

AE-QoL

Quality of Life Questionnaire for Patients with Recurrent Swelling Episodes

Patient name: _____

Date questionnaire completed (dd mmm yyyy): ____ ____ _____

Instructions: This questionnaire asks a number of questions. Please read each question carefully and choose from the five answers the one that fits best for you. Please do not think too long about the questions; be sure to answer all of the questions and to give only one answer to each question, i.e., to check only one box for each question.

Indicate how often within the last 4 weeks you have been restricted in the areas of your daily life listed below because of swelling episodes (angioedema). (regardless of whether or not you have actually experienced swelling episodes during that time period)	Never	Rarely	Occasionally	Often	Very often
1. Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Leisure time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Social relations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Eating and drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the following questions we would like to get more details about the difficulties and problems that may be associated with your recurrent swelling episodes (angioedema) (during the last 4 weeks)	Never	Rarely	Occasionally	Often	Very often
6. Do you have difficulty falling asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you wake up during the night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are you tired during the day because you are not sleeping well at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you have trouble concentrating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the following questions we would like to get more details about the difficulties and problems that may be associated with your recurrent swelling episodes (angioedema) (during the last 4 weeks)	Never	Rarely	Occasionally	Often	Very often
10. Do you feel depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you have to limit your choices of food or beverages?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do the swelling episodes place a burden on you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Are you afraid that a swelling episode could occur suddenly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Are you afraid that the frequency of the swelling episodes might increase?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Are you ashamed to go out in public because of the swelling episodes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do the swelling episodes make you embarrassed or self-conscious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Are you afraid that the treatment of the swelling episodes could have negative long-term effects for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This document must not be copied or used without the permission of MOXIE GmbH. For scientific or commercial use or in case a translation / cross cultural adaptation is intended, please check the terms and conditions on www.moxie-gmbh.de.

Instructions for evaluation of the AE-QoL

The structure of AE-QoL

The AE-QoL consists of four domains and a total score:

Domain	Item (Question)
Functioning	1. Impairment of work
	2. Impairment of physical activity
	3. Impairment of spare time activities
	4. Impairment of social relations
Fatigue/Mood	6. Difficulties of falling asleep
	7. Waking up during the night
	8. Feeling tired during the day
	9. Difficulties in concentrating
	10. Feeling downhearted
Fears/Shame	12. Feeling burdened at having swellings
	13. Fear of new suddenly appearing swellings
	14. Fear of increased frequency of swellings
	15. Ashamed to visit public places
	16. Embarrassed by the appearance of swellings
	17. Fear of long term negative drug effects
Nutrition	5. General limitations in foods and eating
	11. Limitations in the selection of food and beverages
Total Score	Items 1 to 17

How to calculate AE-QoL domain scores and the AE-QoL total score

AE-QoL is meant to be evaluated by determining its four individual domain scores (application as a profile instrument) but it may also be used to determine a total score (application as an index instrument):

Each item answered by the patient scores between 0 and 4 points depending on the answer option chosen by the patient. The 1st answer option gets 0 points, the 2nd option 1 point, the 3rd

option 2 points, etc. (Never=0, Rarely=1, Occasionally=2, Often=3, Very often=4)

The AE-QoL domain scores as well as the AE-QoL total score are calculated by using the following formula:

$$\frac{\text{Sum of all completed items}}{\text{Max. possible sum of all completed items}} \times 100 = \text{AE-QoL Score}$$

Computation of Total Score:

Example 1: All items were completed (Max. possible sum: 68 points)
Sum of all 17 completed items: 41 points

$$\frac{41}{68} \times 100 = 60 \rightarrow \text{AE-QoL Total Score} = 60 \text{ out of possible 100 points}$$

Example 2: 2 items were not completed (Max. possible sum: 60 points).
Sum of all 15 completed items: 41 points

$$\frac{41}{60} \times 100 = 68 \rightarrow \text{AE-QoL Total Score} = 68 \text{ out of possible 100 points}$$

Computation of Domain Scores (Example: Fears/Shame):

Example: Sum of all 6 completed items: 14 points
Max possible sum: 24 points

$$\frac{14}{24} \times 100 = 58 \rightarrow \text{Fears/Shame Score} = 58 \text{ out of possible 100 points}$$

Remarks

Since only answered items are included in the computation (and the calculated domain and total scores are not raw scores but linear transformations to a 0 to 100 scale), the calculated scores are not or only little influenced by missing items.

An AE-QoL domain score should not be calculated if more than one item is left unanswered in that domain. The AE-QoL total score should not be calculated if more than 25% of items (>4 items) are left unanswered.

The minimal and highest possible domain and total scores are 0 and 100, respectively.

References:

Weller K, Groffik A, Magerl M, Tohme N, Martus P, Krause K, Metz M, Staubach P, Maurer M. Development and construct validation of the angioedema quality of life questionnaire. *Allergy*. 2012; 67(10): 1289-98.

Instructions for evaluation of the AE-QoL

This document must not be copied or used without the permission of MOXIE GmbH. For scientific or commercial use or in case a translation / cross cultural adaptation is intended, please check the terms and conditions on www.moxie-gmbh.de.