

SCORING MANUAL FOR THE QUALITY OF LIFE IN EPILEPSY INVENTORY-89 (QOLIE-89)

CONTENT OF QOLIE-89 (Table 1)

QOLIE-89 contains 17 multi-item scales that tap the following health concepts: overall quality of life (2 items), emotional well-being (5 items), role limitations due to emotional problems (5 items), social support (4 items), social isolation (2 items), energy/fatigue (4 items), seizure worry (5 items), medication effects (3 items), health discouragement (2 items), work/driving/social function (11 items), attention/concentration (9 items), language (5 items), memory (6 items), physical function (10 items), pain (2 items), role limitations due to physical problems (5 items), and health perceptions (6 items). A QOLIE-89 overall score is obtained using a weighted average of the multi-item scale scores. QOLIE-89 also includes one item on change in health over the preceding year and two items added after field testing: one on overall health and one on satisfaction with sexual relations.

The generic core of QOLIE-89 is the RAND 36-Item Health Survey 1.0, also known as the SF-36 (Ware and Sherbourne, 1992; Hays, Sherbourne, and Mazel, 1993). Items in this 36-item measure were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (MOS), an observational study of variations in physician practice styles and patient outcomes in different systems of health care delivery (Stewart, Sherbourne, Hays, et al, 1992).

In addition to the generic core, 13 items from longer MOS instruments and 5 items originally developed for the Epilepsy Surgery Inventory-55 (Vickrey, Hays, Graber, et al, 1992) were incorporated into QOLIE-89. The two-item overall quality-of-life scale consists of one Dartmouth COOP Chart (Nelson, Landgraf, Hays, et al, 1990) and one item from a study on patient preferences (Hadorn and Hays, 1991). This latter item was itself adapted from the Faces Scale (Andrews and Withey, 1976). The single item on overall health was adapted from an existing visual analog scale (Brazier, Jones, and Kind, 1993).

The remaining 32 items were developed *de novo* by the QOLIE Development Group based on diverse clinical experience with patients and a review of the literature on patient concerns about health-related quality of life.

FIELD TESTING

Item selection for QOLIE-89 was based on analysis of data collected from a cohort of 304 adult men and women having simple partial, complex partial, grand mal, absence, and/or myoclonic seizures of mild to moderate severity. These patients were enrolled from 25 sites across the United States.

All subjects completed an initial 98-item QOLIE test battery; the majority of subjects completed this same battery again within 3 weeks of the first visit. A brief neuropsychological test battery, selected neurological exam features, a proxy's assessment of the subject's quality of life, and information about seizure occurrence, medications, demographic characteristics, and health care utilization were also obtained (Perrine, 1993).

Data from this study were analyzed, and three measures of quality of life were developed, differing in their number of items: QOLIE-89, QOLIE-31 (Vickrey, Perrine, Hays, et al., 1993), and QOLIE-10.

SCORING RULES

Seventeen Primary Scales. Precoded numeric values for responses on some QOLIE-89 items are in the direction such that a higher number reflects a more favorable health state. For example, a circled response of "10" for item 2 corresponds to best possible quality of life, while a circled response of "0" corresponds to worst possible quality of life. However, precoded numeric values for some other items are in the direction such that a *lower* number reflects a more favorable health state. For example, a circled response of "1" for item 49 corresponds to a more favorable quality of life, while a value of "5" on this item corresponds to a less favorable quality of life. As these examples also demonstrate, different items have different ranges of precoded numeric values.

To account for these differences, the scoring procedure for QOLIE-89 first converts the raw precoded numeric values of items to 0-100 point scores, with higher converted scores always reflecting better quality of life (Table 2). To perform this step, write in the converted score for each item in the column labeled "Subtotal" in Table 2. Next, sum the subtotal scores for each scale and write in these values in the places marked "Total." Finally, divide each "Total" by the number of items that the respondent answered within each scale to get the "Final Score." The possible range of each scale's final score is now from 0 to 100 points. Higher scores reflect better quality of life; lower ones, worse quality of life.

Note that Table 2 shows the divisors to be used only in situations where *every* item within a given scale has been answered. For example, if item 40 in the Seizure Worry scale was left blank and the other four items in the scale were answered, then the "Total" score for Seizure Worry would be divided by "4" (instead of "5") to obtain the "Final Score."

Overall Score. A QOLIE-89 overall score can be derived by weighting and summing QOLIE-89 scale scores (Table 3). QOLIE-89 scale weights were derived in the following way:

A factor analysis of the 17 QOLIE-89 scales was performed. A four-factor solution yielded unique placement of scales into domains of mental health, physical health, cognitive function, and epilepsy-specific areas, based on the magnitude of each scale's factor loadings. Factor scores, which weight each scale by its factor loading, were derived for each domain. These four factor scores were then averaged to produce a single summary score.

To derive QOLIE-89 scale weights, this summary score was regressed on the 17 QOLIE-89 multi-item scales. Standardized beta coefficients from this regression analysis were summed, and each beta coefficient was divided by the sum to derive the relative weight for each QOLIE-89 scale listed in Table 3.

The QOLIE-89 scale overall score is calculated by summing the product of each scale final score from Table 2 times its weight and summing all these subtotals (Table 3).

T-scores. T-scores can be determined for each of the 17 scale final scores (Table 2) and for the overall score (Table 3) using the key in Table 4. These T-scores represent linear transformations of the scores that produce a mean of 50 and standard deviation of 10 for the cohort of 304 adults with epilepsy. Thus, a person with a T-score of 50 has a score equal to that of the mean for the epilepsy cohort. T-scores were computed using the following formula:

$$T\text{-score} = 50 + \left[10 \left(\frac{\text{Observed final scale score } \textit{minus} \text{ scale mean in Table 5}}{\text{Scale standard deviation in Table 5}} \right) \right]$$

Higher T-scores reflect a more favorable quality of life.

RELIABILITY AND DESCRIPTIVE STATISTICS

Table 5 presents reliability coefficients and descriptive statistics for the 17 QOLIE-89 scales derived from analyses of the 304 respondents in the QOLIE development study. Internal consistency reliabilities (Cronbach's alpha) range from $r=0.78$ to $r=0.92$, exceeding the 0.70 standard for group-level comparisons (Nunnally, 1978) for all scales. Test-retest reliabilities were calculated as Pearson product-moment correlations between patient responses at visit 1 and patient responses at visit 2 (up to 3 weeks later). At the second testing, patients were asked whether they had experienced any major life-and-death or health-related events since the first visit; data on those patients responding in the affirmative were excluded from test-retest analyses. The test-retest reliabilities for the 17 scales range from $r=0.58$ to $r=0.86$. All scales, except role limitations due to physical problems ($r=0.58$), role limitations due to emotional problems ($r=0.67$), medication effects ($r=0.64$), and pain ($r=0.69$), exceeded the $r=0.70$ standard for group comparisons. The 3 scales having the lowest test-retest reliabilities also had the 3 largest standard deviations among the 17 scales. The overall score had an internal consistency reliability of 0.97 and test-retest reliability of 0.88.

Means of the 17 self-report scales range from 54.3 for the memory scale to 85.3 for the physical function scale. None of the scales show floor or ceiling effects (scores clustering near the minimum or maximum). Examination of the means and associated standard deviations and ranges show sufficient breadth to assess a broad range of functioning and the potential to detect changes in quality of life.

TABLE 1
KEY TO SOURCES OF ITEMS IN QOLIE-89

Item Number	Source
2	Adapted from the Faces Scale (Andrews and Withey, 1976) by Hadorn and Hays (1991)
1,3,4-17,19,20, 23-35,43*47	From RAND 36-Item Health Survey 1.0 (aka SF-36) (Ware and Sherbourne, 1992; Hays, Sherbourne and Mazel, 1993)
18,21,22,40,50	From Epilepsy Surgery Inventory (ESI)-55 (Vickrey, Hays, Graber, et al, 1992)
37,38,39,41,48,64,73 81-83,86-88	From longer instruments in the Medical Outcomes Study (Stewart, Sherbourne, Hays, et al, 1992)
49	Dartmouth COOP Chart (Nelson, Landgraf, Hays, et al., 1990)
36,42,51-63,65-72, 74-80,84,85	Developed <i>de novo</i> by QOLIE Development Group
89*	Visual analog item adapted from existing measure (Brazier, Jones, and Kind, 1993)

*The wording of items 43 and 89 in the QOLIE-89 Inventory has been modified slightly since field testing and publication of the QOLIE-31 Scoring Manual.

**TABLE 2
QOLIE-89 SCORING FORM**

Scale/Item Numbers	Response (raw score)						Subtotal	Final Score, 0-100 point scale	
	1	2	3	4	5	6			
Health Perceptions									
1.	100	75	50	25	0	—	_____		
44.	0	25	50	75	100	—	_____		
45.	100	75	50	25	0	—	_____		
46.	0	25	50	75	100	—	_____		
47.	100	75	50	25	0	—	_____		
48.	0	25	50	75	100	—	_____		
							TOTAL: 250	÷ 6 = 41.67	
Overall Quality of Life									
2.							40		
	(multiply raw score by 10)								
49.	100	75	50	25	0	—	_____		
							TOTAL: 69	÷ 2 = 32.5	
Physical Function									
4.	0	50	100	—	—	—	_____		
5.	0	50	100	—	—	—	_____		
6.	0	50	100	—	—	—	_____		
7.	0	50	100	—	—	—	_____		
8.	0	50	100	—	—	—	_____		
9.	0	50	100	—	—	—	_____		
10.	0	50	100	—	—	—	_____		
11.	0	50	100	—	—	—	_____		
12.	0	50	100	—	—	—	_____		
13.	0	50	100	—	—	—	_____		
							TOTAL: 550	÷ 10 = 55	
Role Limitations-Physical									
14.	0	100	—	—	—	—	_____		
15.	0	100	—	—	—	—	_____		
16.	0	100	—	—	—	—	_____		
17.	0	100	—	—	—	—	_____		
18.	0	100	—	—	—	—	_____		
							TOTAL: 200	÷ 5 = 40	
Role Limitations-Emotional									
19.	0	100	—	—	—	—	_____		
20.	0	100	—	—	—	—	_____		
21.	0	100	—	—	—	—	_____		
22.	0	100	—	—	—	—	_____		
23.	0	100	—	—	—	—	_____		
							TOTAL: 0	÷ 5 = 0	
Pain									
24.	100	80	60	40	20	0	_____		
25.	100	75	50	25	0	—	_____		
							TOTAL: 200	÷ 2 = 100	

TABLE 2
QOLIE-89 SCORING FORM (cont.)

Scale/Item Numbers	Response (raw score)						Subtotal	Final Score, 0-100 point scale
	1	2	3	4	5	6		
Work/Driving/ Social Function								
26.	100	75	50	25	0	—	_____	
36.	0	20	40	60	80	100	_____	
43.	0	20	40	60	80	100	_____	
65.	0	25	50	75	100	—	_____	
66.	0	25	50	75	100	—	_____	
67.	0	25	50	75	100	—	_____	
68.	0	25	50	75	100	—	_____	
76.	100	75	50	25	0	—	_____	
77.	100	75	50	25	0	—	_____	
78.	100	75	50	25	0	—	_____	
85.	0	25	50	75	100	—	_____	
							TOTAL: 245	÷ 11 = 22.28
Energy/Fatigue								
27.	100	80	60	40	20	0	_____	
31.	100	80	60	40	20	0	_____	
33.	0	20	40	60	80	100	_____	
35.	0	20	40	60	80	100	_____	
							TOTAL: 160	÷ 4 = 40
Emotional Well-Being								
28.	0	20	40	60	80	100	_____	
29.	0	20	40	60	80	100	_____	
30.	100	80	60	40	20	0	_____	
32.	0	20	40	60	80	100	_____	
34.	100	80	60	40	20	0	_____	
							TOTAL: 140	÷ 5 = 28
Attention/Concentration								
37.	0	20	40	60	80	100	_____	
38.	0	20	40	60	80	100	_____	
41.	0	20	40	60	80	100	_____	
60.	0	20	40	60	80	100	_____	
61.	0	20	40	60	80	100	_____	
62.	0	20	40	60	80	100	_____	
63.	0	20	40	60	80	100	_____	
64.	0	20	40	60	80	100	_____	
73.	0	25	50	75	100	—	_____	
							TOTAL: 795	÷ 9 = 88.3
Health Discouragement								
39.	0	20	40	60	80	100	_____	
42.	0	20	40	60	80	100	_____	
							TOTAL: 40	÷ 2 = 20

TABLE 2
QOLIE-89 SCORING FORM (cont.)

Scale/Item Numbers	Response (raw score)						Subtotal	Final Score, 0-100 point scale
	1	2	3	4	5	6		
Seizure Worry								
40.	0	20	40	60	80	100	_____	
69.	0	33.3	66.7	100	—	—	_____	
70.	0	50	100	—	—	—	_____	
71.	0	33.3	66.7	100	—	—	_____	
74.	100	75	50	25	0	—	_____	
							TOTAL: 388.4	÷ 5 = 77.68
Memory								
50.	0	33.3	66.7	100	—	—	_____	
51.	0	20	40	60	80	100	_____	
52.	0	20	40	60	80	100	_____	
53.	0	20	40	60	80	100	_____	
54.	0	20	40	60	80	100	_____	
75.	100	75	50	25	0	—	_____	
							TOTAL: 600	÷ 6 = 100
Language								
55.	0	20	40	60	80	100	_____	
56.	0	20	40	60	80	100	_____	
57.	0	20	40	60	80	100	_____	
58.	0	20	40	60	80	100	_____	
59.	0	20	40	60	80	100	_____	
							TOTAL: 500	÷ 5 = 100
Medication Effects								
72.	0	33.3	66.7	100	—	—	_____	
79.	100	75	50	25	0	—	_____	
80.	100	75	50	25	0	—	_____	
							TOTAL: 25	÷ 3 = 8.33
Social Support								
81.	0	25	50	75	100	—	_____	
82.	0	25	50	75	100	—	_____	
83.	0	25	50	75	100	—	_____	
86.	100	75	50	25	0	—	_____	
							TOTAL: 125	÷ 4 = 31.25
Social Isolation								
87.	0	20	40	60	80	100	_____	
88.	0	20	40	60	80	100	_____	
							TOTAL: 40	÷ 2 = 20
SINGLE ITEMS:								
Change in Health								
3.	100	75	50	25	0	—	_____	75
Sexual Relations								
84.	100	75	50	25	0	—	_____	0
Overall Health								
89.	(no recoding necessary)							

Note: The total number of items in each scale is listed as the divisor for each subtotal. However, where all items in a scale are not answered, the divisor will be lower, as noted in the text for "Scoring Rules," page 4.

**TABLE 3
FORMULA FOR CALCULATING QOLIE-89 OVERALL SCORE**

QOLIE-89 Scale	Final Score (from Table 2)		Weight		Subtotal
Health Perceptions	<u>41.67</u>	×	.06	=	<u>2.5</u> (a)
Overall Quality of Life	<u>32.5</u>	×	.06	=	<u>2.0</u> (b)
Physical Function	<u>55</u>	×	.06	=	<u>3.3</u> (c)
Role Limitations-Physical	<u>40</u>	×	.07	=	<u>2.8</u> (d)
Role Limitations-Emotional	<u>0</u>	×	.05	=	<u>0</u> (e)
Pain	<u>100</u>	×	.07	=	<u>7</u> (f)
Work/Driving/Social Function	<u>22.28</u>	×	.08	=	<u>1.8</u> (g)
Energy/Fatigue	<u>40</u>	×	.05	=	<u>2</u> (h)
Emotional Well-Being	<u>28</u>	×	.05	=	<u>1.4</u> (i)
Attention/Concentration	<u>98.3</u>	×	.08	=	<u>7.1</u> (j)
Health Discouragement	<u>20</u>	×	.07	=	<u>1.4</u> (k)
Seizure Worry	<u>71.68</u>	×	.06	=	<u>4.3</u> (l)
Memory	<u>100</u>	×	.07	=	<u>7</u> (m)
Language	<u>100</u>	×	.06	=	<u>6</u> (n)
Medication Effects	<u>8.33</u>	×	.05	=	<u>0.4</u> (o)
Social Support	<u>31.25</u>	×	.02	=	<u>0.6</u> (p)
Social Isolation	<u>20</u>	×	.04	=	<u>0.8</u> (q)
OVERALL SCORE: Sum subtotals (a) through (q)				=	<u>41.9</u>

TABLE 4 QOLIE-89 PROFILE SHEET

T	Health Perceptions	Overall Quality of Life	Physical Function	Role-Physical	Role-Emotional	Pain	T
73							73
72							72
71							71
70							70
69							69
68		100					68
67		98					67
66	100						66
65		95					65
64	96	93					64
63							63
62	92	90					62
61		88					61
60	88	85				100	60
59		83		100	100		59
58	83						58
57		80	100				57
56		78				90	56
55	79		95			88	55
54		75		80			54
53	75	73			80		53
52		70	90			80	52
51	71					78	51
50		68	85			75	50
49	67	65					49
48		63		60		70	48
47	63		80		60	68	47
46		60				65	46
45	58	58	75			63	45
44						60	44
43	54	55				58	43
42		53	70	40	40	55	42
41	50	50				53	41
40		48	65			50	40
39	46					48	39
38		45				45	38
37	42	43	60			43	37
36				20	20	40	36
35	38	40	55			38	35
34		38				35	34
33						33	33
32	33	35	50			30	32
31		33					31
30	29	30	45	0	0	25	30
29		28				23	29
28	25					20	28
27		25	40				27
26	21	23					26
25			35			13	25
24	17	20				10	24
23		18					23
22	13	15	30				22
21		13					21
20			25			0	20
19	8	10					19
18							18
17	4		20				17
16		5					16
15	0		15				15
14							14
13		0					13
12			10				12
11							11
10			5				10
9							9
8							8
7			0				7
6							6

TABLE 4 QOLIE-89 PROFILE SHEET (cont.)

T	Social Function	Energy/Fatigue	Emotional Well-Being	Attention/Concentration	Health Discouragement	Seizure Worry	T
73							73
72							72
71		100					71
70							70
69		95					69
68							68
67			100				67
66		90					66
65			96	100		100	65
64	98,100	85		98		96	64
63			92	96-97		95	63
62	95	80		94-95		91-93	62
61	91,93		88	92-93	100	88,90	61
60	89			90-91		86-87	60
59		75	84	88-89		83-85	59
58	86			86-87		81-82	58
57	82,84	70	80	84-85	90	78-80	57
56	80			82-83		76-77	56
55		65	76	80-81		73-75	55
54	75,77			78	80	70,72	54
53	73			76		68-69	53
52		60	72			65,67	52
51	70			73		63-34	51
50	66,68	55	68	69,71	70	60-61	50
49	64			67		59	49
48			64			55-57	48
47	59,61	50		64		52-53	47
46	57		60	62	60	50-51	46
45	55	45		60		47-48	45
44	52		56	58		46	44
43	50	40		56	50	42,44	43
42	48		52	53		40	42
41				51		38	41
40	43,45	35	48	49		34,36	40
39	41			47	40	32-33	39
38	39	30	44			29-30	38
37	36			44		27-28	37
36	34	25	40	40,42	30	24-25	36
35	32			38		21,23	35
34	30		36	36		19-20	34
33	27	20				16-17	33
32	25		32	33	20	15	32
31	24	15		31		11-13	31
30	20,22		28	29		7-8	30
29	18	10		27		4	29
28	16		24	24	10		28
27	15			22		0	27
26	11,13	5	20	20			26
25	9			18	0		25
24	7	0		16			24
23	5		16				23
22	2						22
21	0		12	11,13			21
20				9			20
19			8	7			19
18				4			18
17			4	2			17
16				0			16
15			0				15
14							14
13							13
12							12
11							11
10							10
9							9
8							8
7							7
6							6

Note: If the final score is not on this table, either interpolate it or calculate it directly using the formula on page 4.

TABLE 4 QOLIE-89 PROFILE SHEET (cont.)

T	Memory	Language	Medication Effects	Social Support	Social Isolation	Overall Score	T
73							73
72							72
71						100	71
70						99	70
69	100					97-98	69
68	97					96	68
67	96					94-95	67
66	92-94					93	66
65	90		100			91-92	65
64	87-89					89-90	64
63	85-86					88	63
62	83-84	100	92	100		86-87	62
61	80-82		89			85	61
60	78-79	96				83-84	60
59	75-77		83	94	100	82	59
58	73-74	92	81			80-81	58
57	71-72		78	88		79	57
56	68-70	88	75			77-78	56
55	66-67		72		90	75-76	55
54	63-64	84	67.69	81		74	54
53	61-62	80	64			72-73	53
52	58-60		61			71	52
51	56-57	76	58	75	80	69-70	51
50	54		56			68	50
49	51-53	72	53			66-67	49
48	49-50		50	69		65	48
47	46-48	68	47		70	63-64	47
46	44		42.44	63		61-62	46
45	42-43	64	39			60	45
44	39-41		36			58-59	44
43	37-38	60	33	56	60	57	43
42	34-36		31			55-56	42
41	32-33	56	28			54	41
40	29-31		25	50		52-53	40
39	27-28	52	22		50	51	39
38	26		19	44		49-50	38
37	22-24	48	17			47-48	37
36	20-21					46	36
35	17-19	44	11	38	40	44-45	35
34	16	40	8			43	34
33	13-14					41-42	33
32	10-12	36	0	31		40	32
31	8-9				30	38-39	31
30	6-7	32				37	30
29	3			25		35-36	29
28		28				33-34	28
27	0			19	20	32	27
26		24				30-31	26
25						29	25
24		20		13		27-28	24
23					10	26	23
22		16				24-25	22
21				6		23	21
20		12				21-22	20
19					0	19-20	19
18		8		0		18	18
17						16-17	17
16		4				15	16
15						13-14	15
14		0				12	14
13						10-11	13
12						9	12
11						7-8	11
10						5-6	10
9						4	9
8						2-3	8
7						1	7
6						0	6

Note: If the final score is not on this table, either interpolate it or calculate it directly using the formula on page 4.

TABLE 5
RELIABILITY, CENTRAL TENDENCY, AND VARIABILITY OF QOLIE-89 SCALES*

Scale	Number of Items	Reliability		Mean (0-100 range)	Standard Deviation	Observed Range
		Alpha	Test-retest ^b			
Health Perceptions	6	0.78	0.84	68.26	19.61	21-100
Overall Quality of Life	2	0.79	0.84	67.17	18.38	5-100
Physical Function	10	0.89	0.75	85.27	19.82	6-100
Role Limitations-Physical	5	0.81	0.58	67.81	34.53	0-100
Role Limitations-Emotional	5	0.81	0.67	69.29	34.54	0-100
Pain	2	0.87	0.69	75.56	24.80	0-100
Work/Driving/Social Function	11	0.86	0.86	66.91	22.94	4-100
Energy/Fatigue	4	0.84	0.75	55.30	21.10	0-100
Emotional Well-Being	5	0.83	0.77	67.20	19.28	16-100
Attention/Concentration	9	0.92	0.86	69.98	20.70	11-100
Health Discouragement	2	0.82	0.73	69.87	27.74	0-100
Seizure Worry	5	0.79	0.84	58.29	25.76	0-100
Memory	6	0.88	0.82	54.34	24.15	0-100
Language	5	0.88	0.72	74.57	20.99	4-100
Medication Effects	3	0.78	0.64	55.34	30.52	0-100
Social Support	4	0.84	0.78	72.47	22.89	0-100
Social Isolation	2	0.88	0.73	76.78	25.04	0-100
Overall Score	86	0.97 ^c	0.88	67.90	15.55	26-95

*N ranged from 298 to 304 patients with mild or moderate epilepsy for all data except test-retest reliability.

^bN ranged from 229 to 232 in the subset of epilepsy patients who were clinically stable and whose test-retest interval ranged from 1 to 21 days.

^cEstimated using Mosier's (1943) formula.

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