ACTG QOL 601-602 (QOL 601-2) Health Survey Manual

Overview

Quality of life measures are increasingly being recognized as important when comparing the efficacy of AIDS therapies and assessing the impact of HIV/AIDS on peoples' lives. An important question in all HIV/AIDS evaluations is how the virus and related disease, medications and other treatment regimens affect quality of life. The purpose of this manual is to present the procedures involved in measuring patients' quality of life using the ACTG QOL 601-602 survey (QOL 601-2) and to provide a reference for questions that may arise.

For most study coordinators, the most effective way to use this manual is to first read it over and familiarize yourself with the QOL 601-2. This initial reading will introduce you to background information, general interviewing principles and the details of administration.

Background

Overview of Quality of Life Measurement

What is it?

Quality of life is a concept about which everyone has an intuitive understanding, but which is still difficult to define. It is worth differentiating between quality of life and health-related quality of life. Quality of life is a broad construct that can be affected by many factors including income, housing situation, social interactions, and health. In clinical trials, we are particularly interested in how medical or pharmacologic interventions affect health-related quality of life. There is general agreement that health-related quality of life includes at least a person's physical, social, and cognitive functioning and subjective sense of well-being.

Why is quality of life important?

It is important to understand the impact of a disease on many aspects of patients' lives. Furthermore, it is important that the effects of drug treatment and other medical regimens translate into benefits that patients can experience -- that the drug or treatment will help them function and feel better. Although traditional outcomes, such as mortality, physiologic changes, and adverse events provide useful clinical and biological information, they may not accurately represent the effect of treatment on the patient's physical, psychological, and social functioning and their subjective sense of well-being.

In addition, some of the effects of a drug or treatment may be in areas not accessible to physiologic measurement, and may only be evaluated using patients' assessments. These areas might include effects on energy, pain, or generally how patients feel. Although treatments frequently influence these parameters, a clinical trial is unlikely to demonstrate effects in these areas if patient-reported outcomes are excluded.

In AIDS clinical trials, patient-reported health-related quality of life may be especially important when all the therapies being tested are expected to result in physiologic improvement and survival. In these studies, the most important difference in treatment outcome may be the patients' experience.

Quality of life scales have the additional advantage of integrating the positive effects of treatment and the negative effects of treatment and disease to give "net" effects in measurable areas. Without such measures, it can be difficult to interpret if a drug that causes some symptoms and prevents others has a beneficial effect overall. For example, it is difficult for a clinician to decide whether a patient should take a drug that is known to cause headache and anorexia but decreases fatigue.

Ultimately, knowledge of drug or treatment effects on patients' quality of life will allow clinicians to tell patients about the anticipated effects of a treatment in terms they can understand.

How do we measure it?

In general, health-related quality of life is measured by asking a series of questions about specific aspects of functioning and well-being. Asking a series of questions about a specific aspect, such as mental health, allows for a more precise approximation of the person's emotional state. For example, the answers to three questions about mental health can be added up to give an indication of the person's mental health.

Over the past twenty years, significant advances have been made in quality of life measurement. There are a number of well-validated instruments, some of which are comprehensive and intended for use as outcome variables in research studies, and others which are shorter and may be more useful in multicenter clinical trials (Kaplan, Bergner, Brook, Stewart).

The QOL 601-2 traces its genealogy back to several of these well-tested questionnaires, particularly those developed in the late 1970's for the RAND Health Insurance Experiment, and the mid 1980's for the Medical Outcomes Study.

Advantages of patient-reported data on quality of life.

Patient reported data has a number of unique advantages over other sources of data. Most importantly, this form of data gives researchers access to information that is not available from any other source, and which is of great importance to the patient. The most relevant and valid information about ability to function and quality of life must come from the person her/himself. This position is supported by the fact that both clinicians' and family members' estimates of functioning are less reliable, and often do not agree with those of the patient (Sprangers, Wu and Jacobson). (Of course, in those cases where the patient's viewpoint is not known and cannot be obtained, a surrogate's estimate of the patient's functioning and well-being may be used if there is reason to believe that the surrogate accurately represents the patient's views.)

Disadvantages of patient-reported data on quality of life

To a greater extent than with data from other sources, missing quality of life data are precisely the data that you are most interested in having. For example, a patient who misses a visit for a reason related to health is also likely to have worse-than-average quality of life. Therefore, it is important to incorporate strategies to minimize missing data, to document reasons for missing data, and to obtain answers from reliable surrogates when possible.

Patient reports of their quality of life are by their nature subjective. Patient-reported data can differ from data obtained on the patient from other sources. For example, in general patients tend to be more optimistic about their abilities than family members or physicians. Or they may judge their health to be better than others would. Patient reported data can also be idiosyncratic. This may be because of are sources of variability in patients' responses that are not related to the treatment they are receiving. In addition, some aspects of patient's quality of life can be influenced by things other than their illness or treatment. For example, if a person gets evicted from housing, his or her mood may be transiently depressed. This is a source of legitimate variability in a person's quality of life, and will be reflected in the answers they give to the questionnaire. Nonetheless, patient-reported responses are legitimate perceptions of what the patient thinks or feels. Fortunately, we have the benefit of randomization in clinical trials, and there is little reason to believe that such non-health related events will be unevenly distributed between treatment groups.

Development of QOL 601-602

The QOL 601-2 survey is a brief, comprehensive measure of health-related quality of life used extensively in Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). Questions in the QOL 601-2 were drawn from a large pool of existing questions that had been extensively tested for use in the Medical Outcomes Study, a large multi-site study of the effects of different ways of delivering medical care.

A 21-item shorter version (SF-21) of the SF-38 was recently published (Bozzette). Goals of item selection and reduction were to maintain a comprehensive range of dimensions assessed using multi-item scales. Items for the shorter subscales were selected based on the static and dynamic relationships to the longer scales and to indicators of clinical and functional status in 10,399 responses from 1,934 participants. The resulting instrument retains the SF-38 subscales: physical functioning, role functioning, pain, current health perceptions, emotional well-being, cognitive functioning, energy/fatigue, and social functioning. The visual analog scale (overall health) is scored separately.

The ACTG SF-21 (ACTG forms QOL601 and QOL602) is closely related the SF-21. Minor modification were made by the ACTG Outcomes Committee with feedback from community members. An item asking about 'trouble remembering things' was substituted for one asking 'did you forget things that have happened'. Minor changes in working were made to simplify and update items. A visual analog scale health rating item was added after the overall health item, with the intention that the two tend to be recorded at each clinic visit at the time of vital signs collection. The visual analog scale is anchored at 'death or worst possible health (as bad or worse than being dead)' and 'perfect or best health (without HIV infection)' and is intended to provide an estimate of health preference. This item is scored separately from the descriptive subscales.

Factor-analysis based physical and mental health component scores will be available for the ACTG SF-21. A regression-based perceived health index, derived using the same method used for the SF-38 index, is available for both the SF-21 and ACTG-21. The instruments are available in a U.S. Spanish version and take 4-5 minutes to self-administer.

Summary of Concepts and Measures

The QOL 601-2 Health Survey consists of 21 questions which assess 9 dimensions of health-related quality of life including overall health, general health perceptions, physical functioning, role functioning, pain, social functioning, mental health, energy, cognitive functioning. (see Table 1) Eight of the 9 subscales of the QOL 601-2 are scored as summated rating scales on a 0 - 100 scale where higher scores indicate better health. For multi-item scales (two or more items), mean substitution is generally used for missing items if no more than 50% of the items are missing. The feeling thermometer ranges from 0-100. This subscale score is the score indicated on the thermometer by the patient. The QOL 601-2 instrument takes less than 5 minutes to complete and can be self-administered using paper and pencil or a touch screen personal computer or administered as a face-to-face or telephone interview. A brief description of each dimension is presented below.

Feeling thermometer- This is a visual analog scale with a range from 0-100. The lowest score of 0 represents 'death or worst possible health' and 100 represents 'perfect or best possible health'.

General Health Perceptions - This dimension retains two items measuring current health, and a single item general health rating item from the SF-20. Individual items in the scale ask patients to report on their general health, resistance to illnesses and health outlook. Davies and Ware (1981) and Stewart and Ware (1992) have reported substantial empirical evidence of validity for this scale.

Physical Functioning - This dimension consists of four items that assess physical limitations ranging from severe to minor. These items represent different levels and kinds of limitations including lifting heavy objects or participating in strenuous sports, walking uphill or climbing a few flights of stairs. Limitations in self-care activities are measured with a single item assessing the ability to eat, dress, bath or use the toilet by oneself.

The response categories permit estimation of the severity of each limitation. Early versions of these questions measured the duration of each reported limitation. However, most physical limitations are chronic in nature and thus, measures of duration are of little value for data analysis. (Stewart et al., 1981) Analytical precision is increased with the ability to distinguish between patients who are able to perform physical activities with and without some degree of difficulty. (Stewart and Kamberg, 1992) Like the SF-36, the QOL 601-2 Health Survey utilizes a three-level response continuum that measures both the presence and degree of physical limitations. (Ware, 1993).

Table 1. Summary of Health-related QOL Concepts

		Meaning of Scores	
Concepts	**No. of Items**	**Low**	**High**
Feeling thermometer	1	Death or worst possible health (as bad or worse than being dead)	Perfect or best possible health (without HIV infection)
General Health Perceptions	3	Views personal health as poor	Views personal health as excellent
Physical Functioning	4	Very limited in performing physical activities due to poor health including eating, dressing, bathing or using the toilet	Performs all types of physical activities due to poor health including vigorous or strenuous activities without limitations
Role Functioning	2	As a result of physical health, experiences problems with work or daily activities	No problems with work or other daily activities as a result of health
Pain	2	Very severe and limiting pain	No pain or limitations due to pain
Social Functioning	2	Social activities limited due to health	No limitations on social activities as a result of health
Mental Health	3	Feels nervous and depressed all of the time	Feels calm, peaceful and happy all of the time
Energy	2	Feels tired and worn out all of the time	Feels energetic and full of pep all the time
Cognitive Functioning	3	Has difficulty concentrating, reasoning and remembering all of the time	Has no problem concentrating, reasoning and remembering

Role Functioning - Two items are used to assess the impact of patients' health on their ability to perform on the job, around the house or in school. Patients are asked if their health keeps them from working at a job, doing work around the house or going to school. The second item in this scale asks if patients are unable to do certain kinds of work, housework or schoolwork because of their health.

Pain - There are two items used to assess pain. Using questions similar to those found in the SF-20 and SF-36, the QOL 601-2 Health Survey assesses both the intensity of bodily pain and the degree of interference with normal activities due to pain. (Ware,1993)

Social Functioning - These two items ask patients to assess the extent to which their health in the past 4 weeks has limited their social activities. Precision is increased in the QOL 601-2 Health Survey by specifically assessing the impact of patients' health on social activities thus eliminating the influence of non-health factors on social activity. (Stewart Hayes and Ware, 1988)

Mental Health - The QOL 601-2 Health Survey has three items which are found in both the SF-20 and SF-36. Items from major mental health dimensions (anxiety, depression, and psychological well-being) are included in the scale (Veit and Ware, 1983). Items in this scale present a balance between favorably and unfavorably worded items thus controlling for response set effects.

Energy/Fatigue - This two-item scale is included in the QOL 601-2 Health Survey to measure differences in vitality. As in the Mental Health scale, items in this scale control for response set effects.

Cognitive Functioning - Consisting of three-items, this dimension measures the degree of difficulty patients have experienced in the past four weeks with respect to their cognitive abilities. Patients are asked to assess how much of the time they have had difficulty reasoning or solving problems, been forgetful, had difficulty in remaining attentive and concentrating on activities.

Administration of the QOL 601-2 Health Survey

<u>Methodological issues</u>

The following section provides guidelines for administering the QOL 601-2 Health Survey. The instrument can be self-administered or a trained interviewer can conduct a telephone or face-to face interview with patients. The instrument takes less than five minutes to complete.

The QOL 601-2 Health Survey is most frequently completed by patients in a clinical setting. However, the instrument can also be completed as a mailed survey or a telephone or in-person interview in other settings, such as the home. The QOL 601-2 can also be included as one section of a longer interview or questionnaire. More recently, computer assisted administration has been introduced using touch-screen technology.

A study coordinator or someone in a similar role who facilitates the administration of the QOL 601-2 Health Survey plays a crucial role in any data collection effort. The quality of the data will be influenced by the skill and effectiveness of the individual assuming this role.

Unlike lab data, the quality of questionnaire data depends in part on setting an appropriate context -- setting the stage -- for the study participant. If a study participant appreciates the importance of the data being collected, considers the questions carefully, and answers appropriately, the responses will be a more accurate reflection of his or her self-perceived health and quality of life. Study participants will also be more likely to complete the questionnaire if they feel that it is important. When the following procedures are implemented during administration of the survey, the quality of data obtained from study participants will be improved.

- Introduce and explain the survey to study participants
- When handing out the questionnaire, explain how it is to be completed
- Collect and review the returned questionnaire for completeness
- Complete face-to-face interviews if necessary

It is important to be familiar with the content and format of the questionnaire before giving the questionnaire to study participants. A thorough knowledge of the instrument will make it easier to answer study participants' questions about the questionnaire, and to edit completed questionnaires for any errors made by participants in filling out the questionnaire.

Reading ability and the ability to think abstractly vary among respondents. As such, subjects may vary in the extent to which responses to questionnaires are consistent and valid reflections of their subjectively experienced health and well being. The QOL 601-2 is written to correspond to an 8th grade reading level. Thus, subjects who are at least 12 years of age with the corresponding reading level should be able to complete the questionnaire. (Ware, 1993; Stewart and Ware, 1992) Patients who are functionally illiterate or perform below this reading level will require interview administration.

Patients who are visually impaired may require a low-vision version of the questionnaire, or an interview. For example, in the Studies of Ocular Complications of AIDS CMV retinitis retreatment trial (The SOCA Research Group, 1996), all health related quality of life measures were administered as an interview rather than using self-administration because many patients had decreased visual acuity and other impairments and vision might be related to treatment assignment. Furthermore, if there is a high prevalence of severe cognitive impairment, it may be advisable to administer a preliminary mental status examination before

asking patients to complete the survey. Patients who are incapable of abstract thinking, or who have other cognitive impairments, may not be able to provide useful response to the questionnaire.

Timing of data collection

When collecting data in a clinical setting, the QOL 601-2 Health Survey should be administered before the patient is seen by a health care provider so that the patient-provider interaction will not influence the patient's survey responses. Further, the survey should be completed before the patient is asked any other questions about their health or illnesses. (Ware, 1993)

Guidelines for Administering the QOL 601-2 Health Survey

Administration Protocol

The basic steps for self-administration are 1) giving the questionnaire to the study participant, 2) reading the instructions to the participant, 3) answering any questions the participant may have, and 4) leaving the questionnaire with the participant for completion.

The best setting for patients to fill out the questionnaire is a quiet secluded area with a minimum of distractions, such as an exam room or other office. It is preferable that patients be separated from family or friends who accompany them to the study visit, so that only the patient's opinions are measured. It is important to explain that the patient's answers are of interest, and that these answers should not be influenced by others.

When handing out the questionnaire, the study participant should be told the purpose of conducting the study and given an estimate of the time required to complete the survey. The format of the questions and how to complete them should be reviewed with the patient. All study participants are not equally experienced in filling out questionnaires, or answering multiple choice questions.

It should be explained that:

X all questions are about the patient's level of functioning and well-being over that last 4 weeks.

- the questions should be answered by placing a check mark in the box next to the response that most closely corresponds to the patient's answer.

- every question should be answered.

- some questions may appear similar to others, but each one is different.

- if the patient is unsure about how to answer a question, he/she should give the best answer possible or write a comment in the left margin.

X only one answer should be checked, giving the best answer to each question (check only one box)

Completed questionnaires should be checked to assure that every question has been answered and that only one box has be checked.

There are a few situations in which a patient will not be able to fill in the questionnaire on his or her own. Common reasons included lack of reading skills, impaired vision, non-English speaking, extreme malaise, and delirium or dementia. In some cases, a face-to-face interview may be required.

Administering a Face-to-Face Interview

It is a good idea to practice administering the questionnaire as an interview to other co-workers, family members, or friends.

In general, it is important to be prepared when conducting a face-to-face interview. If you are confident and know what you are doing, you will feel more comfortable and this will be perceived by the patient. Practice reading the questionnaire in advance. If you sound like you are reading it, you will get less natural responses. Be willing to answer any questions. If there is a question you cannot answer, explain that you don't know the answer but will find out and call the patient with the answer. Occasionally longer questions may come up. Save these for after the interview.

Establishing rapport with the patient is essential for a successful interview. Strive to achieve a good ("friendly but neutral") relationship with the patient. It is important to be sufficiently neutral to avoid biasing the subject's responses. Make sure the study participant is as comfortable as possible before starting.

A successful interviewer needs to develop and maintain a comfortable reading pace. Read instructions slowly enough for the subject to understand them (new interviewers have a tendency to read instructions very quickly). Read items slowly enough for the subject to consider each statement and respond.

It is also important to try to maintain a reading style that is clear and not monotonous. Try to hold the subject's attention and interest. Clearly emphasize the important words and concepts.

Scoring of the QOL 601-2 Health Survey

Standardization

When utilizing the QOL 601-2 Health Survey, it is important to adhere to the standards of content and scoring outlined in this manual. Changes in either the content of the survey or in the scoring instructions may jeopardize the reliability and validity of scores. Furthermore, changes would prevent comparisons of results across studies. (Ware, 1993)

General information

All items and scales in the QOL 601-2 Health Survey are scored so that a higher score indicates better health status. For example, the four functioning scales, physical, role, social and cognitive, are scored so that a higher score is indicative of better functioning. The items and scales of the QOL 601-2 Health Survey are scored in three steps:

1. item recoding; 7 of the 21 items in the survey require recoding. If the scale scores are being computed using a SAS program, item recoding can be accomplished in the DATA step by subtracting the item score from the number of items in the scale plus 1, (e.g., ghp = (6 - ghp) + 1;

2. item scores in each scale are summed to compute raw scale scores; and

3. raw scale scores are transformed to a 0 - 100 scale (transformed scale scores) to facilitate comparisons with other QOL 601-2 Health Survey data.

Data Entry

Questionnaire responses should be keypunched using the numbers coded on the questionnaire. Item recoding and scale scoring can then most easily be completed using standard data analysis software such as SAS or SPSS. Prior to keypunching, completed surveys should be carefully edited for clarity and accuracy. Solutions for handling common coding problems include:

- if two adjacent responses are selected by the respondent, randomly select one to be entered.

- If two non-adjacent responses are selected, code the item as a missing value.

- If more than one response is selected for a single item, code the item as a missing value.

Item Recoding

Item recoding is conducted after questionnaire editing and data entry has been completed. This process is completed to derive the item values used to calculate scale scores. The process will require one or more of the following steps: 1) recode values for 7 items, 2) change out-of-range values to missing, and 3) substitute person-specific estimates for missing items.

Recode Values for 7 Items: Seven items are reverse scored. These items are worded so that a higher precoded item value indicates a poorer health state. To ensure that a higher item value indicates better health on all QOL 601-2 items and scale, these 7 items require recoding as detailed in Tables 2 - 12.

Out-of-Range Values: All 21 individual items should be checked for out-of-range values prior to recoding items to their final item values. Often the result of data entry errors, out-of-range values are those that are lower or higher than the item precoded range. If possible, out-of-range values should be changed to the corrected by verifying the response on the original questionnaire. If this is not possible, all out-of-range values should recode as missing.

Missing values: Respondents may fail to complete one or more questionnaire items in a scale. Multi-item scales permit the estimation of a scale score even though some items are missing. A scale score can be calculated if the respondent answered at least half of the individual items in a multi-item scale for those scales consisting of 2 or more items. When an item is missing, substitute the respondent's average score across the completed items in the scale. For example, if a respondent leaves one item in the 3-item mental health scale blank, substitute the average score of the two completed items for the missing value.

Computation of Raw Scale Scores

The following tables provide scoring instructions for each of the 9 QOL 601-2 Health survey scales and the reported visual analog item. Each table contains the scale item verbatim from the questionnaire, response choices and both the precoded and final values for scoring each item.

Table 4. Scoring Information: General Health Perceptions

Three items: QL 601-1, QL 602-8a, QL602-8b

VERBATIM ITEMS

QL 601-1. In general, would you say your health is:

QL 602 8a. My health is excellent.
QL 602 8b. I have been feeling bad lately.

Item QL 601-1, QL 602-8a:

Note that values for these items need to be recoded. (If you are programming in SAS, you can accomplish this in your DATA step by subtracting the score from the number of items in the scale plus 1, (e.g., egfp = 6 – egfp). SAS program code for scoring the QL 601-2 is included as Appendix D.)

Response choice	Questionnaire Item Value	Final Value
Excellent	1	5
Very good	2	4
Good	3	3
Fair	4	2
Poor	5	1

Items QL 602-8b

Response choice	Questionnaire Item Value	Final Value
Definitely true	1	1
Mostly true	2	2
Not sure	3	3
Mostly false	4	4
Definitely false	5	5

Scale Scoring:

The score from item QL-1 is summed with the scores for items QL 602-8a and QL 602-8b to form a 3-item General Health Perception scale. The range of scores for this scale before it is standardized is then 3-15.

Table 5. Scoring Information: Physical Functioning

Four items: QL 602-6a-d

VERBATIM ITEMS

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities?

QL 602-6a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports
QL 602-6b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling.
QL 602-6c. Walking uphill or climbing (a few flights of stairs).
QL 602-6d. Eating, dressing, bathing or using the toilet.

ITEM SCORING

Items QL 602-6a-d

Response choice	Questionnaire Coded Value	Final Value
Yes, limited a lot	1	1
Yes, limited a little	2	2
No	3	3

Items in the Physical Function scale are simply summed. The range of possible scores for the Physical Function scale before it is standardized is 4-12.

Table 6. Scoring Information: Role Functioning

Two items: QL 602-1,QL 602-4

VERBATIM ITEMS

1. Does your health keep you from working at a job, doing work around the house or going to school?

4. Have you been unable to do certain kinds or amounts of work, housework or schoolwork because of your health?

ITEM SCORING

Items QL 602-1,QL 602-4

Response choice	Questionnaire Coded Value	Final Value
Yes for all the time	1	1
Yes for some of the time	2	2
No	3	3

Scores are now summed for the Role Function scale. The range is of scores for Role Function before it is standardized is 3-9.

Table 7. Scoring Information: Social Functioning

One item: QL 602-3, QL 602-7a

VERBATIM ITEM

3. During the past 4 weeks, how much has your physical health or emotional problems interfered with your normal social activities?

7a. How much of the time, during the past 4 weeks, has your health limited your social activities (like visiting with friends or close relatives)?

ITEM SCORING

Item QL 602-3

Response choice	Questionnaire Coded Value	Final Value
Not at all	1	5
A little bit	2	4
Moderately	3	3
Quite a bit	4	2
Extremely	5	1

Item QL 602-7a

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	1
Most of the time	2	2
A good bit of the time	3	3
Some of the time	4	4
A little of the time	5	5
None of the time	6	6

The Social Function items are summed and range from 2-11 before the scale is standardized.

Table 8. Scoring Information: Cognitive Functioning

Four items: QL 602-7b,QL 602-7c,QL 602-7i

VERBATIM ITEMS

How much of the time during the past 4 weeks:

7c. Did you have difficulty reasoning and solving problems, for example making plans, making decisions, learning new things?
7b. Did you have trouble keeping your attention on any activity for long?
7i. Did you forget, for example, things that happened recently, where you put things, appointments?

ITEM SCORING

Items QL 602-7b,QL 602-7c,QL 602-7i

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	1
Most of the time	2	2
A good bit of the time	3	3
Some of the time	4	4
A little of the time	5	5
None of the time	6	6

Items in the Cognitive Function scale are scored 1-6. None of the items need to be recoded. When the values of the 3 scale items are summed, the range for the Cognitive Function scale before it is standardized is 3-18.

Table 9. Scoring Information: Pain

Two items: QL 602-2, QL 602-5

VERBATIM ITEM

2. How much bodily pain have you generally had during the past 4 weeks?
5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

ITEM SCORING

Item QL 602-2 - This item must be recoded.

Response choice	Questionnaire Coded Value	Final Value
None	1	6
Very mild	2	5
Mild	3	4
Moderate	4	3
Severe	5	2
Very Severe	6	1

ITEM SCORING

Item QL 602-5 - This item must be recoded.

Response choice	Questionnaire Coded Value	Final Value
Not at all	1	5
A little bit	2	4
Moderately	3	3
Quite a bit	4	2
Extremely	5	1

Note that these items are recoded so that a higher score corresponds to less pain. The range of possible scores for this Pain item before it is standardized is 2-11.

Table 10. Scoring Information: Mental Health

Three items: QL 602-7d,QL 602-7e,QL 602-7h

VERBATIM ITEMS

How much of the time, during the past 4 weeks:

QL 602-7d. Have you felt calm and peaceful?
QL 602-7e. Have you felt downhearted and blue?
QL 602-7h. Have you been a happy person?

ITEM SCORING

Items QL 602-7e

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	1
Most of the time	2	2
A good bit of the time	3	3
Some of the time	4	4
A little of the time	5	5
None of the time	6	6

Items QL 602-7d, QL 702-7h - These items need to be recoded.

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	6
Most of the time	2	5
A good bit of the	3	4
Some of the time	4	3
A little of the time	5	2
None of the time	6	1

Items in the Mental Health scale are scored 1-6. The range is 3-18 for the Mental Health scale before it is standardized.

Table 11. Scoring Information: Energy/Fatigue

Four items: QL 602-7f, QL 702-7g

VERBATIM ITEMS

How often during the last 4 weeks:

QL 602-7f. Did you feel tired?
QL 602-7g. Did you have enough energy to do the things you want to do?

ITEM SCORING

Items QL 602-7g - These items need to be recoded.

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	6
Most of the time	2	5
A good bit of the time	3	4
Some of the time	4	3
A little of the time	5	2
None of the time	6	1

Items QL 602-7f

Response choice	Questionnaire Coded Value	Final Value
All of the time	1	1
Most of the time	2	2
A good bit of the time	3	3
Some of the time	4	4
A little of the time	5	5
None of the time	6	6

Items in the Energy/Fatigue scale are scored 1-6. The range for the Energy/ Fatigue scale is 2-12 before standardization.

Transformation of Scale Scores

The final step in scale construction involves transforming the raw scale scores to a 0 to 100 scale. This transformation permits comparisons among various dimensions which may have different response categories. A score of 0 is the lowest possible score and 100 is the highest score. Formulas for linear transformations for each of the scales are as follows:

Scale	Transformation Formula
General Health Perception	Lgenheal = (100/(15-3)) * (General Health Perception raw score - 3)
Physical Functioning	Lphys = (100/(12-4)) * (Physical Function raw score - 4)
Role Functioning	Lrole = (100/ (6-2)) * (Role Function raw score - 2)
Social Functioning	Lsocial = (100/(11-2)) * (Social Function raw score - 2)
Cognitive Functioning	Lcognitiv = (100/(18-3)) * (Cognitive Function raw score - 3)
Pain	Lpain = (100/(ll-2)) * (Pain - 2)
Mental Health	Lmental = (100/(18-3))*(Mental Health raw score - 3)
Energy/Fatigue	Lvitalit = (100/ (12-2)) *(Energy/Fatigue raw score - 2)

For example, using the transformation formula for the Cognitive Functioning scale, 100 = the highest possible score in the transformation; 18 = the top of the range for the sum of the untransformed item scores, while 3 = the lowest possible score of the untransformed scale. A raw score of 9 on the Cognitive Functioning scale would be transformed as follows:

$$\begin{aligned} \text{Lcognitiv} &= (100/\ (18-3)) * (9 - 3) \\ &= (6.6 * 9) \\ &= 39.6 \end{aligned}$$

Appendices

A.	Instrument
B.	Script for in-person (interview) administration
C.	Script for telephone interview

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