redundancy of items was also taken into consideration throughout the item reduction process.

## Step 3: Development of the questionnaire SarQoL

A focus group was organised with all experts to translate the amended list of items into clear, brief, unambiguous and relevant questions. This meeting also served to define the layout of the questionnaire, the response format and the scoring algorithm. This first version of the questionnaire was submitted to a French linguist to ensure that it was free of any spelling or linguistic errors.

## Step 4: Pretest of the questionnaire SarQoL

Once checked by the linguist, the questionnaire was submitted to a sample of 20 sarcopenic patients, different from those included in Stage 1 and Stage 2, to ensure the good understandability of each question and the acceptability of the questionnaire's format. Subjects were invited to express their misunderstanding and to formulate recommendations over the questions. Following this pretest, the second and final version of the questionnaire SarQoL was established.

## Statistical analysis

Patient's characteristics are described as median (P25–P75) for continuous variables and count and percentage for categorical variables.

For item reduction, the impact of each item was calculated by multiplying the frequency of an item by its mean importance. This calculation was performed for subjects and for experts separately. The items with an impact of ≥0.5 both for subjects and for experts were selected. Other items were excluded from the list.

All analyses were executed with the software Statistica 9.1.

## Results

### Patient population

A total of 46 sarcopenic subjects were included in the development of the questionnaire. 78.3% of subjects were women with a mean age of  $76.3 \pm 6.51$  years. Five sarcopenic subjects were included in the phase of items generation, 21 sarcopenic subjects participated in the phase of items reduction and 20 for the pretest. Subjects' characteristics are given in Table 1.

### Step 1: Item generation

From the literature review, a first list of 67 items was drawn up. After complementing this list with the open interviews of five sarcopenic subjects and the feedback from the semi-structured questionnaires sent to seven experts (E.B., I.B., S.G., J.P., R.R., J.Y.R., Y.R.), a new list of 180 items was generated. A meeting was then held with all the experts to discuss on the basis of this 180-item list which items had to be deleted because of redundancy, similarity or repetition and which items had to be combined or reformulated. These decisions were made on the basis of consensus agreement between the research team and the experts. At the end of the meeting, the list was reduced to 136 items, structured into eight domains: Physical and Mental Health, Locomotion,

Social relations, Body composition, Functionality, Activities of daily living, Leisure activities and Fears.

### Step 2: Item reduction

The 136-item list was given to 21 subjects diagnosed sarcopenic and to the experts. Only the items with a frequency  $\times$  importance product of 0.5 or greater were retained. In three domains, Social relation, Body composition and Fears, no item reached this cut-off point. At this stage, the process reduced the number of items to 48, classified into five domains. Consensus agreement between experts was to keep three items from the domain of Body composition and four items from the domain of Fears and to remove the domain of Social relation from the questionnaire because of its very low score from both patients and experts. The decision of keeping items from the Body composition and Fears domains was based on the fact that the mean rating for these items was  $>1$  for either the experts or the subjects. Following this consensual decision of experts, a final list of 55 items, classified into seven domains was achieved (Table 2).

### Step 3: Development of the questionnaire SarQoL

The 55 items were translated into 22 questions during a meeting organised with the experts. The decision regarding the format of questions was made by general consent of the

**Table 1.** Demographic and clinical characteristics of patients involved in Phase 1, Phase 2 and Phase 4 of the development

	Phase 1: Item generation ( $n = 5$ )	Phase 2: Item reduction ( $n = 21$ )	Phase 4: Pretest ( $n = 20$ )
Age	73.0 (71.0–79.0)	76.1 (71.6–80.1)	75.1 (71.7–80.0)
Sex			
Women	5 (100.0)	13 (61.9)	18 (90.0)
Anthropometric data			
Height (cm)	161.4 (161.0–166.7)	161.3 (156.7–168.1)	157.5 (152.7–162.0)
Weight (kg)	60.3 (50.0–67.5)	58.3 (53.5–61.8)	60.0 (55.2–66.2)
BMI ( $\text{kg}/\text{m}^2$ )	23.1 (17.9–26.0)	22.2 (20.6–23.7)	23.8 (23.2–26.9)
Calf circumference (cm)	33.5 (28.0–33.5)	31.0 (29.5–32.0)	32.0 (30.0–34.2)
Wrist circumference (cm)	15.0 (15.0–15.5)	16.0 (15.0–17.0)	15.5 (15.0–16.5)
Arm circumference (cm)	26.0 (25.0–26.0)	24.5 (23.0–27.0)	26.7 (24.7–27.7)
Civil status			
Married	2 (40.0)	12 (57.1)	12 (60.0)
Divorced	2 (40.0)	3 (14.3)	17 (10.0)
Widow	1 (20.0)	4 (19.0)	4 (20.0)
Single	0 (0.00)	2 (9.52)	2 (10.0)
Level of education			
Without qualification	0 (0.00)	0 (0.00)	0 (0.00)
Primary school	3 (60.0)	2 (9.52)	2 (10.0)
Secondary school	2 (40.0)	11 (52.4)	10 (50.0)
Post-secondary education	0 (0.00)	8 (38.1)	8 (40.0)
Number of diseases	2.0 (2.0–7.0)	5.0 (4.0–8.0)	4.5 (3.0–6.0)
Number of drugs	8.0 (7.0–9.0)	6.0 (5.0–9.0)	6.0 (5.0–10.0)
Gait speed (m/s)	0.95 (0.79–0.97)	0.94 (0.77–1.18)	0.88 (0.78–1.01)
Grip strength maximum (kg)			
Women	24.6 (20.1–25.3)	19.5 (16.0–22.0)	18.0 (16.0–20.5)
Men	–	27.0 (21.5–29.5)	41.7 (38.0–45.5)
SMI ( $\text{kg}/\text{m}^2$ )			
Women	4.97 (4.8–5.3)	5.07 (4.68–5.35)	5.31 (4.76–5.46)
Men	–	6.43 (6.21–6.60)	7.15 (7.10–7.25)

SMI, skeletal muscle index (appendicular lean mass/height<sup>2</sup>).

**Table 2.** Presentation of the final 55 items composing the SarQoL questionnaire

Domains	Items	
Physical and mental health	Loss of arm strength	
	Loss of leg strength	
	Loss of energy	
	Muscle pain	
	Feeling of muscle weakness	
	Feeling of being frail	
	Feeling old	
	Feeling of being physically weak	
	Limitation in walking time	
	Limitation in number of outings outdoor	
Locomotion	Limitation in walking distance	
	Limitation in walking speed	
	Limitation in steps length	
	Feeling of fatigue when walking	
	Need of recovery time when walking	
	Difficulties to cross a road fast enough	
	Difficulties to walk on uneven grounds	
	Physical change	
	Loss of muscle mass	
	Weight change (loss or gain)	
Functionality	Balance problems	
	Falls occurrence	
	Loss of physical capacity	
	Loss of flexibility	
	Climbing one flight of stairs	
	Climbing several flight of stairs	
	Climbing stairs without a banister	
	Stooping	
	Crouching or kneeling	
	To stand from a sitting position	
Get up from a chair		
Activities of daily living	To stand up from the floor without any support	
	Limitation of movement	
	Sexuality	
	Difficulty during light physical effort	
	Fatigue during light physical effort	
	Pain during light physical effort	
	Difficulty during moderate physical effort	
	Fatigue during moderate physical effort	
	Pain during moderate physical effort	
	Difficulty during intensive physical effort	
Fatigue during intensive physical effort		
Pain during intensive physical effort		
Leisure activities	Shopping	
	Household tasks	
	Carrying heavy objects	
	Open a bottle or a jar	
	Take public transportation	
	To get in/out a car	
	Change in physical activities	
	Change in leisure activities	
	Fears	Fear of getting hurt
		Fear of not succeeding
Fear of being tired		
Fear of falling		

experts after discussion. The experts proposed a 4-point Likert scale of frequency (often, sometimes, rarely, never) or intensity (a lot, moderately, a bit, not at all) for all questions at the exception of one question. Seven questions were

displayed in a table including several items, and other questions were displayed as unique questions. No question uses a recall period. The total scoring of the SaQoL questionnaire ranges from 0 (worst imaginable health) to 100 (best imaginable health). At this stage, the first version of the SarQoL questionnaire was established.

#### Step 4: Pretest of the questionnaire SarQoL

Finally, the SarQoL questionnaire was pretested on a group of 20 sarcopenic subjects. It took ~10 min to patients to self-administer the questionnaire. No patient reported any difficulty in completing the questionnaire or interpreting the questions. The questionnaire was consequently kept unchanged.

#### Discussion

In the present study, we report the development of the first specific, self-administrated sarcopenia-related QoL questionnaire, the SarQoL questionnaire. This questionnaire includes 55 items translated into 22 questions rated on a 4-point Likert scale. In view of the pretest, the SarQoL is easy to complete, independently, in ~10 min.

Sarcopenia is associated with the development of physical disability, with nursing home admission, depression, hospitalisation, many co-morbidities, poor physical performance, functional decline, falls and with short- and long-term mortality in hospitalised patients [3]. However, as of today, few studies have assessed the impact of sarcopenia on QoL. In 2012, Kull *et al.* [11] found a reduced QoL in two domains (i.e. physical function and vitality) of the SF-36 questionnaire in sarcopenic subjects. Two other studies found that sarcopenic subjects presented poorer general health and physical functioning scores [12] and presented significantly more problems of mobility, self-care, usual activity and anxiety than non-sarcopenic subjects [25]. Other studies showed an indirect association between sarcopenia and QoL with a significant correlation between reduced grip strength, one of the components of sarcopenia, and reduced QoL in the domains of physical functioning and general health [10, 26]. Another study also showed a correlation between reduced muscle mass in men and reduced general health, assessed with the SF-36 questionnaire [27]. All these results highlight the fact that QoL of subjects suffering from sarcopenia is affected only in specific domains. Even if the SF-36 is widely in use, simple and effective [28], it is acknowledged that this generic tool should be supplemented with disease-specific instruments [29]. There is a need of a specific QoL questionnaire in the field of sarcopenia [8]. This questionnaire should include the physical aspects of the musculoskeletal domains but should also give an even-handed balance to other factors affecting QoL. During the development of the SarQoL, we followed carefully these recommendations and included therefore no less than seven domains of dysfunction: Physical and Mental Health, Locomotion, Body composition, Functionality, Activities of daily living, Leisure activities and Fears.



HR-QoL assessments are obviously important for healthcare providers and regulatory agencies to understand the needs and preoccupation of important segments of the population, such as elderly subjects suffering from sarcopenia. Such a tool could enhance the accuracy of assessments of well-being and physical function, psychological and social implications of sarcopenic subjects. With the future expected development of interventions targeting sarcopenia, this tool will also be useful to measure the effectiveness and relevance of these new therapeutic strategies.

Our study presents several strengths. First of all, we respected guidelines and followed rigorous steps, which have previously been successfully used in many other studies. Next, many experts have been actively involved in the development process; eight clinician experts in the field of sarcopenia, one linguist expert in the French language, two experts in the methodology of questionnaires and one statistician. This large and heterogeneous panel of experts ensured a rigorous methodology, a good use of the French language throughout the questionnaire and a content validity. Moreover, the content validity was also provided by the large range of sources used to generate items and by the inclusion of sarcopenic patients in the two first stages of the development of the questionnaire, the item generation and the reduction of items. Some weaknesses could however be pointed out. First of all, the inclusion of 46 subjects in the development process could be considered as too limited but is in line with the methodology used in other studies [30, 31]. Secondly, these subjects are also enrolled in another study on sarcopenia (the SarcoPhAge study [22]) and might, consequently, be more aware of the impact of sarcopenia given the participant's information and assessments they underwent for the prospective study. We must also note that the majority of the sample is composed of women, which could have some impact on the results. Moreover, in the item generation phase, all included subjects were women. However, the inclusion of subjects in this phase is not formally requested and only ensures a content validity to the questionnaire. Anyway, we acknowledge that if some men would have been included in this phase, it might have resulted in having some items more specific to men added to the list of items generated. Another limitation is that the questionnaire has only been developed with ambulatory community-dwelling subjects and could not be fully adapted to other populations. Finally, only French-speaking subjects were studied, and characteristics of French-speaking Belgian sarcopenic subjects could differ from subjects from other countries.

### Future works

Even if the SarQoL questionnaire is now developed, this questionnaire is not yet ready to be used. Indeed, verification of psychometric properties has still to be done and is currently on the way. Future work includes first the development of a scoring algorithm and a factorial analysis of the included questions; second, the analysis of the convergent and divergent validity of the questionnaire, the internal consistency,

the test–retest reliability, and the potential ceiling and floor effects.

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### Key points

- The generic quality of life tools may not detect subtle effects of sarcopenia on quality of life.
  - A first version of the SarQoL, a specific quality of life questionnaire for sarcopenic subjects, has been developed.
  - The SarQoL has been shown to be comprehensible by the target population.
  - Investigations are now required to test the psychometric properties of this questionnaire.
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### Conflicts of interest

C.B. and E.B. have received the ‘Young Investigator Research Grant’ for this research from the International Osteoporosis Foundation and Servier. C.B. is supported by a Fellowship from the FNRS (Fonds National de la Recherche Scientifique de Belgique—FRS-FNRS—[www.frs-fnrs.be](http://www.frs-fnrs.be)).

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