



# THE WORLD HEALTH ORGANIZATION QUALITY OF LIFE ASSESSMENT (WHOQOL): POSITION PAPER FROM THE WORLD HEALTH ORGANIZATION

THE WHOQOL GROUP\*

**Abstract**—This paper describes the World Health Organization's project to develop a quality of life instrument (the WHOQOL). It outlines the reasons that the project was undertaken, the thinking that underlies the project, the method that has been followed in its development and the current status of the project. The WHOQOL assesses individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It has been developed collaboratively in several culturally diverse centres over four years. Piloting of the WHOQOL on some 4500 respondents in 15 cultural settings has been completed. On the basis of this data the revised WHOQOL Field Trial Form has been finalized, and field testing is currently in progress. The WHOQOL produces a multi-dimensional profile of scores across six domains and 24 sub-domains of quality of life.

*Key word*—quality of life assessment

## RATIONALE FOR THE DEVELOPMENT OF THE WHOQOL

The World Health Organization (WHO) initiated its project to develop an international quality of life assessment for several reasons. The importance of including a consideration of patients' quality of life in treatment decisions, approval of new pharmaceuticals and policy research (programme evaluation and resource allocation) is immediately apparent and has

been extensively documented elsewhere (see Ref. [1]). Not so obvious are the benefits of considering quality of life from a cross-cultural perspective.

Having an international quality of life assessment such as the WHOQOL makes it possible to carry out quality of life research collaboratively in different cultural settings, and to compare directly results obtained in these different settings. In basic research into quality of life, important new questions can be

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An international panel of consultants includes: Dr N. K. Aaronson, Dr P. Bech, Dr M. Bullinger, Dr He-Nian Chen, Dr J. Fox-Rushby, Dr C. Moinpour and Dr R. Rosser. Consultants who have advised WHO at various stages of the development of the project have included: Dr D. Buesching, Dr D. Bucquet, Dr L. W. Chambers, Dr B. Jambon, Dr C. D. Jenkins, Dr D. De Leo, Dr L. Fallowfield, Dr P. Gerin, Dr P. Graham, Dr O. Gureje, Dr K. Kalumba, Dr Kerr-Correa, Dr C. Mercier, Mr J. Oliver, Dr Y. H. Poortinga, Dr R. Trotter and Dr F. van Dam.

Technical support and funds have been provided by the World Health Organization, the participating centres themselves and by support from the Upjohn Company, Kalamazoo, U.S.A., the IPSEN Foundation, Paris, France and the Carnegie Corporation, New York.

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asked. For example, studies can be undertaken to improve our understanding of the quality of life construct itself, and the extent to which it is individually, socially or culturally determined.

In epidemiological research, multi-centre research with the WHOQOL will permit questions to be addressed which would not be possible in single site studies [2]. For example, to what extent are certain diseases and symptoms (e.g. arthritis, schizophrenia, headache, back pain) and their effect on quality of life mediated by social and cultural factors?

Methodologically, multi-centre collaborative studies can provide multiple simultaneous replications of a finding, adding considerably to the confidence with which findings can be accepted. Practically, accumulation of cases in quality of life studies, particularly when studying rare disorders, is sometimes helped by gathering data in several settings.

There are several important projects under way to translate existing standardized quality of life measures for use in different cultural settings [3, 4]. However, these projects have tended to be concerned mostly with the languages of Europe and North America. Furthermore, as we have argued elsewhere [5], the danger with the translation of an existing measure is the distortion in results that can arise from the use of inappropriate health-related quality of life constructs, which are valid in the source language setting, but not in the target language setting. For example, autonomy is an important dimension related to quality of life which is valued in some cultures but has pejorative connotations of selfishness and rejection in others [6]. Equally important, there may be aspects of health-related quality of life which are important in the target culture, but which are not covered by the source instrument.

The development of the WHOQOL assessment arises, therefore, from the need for a genuinely international quality of life assessment. In addition, WHO initiated its work on quality of life assessment as a way of restating its commitment to the promotion of an holistic approach to health and health care. Health care is essentially a humanistic transaction between a health care professional and a patient, where the patient's well-being is the primary aim.

#### THE WHOQOL METHOD

The WHOQOL development method has several unique features. First the measure involves a 'collaborative' or 'simultaneous development' approach to international instrument development [5, 7]. Several culturally diverse centres were involved in operationalizing the instrument's domains of quality of life, drafting and selecting questions, generating response scales and pilot testing. With this approach standardization, equivalence between settings and translation issues were at the forefront of the development process. To ensure that the collaboration was genuinely international, field centres were selected to

provide differences in level of industrialization, available health services, and other markers relevant to the measurement of quality of life (e.g. role of the family, perception of time, perception of self, dominant religion). Fifteen centres participated in the development and piloting of the WHOQOL Pilot Form (Table 1).

A second feature of the WHOQOL method is the iterative input of quality of life researchers and the consolidation and revision of this information at grassroots level at each stage of the instrument's development. This ensures that both existing expertise in quality of life assessment and the views of practising health professionals and patients are represented in the construction of the instrument. In quality of life assessment, where the patients' viewpoint is paramount the acceptability of the measure to patients is fundamental. Furthermore, as it is health professionals and researchers who are likely to use the WHOQOL instrument, it is important that the instrument is acceptable to these groups as well.

A third feature of the WHOQOL method is the use of a tried and tested WHO translation method. WHO has accrued considerable experience in translating health status measures. In brief, an iterative process of forward and backward translation is complemented by a review process by monolingual and bilingual groups to ensure conceptual, semantic and technical equivalence in different language versions of the WHOQOL (see Ref. [8]).

#### STEPS IN THE DEVELOPMENT OF THE WHOQOL

The WHOQOL development process was made up of several stages (Table 2), and is more fully documented elsewhere [9-11].

##### (1) Concept clarification

The first stage, concept clarification involved arriving at an agreed upon definition of quality of life and an approach to international quality of life assessment. Although there is no consensual definition of quality of life, there is considerable agreement among

Table 1. Field centres involved in the development of WHOQOL Pilot Instrument

Melbourne, Australia
Zabreb, Croatia
Paris, France
Delhi, India
Madras, India
Beer-Sheeva, Israel
Tokyo, Japan
Tilberg, The Netherlands
Panama City, Panama
St Petersburg, Russia
Barcelona, Spain
Bangkok, Thailand
Bath, U.K.
Seattle, U.S.A.
Harare, Zimbabwe

Table 2. Stages in the development of the WHOQOL\*

Stage	Method	Products	Objectives
(1) Concept clarification	International expert review	QoL definition Study protocol	Establishing an agreed upon definition of quality of life and an approach to international quality of life assessment
(2) Qualitative pilot	Expert review Focus groups Expert and lay question writing panel	Definitions of domains and sub-domains Global question pool	Exploration of the quality of life concept across cultures and question generation
(3) Development pilot	Administration of WHOQOL Pilot Form in 15 field centres to 250 patients and 50 'healthy' respondents	300 question standardized questionnaire	Refine the WHOQOL structure Reduce the global question pool
(4) Field test	Series of smaller scale studies involving clear and homogeneous populations, longitudinal design and parallel use of other national/international QoL measures	Common core domain structure Common 100-question pool Standardized and cross-nationally equivalent response scales	To further establish the psychometric properties of the WHOQOL

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quality of life researchers about some of the characteristics of the quality of life construct. First, is the growing recognition that quality of life is subjective [12–15].

This 'subjective' defining feature of quality of life can be broken down into levels. Lindström [16] distinguishes perceptions of objective conditions (e.g. material resources) and subjective conditions (e.g. satisfaction with resources). The WHOQOL Group [10] make a similar distinction, but refer to levels of questioning. They propose that questions concerned with the person's perception can ask for:

- (a) information about functioning (e.g. 'How many hours did you sleep last night?');
- (b) global evaluations of functioning (e.g. 'How well do you sleep?'); and
- (c) highly personalized evaluations of functioning (e.g. 'How satisfied are you with your sleep?').

Although the person's report of functioning is important health status information, the WHOQOL Group argues that it is questions about the person's global evaluations of behaviours, states and capacities and satisfaction/dissatisfaction with behaviours, states and capacities that inform about quality of life.

A second area of consensus is the multi-dimensional nature of quality of life [12, 17–19]. At minimum, quality of life includes the following dimensions: physical (individuals' perception of their physical state), psychological (individuals' perception of their cognitive and affective state) and social (individuals' perception of the interpersonal relationships and social roles in their life). Some quality of life measures include further dimensions for conceptual, pragmatic or empirical reasons. The EuroQoL includes a 'usual activities' dimension [20], which is similar to the 'role functioning' dimension included in the Medical Outcomes Study General Health Sur-

vey—Short Form (SF-36) [3]. The Sickness Impact Profile [21] includes 'work' as a separate dimension. The WHOQOL includes a spiritual dimension (the person's perception of 'meaning in life', or the overarching personal beliefs that structure and qualify experience) [10]. We have argued elsewhere that the broad physical, psychological, social and spiritual domains of quality of life are universal values across cultures [5], and there is some evidence that this is so [22].

Third, quality of life includes both positive (e.g. role functioning, contentment and mobility) and negative dimensions (e.g. negative feelings, dependence on medication, fatigue, pain) [23]. An inquiry into quality of life must address individuals' perceptions of both positive and negative dimensions.

Quality of life was defined, therefore, as *individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*. It is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment [9, 10]. This definition highlights the view that quality of life is subjective, includes both positive and negative facets of life and is multi-dimensional.

The recognition of the multi-dimensional nature of quality of life is further reflected in the WHOQOL structure. The WHOQOL is organized into six broad domains of quality of life. These are:

- (a) physical domain;
- (b) psychological domain;
- (c) level of independence;
- (d) social relationships;
- (e) environment; and
- (f) spirituality/religion/personal beliefs.

Within each domain several sub-domains (facets) of quality of life summarize that particular domain of quality of life. For example, the 'physical domain' includes the facets *Pain and discomfort* and *Energy and fatigue*.

Once a definition of quality of life and an approach to international quality of life assessment had been agreed upon, a detailed study protocol for the further development of the WHOQOL was written [9].

## (2) Qualitative pilot

The qualitative pilot involved the exploration of the quality of life construct across cultures, the drafting of questions and the generation of response scales.

*Determining the WHOQOL domains and facets.* Determining the domains and facets of quality of life to be addressed by the WHOQOL involved several steps. First consultants and principal investigators from each of the field centres drafted a provisional list of domains and facets of quality of life.

Focus groups, carefully moderated group interviews, were used as a way of socially generating ideas about quality of life among targeted populations (healthy individuals, individuals with a disease/impairment and health professionals). This method was useful within the context of the WHOQOL project because the same interview schedule can be used in different cultural settings and different groups within a cultural setting (e.g. rural farmers and urban office workers), and the data can be aggregated. To ensure standardization between centres, principal focus group moderators were trained centrally at WHO, Geneva. Because the data yielded by focus groups can be the product of social dynamics within the group, the data from several focus groups sampled from the same population were always compared to protect against this possibility.

A first phase of focus groups was conducted with patients and healthy persons to examine the meaning, variation and perceptual experience of the quality of life construct in each of the WHOQOL field centres [24]. The data from these focus groups were largely confirming of the provisional domain and facet structure that had been drafted by the consultants and principal investigators. For example 'physical health', 'happiness', 'family support', 'work satisfaction' and 'financial status' were among the facets that were spontaneously mentioned in over half the nine field centres participating in this phase of work (Bangkok, Bath, Madras, Melbourne, Panama, St. Petersburg, Seattle, Tilburg and Zagreb). Based on the focus group data several revisions were made to the proposed structure of the instrument. For example religion and spirituality were consistently suggested as important dimensions of quality of life. For subsequent work on the WHOQOL 'Religion/Spirituality/Personal beliefs' was included as a separate domain of quality of life.

On the basis of the focus group data detailed definitions of facets of quality of life were drafted. A facet definition consisted of an explanation of what was meant by the facet, a description of various dimensions along which a rating could be made for that facet, and a listing of some example situations or conditions that might significantly affect that facet at various levels of intensity (e.g. *Appendix*). Further focus groups were then held with patients, healthy persons and health personnel in each of the field centres (Bangkok, Bath, Harare, Madras, Melbourne, Panama, St. Petersburg, Seattle, Tilburg, Zagreb).

Each focus group was made up of six to eight individuals, demographically representative of the target population in terms of gender, age, educational background, socio-economic group and ethnic group. The procedure followed in the focus groups involved detailed orientation and instructions, followed by a facet-by-facet discussion in which participants were asked how each facet affected their quality of life and how one might best ask about that facet.

Focus group participants from the following populations were sampled at each field centre: persons in contact with health services (both inpatients and outpatients with acute and chronic disorders), persons from the general population (including some who were informal caregivers) and health personnel. A minimum of two focus groups were conducted for each of the three population groups. However, where the data from any of these two groups were dissimilar, extra focus groups were conducted until the data showed a marked pattern and further focus groups added nothing new. In addition, in some centres further focus groups were run to sample individuals from very differing populations (e.g. rural and urban, young and old).

This second phase of focus group work provided considerable endorsement of the proposed WHOQOL structure. However, in several instances the data called for revisions to the WHOQOL facet structure and definitions.

*Drafting and selecting questions.* The focus group transcripts contained many valuable suggestions for WHOQOL questions. On completion of the focus group work, a question writing panel was assembled in each field centre. The question writing panel included the field centre's principal investigator, the main focus group moderator and at least one person with good interviewing skills and experience. In addition, a lay person was included to ensure that questions were framed in comprehensible and natural language. Making full use of focus group transcripts, the panel framed a maximum of six questions for each facet, following the guidelines for question writing outlined in Table 3.

Questions from all centres were then pooled to make up a 'global question pool' of some 1800 questions. A content analysis of the questions identified several semantically equivalent questions

Table 3. Criteria for WHOQOL questions

Questions should:
—Be based as far as possible on the suggestions of patients and health personnel participating in the focus groups.
—Give rise to answers that are illuminating about respondents' quality of life, as defined in this project.
—Reflect the meaning conveyed in the facet definition.
—Cover, in combination with other questions for a given facet, the key aspects of that facet as described in the facet definition.
—Use simple language, avoiding ambiguity in terms of either wording or phraseology.
—Be shorter rather than longer.
—Avoid double negatives.
—Be amenable to a rating scale.
—Ask about a single issue/facet.
—Avoid any explicit reference point either in terms of time or in terms of some comparison point (e.g. the ideal or before I was ill).
—Be applicable to individuals with a range of impairment.
—Be phrased as questions and not statements.
—Reflect the typology of questions adopted for the project.

(e.g. 'How much of the time are you tired?' and 'How often are you tired?'), thus reducing the number of questions in the global question pool. Judgements of semantic equivalence were carried out by consensual agreement in a small working group, and were subsequently reviewed by all principal investigators. Questions were then carefully examined to see to what extent they met the criteria for WHOQOL questions (Table 3). This led to a considerable reduction in the number of questions in the global pool to around 1000 questions.

The principal investigator in each of the field centres then rank-ordered the questions for each facet according to 'how much it tells you about a respondent's quality of life in your culture.' From the combined rankings for all centres 235 questions were selected for the WHOQOL pilot instrument [10]. Table 4 shows the number of questions selected for the WHOQOL Pilot instrument contributed by each of the field centres.

*Generating response scales.* Five point semantic differential response scales are used throughout the WHOQOL. This is consistent with the extensive use

Table 4. Number of questions selected for pilot WHOQOL from each of the main study field centres (total number of core questions 235)

Field centre	Number and proportion of questions in the pilot WHOQOL contributed by each field centre
Bangkok, Thailand	33 (14%)
Bath, U.K.	31 (13%)
Harare, Zimbabwe	33 (14%)
Madras, India	41 (17%)
Melbourne, Australia	49 (21%)
Panama	48 (20%)
Paris, France	36 (15%)
St Petersburg, Russia	22 (9%)
Seattle, U.S.A.	46 (20%)
Tilburg, Netherlands	50 (21%)
Zagreb, Croatia	63 (27%)
Questions proposed by the coordinating group	7 (3%)

Note: Because a significant number of questions were proposed in identical or semantically equivalent forms the sum of all the questions comes to more than the 235 questions in the pilot instrument. The seven questions proposed by the WHO coordinating group were proposed where existing questions inadequately covered the key areas of the facet.

and validation of this type of response scale with health status measures (see Ref. [25]). Response scales were derived for each of the WHOQOL's language versions according to a standardized methodology. Although endpoints such as 'Never' and 'Always' are universal, shades of meaning between endpoints (e.g. 'sometimes') are more ambiguous, difficult to translate, and subject to cultural variation in their interpretation. To ensure equivalence across WHOQOL field centres, a methodology was used which specified the anchor points for each of the four types of 5-point response scales (Very satisfied–Very dissatisfied; Not at all–Extremely; Not at all–Completely; and Never–Always), and a scale metric which intermediate descriptors should fit. That is to say descriptors for each of the response scales were derived in each language to find words/terms falling at 25%, 50% and 75% points between the two anchors.

This methodology ensured first that response scales were not simply translated from a source language, with all the problems associated with this process. Second, it secured a high degree of scalar equivalence between languages, which was supported by subsequent bilingual review of back-translated response scale descriptors. Third, it ensured equidistance between descriptors on the scales. In line with the views of recent commentators [26, 27] further formal testing of the dimensional equivalence of these scales in the different cultures is needed, and is planned as part of the WHOQOL's field testing.

### (3) Pilot test

The WHOQOL pilot instrument contained 235 core questions addressing 29 facets of quality of life. In addition, several questions were concerned with overall quality of life and health perceptions. The pilot instrument was standardized in terms of format, instructions, questions and administration.

The pilot testing involved the administration of the instrument to some 250 health care users and 50 healthy respondents in 15 culturally diverse field centres (Total  $N = 4500$ ). The analysis plan aimed to:

- (1) examine the construct validity of the WHOQOL domains and facets;
- (2) select the best questions for each facet; and
- (3) establish the WHOQOL's reliability (internal consistency) and discriminant validity.

At the time of writing, the piloting has been completed. Several publications are in preparation reporting this work. The WHOQOL Field Trial Form has been finalized, and field testing started.

### (4) Field test

The fourth stage of work, field testing, aims to establish the instrument's sensitivity to change, test–retest reliability, and criterion validity, specifically with regard to convergent, discriminant and predictive validity. The WHOQOL Field Trial Form

is a 100-question measure producing six domain scores and 24 facet scores. It includes four global questions enquiring into overall quality of life and general health.

A series of longitudinal studies is in progress involving specific populations (including those with visual impairments, depression, rheumatoid arthritis, diabetes), specific interventions (including cataract operations, various medications, psychological interventions) and the parallel use of other national and international instruments with established psychometric properties. Several studies are also planned to look at the WHOQOL's sensitivity to change through disease stages (e.g. AIDS), socio-development programmes (e.g. housing programmes), and various life changes (e.g. pregnancy and childbirth; older adults entering nursing homes).

Once the field test is concluded the instrument will be reviewed to overcome any difficulties that have become apparent.

#### FURTHER WORK ON WHOQOL DEVELOPMENT

Further language forms of the WHOQOL are currently in development. New language forms are developed through a process of focus group work, pilot testing and field testing that replicates the method used to develop existing language versions. A protocol that describes the procedures to be followed in detail has been developed.

Several add-on modules for the WHOQOL are planned for assessing the quality of life of people with a particular disease, or in circumstances in which the core module does not provide sufficient detail. WHO has identified five priority areas for module development:

- (a) persons suffering from chronic diseases (e.g. epilepsy, arthritis, cancer, AIDS, diabetes);
- (b) caregivers of the ill or disabled (e.g. a person taking care of a terminally sick patient);
- (c) persons living in highly stressful situations (e.g. elderly people living in poorly run institutions, refugees in camps);
- (d) persons with difficulty communicating (e.g. persons with severe learning disabilities); and
- (e) children.

The methodology for the development of modules is detailed elsewhere [9], but includes the same iterative process of input from health professionals and quality of life researchers from around the world, cross-cultural lay review (through focus groups), and international expert review. The methodology also states that any module should be developed simultaneously in at least three culturally diverse centres.

As well as the comprehensive WHOQOL assessment, a short version is planned for use in research requiring repeated measures, in clinical settings and for respondents with difficulty completing the long version. Interviewer assisted and interviewer adminis-

tered forms are planned for respondents who cannot read or write (for cultural, educational or health reasons). Research using a multi-trait, multi-method approach [28] will be conducted to establish the correspondence among these different forms of the WHOQOL.

#### SUMMARY AND CONCLUSIONS

This paper outlines the development of the WHOQOL, a multi-lingual assessment of quality of life. Different language forms of the WHOQOL are directly comparable. The WHOQOL produces a profile of scores across six broad domains of quality of life and some 24 facets of quality of life.

The WHO initiative to develop a quality of life assessment instrument is linked to other important WHO projects. WHO has projects currently under way on the international evaluation of different treatments, the development and improvement of the WHO scheme of 'impairments, disabilities and handicaps' and the development of national guidelines for quality assurance in health care. The WHOQOL project, therefore, is a part of larger drive towards 'Health for All', and the promotion of mental, social and physical well-being.

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## APPENDIX

### Example WHOQOL Facet Definition

#### *Spirituality/religion/personal beliefs*

This facet examines the person's personal beliefs and how these affect his quality of life. This might be by helping the person cope with difficulties in their life, giving structure to their experience, ascribing meaning to spiritual and personal questions, and more generally providing the person with a sense of well-being. This facet addresses people with differing religious beliefs (e.g. Buddhists, Christians, Hindus, Muslims), as well as people with personal and spiritual beliefs that do not fit within a particular religious orientation. For many people religion, personal beliefs and spirituality are a source of comfort, well-being, security, meaning, sense of belonging, purpose and strength. However, some people feel that religion has a negative influence on their life. Questions are framed to allow this aspect of the facet to emerge.

*Examples:* Muslims living in a Hindu area; a person with a terminal illness.