

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. 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.

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