

University of Washington Quality of Life Questionnaire (UW-QOL v4)

Guidance for scoring and presentation

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This updated guidance sets out the preferred way for scoring and presenting the UW-QOL.

Translations of the UW-QOL are available on the www.headandneckcancer.co.uk website, specifically at [http://www.headandneckcancer.co.uk/For-professionals/Quality+of+Life+\(QOL\)/UW-QOLv4+Translations.aspx](http://www.headandneckcancer.co.uk/For-professionals/Quality+of+Life+(QOL)/UW-QOLv4+Translations.aspx)

The introduction of 'quality of life' questionnaires helps identify issues of concern to the individual patient and triggers discussion of these issues in the clinical setting. Questionnaires raise the important issue of what is 'quality of life'? To the patient it is an implicit state of being, something known that cannot be told, whilst to the researcher it is a difficult measurement problem, and to the clinician it is just one of many other equally relevant inputs into a clinical judgement.

Health-related quality of life (HRQOL) is an important outcome parameter following treatment for head and neck cancer. As the value of this concept has become established during the last decade there has been a dramatic increase in the number of publications on HRQOL. The impact of head and neck cancer and its treatment can have such a profound detrimental effect on function and well-being that it is essential that the patient's perspective is taken into account. Two national bodies, the British Association of Head and Neck Oncologists and the British Association of Otorhinolaryngologists Head Neck Surgeons <http://www.bahno.org.uk/bulletin.htm#quality>, both recommend that HRQOL should be longitudinally recorded. Questionnaires give a structured insight into the patients' point of view. They facilitate multidisciplinary team working with the recognition of poor outcome groups, better information for the patient and their carers, and the opportunity to identify problem areas and target support/intervention.

The choice of HRQOL questionnaire depends on the purpose of the study, its design and the available resources. Certain questionnaires may be more applicable in routine practice and others in a research setting.

Questionnaires

It is time consuming and a logistical challenge to ensure patients self-complete questionnaires before treatment and at regular intervals subsequently. Very few units are currently collecting HRQOL information and one of the problems has been the selection of the most appropriate questionnaire. There will never be a perfect head and neck questionnaire² and there is a choice between about 14 validated measures.^{1,2} The most commonly used are the EORTC, FACT and UW-QOL. However HRQOL data collection remains a low priority in many units. One reason for this is that some questionnaires are too long or complicated for members of the head and neck team, including the patient, and seem more suited to research. One questionnaire that has emerged as a simple yet clinically relevant measure suitable for routine clinical practice is the University of Washington questionnaire (UW-QOL).

The University of Washington questionnaire

In the original description, Hassan and Weymuller³ stated that 'the advantages of the UW-QOL head and neck questionnaire are that 1) it is brief and self-administered, 2) it is multi-factorial, allowing sufficient detail to identify subtle change, 3) it provides questions specific to head and neck cancer, and 4) it allows no input from the health provider, thus reflecting the QOL as indicated by the patient'.

The current version 4 of the UW-QOL questionnaire⁷ consists of 12 single question domains, these having between 3 and 6 response options that are scaled evenly from 0 (worst) to 100 (best) according to the hierarchy of response. The domains are pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood and anxiety. Another question asks patients to choose up to three of these domains that have been the most important to them. There are also three global questions, one about how patients feel relative to before they developed their cancer, one about their health-related QOL and one about their overall QOL. In regard to their overall QOL patients are asked to consider not only physical & mental health, but also many other factors, such as family, friends, spirituality or personal leisure activities that were important to their enjoyment of life). The whole questionnaire focuses on current patient health and quality of life within the past 7 days.

Historical development: Version 1 had nine domains - pain, activity, recreation, employment, disfigurement, speech, swallowing, chewing and shoulder function. The UW-QOL has subsequently undergone three major revisions since it was first published (Table 1). In version 2, an importance-rating scale and three new single item 'quality of life' questions were added.⁴ In version 3 two new domains (taste, saliva) were added and the employment domain dropped.^{5,6} These changes addressed several shortcomings⁵, but version 3 still did not include an emotional domain. Because health-related quality of life refers to the physical, emotional, and social impact of diseases and their treatments on patients' lives, mood and anxiety was to version 4.⁷ The evolutionary development of the questionnaire together with the substantial number of published studies using the UW-QOL in combination with other measures have facilitated its rigorous validation.

More information on the UW-QOLv4 can be found at the following website www.headandneckcancer.co.uk

Table 1. Summary of development of the UW-QOL

Domain	Version 1	Version 2	Version 3	Version 4
Pain	X	X	X	X
Appearance	X	X	X	X
Activity	X	X	X	X
Recreation	X	X	X	X
Swallowing	X	X	X	X
Chewing	X	X	X	X
Speech	X	X	X	X
Shoulder	X	X	X	X
Taste	-	-	X	X
Saliva	-	-	X	X
Mood	-	-	-	X
Anxiety	-	-	-	X
Employment	X	X	-	-
Global QOL items	-	X	X	X
Free text	X	X	X	X
Importance rating	-	X	X	X

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Scoring of UW-QOL domains

The UW-QOL has domains based upon discrete ordinal responses. Scoring is scaled to so that a score of 0 represents the worst possible response, and a score of 100 represents the best possible response. Scoring is scaled in equal stages from 0 to 100 to reflect the number of possible responses. Thus the pain domain has 5 possible responses which are scored as 0, 25, 50, 75 & 100. See the UW-QOL questionnaire itself at the end of this document in which the scores are shown against each of the response options for each domain.

Presentation of domain scores.

This next table illustrates how basic UW-QOL data can be presented. The actual data used here comes from our use of the UW-QOL questionnaire since 1995, version 4 since 2000, by patients with oral/oro-pharyngeal SCC cancer whose primary treatment (1992-2009) was by surgery with or without adjuvant radiotherapy. For each domain the table gives the number of patients with each score, the mean and SE of patient scores, and the percentage selecting the best possible response (100). The shaded area denotes values that do not exist for that domain. These data come from 725 patients who were selected because they had QOL data between 9 months and 36 months after surgery. Some had several QOL records and for analysis we just included their record closest to 12 months after surgery. Overall there were 725 records, median 14 months, inter-quartile range 12-19 months, range 9-36 months after surgery.

UW-QOL	N	UW-QOL scores							Mean (SE of mean)	% Best Score (of 100)
		0	25	30	50	70	75	100		
Pain	717	10	50	138	162	357			78 (1)	50
Appearance	721	6	34	141	338	202			74 (1)	28
Activity	719	15	29	247	211	217			70 (1)	30
Recreation	722	8	51	150	299	214			73 (1)	30
Swallowing	719	30		81	276	332			76 (1)	46
Chewing	717	104		355		258			61 (1)	36
Speech	711	3		53	377	278			78 (1)	39
Shoulder	704	39		84	159	422			79 (1)	60
Taste *	561	38		120	154	249			70 (1)	44
Saliva *	554	44		120	154	236			69 (1)	43
Mood *	559	15	68	54	211	211			74 (1)	38
Anxiety *	557	29		68	257	203			72 (1)	36

*These were not in the earliest versions of the UW-QOL but were added later, hence fewer patients.

Standard deviation measures the scatter of raw data scores symmetrically about a mean and is less useful with ordered categorical data with few categories. Standard error measures the precision of the mean, and Mean +/- 2 SE is the approximate 95% confidence interval for the mean. Having few categories renders the median to be an insensitive measure and we therefore do not recommend it to summarise domain scores.

Global Questions

The UW-QOL has domains and general questions based upon discrete ordinal responses. The UW-QOL asks three global questions, one about how patients feel relative to before they developed their cancer, one about their health-related QOL and one about their overall QOL. These are now also scaled from 0 to 100 to enable ease of presentation of all key results using the same 0 to 100 scale. The results presented below are for the same patient group as described above for the previous table. The general question asking about overall QOL has 6 possible responses which are scored as 0, 20, 40, 60, 80 & 100.

	N	Question scores									Mean (SE of mean)	% Best Scores*
		0	20	25	40	50	60	75	80	100		
UW-QOL												
A. Health-related QOL compared to month before had cancer	497	36		90		210		68		93	55 (1)	75%
B. Health-related QOL during the past 7 days	501	9	36		118		177		136	25	59 (1)	67%
C. Overall QOL during the past 7 days	550	6	34		127		186		169	28	60 (1)	70%

KEY to ratings:

A: (0) Much worse (25) Somewhat worse (50) About the same (75) Somewhat better (100) Much better.

B: (0) V Poor (20) Poor (40) Fair (60) Good (80) V Good (100) Outstanding

C: (0) V Poor (20) Poor (40) Fair (60) Good (80) V Good (100) Outstanding

* BEST SCORES: A: % scoring 50, 75 or 100; B & C: % scoring 60, 80 or 100

Importance question

Rogers SN, Laher S, Overend L, Lowe D. Domain importance-rating using the UW-QOL questionnaire in patients treated by primary surgery for oral and oropharyngeal cancer. J Cranio-Maxillofacial Surgery 2002; 30: 125-132.

This asks about which three domain issues were the most important during the past 7 days. Patients are asked to choose up to 3 domains. A column for each domain should be created in the dataset with each column being scored either as '1' if that domain is chosen as important, otherwise as '0'. Very occasionally patients may choose more than 3 – and when this occurs we suggest you score all those they have chosen as '1'.

Results can be presented as % of patients choosing each domain. The domains can also be ranked in order. The data presented below are for the patients described earlier. The five main domains chosen at about 1-2 years after surgery were saliva, swallowing, speech, chewing and appearance. A mean of 2.3 domains were chosen.

N=557 patients

UW-QOL	N of patients choosing the domain	% of patients choosing the domain	Rank order
Saliva	183	33	1
Swallowing	163	29	2
Speech	145	26	3
Chewing	144	26	4
Appearance	99	18	5
Activity	93	17	6
Pain	89	16	7
Anxiety	88	16	8
Taste	85	15	9=
Mood	85	15	9=
Shoulder	73	13	11
Recreation	40	7	12

Defining a 'significant' problem

By comparing UW-QOL responses with responses to more in-depth questionnaires collected at the same time (concurrently) we have been able to suggest algorithm trigger cut-offs that define a 'significant problem' on each UW-QOL domain⁸.

The algorithms are very simply to apply and they use information from domain scores and from the importance question. They are given in the box below:

Significant problem trigger criteria:-
Pain, appearance, activity, recreation, mood: (scores of 0 or 25 or 50 & important)
Swallowing, speech, anxiety: (scores of 0 or 30)
Shoulder, taste, saliva: (scores or 0 or 30 & important)
Chewing: (score of 0)

A column for each domain should be created in the dataset with each column being scored either as '1' if the data suggest a 'significant' problem for the patient or otherwise as '0'.

For the same patient sample described earlier:

UW-QOL	N	N with significant problem	% With significant problem
Pain	686	102	15%
Appearance	688	81	12%
Activity	653	78	12%
Recreation	679	65	10%
Swallowing	719	111	15%
Chewing	717	104	15%
Speech	711	56	8%
Shoulder	689	69	10%
Taste	560	71	13%
Saliva	547	121	22%
Mood	558	92	16%
Anxiety	557	97	17%

Composite scores

Since the addition of anxiety and mood an overall composite score (a simple average of all domain scores) has not been recommended for use because the domains do not move in the same way after treatment. However, more recent work⁹ applying factor analysis to the above data, has suggested two subscale scores, one for 'Physical Function' and another for 'Social-Emotional Function'. The Physical subscale score is computed as the simple average of 6 domain scores – those of chewing, swallowing, speech, taste, saliva and appearance. The Social-Emotional subscale score is also computed as the simple average of 6 domain scores - those of anxiety, mood, pain, activity, recreation and shoulder function. Missing data for the UW-QOL is rare but to accommodate this it is suggested that the Physical and Social-emotional subscale scores be computed so long as there are at least 4 component domain scores available. '0' is the worst possible score, '100' the best possible score.

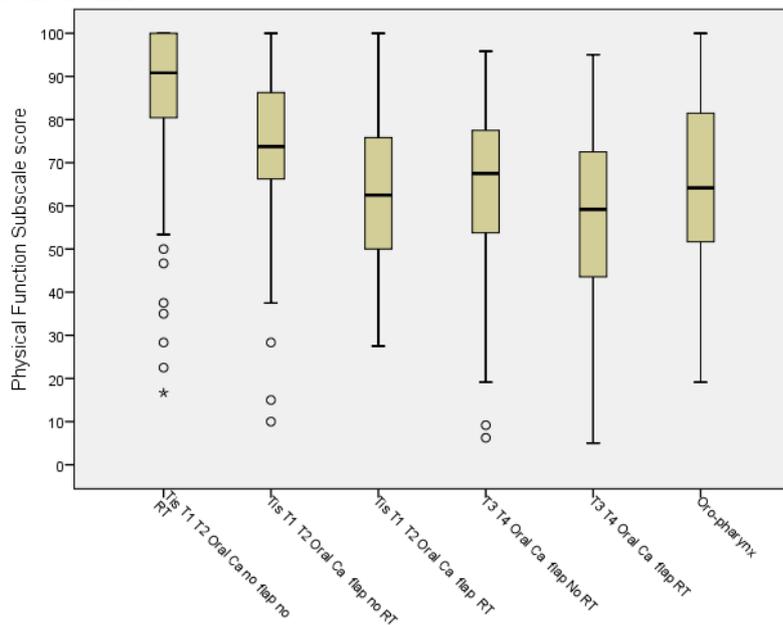
The scores can be regarded as numerical for the purpose of presentation. The overall median (Inter-Quartile Range) scores for the patients described earlier were:-

Physical Function: median 73 (IQR 57 to 88); mean 71 (SD 21), n=715

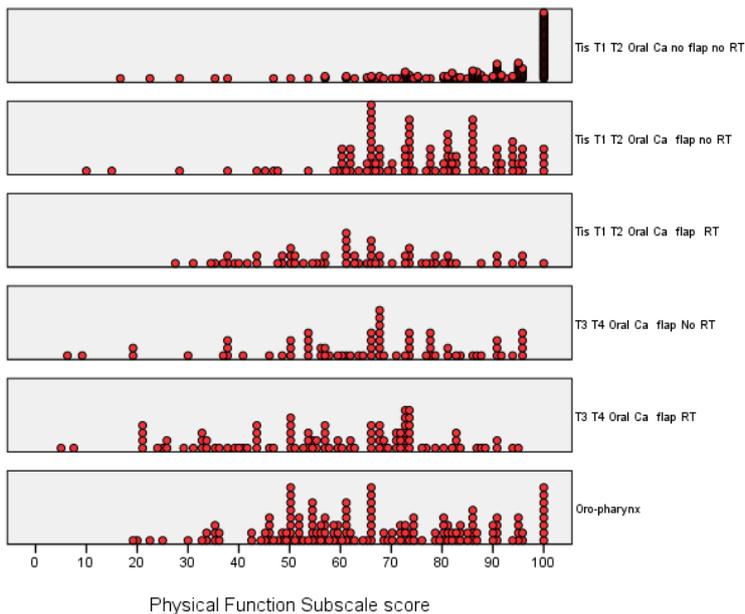
Social Function: median 79 (IQR 62 to 91); mean 74 (SD 20), n=717

No notable 'floor' or 'ceiling' effects can be observed.

A box-plot graphical representation is appropriate, as illustrated for Physical Function below for the patients described earlier.



A dot-plot also informs as it shows numerous points of precision and relative concentrations along the scale.



Subscale score interpretability

The data suggest that two subscales are more appropriate rather than a single composite¹² score⁹. One important area of further development is then to make meaningful clinical interpretations of differences in subscale scores.

Perhaps one of the best papers to demonstrate the value of subscales is Bekiroglu F et al. Oral Oncology 2011; 47: 967-973.

Effect size¹⁰ can be obtained by dividing mean change by the standard deviation (SD) in pre-change data, and a 'small' effect represents about 0.20 of SD, a 'moderate' effect about 0.50 of SD and a 'large' effect about 0.80 of SD. Our results at 1-2 years give subscale standard deviations of about 20 and thus imply a 'small' difference of about 4 subscale scale units, a 'moderate' difference of about 10 units and a 'large' difference of about 16 units. Other results for QOL obtained before treatment gave subscale standard deviations of 15, suggesting 3 units is a 'small' difference, 7.5 units a 'moderate' difference and 12 units a 'large' difference.

Ringash et al¹¹ defined a minimal important difference as the smallest difference that reflects a clinically important change in score and stated that most published minimal important difference estimates fell into the range 5-10% of the instrument range. Our results⁹ were consistent with this and suggested that 160 (80 per group) should be regarded as the minimum requirement for recruitment to a two-armed RCT to detect moderate differences in subscale scores after allowing for 20% patient attrition.

The UW-QOL questionnaire is brief and simple to complete. It has minimum patient burden and in spite of its brevity the questionnaire does have psychometric validity. The identification of two subscales, 'physical function' and 'social-emotional function', potentially increases its responsiveness and precision, and they are to be preferred to a single aggregate composite¹² score. Questionnaire analyses and reporting should include both the 'physical' and 'social-emotional function' subscales.

Normative reference scores

We used a dataset of 349 non-cancer patients routinely attending ten general dental practices¹² to compute 'normative' values. Age and gender reference data for the UW-QOL were collected from these patients and there were no obvious differences in physical and social-emotional function domain scores by age and gender.

The overall median (Inter-Quartile Range) normative scores were:
100 (95 to 100) for physical function
90 (74 to 100) for social-emotional function.

The mean (SD) scores were:
95 (10) for physical function
83 (19) for social-emotional function

UW-QOL domain Mean (SE of mean) scores	
	Routine attenders n=349
Pain	86 (1)
Appearance	93 (1)
Activity	86 (1)
Recreation	86 (1)
Swallowing	98 (1)
Chewing	94 (1)
Speech	98 (1)
Shoulder	91 (1)
Taste	95 (1)
Saliva	97 (1)
Mood	82 (1)
Anxiety	83 (1)

UW-QOL better-stable-worse fields combined with the Patient Concerns Inventory

Naseem Ghazali, Derek Lowe and Simon N Rogers. Enhanced Patient Reported Outcome Measurement Suitable for Head and Neck Cancer Follow-up Clinics Head & Neck Oncology (in press)

Of the 12 single question domains, patients can be also asked to state whether things had got worse (W), stayed the same (S) or got better (B) over the last month. The exact wording was 'For each domain, please indicate if things had got better, stayed the same or had got worse in the last month'.

The W-S-B question adds little questionnaire burden and could help to better identify patients who might benefit from intervention. The results of this study suggest that the UW-QOL with the W-S-B modification should be used together with the PCI to allow optimal identification of issues for patient-clinician discussion during routine outpatient clinics. If you have any questions about the scoring and presentation of the UW-QOLv4 please don't hesitate to contact Professor Rogers at snrogers@doctors.org.uk

Information about the PCI is available at: www.patient-concerns-inventory.co.uk
Rogers SN, El-Sheikha J, Lowe D. The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. *Oral Oncol.* 2009; 45: 555-561

References

Below is a selection of reference material. There are two articles that readers might find particularly helpful.

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Scott B, D'Souza J, Perinparajah N, Lowe D, Rogers SN Longitudinal evaluation of restricted mouth opening (trismus) in patient following primary surgery for oral and oropharyngeal squamous cell carcinoma. *BJOMS* 2011; 49: 106-111.

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University of Washington Quality of Life Questionnaire (UW-QOL v4)

*This questionnaire asks about your health and quality of life **over the past seven days**.
Please answer all of the questions by ticking one box for each question.*

1. **Pain.** (Tick one box:)

- I have no pain. (100)
There is mild pain not needing medication. (75)
I have moderate pain - requires regular medication (e.g. paracetamol). (50)
I have severe pain controlled only by prescription medicine (e.g. morphine). (25)
I have severe pain, not controlled by medication. (0)

2. **Appearance.** (Tick one box:)

- There is no change in my appearance. (100)
The change in my appearance is minor. (75)
My appearance bothers me but I remain active. (50)
I feel significantly disfigured and limit my activities due to my appearance. (25)
I cannot be with people due to my appearance. (0)

3. **Activity.** (Tick one box:)

- I am as active as I have ever been. (100)
There are times when I can't keep up my old pace, but not often. (75)
I am often tired and have slowed down my activities although I still get out. (50)
I don't go out because I don't have the strength. (25)
I am usually in bed or chair and don't leave home. (0)

4. **Recreation.** (Tick one box:)

- There are no limitations to recreation at home or away from home. (100)
There are a few things I can't do but I still get out and enjoy life. (75)
There are many times when I wish I could get out more, but I'm not up to it. (50)
There are severe limitations to what I can do, mostly I stay at home and watch TV (25)
I can't do anything enjoyable. (0)

5. **Swallowing.** (Tick one box:)

- I can swallow as well as ever. (100)
I cannot swallow certain solid foods. (70)
I can only swallow liquid food. (30)
I cannot swallow because it "goes down the wrong way" and chokes me. (0)

6. **Chewing.** (Tick one box:)

- I can chew as well as ever. (100)
I can eat soft solids but cannot chew some foods. (50)
I cannot even chew soft solids. (0)

7. **Speech.** (Tick one box:)

- My speech is the same as always. (100)
- I have difficulty saying some words but I can be understood over the phone. (70)
- Only my family and friends can understand me. (30)
- I cannot be understood. (0)

8. **Shoulder.** (Tick one box:)

- I have no problem with my shoulder. (100)
- My shoulder is stiff but it has not affected my activity or strength. (70)
- Pain or weakness in my shoulder has caused me to change my work / hobbies. (30)
- I cannot work or do my hobbies due to problems with my shoulder. (0)

9. **Taste.** (Tick one box:)

- I can taste food normally. (100)
- I can taste most foods normally. (70)
- I can taste some foods. (30)
- I cannot taste any foods. (0)

10. **Saliva.** (Tick one box:)

- My saliva is of normal consistency. (100)
- I have less saliva than normal, but it is enough. (70)
- I have too little saliva. (30)
- I have no saliva. (0)

11. **Mood.** (Tick one box:)

- My mood is excellent and unaffected by my cancer. (100)
- My mood is generally good and only occasionally affected by my cancer. (75)
- I am neither in a good mood nor depressed about my cancer. (50)
- I am somewhat depressed about my cancer. (25)
- I am extremely depressed about my cancer. (0)

12. **Anxiety.** (Tick one box:)

- I am not anxious about my cancer. (100)
- I am a little anxious about my cancer. (70)
- I am anxious about my cancer. (30)
- I am very anxious about my cancer. (0)

Which issues have been the most important to you during the past 7 days?

Tick **up to 3 boxes.**

Pain	Swallowing	Taste
Appearance	Chewing	Saliva
Activity	Speech	Mood
Recreation	Shoulder	Anxiety

GENERAL QUESTIONS

Compared to the month before you developed cancer, how would you rate your health-related quality of life? (Tick one box:)

Much better	(100)
Somewhat better	(75)
About the same	(50)
Somewhat worse	(25)
Much worse	(0)

In general, would you say your **health-related quality of life** during the past 7 days has been: (Tick one box:)

Outstanding	(100)
Very good	(80)
Good	(60)
Fair	(40)
Poor	(20)
Very poor	(0)

Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your **overall quality of life** during the past 7 days. (Tick one box:)

Outstanding	(100)
Very good	(80)
Good	(60)
Fair	(40)
Poor	(20)
Very poor	(0)

Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions (you may attach additional sheets if needed).