

PROGRAMME ON MENTAL HEALTH

# WHOQOL User Manual

This manual is intended to help users of the WHOQOL-100 and WHOQOL\_BREF in administering and scoring of the instruments. It also describes the process of developing the instruments and their psychometric properties



DIVISION OF MENTAL HEALTH AND  
PREVENTION OF SUBSTANCE ABUSE  
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## **INTRODUCTION**

## **PURPOSE OF THIS MANUAL**

This manual aims to describe the development and use of the WHOQOL-100 and WHOQOL-BREF quality of life assessments, giving the reader a background on the development of the WHOQOL instruments, describing their psychometric properties and facilitating administration and scoring.

## **SUMMARY OF WHOQOL INSTRUMENTS**

The WHOQOL-100 assesses individuals' perceptions 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 was developed collaboratively in some 15 cultural settings over several years and has now been field tested in 37 field centres. It is a 100-question assessment that currently exists in directly comparable forms in 29 language versions. It yields a multi-dimensional profile of scores across domains and sub-domains (facets) of quality of life. More recently, the WHOQOL-BREF, an abbreviated 26 item assessment has been developed.

## **USES OF THE WHOQOL INSTRUMENTS**

The WHOQOL-100 and WHOQOL-BREF have many uses, including use in medical practice, research, audit, policy making and in assessing the effectiveness and relative merits of different treatments. They can also be used to assess variation in quality of life across different cultures, to compare subgroups within the same culture and to measure change across time in response to change in life circumstances.

## **OUTLINE OF CHAPTERS**

The initial chapter describes the rationale for the development of the WHOQOL pilot instrument and the refinement of the original WHOQOL pilot instrument to produce the WHOQOL-100. Chapter 2 reports on the psychometric properties of the WHOQOL-100, whilst Chapter 3 gives guidelines for the preparation and administration of the WHOQOL-100. Chapter 4 serves as a resource for researchers who wish to develop the WHOQOL-100 in a new language version, whilst Chapters 5 and 6 outline the development, psychometric properties and administration procedures for the WHOQOL-BREF. Finally, Chapter 7 outlines some of the proposed uses for the WHOQOL-100 and WHOQOL-BREF and Chapter 8 details their scoring procedures.



## **CHAPTER ONE - DEVELOPMENT OF THE WHOQOL-100**

### **INTRODUCTION**

The WHOQOL-100 was produced from an original WHOQOL pilot assessment. This chapter briefly describes the rationale for the development of the WHOQOL pilot assessment, its conceptual background and the method used in its development. It also describes the development of the WHOQOL-100 from the WHOQOL pilot assessment.

### **RATIONALE FOR THE DEVELOPMENT OF THE WHOQOL**

WHO's initiative to develop a quality of life assessment arose for a number of reasons. In recent years there has been a broadening of focus in the measurement of health, beyond traditional health indicators such as mortality and morbidity (e.g. World Bank, 1993; WHO, 1991), to include measures of the impact of disease and impairment on daily activities and behaviour (e.g. Sickness Impact Profile; Bergner, Bobbitt, Carter et al, 1981), perceived health measures (e.g. Nottingham Health Profile; Hunt, McKenna and McEwan, 1989) and disability / functional status measures (e.g. the MOS SF-36, Ware et al, 1993). These measures, whilst beginning to provide a measure of the impact of disease, do not assess quality of life *per se*, which has been aptly described as "the missing measurement in health" (Fallowfield, 1990).

Second, most measures of health status have been developed in North America and the UK, and the translation of these measures for use in other settings is time-consuming and unsatisfactory for a number of reasons (Sartorius and Kuyken, 1994; Kuyken, Orley, Hudelson and Sartorius, 1994).

Third, the increasingly mechanistic model of medicine, concerned only with the eradication of disease and symptoms, reinforces the need for the introduction of a humanistic element into health care. Health care is essentially a humanistic transaction where the patient's well-being is a primary aim. By calling for quality of life assessments in health care, attention is focused on this aspect of health, and resulting interventions will pay increased attention to this aspect of patients' well-being. WHO's initiative to develop a quality of life assessment arises, therefore, both from a need for a genuinely international measure of quality of life, and restates its commitment to the continued promotion of an holistic approach to health and health care, as emphasised in the WHO definition of health as "A state of physical, mental and social well-being, not merely the absence of disease and infirmity".

## **CONCEPTUAL BACKGROUND**

Due to the lack of a universally agreed upon definition of quality of life, the first step in the development of the WHOQOL was to define the concept. Quality of life is defined by the WHO as “individuals' perceptions 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 the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.

This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context. (As such, quality of life cannot be equated simply with the terms "health status", "life style", "life satisfaction", "mental state" or "well-being"). Because the WHOQOL focuses upon respondents' "perceived" quality of life, it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, nor disability as objectively judged, but rather the perceived effects of disease and health interventions on the individual's quality of life. The WHOQOL is, therefore, an assessment of a multi-dimensional concept incorporating the individual's perception of health status, psycho-social status and other aspects of life.

## **THE WHOQOL METHOD**

The WHOQOL-100 was developed using a unique cross-cultural approach. The WHOQOL development method has several unique features. First, the measure involved a collaborative approach to international instrument development (Bullinger, 1994; Kuyken, Orley, Hudelson and Sartorius, 1994). The aim was to develop a single quality of life instrument collaboratively in several settings. Thus, several culturally diverse centres were involved in operationalizing the instrument's domains of quality of life, question writing, question selection, response scale derivation and pilot testing. With this approach, standardisation, 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). Table 1.1 lists field centres that participated in the development and testing of the WHOQOL pilot instrument.

### **TABLE 1.1 - FIELD CENTRES INVOLVED IN THE DEVELOPMENT OF THE WHOQOL PILOT INSTRUMENT**

<b>Field centre</b>	<b>Language</b>
Zagreb, Croatia	Croatian
Tilburg, the Netherlands	Dutch
Melbourne, Australia	English (Australian)
Bath, United Kingdom	English (UK)
Seattle, USA	English (USA)
Paris, France	French
Beer-Sheva, Israel	Hebrew
Delhi, India*	Hindi
Tokyo, Japan*	Japanese
St Petersburg, Russia	Russian
Harare, Zimbabwe	Shona
Panama City, Panama	Spanish (Panama)
Barcelona, Spain*	Spanish
Madras, India	Tamil
Bangkok, Thailand	Thai

\*These centres joined at a slightly later stage, but, nevertheless, contributed to the pilot testing

A second feature of the WHOQOL method was 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 ensured that both existing expertise in quality of life assessment and the views of practising health professionals and patients were represented in the construction of the instrument. In quality of life assessment, where there is an ever growing acknowledgement that the patients' viewpoint is paramount (Smart and Yates, 1987; Calman, 1987; Breslin, 1991; Gerin, Dazord, Boissel et al, 1992; Patrick and Erikson, 1993) the acceptability of the measure to patients is fundamental. Furthermore, because health professionals and researchers are the most 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. This expertise was used throughout the WHOQOL and the translation methodology is described in Chapter 5.

## STEPS IN THE DEVELOPMENT OF THE WHOQOL-100

The WHOQOL development process was made up of several stages (see Table 1.2).

**TABLE 1.2 - STAGES IN THE DEVELOPMENT OF THE WHOQOL-100**

Stage	Method	Products	Objective
1) <b>Concept clarification</b>	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) <b>Qualitative pilot</b>	Expert review. Focus groups. Expert and lay question writing panel.	Definitions of domains and facets. Global question pool.	Exploration of the quality of life concept across cultures and question generation.
3) <b>Development pilot</b>	Administration of WHOQOL Pilot Form in 15 field centres; 250 patients and 50 healthy respondents in each.	277 item standardised questionnaire.	Refine the WHOQOL structure. Reduce the global question pool.
4) <b>Refinement</b>	Analysis of the WHOQOL pilot data	100 item assessment	Refine the WHOQOL structure.

### 1) CONCEPT CLARIFICATION

In the first stage, concept clarification involved an international collaborative review to establish an agreed upon definition of quality of life. Following extensive review of the literature, consultants and investigators from field centres proposed several broad domains assumed to contribute to an individual's quality of life. Each domain was further divided into a series of specific areas (facets) summarising each particular domain.

### 2) QUALITATIVE PILOT

In the second stage, the qualitative pilot involved 1) the exploration of the quality of life construct across cultures, 2) definition of the facets to be assessed, 3) generation of a global question pool and 4) development of equivalent response scales for different language versions of the WHOQOL. Focus groups were therefore run in 12 field centres in order to achieve these aims. This work was carried out simultaneously in each different cultural setting worldwide, with input and technical support from the WHO co-ordination group in Geneva.

Focus groups in each centre generated suggestions for facets of life that they considered contributed to its quality. Following free discussion, each group was presented with the list of facets derived from a review of existing scales as well as elaborate discussions among members of the WHOQOL group on relevant aspect of a person's life. In this way they could indicate whether or not they considered any of these to be important, had they not done so already. These suggestions were arranged as a set of facets and for each facet a definition was written. The range and definition of facets were developed iteratively, such that each centre involved in the project considered and reconsidered the proposals from their own centres, from other centres, and from the co-ordinating team. Twenty nine facets were developed for the WHOQOL pilot (see Table 1.3; facet descriptions for the 25 facets retained in the WHOQOL-100 are given in Appendix 1).

In each centre the facet definition were translated following the WHOQOL translation methodology outlined in chapter 4.

Separate focus groups comprising individuals with a disease or impairment currently using health services, healthy participants and health personnel were assembled in each centre to deliberate on the facets and to propose questions. The inclusion of facets was based, therefore, on a consensus within and between cultures among health professionals, persons from the general population who were "healthy" and persons who were in contact with health services because of disease or impairment (See Appendix 6).

The focus group also proposed potential questions for consideration of the item writing group. Following the focus group work, question writing panels were established in each of the 12 field centres who participated in this phase of the work. The question writing panel started its work with reviewing the questions proposed by focus group members and then added additional questions. Questions were written in the local language of the field centre. A maximum of twelve questions was written in each centre for each facet. These questions were then translated into English.

**TABLE 1.3 - WHOQOL PILOT ASSESSMENT DOMAINS AND FACETS**

<b>Domain I</b>	<b>Physical</b>
1	Pain and discomfort
2	Energy and fatigue
3	Sexual activity
4	Sleep and rest
5	Sensory functions
<b>Domain II</b>	<b>Psychological</b>
6	Positive feelings
7	Thinking, learning, memory and concentration
8	Self-esteem
9	Bodily image and appearance
10	Negative feelings
<b>Domain III</b>	<b>Level of independence</b>
11	Mobility
12	Activities of daily living
13	Dependence on medicinal substances and medical aids
14	Dependence on nonmedicinal substances (alcohol, tobacco, drugs)
15	Communication capacity
16	Work capacity
<b>Domain IV</b>	<b>Social relationships</b>
17	Personal relationships
18	Social support
19	Activities as provider/supporter
<b>Domain V</b>	<b>Environment</b>
20	Freedom, physical safety and security
21	Home environment
22	Work satisfaction
23	Financial resources
24	Health and social care: accessibility and quality
25	Opportunities for acquiring new information and skills
26	Participation in and opportunities for recreation/ leisure activities
27	Physical environment (pollution/noise/traffic/climate)
28	Transport

**Domain VI      Spirituality/religion/personal beliefs**

**Overall quality of life and general health perceptions**

Three more centres (Barcelona, Delhi and Tokyo) joined at this stage of the WHOQOL development. They translated the core questions, ran focus groups which ensured the language of the questions was locally appropriate, and in the case of Delhi and Tokyo, suggested national questions which they added to their pilot instrument for testing.

The WHOQOL coordinating group then pooled all questions from all centres to make up a "global question pool" of some 1800 questions. A content analysis of the questions identified many semantically equivalent questions (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 (see Appendix 2). 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"* as judged by the discussions in the focus groups. From the combined rankings for all centres, 236 questions were selected for the WHOQOL pilot instrument.

As a final step, it was decided to use five-point Likert scales for all items in the instrument. To ensure equivalence across WHOQOL field centres, a visual analogue scaling methodology was used which specified the anchor points for the different types of response scales to be used in the instrument (that is, using English anchor points scales identified by "Very satisfied - Very dissatisfied", "Not at all - Extremely", "Not at all - Completely", and "Never - Always". The scales with anchor points "Very poor – Very good" and "Very unhappy – Very happy" were also included by some centres), and then obtained the best descriptors for the 25%, 50% and 75% points between the two anchors for each response scale (see pp. 31-32 for further details). Four types of response scale were included to assess intensity, capacity, frequency and evaluation (see Chapter 4 and Appendix 1 for further information; for a full review of this method see Szabo,S., Orley,J. and Saxena,S. on the behalf of the WHOQOL Group, 1997).

This series of steps enabled a pilot WHOQOL comprising 236 questions addressing 29 facets of quality of life as well as overall quality of life and health to be constructed in readiness for translation (where not already in the local language) and field testing. There were approximately eight questions per facet. The number of questions contributed by each field centre is shown in Appendix 3. The 29 facets were grouped into six major domains as shown in Table 1.3.

### **IMPORTANCE RATINGS**

Forty one standardised questions were added by the WHOQOL coordinating group to assess the importance attributed by the respondents to the selected WHOQOL facets, with a view to possible weighting of facets and domains. Items corresponded to the 29 facets of the WHOQOL pilot version, with some facets having more than one item to reflect their content. These items use a five point Likert response scale and are scaled in a positively framed direction. To date, the importance items have not been used to weight the WHOQOL facets or domain scores. Importance ratings included in the WHOQOL-100 are given in Appendix 7.

### **3) DEVELOPMENT PILOT**

In the third stage, the development pilot testing involved the administration of the WHOQOL pilot form in the 15 culturally diverse field centres. The format of the pilot WHOQOL was standardised with respect to instructions, headers and question order. All questions asked about the two weeks prior to administration of the questionnaire. Questions in the pilot instrument were mainly grouped by response format, for example, with all of the “Satisfaction” items grouped together. However, because some facets needed to be elaborated by a short description (Viz., *Mobility, Spirituality / religion / personal beliefs, Work capacity, and Work satisfaction*), questions addressing these facets were grouped on a facet-by-facet basis.

### **PRE-TEST OF THE WHOQOL PILOT**

The pilot WHOQOL, with the response scales added, was pre-tested with a small sample of health care users to provide preliminary feedback on any problems with wording, any problems with the response scales, any problems with the instructions, the relevance of questions, and respondents' overall impression of the measure.

### **NATIONAL ITEMS**

Field centres were free to include up to two additional national/regional questions per facet, in a separate questionnaire, if the coverage of the facet by core questions was felt to be inadequate in the culture of the field centre. These were normally some of the questions that had been suggested by the focus groups in that country, but not included in the 236 core questions. For example, in Thailand, where the vast majority of the population are Buddhists, the additional national questions included the following question for the facet *Negative feelings*, "How well are you able to rid yourself of negative feelings through meditation?" This question would clearly be inappropriate to most respondents in other settings, but addresses an important aspect of psychological well-being in Thailand.

#### **SAMPLE POPULATION USED TO PILOT THE WHOQOL**

The sampling frame was dictated by (1) the required sample size and sample diversity required for the development of a generic health-related quality of life measure and (2) the practical constraints of following a standardised protocol in fifteen culturally diverse centres. The pilot WHOQOL was administered to a minimum of 300 respondents in each of the 15 field centres participating in this phase of the project. Field centres were instructed to administer the pilot WHOQOL to adults, with "adult" being culturally defined. A sampling quota was specified with regard to age (50% > 45, 50% <45), gender (50% male, 50% female), and health status (250 persons with a disease or impairment; 50 "healthy" respondents). Field centres were instructed to recruit a sample of respondents that represented the health care users in their country or region with a variety of diagnoses and varying degrees of severity of disease or disability. In all, 4800 subjects completed and returned questionnaires.

#### **4) REFINEMENT OF THE WHOQOL TO THE WHOQOL-100**

Following this initial pilot, the WHOQOL assessment was further refined. The reader is referred to the relevant publication (The WHOQOL Group, 1998) for full details of the refinement of the WHOQOL pilot instrument to the WHOQOL-100. In brief, data from the WHOQOL pilot was used to determine items with frequency or reliability problems, or items that failed to discriminate between ill and well sample populations. These were excluded from the WHOQOL-100 instrument. Due to the number of items within certain facets that had statistical problems, five facets were dropped from the WHOQOL-100: these were Sensory functions, Dependence on non-medicinal substances, Communication capacity Activities as provider/supporter and Work satisfaction.

**TABLE 1.4 - WHOQOL-100 DOMAINS AND FACETS**

<b>Domain I</b>	<b>Physical Capacity</b>
1	Pain and discomfort
2	Energy and fatigue
3	Sleep and rest
<b>Domain II</b>	<b>Psychological</b>
4	Positive feelings
5	Thinking, learning, memory and concentration
6	Self-esteem
7	Bodily image and appearance
8	Negative feelings
<b>Domain III</b>	<b>Level of Independence</b>
9	Mobility
10	Activities of daily living
11	Dependence on medication or treatments
12	Work capacity
<b>Domain IV</b>	<b>Social Relationships</b>
13	Personal relationships
14	Social support
15	Sexual activity
<b>Domain V</b>	<b>Environment</b>
16	Physical safety and security
17	Home environment
18	Financial resources
19	Health and social care: accessibility and quality
20	Opportunities for acquiring new information and skills
21	Participation in and opportunities for recreation/ leisure activities
22	Physical environment (pollution/noise/traffic/climate)
23	Transport
<b>Domain VI</b>	<b>Spirituality/Religion/ Personal Beliefs</b>
<b>Overall quality of life and general health perceptions</b>	

### **FINAL STRUCTURE OF THE WHOQOL-100**

Statistical reduction of items led to the selection of 24 specific facets and one general facet, with four items included per facet. Although there is support from exploratory and confirmatory factor analysis for the six domain structure, there is some evidence that a four domain solution may be more appropriate. However, the structure that will continue to be used for the WHOQOL-100 is the original six domain one (see The WHOQOL Group, 1998, for details). The structure of the WHOQOL-100 is presented in Table 1.4. A generic version of the WHOQOL-100 is included in Appendix 4.



## CHAPTER 2 - PSYCHOMETRIC PROPERTIES OF THE WHOQOL-100

### INTRODUCTION

This chapter reports on the field testing and psychometric properties of the WHOQOL-100. It reports on global data from all centres participating in the field trial version of the WHOQOL-100. Psychometric data on individual centres can be requested by contacting the field centres directly (see Appendix 5 for contact information on field centres).

**TABLE 2.1 - DATA AVAILABLE ON THE FIELD TRIAL VERSION OF THE WHOQOL-100**

<b>Centre</b>	<b>n</b>	<b>% total</b>
La Plata, Argentina	421	5.1
Bangkok, Thailand	435	5.2
Beer Sheva, Israel	459	5.5
Madras, India	567	6.8
Melbourne, Australia	349	4.2
New Delhi, India	82	1.0
Panama City, Panama	115	1.4
Seattle, USA	192	2.3
Tilburg, The Netherlands	785	9.5
Zagreb, Croatia	96	1.2
Tokyo, Japan	188	2.3
Harare, Zimbabwe	149	1.8
Leipzig/ Mannheim, Germany	1103	12.1
Barcelona, Spain	552	6.5
Bath, England	104	1.3
St Petersburg, Russia	70	0.8
Porto Alegre, Brazil	82	1.0
China	1431	17.3
Hong Kong	847	10.2
<b>Total</b>	<b>8294</b>	<b>100</b>

## **SAMPLE POPULATION USED TO DETERMINE PSYCHOMETRIC PROPERTIES**

All data collected by centres during the field trial of the WHOQOL-100, and that were available by July 1997, were used to determine the psychometric properties of the WHOQOL-100. Data are included from 19 field centres, of which fourteen had participated in the pilot WHOQOL. The number of subjects who participated from each field centre is shown in Table 2.1. The total number of subjects for which data were available was 8294. There is considerable variation in the sample size from each centre, as apparent from Table 2.1. However, it was considered best to make use of all the available data at this stage in the WHOQOL development.

## **STATISTICAL ANALYSIS**

Scoring methods for facets and domains are shown in Chapter 8. Data analyses were carried out using SPSS (Windows) Version 7. Internal consistency, that is, the extent to which each facet forms a reliable scale, was assessed using Cronbach alpha. Discriminant validity for items was determined via t-tests to distinguish differences between ill and well subjects. Test-retest reliability was assessed using Pearson r correlations. Contribution of domain scores to assessing quality of life was assessed using multiple regression. Confirmatory factor analysis of the facets included in the WHOQOL-100 was carried out using the EQS package Version 5.0 (Bentler & Wu, 1995).

## **CONFIRMATORY FACTOR ANALYSIS OF THE WHOQOL-100 STRUCTURE**

The conceptual structure of the WHOQOL-100 assumes that all six domains contribute to the overall assessment of quality of life. These six domains would therefore be expected to load onto one single factor (a hypothetical quality of life construct). This conceptual structure is shown in Figure 2.1. Confirmatory factor analysis is a method used to test whether the data fits a hypothetical model. An acceptable fit for a particular model occurs when a number of conditions are met, for example, when a “fit index” like the Comparative Fit Index (CFI) is greater than 0.9. When data from the global dataset were incorporated into the six domain model, the CFI was .888. When the error variances from the physical domain and the level of independence domain were allowed to covary, as shown in Figure 2.1, the CFI was 0.975, showing that the single factor model fits the data extremely well. Similarly, for both ill and well sample populations, the comparative fit index for the single factor model was well above 0.9 (see Table 2.2).

## **TABLE 2.2 - COMPARATIVE FIT INDICES FOR STRUCTURAL EQUATION MODELLING OF THE SIX WHOQOL-100 DOMAINS**

<b>Model</b>	<b>Comparative Fit Indices for data sets</b>			
	<b>Global</b>	<b>III</b>	<b>Well</b>	<b>Multisample</b>
<b>Domains onto overall QOL</b>	.975	.966	.971	.961
<b>Facets onto Physical domain</b>	.993	.989	.995	.969
<b>Facets onto Psychological domain</b>	.956	.954	.948	.947
<b>Facets onto Level of Independence domain</b>	.999	1.00	.998	.961
<b>Facets onto Social relats. domain</b>	.942	.913	.951	.987
<b>Facets onto Environment domain</b>	.936	.928	.940	.930

Multiple sample analysis is used to assess whether the loadings of the domain scores onto the hypothetical construct of quality of life are comparable across different population groups such as ill and well respondents. The CFI for multiple sample analysis was .961, showing parameter loadings estimated in the model to be invariant across ill and well population groups (see Table 2.2).

The hypothetical structures of the six domains are shown in Figure 2.2. For each domain, the models assume there is only one factor upon which all facets load. Table 2.2 shows tests of the domain structures carried out for each of the domains separately, for both the global dataset and each of the ill and well sample populations. The global dataset and both ill and well sample populations fitted these models well for each domain (see Table 2.2). Parameter estimates for the global dataset, shown in Figure 2.2, indicate that all facets within domains contributed significantly to the domain. As shown in Table 2.2, multiple sample analysis for all domains displayed appropriate CFIs above 0.9 in all cases, suggesting parameter estimates to be invariant across ill and well population groups for all domains.

## DISCRIMINANT VALIDITY

Following confirmation of the six domain structure, mean scores for facets and domains were calculated for both ill and well sample populations (see Table 2.3). Descriptive statistics for age and gender for these groups are shown in Table 2.4. The WHOQOL-100 discriminated between ill and well respondents on all six domains. Largest differences between these groups were found for the level of independence domain, with scores on average 18.5% lower for ill subjects than for well subjects, compared with the environment domain where differences between groups were in the region of 5% (see Table 2.3).

**TABLE 2.3 - DISCRIMINANT VALIDITY OF THE WHOQOL-100**

Facet	Total	Ill (n=4644)	Well (n=3187)	t	p
<b>Physical</b>	<b>62.6 ± 18.2</b>	<b>57.1 ± 18.5</b>	<b>70.4 ± 14.8</b>	<b>35.3</b>	<b>.001</b>
Pain	38.4 ± 21.9	44.4 ± 22.7	29.8 ± 18.1	31.4	.001
Energy	59.0 ± 20.9	53.1 ± 21.4	67.0 ± 17.3	31.5	.001
Sleep	67.3 ± 23.9	62.3 ± 24.6	74.1 ± 21.1	22.6	.001
<b>Psychological</b>	<b>62.5 ± 14.8</b>	<b>59.1 ± 14.9</b>	<b>67.1 ± 13.0</b>	<b>25.0</b>	<b>.001</b>
Pfeel	56.1 ± 19.1	52.4 ± 19.2	60.8 ± 17.6	19.4	.001
Think	59.7 ± 17.9	56.1 ± 18.2	64.7 ± 16.3	21.9	.001
Esteem	61.5 ± 18.1	58.6 ± 18.5	65.6 ± 16.2	17.5	.001
Body	71.7 ± 19.3	69.8 ± 20.0	75.1 ± 17.4	12.7	.001
Neg	37.0 ± 22.6	41.2 ± 23.7	31.6 ± 19.8	19.5	.001
<b>Level of Independ.</b>	<b>68.5 ± 19.8</b>	<b>60.9 ± 19.6</b>	<b>79.4 ± 14.3</b>	<b>48.3</b>	<b>.001</b>
Mobil	68.2 ± 23.5	62.7 ± 23.8	75.9 ± 20.7	26.1	.001
Activ	68.6 ± 21.8	62.1 ± 22.6	77.6 ± 17.0	34.6	.001
Medic	28.6 ± 28.2	39.2 ± 28.2	13.2 ± 19.5	48.2	.001
Work	65.9 ± 25.1	58.0 ± 26.0	77.3 ± 18.7	38.2	.001
<b>Social relations</b>	<b>63.6 ± 15.8</b>	<b>60.6 ± 16.1</b>	<b>67.7 ± 14.3</b>	<b>20.4</b>	<b>.001</b>
Relat	69.9 ± 17.4	67.1 ± 18.1	74.0 ± 15.6	18.2	.001
Supp	61.0 ± 20.6	58.2 ± 20.9	64.5 ± 19.5	13.5	.001
Sex	60.2 ± 20.8	56.7 ± 21.0	64.7 ± 19.1	16.8	.001
<b>Environment</b>	<b>60.4 ± 14.6</b>	<b>58.2 ± 14.1</b>	<b>63.1 ± 14.9</b>	<b>14.8</b>	<b>.001</b>
Safety	62.0 ± 17.9	59.8 ± 18.2	64.3 ± 16.9	11.3	.001
Home	62.3 ± 22.7	60.2 ± 22.8	64.7 ± 22.6	8.5	.001
Finan	58.3 ± 24.5	56.2 ± 25.0	61.5 ± 23.7	9.6	.001
Servic	57.6 ± 18.2	55.8 ± 17.8	59.4 ± 18.6	8.4	.001
Inform	58.4 ± 19.9	55.1 ± 19.3	62.7 ± 20.3	16.5	.001
Leisur	55.7 ± 20.9	52.6 ± 20.5	59.9 ± 21.0	15.2	.001
Envir	59.4 ± 18.2	58.3 ± 18.1	60.3 ± 18.2	4.8	.001
Transp	69.3 ± 22.0	67.3 ± 21.7	72.3 ± 21.9	10.1	.001

<b>Spirit</b>	58.0 ± 23.9	55.7 ± 24.1	60.8 ± 23.5	9.2	.001
<b>Overall</b>	<b>60.3 ± 20.1</b>	<b>55.0 ± 19.9</b>	<b>67.9 ± 17.9</b>	<b>29.9</b>	<b>.001</b>

**TABLE 2.4 - DESCRIPTIVE STATISTICS FOR ILL AND WELL SAMPLE POPULATIONS**

	<b>Global data</b>	<b>Unwell</b>	<b>Well</b>	<b>Statistic</b>	<b>p</b>
<b>Age ± s.d.</b>	44.9 ± 16.6	47.4 ± 15.9	42.1 ± 16.6	t = 13.5	.001
<b>% female</b>	47.2	49.3	44.6	X <sup>2</sup> = 16.4	.001
<b>% male</b>	52.8	50.7	55.4		

### **INTERNAL CONSISTENCY**

Cronbach alpha values for each of the six domain scores ranged from .71 (for domain 4) to .86 (for domain 5), demonstrating good internal consistency (see Table 2.5). Cronbach alpha values for domains 1 and 4 should be read with caution as they were based on three scores rather than the minimum four generally recommended for assessing internal reliability.

### **TEST-RETEST RELIABILITY**

Data used to assess test-retest reliability included a majority of well subjects (87% of respondents) from four centres participating in the field trial of the WHOQOL-100. These were Bath (n=90), Harare (n=100), Tilburg (n=116) and Zagreb (n=85). In all centres, respondents were university students, with the exception of Harare, where subjects were random samples of ill (n=50) and well (n=50) respondents. The interval between test and retest ranged from 2-8 weeks. Correlations between items at time points one and two were generally high (see Table 2.5), ranging from .68 for the Safety facet to .95 for Dependence on Medication. This suggests that the WHOQOL-100 produces comparable scores across time in cases where no interventions or life-altering events have occurred. However, more test-retest reliability data need to be collected for the measure.

### **IMPORTANCE OF DOMAINS IN ASSESSING OVERALL QUALITY OF LIFE**

Multiple regression was used to determine the contribution made by each domain score to explaining the observed variance in the general facet from the WHOQOL-100 assessment (i.e. the Overall Quality of Life and General Health facet). As shown in Table 2.6, all six WHOQOL-100 domain scores made a significant contribution to explaining variance observed in the general facet relating to Overall Quality of Life and General Health, with the environment domain contributing

most highly, and the spirituality domain making least contribution. This contribution is expressed as the standardised beta values, that is, the contribution to the final regression equation made by each domain. These analyses suggest that all six domains should be taken into consideration when evaluating overall quality of life. When ill and well population groups were examined individually, physical domain was seen to contribute most to explaining overall quality of life in the ill sample whilst environment was seen to contribute most to explaining overall quality of life in the well sample population, reflecting a difference in emphasis between population groups.

**TABLE 2. 5 - TEST-RETEST RELIABILITY AND INTERNAL CONSISTENCY OF FACETS AND DOMAINS**

Facet	Test-retest (Pearson r)	Internal consistency (Cronbach Alpha)		
		Total	Ill (n=4644)	Well (n=3187)
<b>Physical*</b>	<b>.74</b>	<b>.76</b>	<b>.74</b>	<b>.68</b>
Pain	.80	.80	.80	.74
Energy	.76	.77	.77	.71
Sleep	.78	.88	.88	.87
<b>Psychological</b>	<b>.83</b>	<b>.81</b>	<b>.80</b>	<b>.79</b>
Pfeel	.75	.78	.75	.78
Think	.70	.76	.73	.75
Esteem	.79	.81	.79	.81
Body	.82	.78	.77	.77
Neg	.83	.85	.85	.81
<b>Level of Independ.</b>	<b>.81</b>	<b>.81</b>	<b>.78</b>	<b>.74</b>
Mobil	.74	.79	.79	.72
Activ	.78	.82	.81	.75
Medic	.95	.93	.92	.90
Work	.71	.92	.91	.89
<b>Social relations*</b>	<b>.81</b>	<b>.71</b>	<b>.70</b>	<b>.68</b>
Relat	.75	.68	.68	.67
Supp	.73	.77	.76	.77
Sex	.83	.79	.77	.78
<b>Environment</b>	<b>.90</b>	<b>.86</b>	<b>.84</b>	<b>.87</b>
Safety	.68	.70	.68	.70

Home	.81	.87	.86	.88
Finan	.93	.86	.86	.86
Servic	.80	.77	.75	.80
Inform	.74	.82	.78	.82
Leisur	.77	.80	.78	.82
Envir	.75	.67	.64	.69
Transp	.88	.83	.81	.84
<b>Spirit</b>	.80	.89	.89	.88
<b>Overall</b>	<b>.78</b>	<b>.84</b>	<b>.83</b>	<b>.84</b>

(\*=Only 3 items, therefore Cronbach alphas may not be reliable).

**TABLE 2.6 - MULTIPLE REGRESSION MODEL USING GENERAL HEALTH AND QUALITY OF LIFE FACET AS THE DEPENDENT VARIABLE AND DOMAIN SCORES AS PREDICTOR VARIABLES (ALL BETA VALUES SIGNIFICANT AT P<.001, EXCEPT \* WHERE P=.02)**

Data set	% of Overall QOL & Gen. Health facet explained	Final equation standardised beta values					
		Domain 1	Domain 2	Domain 3	Domain4	Domain 5	Domain 6
Total	64.6	.13	.23	.19	.17	.26	.04
Ill	59.0	.14	.24	.19	.17	.21	.03*
Well	64.9	.10	.23	.05	.18	.37	.08



## CHAPTER 3 - PREPARATION AND ADMINISTRATION OF THE WHOQOL-100

### ACCESS TO THE WHOQOL-100

The WHOQOL-100 contains 100 questions. This is based on four questions per facet, for 24 facets of quality of life. In addition, four questions address *Overall quality of life and general health*. To date, around 30 language versions of the WHOQOL-100 have been developed (see Table 3.1).

Development work is ongoing on several further language versions of the WHOQOL-100. The required language version of the WHOQOL-100 (instructions, headers, questions and response scales) can be obtained from principal investigators in the respective country / region (see Appendix 5), or failing that, from the Programme on Mental Health, World Health Organization, CH-1211 Geneva 27, Switzerland.

**TABLE 3.1 - EXISTING LANGUAGE VERSIONS OF THE WHOQOL**

<b>Language</b>	<b>Originating field centre</b>
Bulgarian	Sofia, Bulgaria
Chinese	Guang Zhou, China
Chinese (Australian)	Melbourne, Australia
Chinese (Hong Kong)	Hong Kong
Croatian	Zagreb, Croatia
Czech	Bohnice, Czech Republic
Danish	Copenhagen, Denmark
Dutch	Tilburg, the Netherlands
English (Australian)	Melbourne, Australia
English (Canadian)	Victoria BC, Canada
English (UK)	Bath, United Kingdom
English (USA)	Seattle, USA
Estonian	Tallinn, Estonia
French	Paris, France
French (Canadian)	Rimouski PQ, Canada
German	Mannheim & Leipzig, Germany
Hebrew	Beer-Sheva, Israel
Hindi	Delhi, India
Hungarian	Hungary
Italian	Bologna, Italy
Japanese	Tokyo, Japan
Korean	Seoul, Korea
Malay	Kelantan, Malaysia
Norwegian	Bergin, Norway
Polish	Poznan, Poland
Portuguese (Brazil)	Porto Alegre, Brazil
Russian	St Petersburg, Russia
Shona	Harare, Zimbabwe
Slovakian	Bratislava, Slovakia
Spanish (Argentina)	La Plata, Argentina
Spanish (Panama)	Panama City, Panama;
Spanish	Barcelona, Spain
Swedish	Molndal, Sweden
Tamil	Madras India
Thai	Bangkok, Thailand
Turkish	Izmir, Turkey
Urdu (Pakistan)	Rawalpindi, Pakistan
Lozi	Lusaka, Zambia

To reduce the possibility of replication of work and the possibility of two or more WHOQOL-100 versions being used in a given cultural setting, permission should always be sought from the National

field centre for each country for work involving the WHOQOL-100. Under no circumstances should the example WHOQOL-100 included in Appendix 4 be used as it stands. The appropriate language version should be obtained from the appropriate field centre. Nor should the WHOQOL-100 version included in this series of documents be translated for use in a setting where development work has not yet taken place. A methodology has been developed whereby new centres wishing to develop a further language version of the WHOQOL-100 can do so. This is outlined in Chapter 4 but in order to do the work the full protocol must be followed which can be obtained from The WHOQOL Group, Division of Mental Health, World Health Organization, CH-1211 Geneva 27, Switzerland. Copyright for the WHOQOL is held by WHO on behalf of the field centres.

### **PREPARATION OF THE WHOQOL-100**

Questions must appear in the order in which they appear in the example WHOQOL-100 instrument provided in this series of documents, with instructions and headers unchanged in any substantive way. Questions are grouped by response format. However, given that some facets need to be elaborated by a short description (e.g. the broader definition of work as including all major activities) some questions are grouped on a facet-by-facet basis (e.g. *Mobility, Work capacity*). National items should always be added at the end of the questionnaire and not be interspersed with the core 100 items.

### **WHOQOL-100 ADMINISTRATION**

The WHOQOL-100 should be self-administered if respondents have sufficient ability to read; otherwise, interviewer-assisted or interviewer-administered forms should be used. The standardised instructions given in Appendix 4 should be printed on the cover sheet of the WHOQOL questionnaire, or, when interviewer-administered, should be read out to respondents. The response scale included in the instructions is an example only and centres should substitute their own *intensity* response scale as an example.

### **TIME TAKEN TO COMPLETE THE WHOQOL-100**

The time taken to complete the WHOQOL-100 will depend on several factors: whether it is self-administered or interviewer-administered, the motivation of the respondent, the language version of the WHOQOL-100 used, and familiarity with questionnaires in the cultural setting.

Literate respondents would be expected to complete the self-administered version in approximately 30 minutes. Working with semi-literate or illiterate respondents, the interview administered form of the WHOQOL-100 would be expected to take between 40 and 90 minutes.

## **FRAME OF REFERENCE AND TIME FRAME**

The frame of reference for the instrument reflects the definition of quality of life adopted for the project. Respondents' quality of life will be assessed in the context of the culture and value systems in which they live and specifically in relation to respondents' goals, expectations, standards and concerns.

A time frame of two weeks was used in piloting work with the WHOQOL instrument. It is recognised, however, that different time frames may be necessary for particular uses of the instrument in subsequent stages of work. For example, in the assessment of quality of life in chronic conditions such as back pain and arthritis, a longer time frame such as four weeks may be preferable. In the assessment of patients receiving chemotherapy, the treatment cycles should be considered to establish and control for responsiveness and any side effects that are anticipated. Furthermore, the perception of time is different in different cultural settings, and in the interpretation of data this is something that should be explicitly acknowledged.

## **USER AGREEMENT**

The WHOQOL-100 assessment has been undergoing development since 1991 and the WHOQOL-BREF since June 1996. Both are subject to further refinement in the future. This includes periodic modifications to the user manuals as additional data become available in order to update normative data and psychometric properties of the instrument (i.e. reliability and validity data). Users ought therefore to consult WHO, Geneva for information on manual updates. Because we are interested in updating manuals, we ask WHOQOL-100 and WHOQOL-BREF users for information regarding studies being carried out. This information should be sent to:

**The WHOQOL Project**  
**Programme on Mental Health**  
**WHO**  
**1211 Geneva 27**  
**Switzerland**

No users of the WHOQOL-100 or the WHOQOL-BREF are authorised to make substantive changes to the assessments. If during use of the WHOQOL assessments, users have difficulty in administering the instrument (i.e. the language is not appropriate for the population being tested), they are requested to contact the above address.

## **CHAPTER 4 - DEVELOPMENT OF THE WHOQOL-100 IN A NEW LANGUAGE**

### **INTRODUCTION**

The language versions of the WHOQOL that are currently available enable multicentre quality of life research in the settings where development work has taken place. However, there are many further settings where there is a genuine need for an international measure of quality of life, and it is hoped that development work will be extended to these additional cultural settings.

This chapter therefore serves as a resource for those wishing to develop the WHOQOL-100 in new cultural settings, where WHOQOL piloting work has not already been conducted; it describes the process necessary to develop a WHOQOL-100, including a description of the translation methodology that should be used.

### **APPROPRIATENESS OF THE WHOQOL-100 IN NEW CENTRES**

Before developing a regional/language version of the WHOQOL, the prospective centre should first consider a number of issues.

1. Will the WHOQOL-100 assessment be of utility to health practitioners, researchers and/or policy makers in the target setting?
2. Are the stated purposes of the WHOQOL-100 compatible with the requirements in the target culture?
3. Are suitable instruments for the assessment of quality of life in the target culture/language with adequate psychometric properties of validity, reliability and responsiveness to change available? If so, the development of the WHOQOL-100 might not be warranted.
4. Is the approach of the WHOQOL-100 compatible with that of the investigators, and proposed centre that would develop the region/language version of the WHOQOL?
5. Does the prospective centre have access to funding, and other necessary resources to carry out the work?

6. Is the work outlined in this protocol and the main study protocol feasible in the prospective centre? This includes having a principal investigator who can communicate with the WHOQOL coordinating group in English, having access to patients with a range of health problems for research purposes, and expertise in focus group methodology.

If these conditions apply in a prospective centre, and approval for the development of the new WHOQOL-100 region/language version has been given by the WHOQOL Group at WHO Geneva, work on the development of a regional/language version of the WHOQOL-100 can proceed. A study team should be assembled, and all members of this team fully familiarised with the aims and assumptions of the WHOQOL project, the characteristics, structure and proposed uses of the instrument, and development work to date on the WHOQOL-100. This should be done in close collaboration with the WHOQOL coordinating group, who will seek to establish high levels of standardisation between any new centre and centres where the WHOQOL-100 has already been developed, or work on its development is ongoing.

#### **APPROPRIATENESS OF THE WHOQOL DOMAIN AND FACET STRUCTURE**

The WHOQOL-100 structure is derived from extensive qualitative and quantitative work carried out simultaneously in centres selected to provide differences in their levels of industrialisation, 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 religious denomination). Therefore, it is assumed that the domains and facets of quality of life included in the WHOQOL-100 instrument will be relatively universal. However, before further work on a new language version can proceed, this assumption should be explicitly tested. This should in the first instance involve researchers in the proposed study team, behavioural scientists working in the quality of life field, and health personnel involved in clinical work where patients' quality of life is a central issue (e.g. the palliation of cancer patients). They should critically consider the appropriateness of the WHOQOL-100 domain and facet structure in the target culture. Proceeding further will depend on this structure being found to be broadly appropriate. If on the basis of the review process outlined here, and where this is corroborated by the focus group work described below, new centres may add (but not delete), facets in an existing domain. The operationalization of specific facet definitions and question writing should follow the same procedure as in the main study, as outlined in the following sections. The suggested facets and additional questions addressing these facets will have to prove their relevance to quality of life and psychometric robustness in relation to existing WHOQOL facets and questions in the pilot phase outlined below.

## **TRANSLATION OF THE WHOQOL FACET DEFINITIONS AND CORE ITEMS**

WHO has accrued considerable experience in translating health measurements (see Sartorius and Kuyken, 1994). This has facilitated the development of a translation methodology which has significant advantages over the "forward - translation" and the "translation - back-translation" methodologies. The steps outlined below describe a sequence which has been used successfully in a number of studies.

The following individuals will be needed to assist in the translation process.

1. **A bilingual panel** (three to six individuals)

The group should be made up of one or more individuals skilled in interviewing and assessment, a clinician and (say) a behavioural scientist, possibly an anthropologist. All should be able to speak and write English and the national language.

2. **Monolingual individuals** (at least four)

These will be able to comment in an articulate way on the translated document. The monolingual group should be representative of the people who are likely to use the instrument in the target culture, and of those who will be subjects in the proposed studies.

3. **Translators** (at least two)

One or two to be involved in the translation of the materials provided into the local language and another who should be entirely independent of the first and who would be responsible for back-translation.

The translation process has a number of steps. The source instrument is translated into the target language by one or two translators, if two, they can consult one another in the course of their work. These translators should have a clear and detailed understanding of the instrument, and the population who will use the instrument. This will increase the likelihood both that the instrument is translated appropriately, and that the language used in the translated document matches closely the language usage of the target group.

The bilingual panel then reviews the translation, looking for any inconsistencies between the source language version and the translated document, and discussing and resolving issues related to the maintenance of the integrity of the source instrument in terms of conceptual, semantic and technical equivalence.

A group of monolingual individuals, unfamiliar with the instrument, and representative of the population for whom the instrument is intended, then "tests" the document by reading through it, looking for aspects of the translation which are not clearly comprehensible or are ambiguous in the target language. The monolingual group should also be asked to comment on whether the style of questioning and format of the questionnaire is acceptable. The presentation of the instrument to the monolingual group is of considerable importance because they rely only on the text of the target language, and have no prior idea of the concepts the questions were designed to address, nor the form or content of the questions in the source language. Monolingual review can be done in a focus group situation, where focus group participants arrive having read through the instrument, and discuss the instrument in session. This would involve detailed discussion of the instrument's instructions, form and content. Ideally such monolingual focus groups would be moderated by a member of the bilingual panel.

The bilingual group then considers the comments of the monolingual group and, wherever these accurately reflect the source document, incorporates them into the translated document, ensuring that the document is grammatically correct in the target language.

The translated document is then back-translated into the original language by the back-translator. This translator should be briefed about his/her place in the translation methodology being used, and told that he/she is translating a measure concerned with health. This ensures the translator's work is appropriate to the methodology without introducing bias into the process. The back-translator must not see a copy of the original English version before completing the translation.

The bilingual group then considers the original and back-translated documents. Any significant differences should lead to iterations in the process until an acceptable conceptual, semantic and technical equivalence has been achieved.

## **CONDUCT OF FOCUS GROUPS**

Following translation of the core questions and facet definitions, focus groups should be convened in the new centre to:

1. Check on the validity and comprehensiveness of the domain and facet structure in the target culture
2. Evaluate the comprehensiveness of the existing core items represented in the WHOQOL
3. Generate any additional items that may be necessary and
4. Gather information about the translatability of certain concepts and questions.

A series of focus groups should be conducted separately with health personnel and patients. The focus group participants should read the facet definitions and then look at the core questions provided by WHO. On the basis of their examination of the facet definitions and core questions addressing that definition, participants should suggest areas/questions not adequately covered by the WHO core items. It is not the job of focus groups to suggest modifications to existing items, nor the deletion of items felt to be unnecessary, but rather to suggest areas inadequately covered. A feature of the WHOQOL methodology is that any national items will have to compete with the core items derived from all other centres to be retained in the instrument.

The health personnel focus groups should represent the cross section of health personnel who are likely to be involved in patient care in that field centre. This may include professionals such as doctors, nurses, social workers, health and clinical psychologists, occupational therapists, physiotherapists and speech therapists. The health personnel group is convened to discuss the WHOQOL in relation to the quality of life of the patients under their care.

Patient focus groups should be made up of a sample of individuals who are representative of the population of patients in the field centre. This applies to the following demographic features: gender, age, educational background, socio-economic group, marital status, health status and ethnic group. This group should comprise patients who are in some way in contact with local health services. An attempt should be made to include individuals with acute and chronic disorders, and outpatients and inpatients. An untypical sample (e.g. exclusively psychiatric patients, diabetic patients or cancer patients) would be unacceptable. Each focus group should comprise 6-8 people. However, this number may be subject to cultural variation. In general, if smaller numbers of participants are used per focus group, then more focus groups will need to be run.

A minimum of two focus groups with health personnel and two focus groups with patients should be conducted. Most importantly, it is essential that enough focus groups are run so that the data from these groups can confidently be said to be representative of the target population. If the data from the two groups are dissimilar, more focus groups need to be conducted until a consistent pattern is observable. The interview schedule to be used in the running of these focus groups is included in Appendix 6.

### **QUESTION WRITING WORK FOR NATIONAL ITEMS**

After completion of the focus group work, and transcripts of the focus groups have been prepared, a question writing panel should be assembled in each field centre. The principal investigator, the main focus group moderator, and two other individuals who have been involved in the project should arrange this panel. The panel should include at least one person with good interviewing skills and experience, and a lay person, preferably a patient who participated in one of the focus groups, to ensure that questions are framed in comprehensible and natural language.

Making full use of focus group transcripts, the question writing panel frames any additional questions for facets not comprehensively covered by the existing core questions. The expanded group of questions from which the core questions are derived should be consulted to examine if questions already exist addressing the issues considered by focus group participants to be inadequately covered. Questions should be framed in the local language in which the instrument will be used. The criteria outlined in Appendix 2 should be used by the question writing panel in their work.

It should be remembered that "national questions" will only be finally accepted if they can be shown to tap into alternative aspects of facets or domains not adequately covered by the existing items and facets. The analysis of the pilot data must show that they contribute significantly to the assessment of quality of life and are not merely duplications of existing items or facets. In the case of proposed national items exploring alternative aspects of facets and domains, it is advisable for the centre to add several items so that the new concept has some weight in the subsequent analyses. The data from one item are likely to insufficiently represent a concept. An example of successful national questions is a set from a module in Chinese, used with immigrants into Australia. These questions tapped into feelings of alienation, discrimination, etc. Sufficient items were included in the pilot to enable a new facet to be considered on this topic.

Please consult with WHO Geneva about the issue of national questions before finalising your pilot questionnaire, but do remember to get focus groups and the question writing panel to suggest a variety of questions (and not just one item) for any new facet (or aspect of a facet not yet covered).

## **DEVELOPMENT OF RESPONSE SCALES**

Response scales should be prepared in the language of the new centre according to a standardised methodology. This will ensure their metric equivalence to response scales already derived in other WHOQOL field centres. Anchor points for each of the response scales in the WHOQOL assessment, intensity, capacity, frequency and evaluation should be translatable without difficulty, e.g. "Never and Always", "Not at all" and "Completely". However, descriptors such as "Sometimes" and "Rarely" are considerably more difficult to translate. Therefore, a method is described for deriving each response scale in each centre and new centres should follow the steps below in deriving descriptors.

<b>Anchor point</b>	<b>Descriptor</b>	<b>Descriptor</b>	<b>Descriptor</b>	<b>Anchor point</b>
Least	One quarter	Halfway	Three quarters	Most
0%	25%	50%	75%	100%

1. Anchor points are translated into the language of the field centre, being careful to maintain both the exact meaning and magnitude.
2. A list of at least 15 descriptors which should cover the complete range from least to most, is compiled in the language of the new centre for each response scale from dictionaries, relevant literature, and other instruments.
3. For each response scale a minimum of 20 lay subjects, representative of the health care users or possible users in the field centre, are asked to place a mark on a 10 cm line for each descriptor, according to where they think the descriptor lies in relation to the two anchor points. The series of descriptors for a given response scale are presented in random order, and a fresh line is used for each descriptor.
4. To select descriptors for each response scale, mean distances for the 20+ subjects are calculated. To select the 25% descriptor, the mean falling between 20 mm and 30 mm is selected, to select the 50% descriptor the mean falling between 45 mm and 55 mm is selected and to select the 75% descriptor the mean falling between 70 mm and 80 mm is selected. If

there are several descriptors whose mean score falls within the given range, the descriptor with the lowest standard deviation should be selected.

5. To check on the ordinality of response scales, a small group of respondents should be asked to rank order descriptors from less to more for each response scale in a card sort exercise. Any problems identified from this card sort exercise should lead to further development of more appropriate descriptors.

### **CONSTRUCTION OF PILOT INSTRUMENT, PRE-TESTING AND PILOTING**

Following the work outlined above, the pilot instrument should then be constructed (instructions, headers, core questions, additional questions, and demography questionnaire). Questions should appear in the pilot instrument in the standardised order indicated in the example pilot instrument, with instructions and headers unchanged in any substantive way. Any national questions may only be added at the end of the questionnaire. Question codes should be included in the instrument for ease of reference and subsequent data entry. The importance questions and the instructions (see Appendix 7) could also be translated using the WHO methodology. Before piloting begins, the language version and back-translation should be cleared by WHO Geneva for purposes of quality control and standardisation.

The questionnaire should then be pre-tested with a small sample of health care users to provide preliminary feedback on: any problems with wording, any problems with the response scales, any problems with the instructions, the relevance of questions, and respondents' overall impression of the measure. The pilot should be adjusted on the basis of this pre-test.

### **ADMINISTRATION OF PILOT WHOQOL**

The administration of the pilot instrument, and subsequent work on the development of the language/region version of the instrument should follow the procedures outlined in the main study protocol. The instrument should be piloted on at least 300 people. Given the length of the instrument, recruiting this number of respondents is likely to involve considerable investment of time both from the interviewers / researchers and from respondents. In cultures where questionnaire measures are likely to be less familiar, particularly where a significant number of illiterate respondents would have to be assisted, the measure would take significantly longer to complete. In any case, it will be necessary to brief respondents carefully about the reasons why the questionnaire is long, to ensure their cooperation.

The sample of people to whom the questionnaire should be administered would all be adults, with "adult" being culturally defined. While stratified samples are not essential, a sampling quota should apply with regard to:

Age (<45 years 50%, 45+ 50%),

Sex (male 50%, female 50%), and

Health status (250 persons with a disease or impairment; 50 "well" persons).

Principal investigators should obtain information on the demographic and disease characteristics of individuals using local health care resources. On the basis of this data, the recruitment in the new centre should reflect, as far as is possible, the profile of the health care users in the country or region of the new centre. It is important the group should contain a cross-section of people with very varied levels of quality of life. One way of attempting this would be to include some people with quite severe and disabling chronic diseases, some people in contact with health facilities for more transient conditions, possibly some people attending a family practitioner, and others who would be assumed to have a relatively "normal" quality of life and are in contact with the health service for reasons that are not likely to impinge upon their quality of life to any great extent. By sampling patients from a cross-section of primary care settings, hospitals and community care settings this could most likely be achieved. In the first pilot exercise there was found to be a significant and progressive lowering of quality of life from the well group, through out-patients to in-patients.

In some new centres several cultural groups may coexist, often speaking languages other than the national language. In such cases a feasible option at the piloting stage is to pilot the instrument on those individuals fluent in the dominant language of the new centre.

## CHAPTER 5 - DEVELOPMENT OF THE WHOQOL-BREF

### INTRODUCTION

Whilst the WHOQOL-100 allows a detailed assessment of individual facets relating to quality of life, it may be too lengthy for some uses, for example, in large epidemiological studies where quality of life is only one amongst many variables of interest. In these instances, assessments will be more willingly incorporated into studies if they are brief, convenient and accurate (Berwick et al, 1991). The WHOQOL-BREF Field Trial Version has therefore been developed to look at domain level profiles which assess quality of life (see also The WHOQOL Group, in press). This chapter outlines its development.

### SAMPLE POPULATION USED TO SELECT ITEMS FOR THE WHOQOL-BREF

Two datasets were used to select items for inclusion in the WHOQOL-BREF. The first included all data from the fifteen field centres who participated in the WHOQOL pilot study (see Table 5.1). The second dataset included data from the thirteen centres who field-tested the WHOQOL-100. A further dataset including data from five new centres, who had not participated at the pilot stage but had field-tested the WHOQOL-100, and had results available, was also used to test the adequacy of items selected (see Table 5.1).

TABLE 5.1 - CENTRES INCLUDED IN DEVELOPMENT OF THE WHOQOL-BREF

Data from original pilot of the WHOQOL		Data from original centres field testing the WHOQOL-100		Data from new centres field testing the WHOQOL-100	
	n		n		n
Bangkok, Thailand	300	Bangkok, Thailand	435	Hong Kong	856
Beer Sheva, Israel	344	Beer Sheva, Israel	464	Leipzig, Germany	527
Madras, India	412	Madras, India	567	Mannheim, Germany	483
Melbourne, Australia	300	Melbourne, Australia	350	La Plata, Argentina	421
New Delhi, India	304	New Delhi, India	82	Port Alegre, Brazil	82
Panama City, Panama	300	Panama City, Panama	117		
Seattle, USA	300	Seattle, USA	192		
Tilburg, The Netherlands	411	Tilburg, The Netherlands	799		
Zagreb, Croatia	300	Zagreb, Croatia	96		
Tokyo, Japan	286	Tokyo, Japan	190		
Harare, Zimbabwe	300	Harare, Zimbabwe	149		
Barcelona, Spain	303	Barcelona, Spain	558		
Bath, England	319	Bath, England	105		
St Petersburg, Russia	300				
Paris, France	323				
<b>Total</b>	<b>4802</b>		<b>4104</b>		<b>2369</b>

## **METHOD USED TO SELECT ITEMS FOR THE WHOQOL-BREF**

At a conceptual level, it was agreed by the WHOQOL Group that comprehensiveness ought to be maintained in any abbreviated version of the WHOQOL-100, by selecting at least one question from each of the 24 facets relating to quality of life as well as two items from overall quality of life and health. The most general question from each facet (i.e. the item that correlated most highly with the total score, calculated as the mean of all facets) was chosen for inclusion in the WHOQOL-BREF. Individual items selected by this method were then examined by a panel to establish whether the items selected to represent each domain reflected the conceptually derived operationalisations of facets of quality of life. That is to say, that they constituted a cohesive and interpretable domain, with good construct validity. Of the 26 items selected, six were removed and another item substituted. Three items from the environment domain were substituted because they were highly correlated with the psychological domain. A further three items were substituted because it was felt that other items within the facet could better explain the concept. A generic version of the WHOQOL-BREF is included in Appendix 8.

## **CALCULATION OF DOMAIN SCORES**

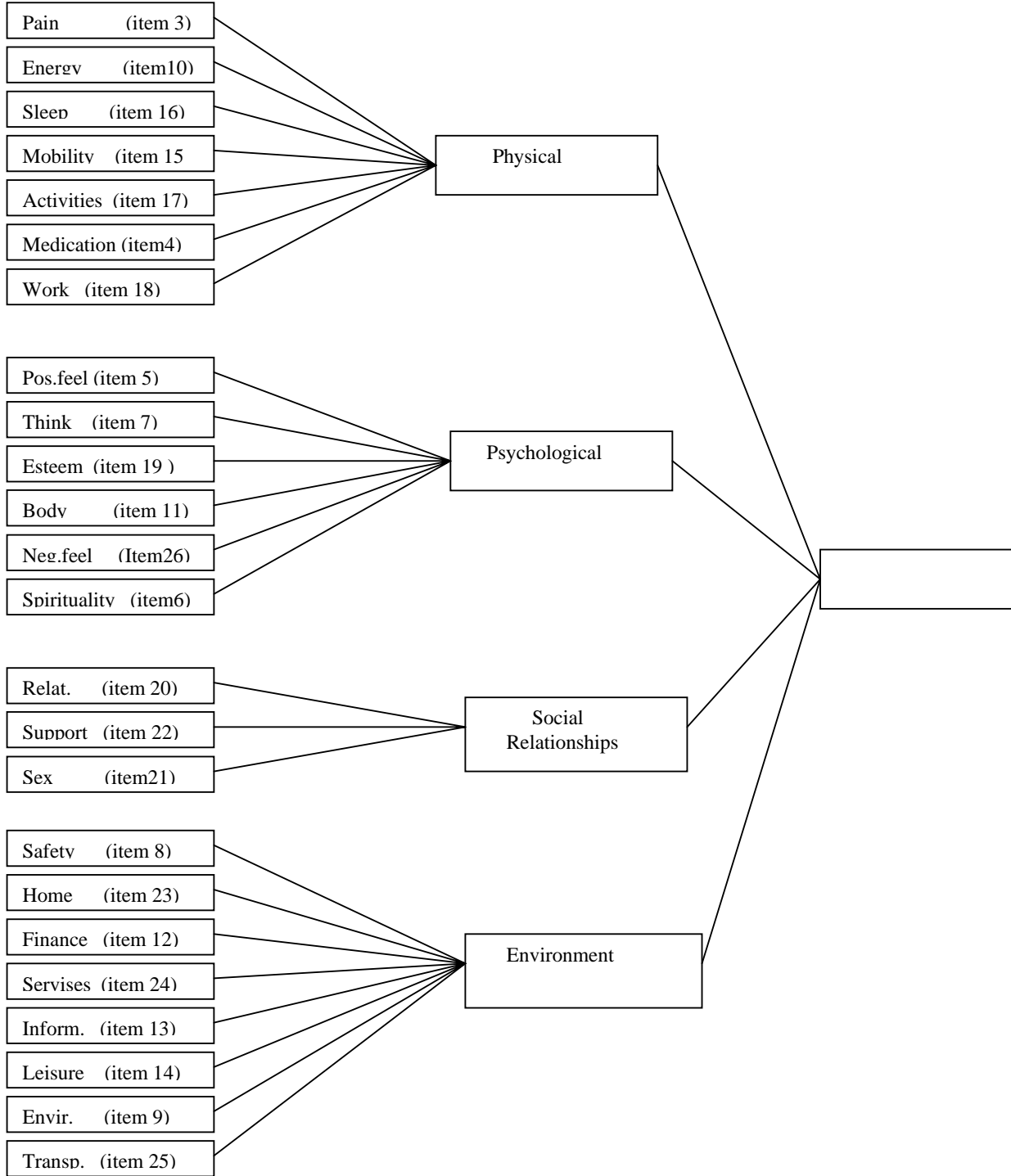
Domain scores for the WHOQOL-BREF are calculated by taking the mean of all items included in each domain and multiplying by a factor of four. These scores are then transformed to a 0-100 scale. Details for scoring the WHOQOL-BREF are given in Appendix 10.

## **CONFIRMATORY FACTOR ANALYSIS OF THE WHOQOL-BREF STRUCTURE**

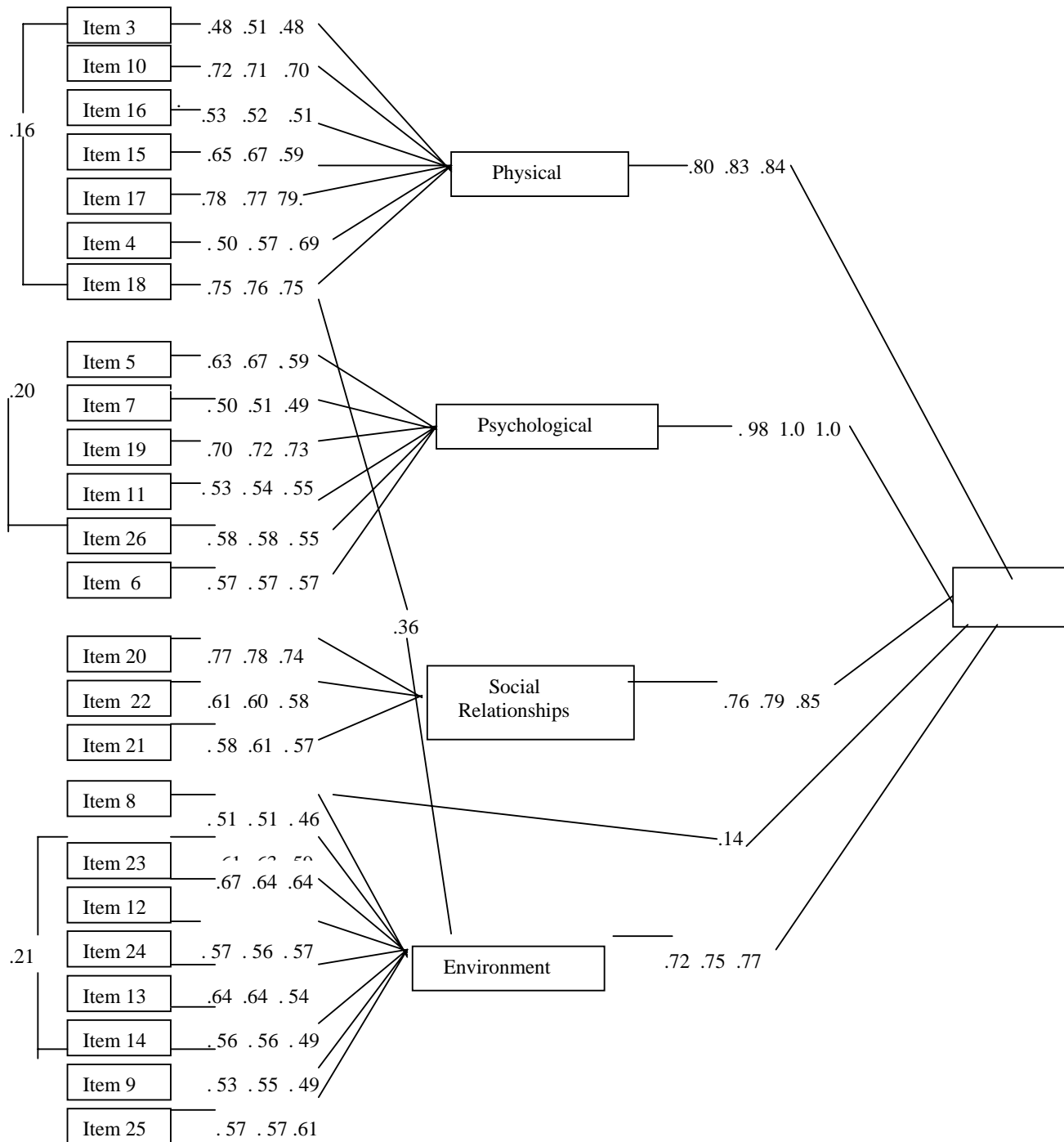
As detailed in Chapter 2, Confirmatory Factor Analysis is a method used to test whether data fits a hypothetical model. Data is said to be an acceptable fit for the model when a number of conditions are met such as where the Comparative Fit Index (CFI) is greater than 0.9. The hypothetical structure of the WHOQOL-BREF is shown in Figure 5.1. The data to be presented here focus on a four domain solution. This solution was motivated in part by the need to avoid a single item domain which would have occurred for the Spirituality item and by some evidence from the analyses of the WHOQOL-100 that a four domain solution may be indicated (see Chapter 2). In both the dataset relating to the original pilot and the data set relating to the field trial of the WHOQOL-100, an

**Figure 5.1 - Four domain confirmatory factor analysis model for the WHOQOL - BREF**

DRAW 2



**Figure 5.2 - Multigroup confirmatory analysis using three data sets**



Three sets of numbers in each pathway show parameter estimates for each of the groups. Estimates from left to right refer to i. The original pilot of the WHOQOL ii. Original field centres testing the WHOQOL-100 iii. New field centres testing the

**WHOQOL-100**

In the new field centres data set, parameter estimates for the error variance allow to covary as follows item3 and item4 =.16, item 3 and item26=.20, item23 and item9= .21. For the two cross-loading parameter estimates were as follows item8 on the second order factor= .14; item4 on the environment domain =-.36

acceptable comparative fit index (CFI) was achieved when the data was applied to the four domain structure using confirmatory factor analysis (CFI = .906 and .903, respectively). In the dataset including new centres field testing the WHOQOL-100, the initial Comparative Fix Index was 0.87, suggesting that alterations to the model were necessary. When three pairs of error variances were allowed to covary (i.e. Pain and Dependence on Medication, Pain and Negative feelings, Home and Physical environment) and two items were allowed to cross-load on other domains (i.e. safety on the global domain and medication negatively on the environment domain), the comparative fit index increased to .901. This would suggest that all datasets fitted the hypothetical four domain structure reasonably well. Figure 5.2 shows how these values varied across the three main datasets.

**TABLE 5.2 - PEARSON CORRELATIONS BETWEEN WHOQOL-100 AND WHOQOL-BREF DOMAIN SCORES**

<b>Domain</b>	<b>Orig. data (n=4802)</b>	<b>Field data (n=4104)</b>	<b>New data (n=2369)</b>
Physical Health	.95	.93	.95
Psychological	.92	.91	.93
Social relationships	.89	.89	.89
Environment	.94	.94	.95

### **COMPARISON BETWEEN WHOQOL-100 AND WHOQOL-BREF SCORES**

As shown in Table 5.2, there were high correlations between domain scores based on the WHOQOL-100 and domain scores calculated using items included in the WHOQOL-BREF. These correlations ranged from .89 (for domain 3) to .95 (for domain 1). Four domain solutions for the WHOQOL-100 have been derived here for comparison purposes only.

### **INTERNAL CONSISTENCY**

Cronbach alpha values for each of the four domain scores ranged from .66 (for domain 3) to .84 (for domain 1), demonstrating good internal consistency (see Table 5.3). Cronbach alpha values for domain 3 should be read with caution as they were based on three scores (i.e. the Personal Relationships, Social Support and Sexual Activity facets), rather than the minimum four generally recommended for assessing internal reliability.

**TABLE 5.3 - INTERNAL CONSISTENCY OF THE WHOQOL-BREF DOMAINS**

	Cronbach alpha		
	Orig. data (n=4802)	Field data (n=3882)	New data (n=2369)
Physical Health	.82	.84	.80
Psychological	.75	.77	.76
Social relationships*	.66	.69	.66
Environment	.80	.80	.80

(\*=Only 3 items, therefore Cronbach alphas may not be reliable).

**TABLE 5.4 - DISCRIMINANT VALIDITY OF THE WHOQOL-100 AND THE WHOQOL-BREF**

	T-test values for 'ill' v 'well' comparisons					
	Orig. data (n=4802)		Field data (n=3882)		New data (n=2369)	
	t	p	t	p	t	p
Physical Health - WHOQOL-100	34.1	.001	39.1	.001	25.4	.001
Physical Health - WHOQOL-BREF	31.2	.001	36.4	.001	24.2	.001
Psychological - WHOQOL-100	13.0	.001	24.0	.001	10.3	.001
Psychological - WHOQOL-BREF	12.3	.001	24.0	.001	10.6	.001
Social relationships - WHOQOL-100	9.8	.001	22.0	.001	7.8	.001
Social relationships - WHOQOL-BREF	8.4	.001	16.2	.001	6.9	.001
Environment - WHOQOL-100	7.0	.001	21.7	.001	2.4	.02
Environment - WHOQOL-BREF	6.6	.001	21.1	.001	2.8	.01

**DISCRIMINANT VALIDITY**

The WHOQOL-BREF was shown to be comparable to the WHOQOL-100 in discriminating between the ill and well groups, with similar values and significant differences between ill and well subjects apparent in all domains (see Table 5.4).

**TABLE 5.5 - MULTIPLE REGRESSIONS FOR THE WHOQOL-BREF USING GENERAL HEALTH AND QUALITY OF LIFE FACET AS THE DEPENDENT VARIABLE AND DOMAIN SCORES AS PREDICTOR VARIABLES**

(\* = SIGNIFICANT AT P<.001)

Data set	% of Overall QOL & General Health facet explained	Final equation standardised beta values*			
		Domain 1	Domain 2	Domain 3	Domain 4
Original		.31	.31	.16	.21
Field test	62.9	.38	.23	.17	.22
New data	61.5	.33	.29	.13	.20

### **IMPORTANCE OF DOMAINS IN ASSESSING OVERALL QUALITY OF LIFE**

Multiple regression was used to determine the contribution made by each domain score to explaining the observed variance in the general facet from the WHOQOL-100 assessment (i.e. the Overall Quality of Life and General Health facet). As shown in Table 5.5, all four WHOQOL-BREF domain scores made a significant contribution to explaining variance observed in the general facet relating to Overall Quality of Life and General Health, with the physical health domain contributing most highly, and the social relationships domain making least contribution. This suggests that all four domains should be taken into consideration when evaluating overall quality of life.

In summary, the WHOQOL-BREF provides an adequate alternative to the assessment of domain profiles using the WHOQOL-100. It provides a rapid means of scoring domain profiles; it does not however allow assessment of the individual facets within these domains. A balance between detail and length of assessment will therefore always remain vital to consider when selecting between assessments.

## **CHAPTER 6 - PREPARATION AND ADMINISTRATION OF THE WHOQOL-BREF**

### **ACCESS TO THE WHOQOL-BREF**

The WHOQOL-BREF is currently being validated in field studies involving 30 languages (see Table 3.1, Chapter 3). The appropriate language version, and permission for using it, can be obtained from the National field centre or for new versions from WHO. Under no circumstances should the WHOQOL-BREF be used without permission. A methodology has been developed for new centres wishing to develop a further language version of the WHOQOL-100 or the WHOQOL-BREF. This methodology has been outlined in Chapter 4. Permission to translate and a detailed manual to do this can be obtained from The Programme on Mental Health, World Health Organisation, CH-1211, Geneva 27, Switzerland.

### **PREPARATION OF THE WHOQOL-BREF**

Questions must appear in the order in which they appear in the example WHOQOL-BREF provided within this document, with instructions and headers unchanged. Questions are grouped by response format. The equivalent numbering of questions between the WHOQOL-BREF and the WHOQOL-100 is given in the example version of the WHOQOL-BREF to enable easy comparison between responses to items on the two versions. The WHOQOL-100 field test permitted centres to include national items or facets that were thought to be important in assessing quality of life. Where centres wish to include additional national items or modules for the WHOQOL-BREF, these should be included on a separate sheet of paper and not interspersed amongst the existing 26 items or inserted before the other comments.

### **WHOQOL-BREF ADMINISTRATION**

For any new centre not previously involved in either the development or field testing of the WHOQOL-100, the procedure followed to field test the WHOQOL-BREF should be identical to that used to field test the WHOQOL-100.

The WHOQOL-BREF should be self-administered if respondents have sufficient reading ability; otherwise, interviewer-assisted or interview-administered forms should be used. Standardised instructions, given on the second page of the WHOQOL-BREF example assessment, should be read out to respondents in instances where the assessment is interviewer-administered.

For centres who have already participated in the development and field testing of the WHOQOL-100, the above option of testing the WHOQOL-BREF is preferred, but not imperative, where specific studies of patient groups are planned.

#### **FRAME OF REFERENCE AND TIME FRAME**

A time frame of two weeks is indicated in the assessment. It is recognised that different time frames may be necessary for particular uses of the instrument in subsequent stages of work. For example, in the assessment of quality of life in chronic conditions such as arthritis, a longer time frame such as four weeks may be preferable. Furthermore, the perception of time is different within different cultural settings and therefore changing the time scale may be appropriate.

## CHAPTER 7 - PROPOSED USES OF THE WHOQOL-100 AND THE WHOQOL-BREF

It is anticipated that the WHOQOL assessments will be used in broad-ranging ways. They will be of considerable use in clinical trials, in establishing baseline scores in a range of areas, and looking at changes in quality of life over the course of interventions. It is expected that the WHOQOL assessments will also be of value where disease prognosis is likely to involve only partial recovery or remission, and in which treatment may be more palliative than curative.

For epidemiological research, the WHOQOL assessments will allow detailed quality of life data to be gathered on a particular population, facilitating the understanding of diseases, and the development of treatment methods. The international epidemiological studies that would be enabled by instruments such as the WHOQOL-100 and the WHOQOL-BREF will make it possible to carry out multi-centre quality of life research, and to compare results obtained in different centres. Such research has important benefits, permitting questions to be addressed which would not be possible in single site studies (Sartorius and Helmchen, 1981). For example, a comparative study in two or more countries on the relationship between health care delivery and quality of life requires an assessment yielding cross-culturally comparable scores. Sometimes accumulation of cases in quality of life studies, particularly when studying less frequent disorders, is helped by gathering data in several settings. Multi-centre collaborative studies can also provide simultaneous multiple replications of a finding, adding considerably to the confidence with which findings can be accepted.

In clinical practice the WHOQOL assessments will assist clinicians in making judgements about the areas in which a patient is most affected by disease, and in making treatment decisions. In some developing countries, where resources for health care may be limited, treatments aimed at improving quality of life through palliation, for example, can be both effective and inexpensive (Olweny, 1992). Together with other measures, the WHOQOL-BREF will enable health professionals to assess changes in quality of life over the course of treatment.

It is anticipated that in the future the WHOQOL-100 and the WHOQOL-BREF will prove useful in health policy research and will make up an important aspect of the routine auditing of health and social services. Because the instrument was developed cross-culturally, health care providers, administrators and legislators in countries where no validated quality of life measures currently exist can be confident that data yielded by work involving the WHOQOL assessments will be genuinely sensitive to their setting.

## CHAPTER 8 - SCORING OF THE WHOQOL-100 AND THE WHOQOL-BREF

### INTRODUCTION

This chapter outlines the procedure for scoring both the WHOQOL-100 and the WHOQOL-BREF.

### SCORING OF THE WHOQOL-100

The WHOQOL-100 produces a quality of life profile. It is possible to derive six domain scores, 24 specific facet scores, and one general facet score that measures overall quality of life and general health. The six domain scores denote an individual's perception of quality of life in the following domains: Physical, Psychological, Level of Independence, Social Relationships, Environment, and Spirituality. Domain and facet scores are scaled in a positive direction where higher scores denote higher quality of life. Some facets (pain and Discomfort, Negative Feelings, dependence on medication) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. Thus a total quality of life score derived by summing data from all WHOQOL items is not recommended. The scores from the four items in the Overall Quality of Life and General Health facet can be summed and presented as part of a profile. Explicit instructions for checking and cleaning data, and for computing facet and domain scores are given in Appendix 9. Instructions for the manual calculation of scores are given below.

### FACET SCORES

Facets are scored through summative scaling. Each item contributes equally to the facet score. Scaling is in the direction of the facet, determined by whether the facet is positively or negatively framed. Significant numbers of facets contain questions which need to be reverse scored (see Appendix 9). For a positively framed facet, any negatively framed constituent questions are reverse scored. None of the three negatively framed facets (Pain and Discomfort, Negative Feelings, Dependence on Medication) has any positively framed questions. Any additional questions included by the new centre and approved by the WHOQOL Group would contribute to the facet score in the direction in which the facet is scored. An example of how to score facets is given below:

For facets with no reverse scoring:

$$\text{POSITIVE FEELINGS} = (F4.1 + F4.2 + F4.3 + F4.4).$$

For facets where certain items need to be reverse scored:

$$\text{ENERGY AND FATIGUE} = (F2.1 + (6-F2.2) + F2.3 + (6-F2.4)).$$

## Domain Scores

Each facet is taken to contribute equally to the domain score. Any additional facets suggested by the new centre should contribute to the respective domain score in a positively scaled direction. Domain score are calculated by computing the mean of the facet score within the domain, according to the following formulae, noting that negatively phrased facets are reverse score according to the procedure given below.

Physical domain =  $((24 - \text{PAIN score}) + \text{ENERGY score} + \text{SLEEP score}) / 3$

Psychological domain =  $(\text{POSITIVE FEEL. Score} + \text{THINKING score} + \text{SELF ESTEEM score} + \text{BODY IMAGE score} + (24 - \text{NEGATIVE FEEL. Score})) / 5$

Level of Indep. domain =  $(\text{MOBILITY score} + \text{ACTIVITIES OF DAILY LIVING score} + (24 - \text{MEDICATION score}) + \text{WORK score}) / 4$ .

Social relationships domain =  $(\text{PERSONAL RELATIONSHIPS score} + \text{SOCIAL SUPPORT score} + \text{SEXUAL ACTIVITY score}) / 3$ .

Environment domain =  $(\text{SAFETY score} + \text{HOME ENVIRONMENT score} + \text{FINANCIAL RESOURCES score} + \text{ACCESS TO SERVICES score} + \text{ACCESS TO INFORMATION score} + \text{LEISURE ACTIVITIES score} + \text{PHYSICAL ENVIRONMENT score} + \text{ACCESS TO TRANSPORT score}) / 8$ .

Spirituality domain = SPIRITUALITY facet score

## TRANSFORMATION OF SCORES TO A 0-100 SCALE

Domain and facet scores can be transformed to a 0-100 scale using the following formula:

$\text{TRANSFORMED SCORE} = (\text{SCORE} - 4) \times (100/16)$ .

## MISSING DATA

Where more than 20% of data are missing from an assessment, the assessment should be discarded. Where an item is missing within a facet, the mean of other items in the facet is substituted. Where more than two items are missing from the facet, the facet score should not be calculated. For the Physical, Psychological and Social Relationships domains, where one facet score is missing, the mean of the other facet scores may be substituted. For the Environment domain, up to two missing facet scores may be substituted with the mean of the other facet scores.

## **SYNTAX FILES FOR AUTOMATIC COMPUTATION OF SCORES USING SPSS**

An SPSS syntax file that automatically checks, recodes data and computes domain scores may be obtained from Professor Mick Power, Department of Psychiatry, Royal Edinburgh Hospital, Morningside Park, Edinburgh, EH10 5HF, Scotland (e-mail: mj@srv2.med.ed.ac.uk; fax: + 131 447 6860). This syntax file is also given in Appendix 9.

## **SCORING OF THE WHOQOL-BREF**

The WHOQOL-BREF (Field Trial Version) produces four domain scores. There are also two items that are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of his or her health. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100, and subsequently transformed to a 0-100 scale, using the formula above. Explicit instructions for checking and cleaning data, and for computing domain scores, are given in Appendix 10. A method for the manual calculation of individual scores is below:

$$\begin{aligned}\text{Physical domain} &= ((6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18) \times 4. \\ \text{Psychological domain} &= (Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)) \times 4. \\ \text{Social Relationships domain} &= (Q20 + Q21 + Q22) \times 4. \\ \text{Environment domain} &= (Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25) \times 4.\end{aligned}$$

Where more than 20% of data are missing from an assessment, the assessment should be discarded (see Step 4 in Table 3). Where up to two items are missing, the mean of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if  $\leq$  1 item is missing). Syntax files for automatic computation of domains are available as for the WHOQOL-100.

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## **APPENDIX 1 - FACET DEFINITIONS AND RESPONSE SCALES**

### **INTRODUCTION**

Each WHOQOL facet can be characterised as a description of a behaviour, a state of being, a capacity or potential, or a subjective perception or experience. For example, pain is a subjective perception or experience; fatigue may be defined as a state; mobility may be defined either as a capacity (ability to move around) or as a behaviour (actual report of walking). A definition was written for each of the facets of quality of life covered by the WHOQOL assessment.

### **OVERALL QUALITY OF LIFE AND HEALTH**

These questions examine the ways in which a person assesses his/her overall quality of life, health and well-being.

### **DOMAIN I - PHYSICAL DOMAIN**

#### **1. Pain and discomfort**

This facet explores unpleasant physical sensations experienced by a person and, the extent to which these sensations are distressing and interfere with life. Questions within the facet include the control the person has over the pain and the ease with which relief from pain can be achieved. The assumption is made that the easier the relief from pain, the less the fear of pain and its resulting effect on quality of life. Similarly changes in levels of pain may be more distressing than pain itself. Even when a person is not actually in pain, either through taking drugs or because the pain is by its very nature on and off (e.g. migraine), his/her quality of life may be affected by the constant threat of pain. It is acknowledged that people respond to pain differently, and differing tolerance and acceptance of pain is likely to affect its impact on quality of life.

Unpleasant physical sensations such as stiffness, aches, long-term or short-term pain, or itches are included. Pain is judged to be present if a person reports it to be so, even if there is no medical reason to account for it.

#### **2. Energy and fatigue**

This facet explores the energy, enthusiasm and endurance that a person has in order to perform the necessary tasks of daily living, as well as other chosen activities such as recreation. This may extend from reports of disabling tiredness to adequate levels of energy, to feeling really alive. Tiredness may

result from any one of a number of causes, for example illness, problems such as depression, or over-exertion.

The impact of fatigue on social relationships, the increased dependence on others due to chronic fatigue and the reason for any fatigue are beyond the scope of questioning, although they are implicit to the questions in this facet and facets concerned specifically with daily activities and interpersonal relationships.

### **3. Sleep and rest**

This facet concerns how much sleep and rest, and problems in this area, affect the person's quality of life. Sleep problems might include difficulty going to sleep, waking up during the night, waking up early in the morning and being unable to go back to sleep and lack of refreshment from sleep.

The facet's focus is on whether sleep is disturbed or not; this can be for any reason, both to do with the person or to do with the environment.

The questions in this facet do not inquire into specific aspects of sleep such as waking up early in the morning or whether or not a person takes sleeping pills. The question of whether a person is dependent on substances (e.g. sleeping pills) to help him/her sleep is covered in a separate facet.

## **DOMAIN II - PSYCHOLOGICAL**

### **4. Positive feelings**

This facet examines how much a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy and enjoyment of the good things in life. A person's view of, and feelings about the future are seen as an important part of this facet. For many respondents this facet may be regarded as synonymous with quality of life. Negative feelings are not included as these are covered elsewhere.

### **5. Thinking, learning, memory and concentration**

This facet explores a person's view of his/her thinking, learning, memory, concentration and ability to make decisions. This incorporates the speed of thinking and clarity of thought. Questions disregard whether a person is alert, aware or awake, even though these underlie thinking, memory and concentration. It is acknowledged that some people with cognitive difficulties may have no insight

into their difficulties, and in these cases proxy evaluations may be a necessary addition to the person's subjective evaluation. A similar problem may be a reluctance to admit to problems in this area among some respondents.

## **6. Self-esteem**

This facet examines how people feel about themselves. This might range from feeling positive about themselves to feeling extremely negative about themselves. A person's sense of worth as a person is explored. The aspect of self esteem concerned with a person's feeling of self-efficacy, satisfaction with oneself and control is also included in the focus of this facet.

Questions are likely to include people's feelings about themselves in a range of areas: how they are able to get along with other people; their education; their appraisal of their ability to change or accomplish particular tasks or behaviours; their family relations; and their sense of dignity and self-acceptance. To some people self-esteem depends largely on how they function, whether at work, at home or how they are perceived and treated by others. In some cultures self-esteem is the esteem felt within the family rather than individual self-esteem. It is assumed that questions will be interpreted by respondents in ways that are meaningful and relevant to their position in life.

Questions do not include specific references to body image and social relationships as these are covered in different areas. However, the sense of self-worth that comes from these areas is intended to be covered by the questions though at a more general level. It is acknowledged that some people may find self-esteem difficult to talk about, and questions are framed to try take this into account.

## **7. Body image and appearance**

This facet examines the person's view of his/her body. Whether the appearance of the body is seen in a positive or negative way is included in this facet. The focus is on the person's satisfaction with the way he/she looks and the effect it has on his/her self-concept. This includes the extent to which "perceived" or actual bodily impairments, if present, can be corrected (e.g. by make-up, clothing, artificial limbs etc.).

How others respond to a person's appearance is likely to affect the person's body image very considerably. The phrasing of the questions aims to encourage respondents to answer how they really feel rather than how they feel they should respond. In addition they are phrased so as to be able to

include a person who is happy with the way they look as well as someone who is severely physically handicapped.

#### **8. Negative feelings**

This facet concerns how much a person experiences negative feelings, including despondency, guilt, sadness, tearfulness, despair, nervousness, anxiety and a lack of pleasure in life. The facet includes a consideration of how distressing any negative feelings are and their impact on the person's day-to-day functioning. Questions are framed so as to include people with quite disabling psychological difficulties such as severe depression, mania or panic attacks.

Questions do not include poor concentration, nor the relationship between negative affect and the person's social relationships because these are covered elsewhere. Nor do questions include any detailed assessment of the severity of the negative feelings.

### **DOMAIN III - LEVEL OF INDEPENDENCE**

#### **9. Mobility**

This facet examines the person's view of his/her ability to get from one place to another, to move around the home, move around the work place, or to and from transportation services.

The focus is on the person's general ability to go wherever he/she wants to go without the help of others regardless of the means used to do so. The assumption is made that wherever a person is dependent to a significant extent for his/her mobility on another person this is likely to affect quality of life adversely. In addition, questions address people with mobility difficulties regardless of whether changes in their mobility were sudden or more gradual, although it is acknowledged that this is likely to affect the impact on quality of life significantly.

A person's impairment does not necessarily affect his/her mobility. So for example someone using a wheelchair or walking frame may have satisfactory mobility in an adequately adapted home or workplace. Nor does this facet include transportation services (e.g. car, bus) as this is covered in a separate facet (*Transport*).

## **10. Activities of Daily Living**

The facet explores a person's ability to perform usual daily living activities. This includes self-care and caring appropriately for property. The focus is on a person's ability to carry out activities, which he/she is likely to need to perform on a day-to-day basis. The degree to which people are dependent on others to help them in their daily activities is also likely to affect their quality of life.

The questions do not include aspects of daily living which are covered in other areas; namely, specific activities affected by fatigue, sleep disturbances, depression, anxiety, mobility, and so on. Questions disregard whether a person has a home or a family.

## **11. Dependence on medication or treatments**

This facet examines a person's dependence on medication or alternative medicines (such as acupuncture and herbal remedies) for supporting his/her physical and psychological well-being. Medications may in some cases affect a person's quality of life in a negative way (e.g. side effects of chemotherapy) whilst in other cases it may enhance the person's quality of life (e.g. cancer patients using pain killers).

This facet includes medical interventions that are not pharmacological, but on which the person is still dependent, for example a pacemaker, artificial limb or colostomy bag. The questions do not include detailed enquiry into the type of medication.

## **12. Working capacity**

This facet examines a person's use of his or her energy for work. "Work" is defined as any major activity in which the person is engaged. Major activities might include paid work, unpaid work, voluntary community work, full-time study, care of children and household duties. Because such questions refer to these possible types of major activities, the facet focuses on a person's ability to perform work, regardless of the type of work.

The questions do not include how people feel about the nature of the work that they do, nor do they include the quality of their work environment.

## **DOMAIN IV - SOCIAL RELATIONSHIPS**

### **13. Personal relationships**

This facet examines the extent to which people feel the companionship, love and support they desire from the intimate relationship(s) in their life. This facet also addresses commitment to and current experience of caring for and providing for other people.

This facet includes the ability and opportunity to love, to be loved and to be intimate with others both emotionally and physically. The extent to which people feel they can share moments of both happiness and distress with loved ones, and a sense of loving and being loved are included. The physical aspects of intimacy such as hugging and touch are also included. It is acknowledged, however, that this facet is likely to overlap considerably with the intimacy of sex which is covered in the facet *Sexual activity*.

The questions include how much satisfaction a person gets from, or has problems managing the burdens of caring for others. The possibility of this being both a positive as well as a negative experience is implicit to the facet.

This facet addresses all types of loving relationships, such as close friendships, marriages and both heterosexual and homosexual partnerships.

#### **14. Social support**

This facet examines how much a person feels the commitment, approval, and availability of practical assistance from family and friends. Questions explore how much family and friends share in responsibility and work together to solve personal and family problems. The facet's focus is on how much the person feels he/she has the support of family and friends, in particular to what extent he/she might depend on this support in a crisis.

This includes how much the person feels he/she receives approval and encouragement from family and friends. The potentially negative role of family and friends in a person's life is included in this facet and questions are framed to allow negative effects of family and friends such as verbal and physical abuse to be recorded.

#### **15. Sexual activity**

This facet concerns a person's urge and desire for sex, and the extent to which the person is able to express and enjoy his/her sexual desire appropriately.

Sexual activity and intimacy are for many people intertwined. Questions, however, enquire only about sex drive, sexual expression and sexual fulfilment, with other forms of physical intimacy being covered elsewhere. In some cultures fertility is central to this facet, and child bearing is an extremely valued role. This facet incorporates this aspect of sex in these cultures, and is likely to be interpreted in these terms in these cultures. Questions do not include the value judgements surrounding sex, and address only the relevance of sexual activity to a person's quality of life. Thus the person's sexual orientation and sexual practices are not seen as important in and of themselves: rather it is the desire for, expression of, opportunity for and fulfilment from sex that is the focus of this facet.

It is acknowledged that sexual activity is difficult to ask about, and it is likely that responses to these questions in some cultures may be more guarded. It is further anticipated that people of different ages and different gender will answer these questions differently. Some respondents may report little or no desire for sex without this having any adverse effects on their quality of life.

## **DOMAIN V - ENVIRONMENT**

### **16. Physical safety and security**

This facet examines the person's sense of safety and security from physical harm. A threat to safety or security might arise from any source such as other people or political oppression. As such this facet is likely to bear directly on the person's sense of freedom. Hence, questions are framed to allow answers that range from a person having the opportunities to live without constraints, to the person living in a state or neighbourhood that is oppressive and felt to be unsafe.

Questions include a sense of how much the person thinks that there are 'resources' which protect or might protect his/her sense of safety and security. This facet is likely to have particular significance for certain groups, such as victims of disasters, the homeless, people in dangerous professions, relations of criminals, and victims of abuse.

Questions do not explore in depth the feelings of those who might be seriously mentally ill and perceive that their safety is threatened by "being persecuted by aliens", for example.

Questions focus on a person's own feeling of safety / lack of safety, security / insecurity in so far as these affect quality of life.

## **17. Home Environment**

This facet examines the principal place where a person lives (and, at a minimum, sleeps and keeps most of his/her possessions), and the way that this impacts on the person's life. The quality of the home would be assessed on the basis of being comfortable, as well as affording the person a safe place to reside.

Other areas which are included implicitly are: crowdedness; the amount of space available; cleanliness; opportunities for privacy; facilities available (such as electricity, toilet, running water); and the quality of the construction of the building (such as roof leaking and damp).

The quality of the immediate neighbourhood around the home is important for quality of life, and questions include reference to the immediate neighbourhood. Questions are phrased so as to include the usual word for 'home', i.e. where the person usually lives with his/her family. However, questions are phrased to include people who do not live in one place with their family, such as refugees, or people living in institutions. It would not usually be possible to phrase questions to allow homeless people to answer meaningfully.

## **18. Financial resources**

The facet explores the person's view of how his/her financial resources (and other exchangeable resources) and the extent to which these resources meet the needs for a healthy and comfortable life style. The focus is on what the person can afford or cannot afford which might affect quality of life.

The questions include a sense of satisfaction / dissatisfaction with those things which the person's income enables them to obtain. Questions include a sense of the dependence / independence provided by the person's financial resources (or exchangeable resources), and the feeling of having enough.

Assessment will occur regardless of the respondent's state of health or whether or not the person is employed. It is acknowledged that a person's perspective on financial resources as "enough", "meeting my needs" etc. is likely to vary greatly, and the questions are framed to allow this variation to be accommodated.

### **19. Health and social care: availability and quality**

The facet examines the person's view of the health and social care in the near vicinity. "Near" is the time it takes to get help.

Questions include how the person views the availability of health and social services as well as the quality and completeness of care that he/she receives or expects to receive should these services be required. Questions include volunteer community support (religious charities, temples ...) which either supplements or may be the only available health care system in the person's environment. Questions include how easy / difficult it is to reach local health and social services and to bring friends and relatives to these facilities.

The focus is on the person's view of the health and social services. Questions do not ask about aspects of health care which have little personal meaning or relevance to the person who will be answering the question.

### **20. Opportunities for acquiring new information and skills**

This facet examines a person's opportunity and desire to learn new skills, acquire new knowledge, and feel in touch with what is going on. This might be through formal education programs, or through adult education classes or through recreational activities, either in groups or alone (e.g. reading).

This facet includes being in touch and having news of what is going on, which for some people is broad (the "world news") and for others is more limited (village gossip). Nevertheless, a feeling of being in touch with what is going on around them is important for many people and is included.

The focus is on a person's chances to fulfil a need for information and knowledge whether this refers to knowledge in an education sense, or to local, national or international news that has some relevance to the person's quality of life.

Questions are phrased in order to be able to capture these different aspects of acquiring new information and skills ranging from world news and local gossip to formal educational programs and vocational training. It is assumed that questions will be interpreted by respondents in ways that are meaningful and relevant to their position in life.

## **21. Participation in and opportunities for recreation and leisure**

This facet explores a person's ability, opportunities and inclination to participate in leisure, pastimes and relaxation.

The questions include all forms of pastimes, relaxation and recreation. This might range from seeing friends, to sports, to reading, to watching television or spending time with the family, to doing nothing.

Questions focus on three aspects: the person's capacity for, opportunities for and enjoyment of recreation and relaxation.

## **22. Physical environment (pollution/ noise/ traffic/ climate)**

This facet examines the person's view of his/her environment. This includes the noise, pollution, climate and general aesthetic of the environment and whether this serves to improve or adversely affect quality of life. In some cultures certain aspects of the environment may have a very particular bearing on quality of life, such as the central nature of the availability of water or air pollution.

This facet does not include *Home environment* or *Transport* as these are covered in separate facets.

## **23. Transport**

This facet examines the person's view of how available or easy it is to find and use transport services to get around.

Questions include any mode of transport that might be available to the person (bicycle, car, bus ...). The focus is on how the available transport allows the person to perform the necessary tasks of daily life as well as the freedom to perform chosen activities.

Questions do not enquire into the type of transport, nor do they explore means that are used to get around in the home itself. In addition the personal mobility of the individual is not included because this is covered elsewhere (*Mobility*).

## DOMAIN VI - SPIRITUALITY / RELIGION / PERSONAL BELIEFS

### 24. Spirituality / religion / personal beliefs

This facet examines the person's personal beliefs and how these affect quality of life. This might be by helping the person cope with difficulties in his/her life, giving structure to 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.

#### Response scales

The questions, which make up the WHOQOL-100 arose from a process designed to capture both the culture-specific interpretation of quality of life facets as well as language idiom. There was therefore, of necessity, some diversity in the nature and structure of the questions. Consequently, there was a trade-off between a minimum number of standardised question-response scale formats whilst still allowing an enquiry into difficult aspects of quality of life, and maintaining the unique face validity of the questions in the WHOQOL-100 in different cultures. To accommodate this there are four five-point response scales concerned with the intensity, capacity, frequency and evaluation of states or behaviours.

The **Intensity** response scale refers to the degree or extent to which a person experiences a state or situation e.g. the intensity of pain. Questions may also refer to the vigour or strength of a behaviour. The assumption is that the experience of a more intense state is associated with corresponding changes in quality of life. Example questions include: "Do you worry about any pain or discomfort?" and "Do you have any difficulties with sleeping?". One response scale is used to assess intensity. In English, the anchors on the scale are "Not at all" and "Extremely" or "An extreme amount".

The **Capacity** response scale refers to a capacity for a feeling, state or behaviour. The assumption is that a more complete capacity is associated with corresponding changes in quality of life. Example questions include: "Do you have enough energy for everyday life?" and "To what extent are you able to carry out your daily activities?". In English, the anchor points are "Not at all" and "Completely".

The **Frequency** response scale pairings refer to the number, frequency, commonness, or rate of a state or behaviour. The time frame is crucial to these questions, such that the frequency refers to its frequency in the specified time period. The assumption is that a greater number of occurrences of the state or behaviour is associated with corresponding changes in quality of life. Example questions are: "How often do you have negative feelings, such as blue mood, despair, anxiety, depression?" and "How often do you suffer (physical) pain?". In English, the anchor points are "Never" and "Always".

The **Evaluation** response scale refers to the appraisal of a state, capacity or behaviour. The assumption is that a more positive evaluation is associated with a corresponding increase in the respondent's quality of life. Example questions are: "How satisfied are you with your capacity for work?" and "How satisfied are you with your personal relationships?". Several evaluation scales are employed. In English, the anchor points are "Very happy" - "Very unhappy"; "Very satisfied" - "Very dissatisfied"; and "Very good" - "Very poor". This response scale differs from the intensity, frequency and capacity response scales in that it has a neutral midpoint and the anchor points are not extreme points, to maximise full usage of the scale. In several languages (e.g. Croatian and Dutch) the distinction between the two question stems "How satisfied...?" and "How happy ... ?" does not translate and all of these questions and response scales therefore become "How satisfied... ?".

Response scales have been derived for each of the WHOQOL-100's language versions according to a standardised methodology. Ensuring equivalence in response scales required a methodology that goes beyond translation of standardised English language scale descriptors. 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 (Evaluation, Intensity, Capacity and Frequency), and a scale metric which intermediate descriptors should fit. That is, descriptors for each of the response scales were derived 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. Third, it

ensured equidistance between descriptors on the scales. The method whereby response scales were derived is described more fully elsewhere (Szabo, S., Orley, J. and Saxena, S. On behalf of the WHOQOL Group, 1997).

## APPENDIX 2 - CRITERIA FOR GENERATING AND SELECTING WHOQOL ITEMS

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Questions should:

1. Be based as far as possible on the suggestions of patients and health personnel participating in the focus groups
2. Give rise to answers that are illuminating about the respondents' quality of life, as defined in this project
3. Reflect the meaning conveyed in the facet definition
4. Cover, in combination with other questions for a given facet, the key aspects of that facet as described in the facet definition
5. Use simple language, avoiding ambiguity in terms of either wording or phraseology
6. Be shorter rather than longer
7. Avoid double negatives
8. Be amenable to a rating scale
9. Ask about a single issue / facet
10. 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)
11. Be applicable to individuals with a range of impairment (from very little to a lot)
12. Be phrased as questions and not statements
13. Reflect the typology of questions adopted for the project.

**APPENDIX 3 - NUMBER OF QUESTIONS SELECTED FOR PILOT WHOQOL (236 QUESTIONS) AND FIELD TRIAL WHOQOL (100 QUESTIONS) FROM EACH OF THE MAIN STUDY FIELD CENTRES**

Field centre	Number and % of questions in the pilot WHOQOL (236 questions) arising in each field centre	Number of questions in the Field Trial WHOQOL (100 questions) arising in each field centre
Bangkok, Thailand	33 (14%)	13
Bath, UK	31 (13%)	13
Harare, Zimbabwe	33 (14%)	24
Madras, India	41 (17%)	18
Melbourne, Australia	49 (21%)	24
Panama	48 (20%)	23
Paris, France	36 (15%)	15
St Petersburg, Russia	22 (9%)	14
Seattle, USA	46 (20%)	19
Tilburg, Netherlands	50 (21%)	27
Zagreb, Croatia	63 (27%)	27
Questions proposed by coordinating group	7 (3%)	3
<p>Note Because a significant number of questions were proposed in identical or semantically equivalent forms by two or more centres, the sum of all the questions comes to more than the total number of questions in the pilot and field trial instrument. The questions proposed by the WHO coordinating group were proposed where existing questions inadequately covered the key areas of the facet.</p>		

## APPENDIX 4 – THE WHOQOL-100

### Instructions

This questionnaire asks how you feel about your quality of life, health, and other areas of your life.

Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

For example, thinking about the last two weeks, a question might ask:

How much do you worry about your health?

Not at all	A little	A moderate	Very much	An extreme
1	2	amount	4	amount
		3		5

You should circle the number that best fits how much you have worried about your health over the last two weeks. So you would circle the number 4 if you worried about your health “Very much”, or circle number 1 if you have worried “Not at all” about your health. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

Thank you for your help

The following questions ask about how much you have experienced certain things in the last two weeks, for example, positive feelings such as happiness or contentment. If you have experienced these things an extreme amount circle the number next to “An extreme amount”. If you have not experienced these things at all, circle the number next to “Not at all”. You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between “Not at all” and “Extremely”. Questions refer to the last two weeks.

F1.2 Do you worry about your pain or discomfort?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F1.3 How difficult is it for you to handle any pain or discomfort?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F1.4 To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F2.2 How easily do you get tired?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F2.4 How much are you bothered by fatigue?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F3.2 Do you have any difficulties with sleeping?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F3.4 How much do any sleep problems worry you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F4.1 How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

**F4.3** How positive do you feel about the future?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

**F4.4** How much do you experience positive feelings in your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

**F5.3** How well are you able to concentrate?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

**F6.1** How much do you value yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

**F6.2** How much confidence do you have in yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

**F7.2** Do you feel inhibited by your looks?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

**F7.3** Is there any part of your appearance which makes you feel uncomfortable?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

**F8.2** How worried do you feel?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

**F8.3** How much do any feelings of sadness or depression interfere with your everyday functioning?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F8.4 How much do any feelings of depression bother you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.2

F15.2 How well are your sexual needs fulfilled?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F15.4 Are you bothered by any difficulties in your sex life? To what extent do you have difficulty in performing your routine activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.4 How much are you bothered by any limitations in performing everyday living activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.2 How much do you need any medication to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.3 How much do you need any medical treatment to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.4 To what extent does your quality of life depend on the use of medical substances or medical aids?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F13.1 How alone do you feel in your life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F15.2 How well are your sexual needs fulfilled?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F15.4 Are you bothered by any difficulties in your sex life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

<b>F16.1 How safe do you feel in your daily life?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F16.2 Do you feel you are living in a safe and secure environment?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F16.3 How much do you worry about your safety and security?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F17.1 How comfortable is the place where you live?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F17.4 How much do you like it where you live?</b>				
Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5
<b>F18.2 Do you have financial difficulties?</b>				
Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5
<b>F18.4 How much do you worry about money?</b>				
Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5
<b>F19.1 How easily are you able to get good medical care?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F21.3 How much do you enjoy your free time?</b>				
Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5
<b>F22.1 How healthy is your physical environment?</b>				
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
<b>F22.2 How concerned are you with the noise in the area you live in?</b>				
Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F23.2 To what extent do you have problems with transport?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F23.4 How much do difficulties with transport restrict your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks, for example activities of daily living such as washing, dressing or eating. If you have been able to do these things completely, circle the number next to "Completely". If you have not been able to do these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Completely". Questions refer to the last two weeks.

F2.1 Do you have enough energy for everyday life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F7.1 Are you able to accept your bodily appearance?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F10.1 To what extent are you able to carry out your daily activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F11.1 How dependent are you on medications?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.1 Do you get the kind of support from others that you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.2 To what extent can you count on your friends when you need them?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F17.2 To what degree does the quality of your home meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F18.1 Have you enough money to meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.1 How available to you is the information that you need in your day-to-day life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.2 To what extent do you have opportunities for acquiring the information that you feel you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.1 To what extent do you have the opportunity for leisure activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.2 How much are you able to relax and enjoy yourself?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F23.1 To what extent do you have adequate means of transport?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

The following questions ask you to say how satisfied, happy or good you have felt about various aspects of your life over the last two weeks. For example, about your family life or the energy that you have. Decide how satisfied or dissatisfied you are with each aspect of your life and circle the number that best fits how you feel about this. Questions refer to the last two weeks.

G2 How satisfied are you with the quality of your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

G3 In general, how satisfied are you with your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

G4 How satisfied are you with your health?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F2.3 How satisfied are you with the energy that you have?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F3.3 How satisfied are you with your sleep?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F5.2 How satisfied are you with your ability to learn new information?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F5.4 How satisfied are you with your ability to make decisions?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F6.3 How satisfied are you with yourself?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F6.4 How satisfied are you with your abilities?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F7.4 How satisfied are you with the way your body looks?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F10.3 How satisfied are you with your ability to perform your daily living activities?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F13.3 How satisfied are you with your personal relationships?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F15.3 How satisfied are you with your sex life?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F14.3 How satisfied are you with the support you get from your family?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F14.4 How satisfied are you with the support you get from your friends?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

**F13.4 How satisfied are you with your ability to provide for or support others?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F16.4	How satisfied are you with your physical safety and security?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F17.3	How satisfied are you with the conditions of your living place?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F18.3	How satisfied are you with your financial situation?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F19.3	How satisfied are you with your access to health services?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F19.4	How satisfied are you with the social care services?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F20.3	How satisfied are you with your opportunities for acquiring new skills?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F20.4	How satisfied are you with your opportunities to learn new information?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F21.4	How satisfied are you with the way you spend your spare time?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F22.3	How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness)?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5
F22.4	How satisfied are you with the climate of the place where you live?			
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F23.3 How satisfied are you with your transport?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5
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F13.2 Do you feel happy about your relationship with your family members?

Very unhappy 1	Unhappy 2	Neither happy nor unhappy 3	Happy 4	Very happy 5
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G1 How would you rate your quality of life?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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F15.1 How would you rate your sex life?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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F3.1 How well do you sleep?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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F5.1 How would you rate your memory?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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F19.2 How would you rate the quality of social services available to you?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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The following questions refer to how often you have felt or experienced certain things, for example the support of your family or friends or negative experiences such as feeling unsafe. If you have not experienced these things at all in the last two weeks, circle the number next to the response "never". If you have experienced these things, decide how often and circle the appropriate number. So for example if you have experienced pain all the time in the last two weeks circle the number next to "Always". Questions refer to the last two weeks.

F1.1 How often do you suffer (physical) pain?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F4.2 Do you generally feel content?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

F8.1 How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

Never	Seldom	Quite often	Very often	Always
1	2	3	4	5

The following questions refer to any “work” that you do. Work here means any major activity that you do. This includes voluntary work, studying full-time, taking care of the home, taking care of children, paid work or unpaid work. So work, as it is used here, means the activities you feel take up a major part of your time and energy. Questions refer to the last two weeks.

F12.1 Are you able to work?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F12.2 Do you feel able to carry out your duties?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F12.4 How satisfied are you with your capacity for work?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F12.3 How would you rate your ability to work?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

The next few questions ask about how well you were able to move around in the last two weeks. This refers to your physical ability to move your body in such a way as to allow you to move about and do the things you would like to do, as well as the things that you need to do. Once again these questions refer to the last two weeks.

F9.1 How well are you able to get around?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
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F9.3 How much do any difficulties in mobility bother you?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5
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F9.4 To what extent do any difficulties in movement affect your way of life?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5
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F9.2 How satisfied are you with your ability to move around?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5
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The following few questions are concerned with **your personal beliefs**, and how these affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. Once again these questions refer to the last two weeks.

F24.1 Do your personal beliefs give meaning to your life?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5
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F24.2 To what extent do you feel your life to be meaningful?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5
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F24.3 To what extent do your personal beliefs give you the strength to face difficulties?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5
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F24.4 To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5



## APPENDIX 5 - CORRESPONDENCE ADDRESSES FOR FIELD CENTRES

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## **APPENDIX 6 - FOCUS GROUP INTERVIEW SCHEDULE**

### **WELCOME**

The moments before the focus group begins provide an excellent opportunity for participants to get to know one another a little, for the moderator(s) to hand out name badges (wherever appropriate), and for the moderators to try to identify individuals who are prone to be quiet and those prone to dominate a discussion.

### **WARM-UP**

In some settings a warm up exercise may familiarise participants with what is expected of them and facilitate subsequent discussion. One possible exercise might be for respondents to free-list areas of their life which have contributed to their quality of life in a positive way over the previous two weeks.

### **ORIENTATION AND INSTRUCTIONS**

All the following points should be covered in the orientation of participants before beginning the discussion.

1. What is a focus group? A type of "group interview" to generate ideas about an issue.
2. Focus groups are a "different" and "new" way of collecting information.
3. Very brief outline of WHOQOL project and the place of focus groups within it. The WHO definition of quality of life should be described in lay terms.
4. What is the purpose of this particular focus group? To check on the validity and comprehensiveness of the domain and facet structure in the target culture; to evaluate the comprehensiveness of the existing core items represented in the WHOQOL; and to generate any additional items that may be necessary.
5. The focus group is "time out" from normal cultural and social rules about what is and what is not acceptable to discuss.
6. There are no right and wrong answers, merely differing points of view. For the purpose of the focus group all participants' ideas and views are equally valuable.

7. Participants should try to say as honestly as they can what they think rather than what they think they should or are expected to say.
8. The session will be recorded, but data is confidential.
9. Time the session is expected to take, and whether or not there will be any breaks for refreshments etc.

Wherever possible participants should have read through the facet definitions and core questions before the focus group session. If this is not possible, time will need to be made during the focus group for participants to read carefully through each of the facets, and questions for each facet. In certain circumstances it may be necessary for the moderator and/or assistant moderator to assist the person with reading through the facet definitions.

It is suggested that an overhead, or flip chart with a facet definition and core questions on each page should be used in this part of the focus group. The moderator may wish to discuss facets in a certain order, or randomise the order in which facets are discussed. In any case it will save a great deal of time if related facets are discussed together: e.g. those concerned with social relationships, those concerned with work ...

Before beginning on a facet-by-facet discussion the moderator should ask:

**Are there any issues important to your (patients') quality of life which have been missed out of this list?**

As with all subsequent discussion, after an opinion has been stated, the moderator should enquire of the group if this opinion is consensually held.

Questions to be asked in the discussion of each facet:

**"Do the questions for <INSERT FACET> fully address your (patients') quality of life?"**

If an issue is consensually felt to be inadequately covered:

**"How would you ask about <INSERT ISSUE>?"**

Translation issues:

The focus group moderator should flag any concepts or words that had proved difficult to translate. These can then be discussed in the focus group as the relevant facets/items arise. Focus group participants should be asked to explain how translated items are understood and suggest

improvements where appropriate. This can be regarded as an extension of the monolingual review in the translation process.

**Closure, Debriefing and Thank you**

## APPENDIX 7 - WHOQOL-100 IMPORTANCE QUESTIONS

The following questions ask about **how important** various aspects of your life are to you. We ask that you think about how much these affect your quality of life. For example one question asks about how important sleep is to you. If sleep is not important to you, circle the number next to "not important". If sleep is "very important" to you, but not "extremely important", you should circle the number next to "Very important". Unlike earlier questions, these questions do not refer only to the last two weeks.

Thank you for your help.

ImpG.1 How important to you is your overall quality of life?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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ImpG.2 How important to you is your health?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp1.1 How important to you is it to be free of any pain?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp2.1 How important to you is having energy?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp3.1 How important to you is restful sleep?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp4.1 How important to you is it to feel happiness and enjoyment of life?

		Moderately		
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Not important 1	A little important 2	important 3	Very important 4	Extremely important 5
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Imp4.2 How important to you is it to feel content?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp4.3 How important to you is it to feel hopeful?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp5.1 How important to you is being able to learn and remember important information?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp5.2 How important to you is being able to think through everyday problems and make decisions?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp5.3 How important to you being able to concentrate?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp6.1 How important to you is feeling positive about yourself?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp7.1 How important to you is your body image and appearance?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp8.1 How important to you is it to be free of negative feelings (sadness, depression, anxiety, worry...)?

Not important	A little important	Moderately important	Very important	Extremely
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1	2	3	4	important 5
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Imp9.1 How important to you is it to be able to move around?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp10.1 How important to you is being able to take care of your daily living activities (e.g. washing, dressing, eating)?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp11.1 How important to you is it to be free of dependence on medicines or treatments?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp12.1 How important to you is being able to work?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp13.1 How important to you are relationships with other people?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp14.1 How important to you is support from others?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp15.1 How important to you is your sexual life?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp16.1 How important to you is feeling physically safe and secure?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp17.1 How important to you is your home environment?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp18.1 How important to you are your financial resources?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp19.1 How important to you is being able to get adequate health care?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp19.2 How important to you is being able to get adequate social help?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp20.1 How important to you are chances for getting new information or knowledge?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp20.2 How important to you are chances to learn new skills?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp21.1 How important to you is relaxation / leisure?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp22.1 How important to you is your environment (e.g. pollution, climate, noise, attractiveness)?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp23.1 How important to you is adequate transport in your everyday life?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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Imp24.1 How important to you are your personal beliefs?

Not important 1	A little important 2	Moderately important 3	Very important 4	Extremely important 5
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## APPENDIX 8- THE WHOQOL-BREF

### ABOUT YOU

I.D. number

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Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?

Male                  Female

What is your **date of birth**?

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day                  / Month                  / Year

What is the highest **education** you received?

None at all  
Primary school  
Secondary school  
Tertiary

What is your **marital status**?

Single    Separated  
Married    Divorced  
Living as married                                  Widowed

Are you currently **ill**?

Yes                  No

If something is wrong with your health what do you think it is? \_\_\_\_\_

### Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

	Do you get the kind of support from others that you need?	Not at all 1	Not much 2	Moderately 3	A great deal 4	Completely 5
--	---	-----------------	---------------	-----------------	-------------------	-----------------

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Do you get the kind of support from others that you need?	Not at all 1	Not much 2	Moderately 3	A great deal 4	Completely 5
--	---	-----------------	---------------	-----------------	-------------------	-----------------

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.  
Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

**THE WHOQOL-BREF**

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your	1	2	3	4	5

(F18.1)	needs?					
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

**Do you have any comments about the assessment?**

.....

...

.....

...

**THANK YOU FOR YOUR HELP**

**APPENDIX 9 - STEPS FOR CHECKING AND CLEANING DATA AND COMPUTING DOMAIN SCORES FOR THE WHOQOL-100**

Steps	SPSS syntax for carrying out data checking, cleaning and computing total scores
Check all 100 items from assessment have a range of 1-5	<p>RECODE f11 f12 f13 f14 f21 f22 f23 f24 f31 f32 f33 f34 f41 f42 f43 f44  f51 f52 f53 f54 f61 f62 f63 f64 f71 f72 f73 f74 f81 f82 f83 f84 f91 f92 f93 f94  f101 f102 f103 f104 f111 f112 f113 f114 f121 f122 f123 f124  f131 f132 f133 f134 f141 f142 f143 f144 f151 f152 f153 f154 f161 f162 f163  f164 f171 f172 f173 f174 f181 f182 f183 f184 f191 f192 f193 f194 f201 f202  f203 f204 f211 f212 f213 f214 f221 f222 f223 f224 f231 f232 f233 f234 f241  f242 f243 f244 g1 g2 g3 g4  (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).</p> <p>(This recodes all data outside the range 1-5 to system missing).</p>
Reverse negatively phrased items	<p>RECODE f22 f24 f32 f34 f72 f73 f93 f94 f102 f104 f131 f154 f163 f182 f184  f222 f232 f234 (1=5) (2=4) (3=3) (4=2) (5=1).</p> <p>(This transforms negatively framed questions to positively framed questions)</p>
Compute facet and domain scores	<p>COMPUTE pain=(MEAN.3(f11,f12,f13,f14))*4.  COMPUTE energy=(MEAN.3(F21,F22,F23,F24))*4.  COMPUTE sleep=(MEAN.3(F31,F32,F33,F34))*4.  COMPUTE pfeel=(MEAN.3(F41,F42,F43,F44))*4.  COMPUTE think=(MEAN.3(F51,F52,F53,F54))*4.  COMPUTE esteem=(MEAN.3(F61,F62,F63,F64))*4.  COMPUTE body=(MEAN.3(F71,F72,F73,F74))*4.  COMPUTE neg=(MEAN.3(F81,F82,F83,F84))*4.  COMPUTE mobil=(MEAN.3(F91,F92,F93,F94))*4.  COMPUTE activ=(MEAN.3(F101,F102,F103,F104))*4.  COMPUTE medic=(MEAN.3(F111,F112,F113,F114))*4.  COMPUTE work=(MEAN.3(F121,F122,F123,F124))*4.  COMPUTE relat=(MEAN.3(F131,F132,F133,F134))*4.  COMPUTE supp=(MEAN.3(F141,F142,F143,F144))*4.  COMPUTE sexx=(MEAN.3(F151,F152,F153,F154))*4.  COMPUTE safety=(MEAN.3(F161,F162,F163,F164))*4.  COMPUTE home=(MEAN.3(F171,F172,F173,F174))*4.  COMPUTE finan=(MEAN.3(F181,F182,F183,F184))*4.  COMPUTE servic=(MEAN.3(F191,F192,F193,F194))*4.  COMPUTE inform=(MEAN.3(F201,F202,F203,F204))*4.  COMPUTE leisur=(MEAN.3(F211,F212,F213,F214))*4.  COMPUTE envir=(MEAN.3(F221,F222,F223,F224))*4.  COMPUTE transp=(MEAN.3(F231,F232,F233,F234))*4.  COMPUTE spirit=(MEAN.3(F241,F242,F243,F244))*4.  COMPUTE overll=(MEAN.3(G1,G2,G3,G4))*4.  COMPUTE PHYS=MEAN.2((24-pain),energy,sleep).  COMPUTE PSYCH=MEAN.4(pfeel,think,esteem,body,(24-neg)).  COMPUTE IND=MEAN.3(mobil,activ,(24-medic),work).  COMPUTE SOCIAL==MEAN.2(relat,supp,sexx).  COMPUTE ENVIR=  MEAN.6(safety,home,finan,servic,inform,leisur,envir,transp).</p> <p>(These equations calculate the facet and domain scores. All facet scores are multiplied by 4 so as to provide total scores while permitting up to one item per facet to be missing. The '.6' in 'mean.6' specifies that at least 6 items must be endorsed or not missing for the score to be calculated).</p>

Steps	SPSS syntax for carrying out data checking, cleaning and computing total scores
Transform scores to a 0-100 scale	<pre> COMPUTE pain =(pain-4)*(100/16). COMPUTE energy=(energy-4)*(100/16). COMPUTE sleep=(sleep-4)*(100/16). COMPUTE pfeel=(pfeel-4)*(100/16). COMPUTE think=(think-4)*(100/16). COMPUTE esteem=(esteem-4)*(100/16). COMPUTE body=(body-4)*(100/16). COMPUTE neg=(neg-4)*(100/16). COMPUTE mobil=(mobil-4)*(100/16). COMPUTE activ=(activ-4)*(100/16). COMPUTE medic=(medic-4)*(100/16). COMPUTE work=(work-4)*(100/16). COMPUTE relat=(relat-4)*(100/16). COMPUTE supp=(supp-4)*(100/16). COMPUTE sexx=(sexx-4)*(100/16). COMPUTE safety=(safety-4)*(100/16). COMPUTE home=(home-4)*(100/16). COMPUTE finan=(finan-4)*(100/16). COMPUTE servic=(servic-4)*(100/16). COMPUTE inform=(inform-4)*(100/16). COMPUTE leisur=(leisur-4)*(100/16). COMPUTE envir=(envir-4)*(100/16). COMPUTE transp=(transp-4)*(100/16). COMPUTE spirit=(spirit-4)*(100/16). COMPUTE overll=(overll-4)*(100/16). COMPUTE PHYS=(dom1-4)*(100/16). COMPUTE PSYCH=(dom2-4)*(100/16). COMPUTE IND=(dom3-4)*(100/16). COMPUTE SOCIAL=(dom4-4)*(100/16). COMPUTE ENVIR=(dom5-4)*(100/16). COMPUTE SPIR=(dom6-4)*(100/16). </pre>
Delete cases with >20% missing data	<pre> COUNT TOTAL=F12 TO F244 (1 THRU 5). FILTER OFF. </pre> <p>(This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-100 items with the values 1-5 that have been endorsed by each subject. The 'F12 TO F244' means that consecutive columns from 'F12', the first item, to 'F244', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment and that the "decimal point" is dropped from the item name.)</p> <pre> SELECT IF (TOTAL&gt;=80). EXECUTE. </pre> <p>(This second command selects only those cases where 'total', the total number of items completed, is greater than or equal to 80%. It deletes the remaining cases from the dataset.)</p>

**APPENDIX 10 - STEPS FOR CHECKING AND CLEANING DATA AND COMPUTING DOMAIN SCORES FOR THE WHOQOL-BREF**

Steps	SPSS syntax for carrying out data checking, cleaning and computing total scores
Check all 26 items from assessment have a range of 1-5	<p>RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26</p> <p>(1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).</p> <p>(This recodes all data outside the range 1-5 to system missing.)</p>
Reverse 3 negatively phrased items	<p>RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1).</p> <p>(This transforms negatively framed questions to positively framed questions.)</p>
Compute domain scores	<p>COMPUTE PHYS=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4.</p> <p>COMPUTE PSYCH=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4.</p> <p>COMPUTE SOCIAL=MEAN.2(Q20,Q21,Q22)*4.</p> <p>COMPUTE ENVIR=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4.</p> <p>(These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated.)</p>
Transform scores to a 0-100 scale	<p>COMPUTE PHYS=(PHYS-4)*(100/16).</p> <p>COMPUTE PSYCH=(PSYCH-4)*(100/16).</p> <p>COMPUTE SOCIAL=(SOCIAL-4)*(100/16).</p> <p>COMPUTE ENVIR=(ENVIR-4)*(100/16).</p>
Delete cases with >20% missing data	<p>COUNT TOTAL=Q1 TO Q26 (1 THRU 5).</p> <p>(This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-BREF items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment.)</p> <p>SELECT IF (TOTAL&gt;=21).</p> <p>EXECUTE.</p> <p>(This second command selects only those cases where 'total', the total number of items completed, is greater than or equal to 80%. It deletes the remaining cases from the dataset.)</p>