University of Washington Quality of Life Questionnaire

**(UW-QOL v4 and v4.1)**

# Guidance for scoring and presentation

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***(Updated 28-8-2020)***

**1. Introduction**

# This updated guidance sets out the preferred way for scoring and presenting the UW-QOL. For those using SPSS, relevant syntax for UW-QOLv4.1 is given at the end of this document.

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 (at Aintree) 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 4.1now 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 can be found at the following website <http://www.hancsupport.com.>

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 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 UW-QOL (UW-QOLv4). For this we illustrate with results from our pool of results for all head and neck cancer patients treated between 1992 and 2012 for whom we have UW-QOLv4 data on from March 2000 to March 2013. The first available UW-QOLv4 record after 9 months from diagnosis was analysed for 1424 patients.

We then suggest how to present results from UW-QOLv4.1 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). The first available UW-QOLv4.1 records for 511 patients were analysed.

**2. Presentation of UW-QOL v4**

***UW-QOLv4 Domain scores***

This next table illustrates how basic UW-QOLv4 data can be presented. For each domain the table gives the number of patients with each score, the mean scores, and the percentage selecting the best possible response (100). The shaded area denotes values that do not exist for that domain. Overall the QOL record was a median (IQR) 18.8 (13.8-27.8) months after diagnosis.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | |  | UW-QOL scores | | | | | | | Mean | %  Best  Score  (of 100) |
| UW-QOL | | N | 0 | 25 | 30 | 50 | 70 | 75 | 100 |
| Physical function subscale: | | | | | | | | | | | |
| Appearance | 1419 | | 4 | 57 |  | 234 |  | 600 | 524 | 78 | 37 |
| Swallowing | 1420 | | 56 |  | 111 |  | 606 |  | 647 | 78 | 46 |
| Chewing | 1409 | | 146 |  |  | 643 |  |  | 620 | 67 | 44 |
| Speech | 1406 | | 19 |  | 110 |  | 626 |  | 651 | 80 | 46 |
| Taste | 1413 | | 79 |  | 302 |  | 386 |  | 646 | 71 | 46 |
| Saliva | 1391 | | 121 |  | 296 |  | 404 |  | 570 | 68 | 41 |
| Social-emotional subscale: | | | | | | | | | | | |
| Pain | 1410 | | 15 | 83 |  | 285 |  | 328 | 699 | 79 | 50 |
| Activity | 1418 | | 23 | 40 |  | 521 |  | 390 | 444 | 71 | 31 |
| Recreation | 1419 | | 13 | 90 |  | 268 |  | 584 | 464 | 75 | 33 |
| Shoulder | 1386 | | 82 |  | 198 |  | 293 |  | 813 | 78 | 59 |
| Mood | 1413 | | 34 | 164 |  | 143 |  | 530 | 542 | 74 | 38 |
| Anxiety | 1408 | | 69 |  | 172 |  | 651 |  | 516 | 73 | 37 |

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 gives 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 UW-QOLv4***

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. In recent work we have only used the overall QOL question and have tended to focus on a binary categorisation – the % with less than good overall QOL (scores of 0, 20 or 40).

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | |  | Question scores | | | | | | | | |  |  |
| UW-QOL | | N | 0 | 20 | 25 | 40 | 50 | 60 | 75 | 80 | 100 | Mean | %  Best  Scores\*\* |
| A. Health-related QOL compared to month before had cancer\* | 497 | | 36 |  | 90 |  | 210 |  | 68 |  | 93 | 55 | 75 |
| B. Health-related QOL during the past 7 days\* | 501 | | 9 | 36 |  | 118 |  | 177 |  | 136 | 25 | 59 | 67 |
| C. Overall QOL during the past 7 days | 1390 | | 23 | 85 |  | 304 |  | 466 |  | 440 | 72 | 61 | 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

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 binary categorisation of Overall QOL (% with less than good overall QOL) Fishers exact test is preferred to test between 2 or more distinct patient groups (e.g. early Vs later clinical staging), with the chi-squared test as a possible approximate alternative.

***Importance question in UW-QOLv4***

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 four main domains chosen at about 2 years after surgery were saliva, swallowing, speech and chewing.

N=1409 patients

|  |  |  |  |
| --- | --- | --- | --- |
| UW-QOLv4 | Patients choosing the domain | % of patients choosing the domain | Rank order |
| Saliva | 478 | 34 | 1 |
| Swallowing | 417 | 30 | 2 |
| Speech | 337 | 24 | 3 |
| Chewing | 303 | 22 | 4 |
| Appearance | 242 | 17 | 5 |
| Activity | 237 | 17 | 6 |
| Pain | 232 | 16 | 7 |
| Anxiety | 228 | 16 | 8 |
| Mood | 210 | 15 | 9 |
| Shoulder | 209 | 15 | 10 |
| Taste | 200 | 14 | 11 |
| Recreation | 126 | 9 | 12 |

***Defining a ‘significant’ problem in UW-QOLv4***

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

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 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | |  | N with significant problem | %  With significant problem\* |  |
| UW-QOL | | N | 95% Confidence Interval for % with significant problem |
| Physical function subscale: | | | | | |
| Appearance | 1419 | | 145 | **10** | 8.7-11.9 |
| Swallowing | 1420 | | 167 | **12** | 10.1-13.6 |
| Chewing | 1409 | | 146 | **10** | 8.8-12.1 |
| Speech | 1406 | | 129 | **9** | 7.7-10.8 |
| Taste | 1413 | | 166 | **12** | 10.1-13.5 |
| Saliva | 1390 | | 315 | **23** | 20.5-25.0 |
| Social-emotional subscale: | | | | | |
| Pain | 1409 | | 211 | **15** | 13.2-16.9 |
| Activity | 1414 | | 167 | **12** | 10.2-13.6 |
| Recreation | 1417 | | 121 | **9** | 7.1-10.1 |
| Shoulder | 1386 | | 165 | **12** | 10.2-13.7 |
| Mood | 1412 | | 222 | **16** | 13.9-17.7 |
| Anxiety | 1408 | | 241 | **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 | Best response | | Between the two extremes | | Significant problem | |
|  |  | **%** | N | **%** | N | **%** | N |
| Physical function subscale: | | | | | | | |
| Appearance | 1419 | **37** | 524 | **53** | 750 | **10** | 145 |
| Swallowing | 1420 | **46** | 647 | **43** | 606 | **12** | 167 |
| Chewing | 1409 | **44** | 620 | **46** | 643 | **10** | 146 |
| Speech | 1406 | **46** | 651 | **45** | 626 | **9** | 129 |
| Taste | 1413 | **46** | 646 | **43** | 601 | **12** | 166 |
| Saliva | 1390 | **41** | 570 | **36** | 505 | **23** | 315 |
| Social-emotional subscale: | | | | | | | |
| Pain | 1409 | **50** | 699 | **35** | 499 | **15** | 211 |
| Activity | 1414 | **31** | 444 | **57** | 803 | **12** | 167 |
| Recreation | 1417 | **33** | 464 | **59** | 832 | **9** | 121 |
| Shoulder | 1386 | **59** | 813 | **29** | 408 | **12** | 165 |
| Mood | 1412 | **38** | 542 | **46** | 648 | **16** | 222 |
| Anxiety | 1408 | **37** | 516 | **46** | 651 | **17** | 241 |

**Comparison of domain variation by clinical stage**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| UW-QOL | Clinical stage | N | Best response | | Between the two extremes | | Significant problem | | P value\* (significant problem) |
|  |  |  | **%** | N | **%** | N | **%** | N |  |
| Physical function subscale: | | | | | | | | | |
| Appearance | Early | 765 | **51** | 387 | **43** | 327 | **7** | 51 | <0.001 |
|  | Late | 639 | **21** | 131 | **65** | 415 | **15** | 93 |
| Swallowing | Early | 769 | **61** | 472 | **33** | 252 | **6** | 45 | <0.001 |
|  | Late | 636 | **26** | 166 | **55** | 348 | **19** | 122 |
| Chewing | Early | 758 | **56** | 427 | **39** | 299 | **4** | 32 | <0.001 |
|  | Late | 636 | **29** | 185 | **53** | 337 | **18** | 114 |
| Speech | Early | 758 | **54** | 410 | **40** | 301 | **6** | 47 | <0.001 |
|  | Late | 633 | **36** | 231 | **51** | 321 | **13** | 81 |
| Taste | Early | 766 | **60** | 460 | **33** | 253 | **7** | 53 | <0.001 |
|  | Late | 632 | **28** | 179 | **54** | 343 | **17** | 110 |
| Saliva | Early | 753 | **56** | 424 | **30** | 223 | **14** | 106 | <0.001 |
|  | Late | 623 | **23** | 144 | **44** | 273 | **33** | 206 |
| Social-emotional subscale: | | | | | | | | | |
| Pain | Early | 760 | **59** | 451 | **29** | 218 | **12** | 91 | 0.002 |
|  | Late | 634 | **38** | 241 | **44** | 279 | **18** | 114 |
| Activity | Early | 765 | **40** | 306 | **51** | 391 | **9** | 68 | <0.001 |
|  | Late | 634 | **21** | 135 | **64** | 404 | **15** | 95 |
| Recreation | Early | 767 | **42** | 325 | **52** | 401 | **5** | 41 | <0.001 |
|  | Late | 636 | **21** | 134 | **67** | 423 | **12** | 79 |
| Shoulder | Early | 743 | **68** | 505 | **23** | 171 | **9** | 67 | <0.001 |
|  | Late | 628 | **47** | 298 | **37** | 234 | **15** | 96 |
| Mood | Early | 763 | **45** | 347 | **42** | 318 | **13** | 98 | 0.001 |
|  | Late | 634 | **30** | 192 | **50** | 319 | **19** | 123 |
| Anxiety | Early | 762 | **39** | 294 | **48** | 365 | **14** | 103 | <0.001 |
|  | Late | 631 | **35** | 219 | **44** | 277 | **21** | 135 |

\*Fishers exact test

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 669 (451+218) and 91 for early staging and 520 (241+279) and 114 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 451 and 309 (218+91) for early staging, 241 and 393 (279+114) for later staging.

If the main interest is in comparing across the three domain groups between early and later staged patients (451,218,91 Vs 241,279,114 for pain) then either Fishers exact test (preferably) or the chi- squared 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 for comparing two groups; the Kruskal-Wallis test for comparing more than two groups.

***Composite scores using the 12 UW-QOLv4 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, workapplying factor analysis, has suggested two subscale scores, one for ‘Physical Function’ and another for ‘Social-Emotional Function’9. 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 77 (IQR 59 to 91); mean 73 (SD 21), n=1422
* Social Function: median 78 (IQR 63 to 91); mean 75 (SD 20), n=1424

No notable ‘floor’ or ‘ceiling’ effects can be observed.

A box-plot graphical representation is suitable, as illustrated below:

|  |  |
| --- | --- |
| **Physical Function composite** | **Social-Emotional Function composite** |
|  |  |
|  |  |

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.

## UW-QOLv4 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 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 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 UW-QOL v4.1**

***Scoring of the new saliva domain***

The UW-QOLv4 saliva domain had 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'. From paper questionnaire surveys before 2007 it was clear that some patients had difficulty in responding because they had too much saliva and many settled for ‘(100) my saliva is of normal consistency’ as this was the closest option. Adding a new 'too much saliva' response posed the question of how to score this within the range 0-100. Subsequent research12 incorporating a wide range of HRQOL outcomes indicated that HNC patients with too much saliva (16%) had outcomes similar to those with too little or no saliva at all. This implied a score at the lower end of the 0-100 scale and for pragmatic reasons patients having too much saliva were allocated the same score as those having too little saliva, i.e. a score of 30. Though the scores are the same the two distinct response options should be stated on the UW-QOLv4.1 questionnaire. An inevitable consequence of amending the saliva domain is that the saliva mean scores will be lower when compared with historical data; how much lower depends on the ratio of patients with ‘too much saliva’ to ‘too little saliva’ in the sample being analysed. The physical function subscale score, which is the mean of six domain scores including saliva, will also be lower when compared with historical data.

***Significant problem/dysfunction algorithm for the new saliva domain***

The trigger for the saliva dysfunction is either a score of 0 (I have no saliva) or as a score of 30 (I have too little or too much saliva) if selected as one of the three most important issues by the patient.

***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 

We kept the questions about the importance of these two domains in the past week separate from a similar question asking about importance of the 12 UW-QOLv4 domains. This was because UW-QOLv4 asks patients to select at most 3 from the 12 domains that have been important to them during the past week. To have thrown the two new domains into the mix would have asked patients to select at least 3 from 14 which would have affected the balance of the responses that form an integral part of the algorithms for indicating a significant problem/dysfunction in each of the 12 domains.

***UW-QOLv4.1 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 the first available record from 511 oral cancer patients attending routine outpatient reviews. For each domain the table gives the number of patients with each score, the mean scores, and the percentage selecting the best possible response (100).

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | |  | UW-QOL scores | | | | | | | Mean | % Best Score  (of 100) |
| UW-QOLv4.1 | | N | 0 | 25 | 30 | 50 | 70 | 75 | 100 |
| Physical function subscale: | | | | | | | | | | | |
| Appearance | 511 | | 6 | 16 |  | 101 |  | 214 | 174 | 76 | 34 |
| Swallowing | 511 | | 27 |  | 60 |  | 199 |  | 225 | 75 | 44 |
| Chewing | 511 | | 78 |  |  | 238 |  |  | 195 | 61 | 38 |
| Speech | 511 | | 5 |  | 50 |  | 221 |  | 235 | 79 | 46 |
| Taste | 511 | | 41 |  | 122 |  | 127 |  | 221 | 68 | 43 |
| Saliva | 511 | | 38 |  | 195\* |  | 120 |  | 158 | 59 | 31 |
| Social-emotional subscale: | | | | | | | | | | | |
| Pain | 511 | | 9 | 49 |  | 126 |  | 91 | 236 | 74 | 46 |
| Activity | 511 | | 11 | 23 |  | 187 |  | 140 | 150 | 69 | 29 |
| Recreation | 511 | | 6 | 41 |  | 88 |  | 194 | 182 | 75 | 36 |
| Shoulder | 511 | | 25 |  | 56 |  | 109 |  | 321 | 81 | 63 |
| Mood | 511 | | 12 | 69 |  | 50 |  | 193 | 187 | 73 | 37 |
| Anxiety | 511 | | 26 |  | 68 |  | 249 |  | 168 | 71 | 33 |
| Additional domains: | | | | | | | | | | | |
| Intimacy | 494 | | 21 |  | 50 |  | 77 |  | 346 | 84 | 70 |
| Fear of recurrence | 141 | | 4 | 9 |  | 40 |  | 64 | 24 | 67 | 17 |

The shaded areas denote scores that are not possible for that domain

\*of which 105 had too little saliva and 90 had too much saliva.

Note that under UW-QOLv4, 105 patients would have been scored as 30 and 248 (158+90) scored as 100, with a mean score of 71 and 49% having the best score.

***Defining a ‘significant’ problem in UW-QOLv4.1***

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:** scores of 0 or 25 or (50 & important)  **Swallowing, speech, anxiety:** scores of 0 or 30  **Shoulder, taste, saliva:** scores of 0 or (30 & important)  **Chewing:** (score of 0)  **Intimacy:** scores of 0 or (30 & important)  **Fears of recurrence:** scores of 0 or 25 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | |  | N with significant problem | %  With significant problem\* |  |
| UW-QOL | | N | 95% CI for % with significant problem |
| Physical function subscale: | | | | | |
| Appearance | 511 | | 53 | **10** | 7.9-13.3 |
| Swallowing | 511 | | 87 | **17** | 13.9 -20.6 |
| Chewing | 511 | | 78 | **15** | 12.3-18.7 |
| Speech | 511 | | 55 | **11** | 8.2-13.8 |
| Taste | 511 | | 76 | **15** | 11.9-18.3 |
| Saliva | 511 | | 166 | **32** | 28.4-36.7 |
| Social-emotional subscale: | | | | | |
| Pain | 511 | | 118 | **23** | 19.5-27.0 |
| Activity | 511 | | 51 | **10** | 7.5-12.9 |
| Recreation | 511 | | 49 | **10** | 7.2-12.5 |
| Shoulder | 511 | | 54 | **11** | 8.0-13.6 |
| Mood | 511 | | 87 | **17** | 13.9-20.6 |
| Anxiety | 511 | | 94 | **18** | 15.1-22.0 |
| Additional domains: |  | |  |  |  |
| Intimacy | 494 | | 27 | **5** | 3.6-7.9 |
| Fears of recurrence | 141 | | 13 | **9** | 5.0-15.3 |

\* 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 | | % scoring between the two extremes | | % with significant problem | |
|  |  | **%** | N | **%** | N | **%** | N |
| Physical function subscale: | | | | | | | |
| Appearance | 511 | **34** | 174 | **56** | 284 | **10** | 53 |
| Swallowing | 511 | **44** | 225 | **39** | 199 | **17** | 87 |
| Chewing | 511 | **38** | 195 | **47** | 238 | **15** | 78 |
| Speech | 511 | **46** | 235 | **43** | 221 | **11** | 55 |
| Taste | 511 | **43** | 221 | **42** | 214 | **15** | 76 |
| Saliva | 511 | **31** | 158 | **37** | 187 | **32** | 166 |
| Social-emotional subscale: | | | | | | | |
| Pain | 511 | **46** | 236 | **31** | 157 | **23** | 118 |
| Activity | 511 | **29** | 150 | **61** | 310 | **10** | 51 |
| Recreation | 511 | **36** | 182 | **55** | 280 | **10** | 49 |
| Shoulder | 511 | **63** | 321 | **27** | 136 | **11** | 54 |
| Mood | 511 | **37** | 187 | **46** | 237 | **17** | 87 |
| Anxiety | 511 | **33** | 168 | **49** | 249 | **18** | 94 |
| Additional domains: | | | | | | | |
| Intimacy | 494 | **70** | 346 | **24** | 121 | **5** | 27 |
| Fear of recurrence | 141 | **17** | 24 | **74** | 104 | **9** | 13 |

Note that under UW-QOLv4, the saliva row would have read 49% (248) with best score , 30% (151) intermediate category and 22% (112) with significant problem

***Composite scores using the UW-QOLv4.1***

We recommend using the composite scores as derived and validated for the UW-QOLv4 (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.

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.

The two new domains of intimacy and fears of recurrence are not part of the composite scoring.

For the 511 oral cancer patients:

* Median (IQR) social-emotional subscale score was 78 (62-91), with mean (standard deviation) of 74 (19).
* Median (IQR) physical function subscale score, with ‘too much saliva’ scored as 30’, was 70 (54-91), with mean (standard deviation) of 70 (22).
* Reverting back to UW-QOLv4 with ‘too much saliva scored as 100’ the median (IQR) was 73 (57-91) and mean (standard deviation) was72 (21).

***Significance testing using the UW-QOLv4.1***

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 practices13 to compute ‘normative’ values. Age and gender reference data for the UW-QOLv4 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@doctors.org.uk

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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 speechis 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).

**University of Washington Quality of Life Questionnaire**

**(UW-QOL v4.1)**

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 speechis 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 (30)

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

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: 🗹 )

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).

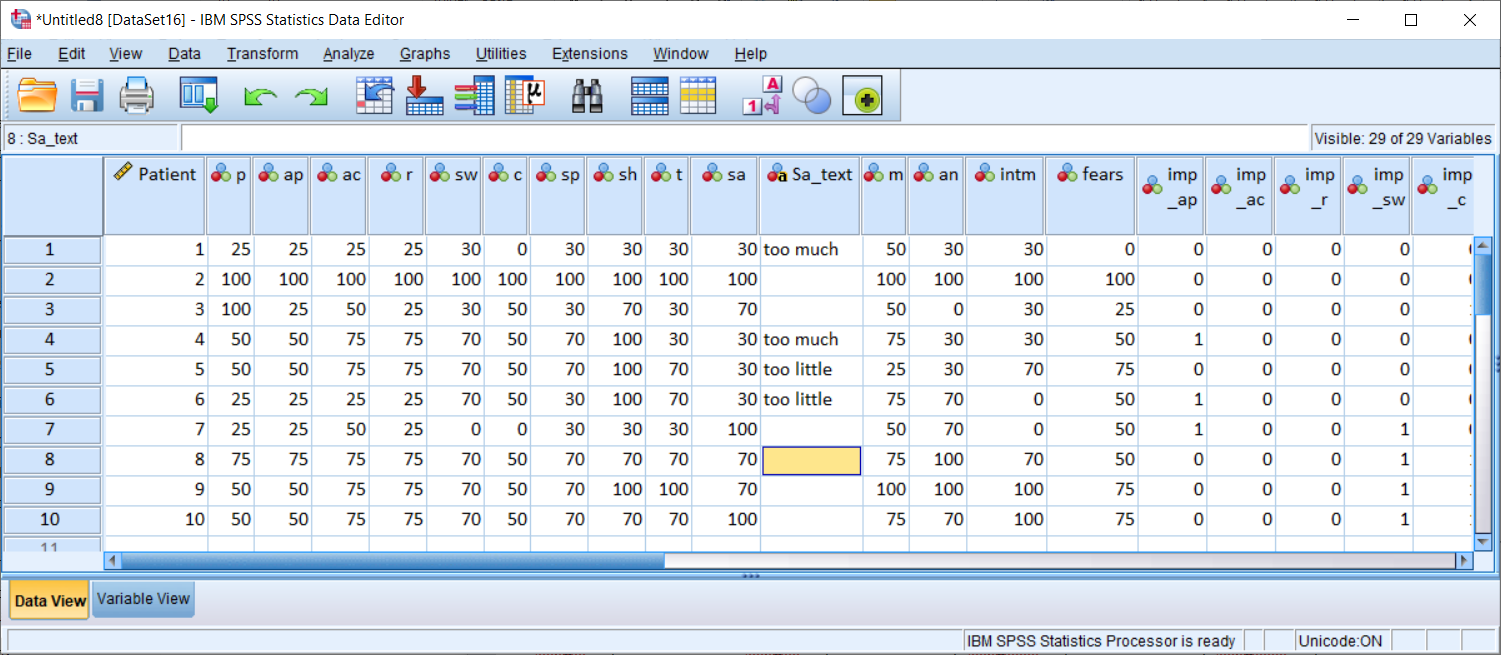
SPSS SYNTAX FOR UW-QOL v4.1

First you name the UW-QOL domains and then score the responses as in the table below. The dataset will comprise patients (rows) and UW-QOL data (columns). For each patient you enter the scores of each domain (e.g. 0,25,50,75,100) according to the questionnaire above as well as whether the domain was important to the patient (0 or 1). We suggest you also create an extra column for saliva that retains the distinction between too little and too much saliva, both scored as 30. The syntax ran fine using SPSS v25, but should run OK for earlier versions as well. For missing data just leave the data cell blank.

|  |  |  |
| --- | --- | --- |
| Variable name | Variable label | Possible values for the response options (0=worst, 100=best) |
| Domain scores: |  |  |
| p | Pain | 0,25,50,75,100 |
| ap | Appearance | 0,25,50,75,100 |
| ac | Activity | 0,25,50,75,100 |
| r | Recreation | 0,25,50,75,100 |
| sw | Swallowing | 0,30,70,100 |
| c | Chewing | 0,50,100 |
| sp | Speech | 0,30,70,100 |
| sh | Shoulder | 0,30,70,100 |
| t | Taste | 0,30,70,100 |
| sa | Saliva | 0,30\*,70,100 |
| m | Mood | 0,25,50,75,100 |
| an | Anxiety | 0,30,70,100 |
| intm | Intimacy | 0,30,70,100 |
| fears | Fear of recurrence | 0,25,50,75,100 |
| Importance of domain: | | |
| imp\_p | Pain | 1=Yes, 0=No |
| imp\_ap | Appearance | 1=Yes, 0=No |
| imp\_ac | Activity | 1=Yes, 0=No |
| imp\_r | Recreation | 1=Yes, 0=No |
| imp\_sw | Swallowing | 1=Yes, 0=No |
| imp\_c | Chewing | 1=Yes, 0=No |
| imp\_sp | Speech | 1=Yes, 0=No |
| imp\_sh | Shoulder | 1=Yes, 0=No |
| imp\_t | Taste | 1=Yes, 0=No |
| imp\_sa | Saliva | 1=Yes, 0=No |
| imp\_m | Mood | 1=Yes, 0=No |
| imp\_an | Anxiety | 1=Yes, 0=No |
| imp\_p | Intimacy | 1=Yes, 0=No |
| imp\_ap | Fear of recurrence | 1=Yes, 0=No |

\*too little saliva and too much saliva both scored as 30

The dataset will look something like this:



NOTE that If you want to run the syntax for UW-QOLv4 then you will still need to insert columns for intimacy (intm, imp\_intm) and fear of recurrence (fears, imp\_fears) and leave the data cells blank, otherwise some of the later syntax will not work properly.

**SPSS SYNTAX - ONCE YOU HAVE YOUR DATASET DEFINED AS ABOVE THEN COPY EVERYTHING BELOW (including the comments) INTO AN SPSS SYNTAX FILE AND PRESS THE RUN BUTTON.**

COMMENT: the following syntax will create SPSS variable labels and SPSS value labels.

VARIABLE LABELS p 'Pain' ap 'Appearance' ac 'Activity' r 'recreation' sw 'Swallowing' c 'Chewing' sp 'Speech' sh 'Shoulder' t 'Taste'

sa 'Saliva' m 'Mood' an 'Anxiety' intm 'Intimacy' fears 'Fears of recurrence' imp\_p 'Importance of Pain' imp\_ap 'Importance of appearance'

imp\_ac 'Importance of activity' imp\_r 'Importance of recreation' imp\_sw 'Importance of swallowing' imp\_c 'Importance of chewing'

imp\_sp 'Importance of speech' imp\_sh 'Importance of shoulder' imp\_t 'Importance of taste' imp\_sa 'Importance of saliva'

imp\_m 'Importance of mood' imp\_an 'Importance of anxiety' imp\_intm 'Importance of intimacy' imp\_fears 'Importance of fears of recurrence'.

EXECUTE.

VALUE LABELS p

0 'I have severe pain, not controlled by medication'

25 'I have severe pain controlled only by prescription medicine (eg morphine)'

50 'I have moderate pain - requires regular medication (eg paracetamol)'

75 'There is mild pain not needing medication'

100 'I have no pain'.

EXECUTE.

VALUE LABELS ap

0 'I cannot be with people due to my appearance'

25 'I feel significantly disfigured and limit my activities due to my appearance'

50 'My appearance bothers me but I remain active'

75 'The change in my appearance is minor'

100 'There is no change in my appearance'.

EXECUTE.

VALUE LABELS ac

0 'I am usually in bed or chair and dont leave home'

25 'I dont go out because I dont have the strength'

50 'I am often tired and have slowed down my activities although I still get out'

75 'There are times when I cant keep up my old pace but not often'

100 'I am as active as I have ever been'.

EXECUTE.

VALUE LABELS r

0 'I cant do anything enjoyable'

25 'There are severe limitations to what I can do, mostly I stay at home at watch TV'

50 'There are many times when I wish I could get out more, but Im not up to it'

75 'There are a few things I cant do but I still get out and enjoy life'

100 'There are no limitations to recreation at home or away from home'.

EXECUTE.

VALUE LABELS sw

0 'I cannot swallow because it goes down the wrong way and chokes me'

30 'I can only swallow liquid food'

70 'I cannot swallow certain solid foods'

100 ' I can swallow as well as ever'.

EXECUTE.

VALUE LABELS c

0 'I cannot even chew soft solids'

50 'I can eat soft solids but cannot chew some foods'

100 'I can chew as well as ever'.

EXECUTE.

VALUE LABELS sp

0 'I cannot be understood'

30 'Only my family and friends can understand me'

70 'I have difficulty saying some words but I can be understood over the phone'

100 'My speech is the same as always'.

EXECUTE.

VALUE LABELS sh

0 'I cannot work or do my hobbies due to problems with my shoulder'

30 'Pain or weakness in my shoulder has caused me to change my work/hobbies'

70 'My shoulder is stiff but it has not affected my activity or strength'

100 'I have no problem with my shoulder'.

EXECUTE.

VALUE LABELS t

0 'I cannot taste any foods'

30 'I can taste some foods'

70 'I can taste most foods normally'

100 'I can taste food normally'.

EXECUTE.

VALUE LABELS sa

0 'I have no saliva'

30 'I have too little / too much saliva'

70 'I have less saliva than normal, but it is enough'

100 'My saliva is of normal consistency'.

EXECUTE.

VALUE LABELS m

0 'I am extremely depressed about my cancer'

25 'I am somewhat depressed about my cancer'

50 'I am neither in a good mood nor depressed about my cancer'

75 'My mood is generally good and only occasionally affected by my cancer'

100 'My mood is excellent and unaffected by my cancer'.

EXECUTE.

VALUE LABELS an

0 'I am very anxious about my cancer.'

30 'I am anxious about my cancer'

70 'I am a little anxious about my cancer'

100 'I am not anxious about my cancer'.

EXECUTE.

VALUE LABELS intm

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'.

EXECUTE.

VALUE LABELS fears

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 they dont really bother me'

100 'I have no fear of recurrence'.

EXECUTE.

RECODE imp\_p imp\_ap imp\_ac imp\_r imp\_sw imp\_c imp\_sp imp\_sh imp\_t imp\_sa imp\_m imp\_an imp\_intm imp\_fears (1=1) (0=0) (MISSING=9).

EXECUTE.

VALUE LABELS imp\_p imp\_ap imp\_ac imp\_r imp\_sw imp\_c imp\_sp imp\_sh imp\_t

Imp\_sa imp\_m imp\_an imp\_intm imp\_fears

1 'Yes'

0 ‘No’

9 'Missing'.

EXECUTE.

COMMENT: the following syntax computes the physical function and social-emotional subscale scores.

COMPUTE PHYSICAL=MEAN.4(ap,sw,c,sp,t,sa).

EXECUTE.

COMPUTE SOCEMOT=MEAN.4(an,m,p,sh,r,ac).

EXECUTE.

RECODE PHYSICAL SOCEMOT (MISSING=999) (0 thru 49.999999999999=1) (50.000000 thru 59.999999999=2) (60.00000000 thru 69.999999999=3)

(70.0000000 thru 79.9999999=4) (80.0000000 thru 89.9999999999=5) (90.0000000000 thru 100=6) INTO PHYSg SOCEMg.

VARIABLE LABELS PHYSICAL 'Physical function subscale score' SOCEMOT 'Social-emotional function subscale score'

SOCEMg 'Social - Emotional subscale score' PHYSg 'Physical function subscale score'.

EXECUTE.

VALUE LABELS PHYSg SOCEMg 1 '<50' 2 '50-59' 3 '60-69' 4 '70-79' 5 '80-89' 6 '90-100' 999 'NK'.

EXECUTE.

COMMENT: The following syntax runs an algorithm to indicate dysfunction.

IF (p = 0 | p = 25 |(p = 50 & imp\_p = 1)) ALGp=1.

EXECUTE.

IF (p = 100 | p = 75 |(p = 50 & imp\_p = 0)) ALGp=0.

EXECUTE.

VARIABLE LABELS ALGp 'Significant Pain problem flagged by algorithm'.

EXECUTE.

IF (ap = 0 | ap = 25 |(ap = 50 & imp\_ap = 1)) ALGap=1.

EXECUTE.

IF (ap = 100 | ap = 75 |(ap = 50 & imp\_ap = 0)) ALGap=0.

EXECUTE.

VARIABLE LABELS ALGap 'Significant Appearance problem flagged by algorithm'.

EXECUTE.

IF (ac = 0 | ac = 25 |(ac = 50 & imp\_ac = 1)) ALGac=1.

EXECUTE.

IF (ac = 100 | ac = 75 |(ac = 50 & imp\_ac = 0)) ALGac=0.

EXECUTE.

VARIABLE LABELS ALGac 'Significant Activity problem flagged by algorithm'.

EXECUTE.

IF (r = 0 | r = 25 |(r = 50 & imp\_r = 1)) ALGr=1.

EXECUTE.

IF (r = 100 | r = 75 |(r = 50 & imp\_r = 0)) ALGr=0.

EXECUTE.

VARIABLE LABELS ALGr 'Significant Recreation problem flagged by algorithm'.

EXECUTE.

IF (sw = 0 | sw = 30) ALGsw=1.

EXECUTE.

IF (sw = 100 | sw = 70 ) ALGsw=0.

EXECUTE.

VARIABLE LABELS ALGsw 'Significant Swallowing problem flagged by algorithm'.

EXECUTE.

IF (c = 0 ) ALGc=1.

EXECUTE.

IF (c = 100 | c = 50 ) ALGc=0.

EXECUTE.

VARIABLE LABELS ALGc 'Significant Chewing problem flagged by algorithm'.

EXECUTE.

IF (sp = 0 | sp = 30) ALGsp=1.

EXECUTE.

IF (sp = 100 | sp = 70 ) ALGsp=0.

EXECUTE.

VARIABLE LABELS ALGsp 'Significant Speech problem flagged by algorithm'.

EXECUTE.

IF (sh = 0 |(sh = 30 & imp\_sh = 1)) ALGsh=1.

EXECUTE.

IF (sh = 100 | sh = 70 |(sh = 30 & imp\_sh = 0)) ALGsh=0.

EXECUTE.

VARIABLE LABELS ALGsh 'Significant Shoulder problem flagged by algorithm'.

EXECUTE.

IF (t = 0 |(t = 30 & imp\_t = 1)) ALGt=1.

EXECUTE.

IF (t = 100 | t = 70 |(t = 30 & imp\_t = 0)) ALGt=0.

EXECUTE.

VARIABLE LABELS ALGt 'Significant Taste problem flagged by algorithm'.

EXECUTE.

IF (sa = 0 |(sa = 30 & imp\_sa = 1)) ALGsa=1.

EXECUTE.

IF (sa = 100 | sa=65 | sa = 70 |(sa = 30 & imp\_sa = 0)) ALGsa=0.

EXECUTE.

VARIABLE LABELS ALGsa 'Significant Saliva problem flagged by algorithm'.

EXECUTE.

IF (m = 0 | m = 25 |(m = 50 & imp\_m = 1)) ALGm=1.

EXECUTE.

IF (m = 100 | m = 75 |(m = 50 & imp\_m = 0)) ALGm=0.

EXECUTE.

VARIABLE LABELS ALGm 'Significant Mood problem flagged by algorithm'.

EXECUTE.

IF (an = 0 | an = 30) ALGan=1.

EXECUTE.

IF (an = 100 | an = 70 ) ALGan=0.

EXECUTE.

VARIABLE LABELS ALGan 'Significant Anxiety problem flagged by algorithm'.

EXECUTE.

IF (intm = 0 |(intm = 30 & imp\_intm = 1)) ALGintm=1.

EXECUTE.

IF (intm = 100 | intm = 70 |(intm = 30 & imp\_intm = 0)) ALGintm=0.

EXECUTE.

VARIABLE LABELS ALGintm 'Significant Intimacy problem flagged by algorithm'.

EXECUTE.

IF (fears = 0 | fears = 25) ALGfears=1.

EXECUTE.

IF (fears= 100 | fears= 75 | fears=50) ALGfears=0.

EXECUTE.

VARIABLE LABELS ALGfears 'Significant Fears of recurrence problem flagged by algorithm'.

EXECUTE.

RECODE ALGp ALGap ALGac ALGr ALGsw ALGc ALGsp ALGsh ALGt ALGsa ALGm ALGan ALGintm ALGfears(1=1) (0=0) (MISSING=9).

EXECUTE.

VALUE LABELS ALGp ALGap ALGac ALGr ALGsw ALGc ALGsp ALGsh ALGt ALGsa ALGm ALGan

ALGintm ALGfears

1 'Dysfunction'

9 'Missing'.

EXECUTE.

COMMENT: the following syntax creates three categories for each domain - 1. dysfunction, 3. best score (100)

and 2. somewhere between these two extremes.

IF (p=100) p3=1.

EXECUTE.

IF (ap=100) ap3=1.

EXECUTE.

IF (ac=100) ac3=1.

EXECUTE.

IF (r=100) r3=1.

EXECUTE.

IF (sw=100) sw3=1.

EXECUTE.

IF (c=100) c3=1.

EXECUTE.

IF (sp=100) sp3=1.

EXECUTE.

IF (sh=100) sh3=1.

EXECUTE.

IF (t=100) t3=1.

EXECUTE.

IF (sa=100) sa3=1.

EXECUTE.

IF (m=100) m3=1.

EXECUTE.

IF (an=100) an3=1.

EXECUTE.

IF (intm=100) intm3=1.

EXECUTE.

IF (fears=100) fears3=1.

EXECUTE.

IF (ALGp=1) p3=3.

EXECUTE.

IF (ALGap=1) ap3=3.

EXECUTE.

IF (ALGac=1) ac3=3.

EXECUTE.

IF (ALGr=1) r3=3.

EXECUTE.

IF (ALGsw=1) sw3=3.

EXECUTE.

IF (ALGc=1) c3=3.

EXECUTE.

IF (ALGsp=1) sp3=3.

EXECUTE.

IF (ALGsh=1) sh3=3.

EXECUTE.

IF (ALGt=1) t3=3.

EXECUTE.

IF (ALGsa=1) sa3=3.

EXECUTE.

IF (ALGm=1) m3=3.

EXECUTE.

IF (ALGan=1) an3=3.

EXECUTE.

IF (ALGintm=1) intm3=3.

EXECUTE.

IF (ALGfears=1) fears3=3.

EXECUTE.

IF (ALGp=9) p3=9.

EXECUTE.

IF (ALGap=9) ap3=9.

EXECUTE.

IF (ALGac=9) ac3=9.

EXECUTE.

IF (ALGr=9) r3=9.

EXECUTE.

IF (ALGsw=9) sw3=9.

EXECUTE.

IF (ALGc=9) c3=9.

EXECUTE.

IF (ALGsp=9) sp3=9.

EXECUTE.

IF (ALGsh=9) sh3=9.

EXECUTE.

IF (ALGt=9) t3=9.

EXECUTE.

IF (ALGsa=9) sa3=9.

EXECUTE.

IF (ALGm=9) m3=9.

EXECUTE.

IF (ALGan=9) an3=9.

EXECUTE.

IF (ALGintm=9) intm3=9.

EXECUTE.

IF (ALGfears=9) fears3=9.

EXECUTE.

RECODE p3 ap3 ac3 r3 sw3 c3 sp3 sh3 t3 sa3 m3 an3 intm3 fears3 (1=1) (3=3) (9=9) (MISSING=2).

EXECUTE.

VARIABLE LABELS p3 'Pain' ap3 'Appearance' ac3 'Activity' r3 'recreation' sw3 'Swallowing' c3 'Chewing'

sp3 'Speech' sh3 'Shoulder' t3 'Taste' sa3 'Saliva' m3 'Mood' an3 'Anxiety' intm3 'Intimacy' fears3 'Fears of recurrence' .

EXECUTE.

VALUE LABELS p3 ap3 ac3 r3 sw3 c3 sp3 sh3 t3 sa3 m3 an3 intm3 fears3

1 'best score (100)'

2 'Intermediate - between the extremes'

3 'Significant problem/dysfunction'

9 'Missing' .

EXECUTE.