University of Washington Quality of Life Questionnaire
(UW-QOL v4 and v4.1)

Guidance for scoring and presentation

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1. Introduction

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

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 there has been a dramatic increase in the number of publications on HRQOL (Handle on QOL website). The impact of head and heck 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. The measurement of HRQOL outcomes is part of a national agenda such as 'Achieving world-class cancer outcomes: A strategy for England 2015-2020', national audits (BAHNO), and clinical trials. Ideally HRQOL should be longitudinally recorded. Questionnaires give a structured insight into the patients' point of view and are complemented by tools such as the item prompt list – Patient Concerns Inventory. 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.

There are many different questionnaires and the choice 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. However the advent of touch screen technology has created the possibility of paper-less collecting and collating of such data within the outpatient clinical setting so that it can inform real-time conversations between clinicians and patients. Few units are currently routinely collecting HRQOL information. In the past one of the barriers was the selection of the most appropriate questionnaire. There will never be a perfect head and neck questionnaire. The most commonly used are the EORTC, FACT and UW-QOL. 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 Weymuller 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'.

Version 4 of the UW-QOL questionnaire 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.

We now use what we call 'UW-QOL version 4.1', which in effect is the version 4 but with a few extras. In particular, there are two new domains added, one about intimacy (with 4 response options) and another about fears of recurrence (with 5 response options). These use the same logical hierarchical response format seen throughout version 4. There is also an importance question specific to these two new domains. Furthermore, for the existing saliva domain there is also an extra response option of 'too much saliva'. This was added because several patients raised this as an outcome and were unable to complete the saliva domain without an additional response. The change has been driven by the patients themselves.

Historical development: Version 1 had nine domains - pain, activity, recreation, employment, disfigurement, speech, swallowing, chewing and shoulder function. The UW-QOL has subsequently undergone various 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. In version 3 two new domains (taste, saliva) were added and the employment domain dropped. These changes addressed several shortcomings, 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. The new version 4.1 now includes domains for intimacy and fears of recurrence. Since the inception of the questionnaire there have been regular and substantial published studies using the UW-QOL in combination with other measures to facilitate validation.

More information on the UW-QOL and its translations can be found at the following website
http://www.hancsupport.com/professionals/quality-life/qol-questionnaires/uw-hrqol/uw-qol-v4-translations

Table 1. Summary of development of the UW-QOL

Domain	Version 1	Version 2	Version 3	Version 4	Version 4.1
Pain	X	X	X	X	X
Appearance	X	X	X	X	X
Activity	X	X	X	X	X
Recreation	X	X	X	X	X
Swallowing	X	X	X	X	X
Chewing	X	X	X	X	X
Speech	X	X	X	X	X
Shoulder	X	X	X	X	X
Taste	-	-	X	X	X
Saliva	-	-	X	X	X
Mood	-	-	-	X	X
Anxiety	-	-	-	X	X
Employment	X	X	-	-	-
Intimacy	-	-	-	-	X
Fear of recurrence	-	-	-	-	X
Global QOL items	-	X	X	X	x
Free text	X	X	X	X	X
Importance rating	-	X	X	X	X

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 results

We will first suggest how to present the results from version 4 of the UWQOL (UWQOLv4). For this we illustrate with results from our pool of results for all head and neck cancer patients treated between 1992 and 2012.

We then suggest how to present results from UWQOLv4.1 and for this we will illustrate with accumulating results between 2008 and 2016 from a different dataset collected using touch screen technology from oral cancer patients seeing one consultant at routine follow-up clinics and using the Patient Concerns Inventory (PCI).

2. Presentation of UWQOL v4

UWQOLv4 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 head and neck SCC cancer. 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 1571 patients who were selected because they had QOL data at least 9 months on from surgery (or diagnosis if no surgery). Some had several QOL records and for analysis we just included their record closest to 12 months after surgery. Overall the QOL record was a median 24 months, inter-quartile range 12-19 months, range 19-29 months after surgery.

		UW-QOL scores								
UW-QOL	N	0	25	30	50	70	75	100	Mean (SE of mean)	% Best Score (of 100)
Pain	1557	15	100		311		353	778	79 (1)	50
Appearance	1565	9	65		258		676	557	77 (1)	36
Activity	1562	27	56		563		435	481	71 (1)	31
Recreation	1559	21	104		290		647	497	74 (1)	33
Swallowing	1560	57		126		655		722	78 (1)	46
Chewing	1547	166			710			671	66 (1)	43
Speech	1543	23		111		704		705	80 (1)	46
Shoulder	1519	99		200		334		886	78 (1)	58
Taste *	1407	78		290		411		628	71 (1)	45
Saliva *	1383	112		300		413		558	68 (1)	40
Mood *	1404	37	159		141		509	558	75 (1)	40
Anxiety *	1398	66		173		625		534	70 (1)	38

*These were not in the earliest versions of the UW-QOL but were added later, hence fewer patients. Otherwise the variation in total numbers reflects missing data from the paper questionnaire returns. Note that the use of touch-screen data entry technology can prevent such loss of data.

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 the median to summarise domain scores.

Given the ordered categorical nature of the data then comparisons between two distinct patient groups (e.g. early Vs later clinical staging) can be made using the Mann-Whitney test, and between three of more distinct patient groups (e.g. surgery only Vs chemo/radiotherapy only Vs surgery and chemo/radiotherapy) can be made using the Kruskall-Wallis test.

Global Questions in UWQOLv4

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 can also be 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.

		Question scores										
UW-QOL	N	0	20	25	40	50	60	75	80	100	Mean (SE of mean)	% Best Scores**
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	1390	23	85		304		466		440	72	61 (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

* We have not really used these in recent work and the numbers here reflect the data we held in 2012.
** BEST SCORES: A: % scoring 50, 75 or 100; B & C: % scoring 60, 80 or 100 (i.e. the % with good or better overall QOL)

Given the ordered categorical nature of the data then comparisons between two distinct patient groups (e.g. early Vs later clinical staging) can be made using the Mann-Whitney test, and between three or more distinct patient groups (e.g. surgery only Vs chemo/radiotherapy only Vs surgery and chemo/radiotherapy) can be made using the Kruskall-Wallis test.

In regard to the Overall QOL we now usually focus on the % of patients with good or better QOL and for this either Fishers exact test (for 2 distinct patient groups being compared, such as early Vs later clinical stage) or chi-squared test (for 3 or more distinct groups, such as for treatment options) can be used.

Importance question in UWQOLv4

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'. Note that the use of touch-screen data collection technology can restrict the number selected to the most important 3 issues.

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

N=1411 patients

UW-QOLv4	Patients choosing the domain	% of patients choosing the domain	Rank order
Saliva	483	34	1
Swallowing	440	31	2
Speech	293	21	3
Chewing	278	20	4
Activity	244	17	5
Pain	232	16	6
Anxiety	226	16	7
Shoulder	220	16	8
Appearance	211	15	9
Taste	208	15	10
Mood	202	14	11
Recreation	130	9	12

Defining a 'significant' problem in UWQOLv4

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 domain.

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

Significant problem/dysfunction triggered by:-

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'.

UW-QOL	N	N with significant problem	% With significant problem*	95% CI for % with significant problem
Pain	1523	216	**14%**	12.5-16.0
Appearance	1537	144	**9%**	8.0-10.9
Activity	1505	185	**12%**	10.7-14.1
Recreation	1528	146	**10%**	8.1-11.1
Swallowing	1560	183	**12%**	10.2-13.4
Chewing	1547	166	**11%**	9.2-12.4
Speech	1543	134	**9%**	7.3-10.2
Shoulder	1509	186	**12%**	10.7-14.1
Taste	1407	171	**12%**	10.5-14.0
Saliva	1385	305	**22%**	19.9-24.3
Mood	1403	216	**15%**	13.5-17.4
Anxiety	1400	239	**17%**	15.2-19.2

* as defined by the algorithm

Just concentrating on the worse outcomes - an 'index of misery' so to speak - can be overly negative and it may also be helpful to see the effect on the other extreme, the proportion giving the best possible response. Logically there is a middle ground between these two extremes and by creating three categories - best response, significant problem/dysfunction and somewhere between these two extremes - we can get a simple summary of variation within each domain as well as a simple means of comparing distinct groups of patients by age, gender, tumour location, tumour staging and treatment modality.

UW-QOL	N	% with best response		% scoring between the two extremes		% with significant problem		95% CI for % with significant problem
Pain	1523	**51%**	778	**35%**	529	**14%**	216	12.5-16.0
Appearance	1537	**36%**	557	**54%**	836	**9%**	144	8.0-10.9
Activity	1505	**52%**	481	**56%**	839	**12%**	185	10.7-14.1
Recreation	1528	**33%**	497	**58%**	885	**10%**	146	8.1-11.1
Swallowing	1560	**46%**	722	**42%**	655	**12%**	183	10.2-13.4
Chewing	1547	**43%**	671	**46%**	710	**11%**	166	9.2-12.4
Speech	1543	**46%**	705	**46%**	704	**9%**	134	7.3-10.2
Shoulder	1509	**59%**	886	**29%**	437	**12%**	186	10.7-14.1
Taste	1407	**45%**	628	**43%**	608	**12%**	171	10.5-14.0
Saliva	1385	**40%**	558	**38%**	522	**22%**	305	19.9-24.3
Mood	1403	**40%**	558	**45%**	629	**15%**	216	13.5-17.4
Anxiety	1398	**38%**	534	**45%**	625	**17%**	239	15.2-19.2

Comparison of domain variation by clinical stage

UW-QOL	Clinical stage	N	% with best response		% scoring between the two extremes		% with significant problem		P value (significant problem)
Pain	Early	806	**61%**	489	**28%**	225	**11%**	92	0.001
	Late	696	**40%**	275	**43%**	300	**17%**	121	
Appearance	Early	817	**50%**	407	**44%**	356	**7%**	54	<0.001
	Late	698	**20%**	140	**67%**	469	**13%**	89	
Activity	Early	803	**39%**	313	**51%**	408	**10%**	82	0.009
	Late	680	**23%**	157	**62%**	423	**15%**	100	
Recreation	Early	808	**41%**	334	**52%**	421	**7%**	53	<0.001
	Late	699	**22%**	152	**65%**	455	**13%**	92	
Swallowing	Early	824	**63%**	515	**31%**	259	**6%**	50	<0.001
	Late	714	**28%**	197	**54%**	384	**19%**	133	
Chewing	Early	814	**56%**	454	**39%**	319	**5%**	41	<0.001
	Late	711	**29%**	207	**53%**	380	**17%**	124	
Speech	Early	814	**54%**	437	**41%**	335	**5%**	42	<0.001
	Late	708	**36%**	258	**51%**	360	**13%**	90	
Shoulder	Early	789	**68%**	537	**23%**	182	**9%**	70	<0.001
	Late	698	**48%**	333	**36%**	251	**16%**	114	
Taste	Early	747	**59%**	441	**34%**	253	**7%**	53	<0.001
	Late	639	**28%**	178	**54%**	345	**18%**	116	
Saliva	Early	737	**57%**	421	**31%**	225	**12%**	91	<0.001
	Late	627	**21%**	130	**45%**	285	**34%**	212	
Mood	Early	746	**49%**	362	**39%**	291	**12%**	93	0.001
	Late	636	**30%**	190	**51%**	324	**19%**	122	
Anxiety	Early	743	**41%**	303	**45%**	334	**14%**	106	0.003
	Late	635	**35%**	224	**44%**	282	**20%**	129	

There may be various tests of significance that one can apply to the above table depending on the part of the distribution of main interest.

If the main focus is on differences in the proportion with significant problems, as in the table above then Fishers exact test would provide the P value. The P value for Pain derives from using the cell frequencies of 714 (489+225) and 92 for early staging and 575 (275+300) and 121 for later staging.

If the interest is primarily on comparing the proportion having best responses then the Fishers exact test P value for Pain would derive from using the cell frequencies of 489 and 317 (225+92) for early staging and 275 and 421 (300+121) for later staging.

If the main interest is in comparing across the three domain groups between early and later staged patients (489,225,92 Vs 275,300,121 for pain) then either the chi- squared test or (given today's computing power) a Fishers exact test would generate a P value. The three domain categories however have an underlying order to them (best, middling, worse) and the Mann-Whitney test might be a more appropriate test.

Composite scores using the 12 UWQOLv4 domains

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, work applying factor analysis, 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.

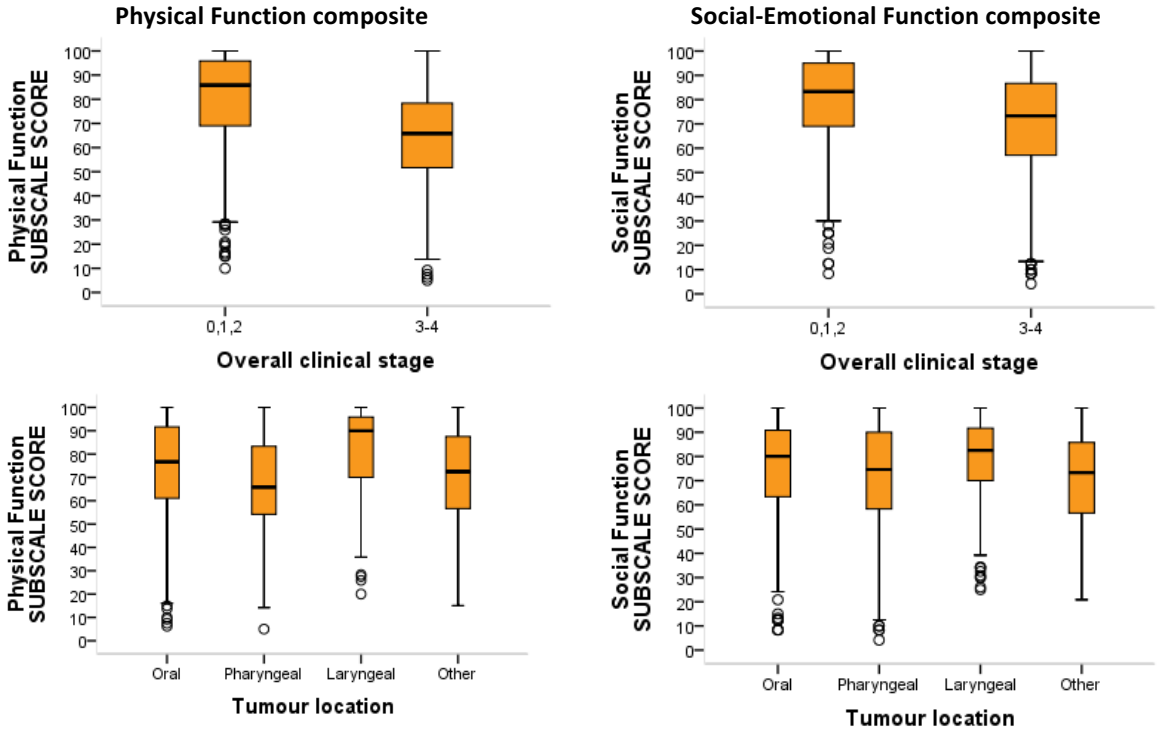
The scores can be regarded as numerical for the purpose of presentation.

The overall median (Inter-Quartile Range) scores for the patients described earlier were:-

- Physical Function: median 73 (IQR 60 to 91); mean 73 (SD 21), n=1556
- Social Function: median 78 (IQR 63 to 91); mean 75 (SD 20), n=1560

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

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



Given the ordered categorical nature of the composite scores and the skewness of the distributions we usually compare between two distinct patient groups (e.g. early Vs later clinical staging) using the Mann-Whitney test, and between three of more distinct patient groups (e.g. between tumour locations) using the Kruskall-Wallis test.

UWQOLv4 composite score interpretability

The data suggest that two composite subscale scores are more appropriate rather than a single composite12 domain score. One important area of further development was to make meaningful clinical interpretations of differences in subscale scores.

Effect size[10] 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 al[11] 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 results were consistent with this and suggested that 160 (80 per group) should be regarded as the minimum requirement for recruitment to a two-armed Randomised Controlled Trial to detect moderate differences in subscale scores after allowing for 20% patient attrition.

The UW-QOLv4 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 composite 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.

2. The UWQOL v4.1

Scoring of the new saliva domain

The UWQOL V4 saliva domain has four possible responses scored as: 100='My saliva is of normal consistency', 70= 'I have less saliva than normal, but it is enough', 30= 'I have too little saliva' and 0=' I have no saliva'. One limitation of this domain was that for some time many patients have reported difficulty in answering it because they had too much saliva. From 2008 as part of a wider touch-screen data collection underpinning the development of the Patient Concerns Inventory (PCI-HN) (Ref our 2009 paper) we have added the response option of 'too much saliva'.

The new 'too much saliva' response option doesn't fit hierarchically alongside the rest of the saliva responses, and at the time of writing this update we are not sure how it ought to be scored within the range 0-100. Patients having too much saliva previously responded as having saliva of normal consistency (since other options indicate too little) and would have been scored as 100. For now the allocated score to having too much saliva should also be as 100. Further research is required.

Significant problem/dysfunction algorithm for the new saliva domain

At the time of writing this update the occurrence of having too much saliva does not trigger the algorithm in analysis and in presentation, which remains as either a score of 0 (I have no saliva) or as a score of 30 (I have too little saliva) if selected as one of the three most important issues by the patient. This may need revising following further research on the scoring of the new response option.

Scoring of the new intimacy domain

0=I have major problems with intimacy and this causes me considerable concern
30=I have problems with intimacy and this causes me some concern
70=I have problems with intimacy but it does not bother me very much
100= I have no problems with intimacy as a result of my cancer

Scoring of the new fears of recurrence domain

0=I am fearful all the time that my cancer might return and I struggle with this
25=I get a lot of fears of recurrence and these can really preoccupy my thoughts
50=I am sometimes having fearful thoughts but I can usually manage these
75=I have a little fear, with occasional thoughts but I can usually manage these
100=I have no fear of recurrences

Importance question relating to intimacy and fears of recurrence

This is a separate add-on question that asks specifically about the importance of these two domains.

Which of these issues have been important to you during the past 7 days? Tick ✓
Intimacy ☐ Fear of Recurrence ☐

This is asked separately because it then doesn't affect the balance of the responses selected to the three most important issues for the patient from the 12 domains of the UWQOLv4, responses which in turn affect the algorithms for indicating a significant problem/dysfunction on the 12 domains.

Defining a 'significant' problem for intimacy and fears of recurrence

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

Significant problem/dysfunction triggered by:-

Intimacy: (scores or 0 or 30 & important)
Fears of recurrence: (scores of 0 or 25 or 50 & important)

UWQOLv4.1 Domain scores

This next table illustrates how basic UW-QOL data can be presented. The actual data used here comes from our touch-screen dataset 2008-2016 comprising 1506 pre-consultation records from 511 oral cancer patients attending routine outpatient reviews, median (IQR) per patient of 2 (1-4). 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.

1506 pre-consultation records from 511 oral cancer patients attending routine outpatient reviews, apart from for intimacy and fears of recurrence that were added later during the study period.

		UW-QOL scores							Mean (SE of mean)	% Best Score (of 100)
UW-QOL	N	0	25	30	50	70	75	100		
Pain	1506	26	124		332		288	736	76 (1)	49%
Appearance	1506	16	43		251		609	587	78 (1)	39%
Activity	1506	30	57		535		425	459	70 (1)	30%
Recreation	1506	23	103		257		617	506	75 (1)	34%
Swallowing	1506	68		189		575		674	75 (1)	45%
Chewing	1506	215			711			580	62 (1)	39%
Speech	1506	14		133		660		699	80 (1)	46%
Shoulder	1506	62		181		357		906	80 (1)	60%
Taste	1506	115		340		416		635	68 (1)	42%
Saliva	1506	134		339		392		641*	63 (1)	43%
Mood	1506	34	181		147		589	555	74 (1)	37%
Anxiety	1506	63		201		728		514	72 (1)	34%
Intimacy	1436	54		128		230		1024	85 (1)	71%
Fears of recurrence	464	14	31		127		210	82	67 (1)	18%

*of which 420 (28%) had saliva of normal consistency and 221 had too much saliva
** with saliva normal consistency only, i.e. excluding those with too much saliva

Importance question in UWQOLv4.1

There are two questions about importance: firstly as in UWQOLv4 asking about which three domain issues were the most important during the past 7 days from the 12 domains of the UWQOLv4; secondly asking separately about the importance for each of the two new domains intimacy and fears of recurrence.

Results can be presented as the % of patients choosing each domain. The 12 UWQOLv4 domains can also be ranked in order.

UW-QOLv4	Patients choosing the domain as one of 3 from 12 important to them during the past 7 days (N=1506 consultations)	% of patients choosing the domain	Rank order
Saliva	602	40	1
Swallowing	382	25	2
Chewing	351	23	3
Pain	329	22	4
Speech	264	18	5
Anxiety	246	16	6
Shoulder	220	15	7
Taste	191	13	8
Mood	162	11	9
Appearance	155	10	10
Activity	100	7	11
Recreation	39	3	12
	Patients choosing the domain as important to them during the past 7 days	% of patients choosing the domain	
Intimacy	54/1436	4	
Fears of recurrence	35/464	8	

Defining a 'significant' problem in UWQOLv4.1

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

Significant problem/dysfunction triggered by:-

Pain, appearance, activity, recreation, mood, fears of recurrence: (scores of 0 or 25 or 50 & important)

Swallowing, speech, anxiety: (scores of 0 or 30)

Shoulder, taste, saliva, intimacy: (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'.

UW-QOL	N	N with significant problem	% With significant problem*	95% CI for % with significant problem
Pain	1506	293	**19%**	17.5-21.5
Appearance	1506	128	**8%**	7.1-10.0
Activity	1506	136	**9%**	7.6-10.6
Recreation	1506	132	**9%**	7.4-10.3
Swallowing	1506	257	**17%**	15.2-19.1
Chewing	1506	215	**14%**	12.5-16.1
Speech	1506	147	**10%**	8.3-11.4
Shoulder	1506	144	**10%**	8.1-11.2
Taste	1506	211	**14%**	12.3-15.9
Saliva	1506	360	**24%**	21.8-26.1
Mood	1506	238	**16%**	14.0-17.7
Anxiety	1506	264	**18%**	15.6-19.5
Intimacy	1436	72	**5%**	3.9-6.3
Fears of recurrence	464	59	**13%**	9.8-16.1

* as defined by the algorithm

Just concentrating on the worse outcomes - an 'index of misery' so to speak - can be overly negative and it may also be helpful to see the effect on the other extreme, the proportion giving the best possible response. Logically there is a middle ground between the two extremes and by creating three categories - best response, significant problem/dysfunction and somewhere between these two extremes - we can get a simple summary of variation within each domain as well as a simple means of comparing distinct groups of patients by age, gender, tumour location, tumour staging and treatment modality.

UW-QOL	N	% with best response		% between the two extremes		% with significant problem		95% CI for % with significant problem
Pain	1506	**49%**	736	**32%**	477	**19%**	293	12.5-16.0
Appearance	1506	**39%**	587	**53%**	791	**8%**	128	8.0-10.9
Activity	1506	**30%**	459	**60%**	911	**9%**	136	10.7-14.1
Recreation	1506	**34%**	506	**58%**	868	**9%**	132	8.1-11.1
Swallowing	1506	**45%**	674	**38%**	575	**17%**	257	10.2-13.4
Chewing	1506	**39%**	580	**47%**	711	**14%**	215	9.2-12.4
Speech	1506	**46%**	699	**44%**	660	**10%**	147	7.3-10.2
Shoulder	1506	**60%**	906	**30%**	456	**10%**	144	10.7-14.1
Taste	1506	**42%**	635	**44%**	660	**14%**	211	10.5-14.0
Saliva	1506	**43%**	641	**34%**	505	**24%**	360	19.9-24.3
Mood	1506	**37%**	555	**47%**	713	**16%**	238	13.5-17.4
Anxiety	1506	**34%**	514	**48%**	728	**18%**	264	15.2-19.2
Intimacy	1436	**71%**	1024	**24%**	340	**5%**	72	3.9-6.3
Fears of recurrence	464	**18%**	82	**70%**	323	**13%**	59	9.8-16.1

Best response= score of 100.

Composite scores using the UWQOLv4.1

We recommend using the composite scores as derived and validated for the UWQOLv4 (see earlier section).

The Physical subscale score is computed as the simple average of 6 domain scores – those of chewing, swallowing, speech, taste, saliva and appearance. At the moment for this purpose patients having too much saliva score 100, the same as if their saliva was of normal consistency.

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, especially if touch-screen technology is used, 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.

At this present time, the two new domains intimacy and fears of recurrence are not part of the composite scoring.

Significance testing using the UWQOLv4.1

See the relevant sections for the UVQOLv4.

3. Normative reference scores

We used a dataset of 349 non-cancer patients routinely attending ten general dental practices[12] 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)

If you have any questions about the scoring and presentation of the UW-QOL please don't hesitate to contact Professor Rogers at snrogers.aintree@gmail.com

Reference material

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An excellent source of additional reference can be found at HaNDLE-on-QoL.
http://www.handle-on-qol.com/About.aspx
This is a unique online searchable database of all papers published from 1982 to present on quality of life in head and neck cancer that have used questionnaires. The search facility allows a specific search on the UW-QOL.

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).

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   - ☐ 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)

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   - ☐ 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)

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   - ☐ 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: ☑)

- ☐ I have too much saliva (100)
- ☐ 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)

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- ☐ 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

13. **Intimacy**. (Tick one box: ☑)

- ☐ I have no problem with intimacy as a result of my cancer (100)
- ☐ I have problems with intimacy but it does not bother me very much (70)
- ☐ I have problems with my intimacy and this causes me some concern (30)
- ☐ I have major problems with intimacy and this causes me considerable concern (0)

14. **Fear of cancer recurrence**. (Tick one box: ☑)

- ☐ I have no fear of recurrence (100)
- ☐ I have a little fear, with occasional thoughts but they don't really bother me (75)
- ☐ I am sometimes having fearful thoughts but I can usually manage these (50)
- ☐ I get a lot of fears of recurrence and these can really preoccupy my thoughts (25)
- ☐ I am fearful all the time that my cancer might return and I struggle with this (0)

Which of these issues have been important to you during the past 7 days? Tick ☑ **up to 2 boxes.**

Intimacy ☐ Fear of Recurrence ☐

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: ☑)

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- ☐ 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).