AE-QoL

Quality of Life Questionnaire for Patients with Recurrent Swelling Episodes

Instructions for evaluation of the AE-QoL
(German Version)

The structure of AE-QoL

The German version of AE-QoL consists of four dimensions and a total score:

Dimensions	Item
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 apppearence 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 scales and the AE-QoL total score

AE-QoL is meant to be evaluated by using its four individual dimensions (profile instrument) but is can also be used to determine a total score (index instrument):

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

(Σ items – min Σ items / max Σ items – min Σ items) x 100

Example:
Dimension "Functioning":
Item 1: answer 3
Item 2: answer 2
Item 3: answer 4
Item 4: answer 5
Σ items: (3+2+4+5) = 14
min Σ items: (1+1+1+1) = 4
max Σ items: (5+5+5+5) = 20
Enter values in formula: (14 - 4 / 20 – 4) x 100 = 62.5%

The AE-QoL dimension scores correspond to the mean of the items within each dimension. If some items are missing, the total of the items within the dimension is divided by the number of the non missing items. The same holds for the AE-QoL total score.

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

Please note that only calculating the raw dimension scores (mean of the item scores within each scale) and the raw total score score (mean of all item scores) would be easier than the above described procedure. However, in case of missing answers, an interindividual as well as an intraindividual comparison of AE-QoL results would be limited. The above described linear transformation of all raw scores into percentage scores (indicating the location of the raw scores in relation (in percent) to its maximum possible score) solves this problem and makes it possible to judge and compare AE-QoL results even when single items are missing. The linear transformation of raw scores results in minimal and highest possible scale and total scores of 0 and 100, respectively.