WHOQOL-HIV Instrument

Users Manual

Scoring and Coding for the

WHOQOL-HIV Instruments

MENTAL HEALTH: EVIDENCE AND RESEARCH
DEPARTMENT OF MENTAL HEALTH
AND SUBSTANCE DEPENDENCE
WORLD HEALTH ORGANIZATION
GENEVA

Further copies of this document may be obtained from

Department of Mental Health and Substance Dependence
World Health Organization
CH-1211 Geneva 27
Switzerland

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WHOQOL-HIV INSTRUMENT

The WHOQOL-HIV has been developed from an extensive test of 115 questions, plus the WHOQOL-100 in 10 centres around the world. These questions represent the finalised version of the WHOQOL-HIV to be used for field trials.

The WHOQOL-HIV is based on the WHOQOL-100. It is a generic English version and should never be used as it stands, nor just be translated. Versions suitable for use in an HIV population are available from the listed field trial centres. These versions are constructed by taking the corresponding 120 questions and response scales exactly as they stood in the language version that was used in the pilot test. (It should be noted that some variations exist even between the versions from the three English language centres).

These questions respond to the definition of Quality of Life 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.*

Centres wishing to develop a new language or cultural version, must follow the protocol for new centres under the supervision of the Department of Mental Health & Substance Dependence, WHO, Geneva, and as mentioned above must never just make a direct translation or an unsupervised adaptation of the WHOQOL-HIV Instrument. For further information contact: The Coordinator, WHOQOL-HIV Group, Department of Mental Health and Substance Dependence, WHO, CH-1211 Geneva 27, Switzerland.

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HIV/AIDS QUALITY OF LIFE GROUP

The WHOQOL-HIV Group comprises a coordinating group of collaborating investigators in each of the field sites and a panel of consultants. Dr Shekhar Saxena directed the project that was initiated by Dr Rex Billington and Dr John Orley. Technical assistance on the project was given by Ms. M. Lotfy and Ms K. O'Connell. The instrument was developed in 10 field sites: Mr Michael Bartos, Centre for the Study of Sexually Transmissible Disease, Faculty of Health Sciences, Locked Bar 12, La Trobe University, Victoria, Australia; Dr Prabha Chandra, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India; Dr Marcelo Fleck, Department of Psychiatry and Legal Medicine, University of the State of Rio Grande do Sul, Rua Ramiro Barcelos 2350, Porto Alegre, Brazil; Dr Leng Bun Hor, NCHADS, Ministry of Health, Phnom Penh, Cambodia; Dr Rachna Bhargava, Department of Psychiatry, All India Institute of Medical Sciences, New Delhi, India; Prof. F. Starace, Consultation Psychiatry and Behavioural Epidemiology Service, Naples, Italy; Dr Svetlana Pkhidenko, Dniepropetrovsk State Medical Academy, Dniepropetrovsk , Ukraine; Dr. Kitikorn Meesapya, Branch of Preventive Mental Health Technical development, Department of Mental Health, Ministry of Public Health, Bangkok, Thailand; Dr Alan Haworth, Department of Psychiatry, University of Zambia, Lusaka, Zambia; Dr Jane Mutambirwa, Department of Psychiatry, University of Zimbabwe, Harare, Zimbabwe. Analysis was conducted by Prof. S. Skevington at the University of Bath, Department of Psychology, U.K. and at WHO, Geneva. Funding for the project was provided by the FETZER Institute and UNAIDS. Further information on the WHOQOL can be obtained at:

 http://www.who.int/msa/qol/

Further information and detail regarding the project can be obtained from:

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WHOQOL-HIV INSTRUMENT: USERS MANUAL

This manual describes scoring and coding for the two WHOQOL-HIV Instruments. These are the WHOQOL-120, which is based on the WHOQOL-100, and the WHOQOL-HIV BREF, which is based on the shorter WHOQOL-BREF.

The WHOQOL-120 HIV was developed from an extensive pilot and field test of 115 questions, plus the WHOQOL-100 in 10 centres around the world. These questions represent the finalised version of the WHOQOL-HIV to be used for field trials. It is a generic English version and should never be used as it stands, nor just be translated. Versions suitable for use in an HIV population are available from the listed field trial centres. These versions are constructed by taking the corresponding 120 questions and response scales exactly as they stood in the language version that was used in the pilot test. (It should be noted that some variations exist even between the versions from the three English language centres.) These questions respond to the definition of Quality of Life 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.*

The WHOQOL-HIV BREF is based on the WHOQOL-BREF, the shorter form of the WHOQOL-100. This contains five extra items specific to PLWHA, and in total contains 31 items.

Centres wishing to develop a new language or cultural version, must follow the protocol for new centres under the supervision of the Coordinator, Mental Health: Evidence and Research, Department of Mental Health and Substance Dependence, World Health Organization, Geneva, Switzerland, and, as mentioned above, must never just make a direct translation or an unsupervised adaptation of the WHOQOL-HIV Instruments.

Table 1. WHOQOL-HIV DOMAINS AND FACETS*

Domain I	**Physical**
1	Pain and discomfort
2	Energy and fatigue
3	Sleep and rest
50	**Symptoms of PLWHA***
Domain II	**Psychological**
4	Positive feelings
5	Thinking, learning, memory and concentration
6	Self-esteem
7	Bodily image and appearance
8	Negative feelings
Domain III	**Level of Independence**
9	Mobility
10	Activities of daily living
11	Dependence on medication or treatments
12	Work capacity
Domain IV	**Social Relationships**
13	Personal relationships
14	Social support
15	Sexual activity
51	**Social Inclusion**
Domain V	**Environment**
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
Domain VI	**Spirituality/Religion/ Personal Beliefs**
24	SRPB
52	**Forgiveness and Blame**
53	**Concerns about the Future**
54	**Death and Dying**
Overall quality of life and general health perceptions	

* *Facets that are highlighted in bold are specific to the Persons Living with HIV/AIDS, and as such have been added to the original WHOQOL Instrument.*

SCORING OF THE WHOQOL-120 HIV INSTRUMENT

The WHOQOL-120 HIV produces a quality of life profile. It is possible to derive six domain scores, 29 facet scores, and one general facet score that measures overall quality of life and general health. Five of these are specific to HIV/AIDS, and these are highlighted in bold in Table 1. The specific HIV facets are labelled F50 – F54, to distinguish them from the generic WHOQOL-100 facets. Each HIV facet, like the WHOQOL-100, has four items to represent these facets.

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. Individual items are rated on a 5 point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. For example, an item in the positive feeling facet asks "How much do you enjoy life?" and the available responses are 1 (not at all), 2 (a little) 3 (a moderate amount), 4 (very much) and 5 (an extreme amount). As such, 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, Death and Dying) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that high scores reflect better QoL. 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. Items are organised by response scale (capacity, frequency, intensity or satisfaction). Instructions for calculation of scores are given below. These follow the syntax file, which can be obtained from: The WHOQOL HIV Coordinator, Mental Health: Evidence and Research, Department of Mental Health and Substance Dependence, CH-1211 Geneva 27, Switzerland.

SCORING PROCEDURE

First, all scores need to be checked that they are in the appropriate range (between 1 and 5).

Check all items from assessment have a range of 1-5

RECODE f1.1 f1.2 f1.3 f1.4 f2.1 f2.2 f2.3 f2.4 f3.1 f3.2 f3.3 f3.4 f50.1 f50.2 f50.3 f50.4 f4.1 f4.2 f4.3 f4.4 f5.1 f5.2 f5.3 f5.4 f6.1 f6.2 f6.3 f6.4 f7.1 f7.2 f7.3 f7.4 f8.1 f8.2 f8.3 f8.4 f9.1 f9.2 f9.3 f9.4 f10.1 f10.2 f10.3 f10.4 f11.1 f11.2 f11.3 f11.4 f12.1 f12.2 f12.3 f12.4 f13.1 f13.2 f13.3 f13.4 f14.1 f14.2 f14.3 f14.4 f15.1 f15.2 f15.3 f15.4 f51.1 f51.2 f51.3 f51.4 f16.1 f16.2 f16.3 f16.4 f17.1 f17.2 f17.3 f17.4 f18.1 f18.2 f18.3 f18.4 f19.1 f19.2 f19.3 f19.4 f20.1 f20.2 f20.3 f20.4 f21.1 f21.2 f21.3 f21.4 f22.1 f22.2 f22.3 f22.4 f23.1 f23.2 f23.3 f23.4 f24.1 f24.2 f24.3 f24.4 f52.1 f52.2 f52.3 f52.4 f53.1 f53.2 f53.3 f53.4 f54.1 f54.2 f54.3 f54.4 g.1 g.2 g.3 g.4 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS) .

(This recodes all data outside the range 1-5 to system missing).

Forty eight items are negatively phrased. All negatively framed items need to be recoded, so that all scores reflect better quality of life. These items need to be reverse scored to ensure that higher scores reflect better QoL. For example, a negatively phrased item includes "Do you worry about pain or discomfort?" A participant who answers (1) (not at all), would therefore have good QoL for this facet. As the WHOQOL ensures that higher scores reflect better QoL, the score therefore needs to be reversed so that one is changed to five. This can be calculated as follows:

Reverse negatively phrased items

RECODE f1.1 f1.2 f1.3 f1.4 f2.1 f2.2 f2.4 f3.2 f3.4 f7.2 f7.3 f8.1 f8.2 f8.3 f8.4 f9.3

f9.4 f10.2 f10.4 f11.1 f11.2 f11.3 f11.4 f13.1 f15.4 f16.3 f18.2 f18.4 f22.2 f23.2 f23.4 f50.1 f50.2 f50.3

f50.4 f51.4 f51.2 f52.1 f52.2 f52.3 f52.4 f53.1 f53.2 f53.3 f53.4 f54.1 f54.2 f54.4

f54.3 (1=5) (2=4) (3=3) (4=2) (5=1). (1=5) (2=4) (3=3) (4=2) (5=1).

(This transforms negatively framed questions to positively framed questions)

CALCULATION OF FACET SCORES

Facets are scored through summative scaling. Each item contributes equally to the facet score. Mean scores are then calculated. In this case, all the items in the respective facet are added, and divided by four.

Calculate Facets Means

pain = (f1.1 + f1.2 + f1.3 + f1.4)/4 .
energy = (f2.1 + f2.2 + f2.3 + f2.4)/4 .
sleep = (f3.1 + f3.2 + f3.3 + f3.4)/4 .
symptom = (f50.1 + f50.2+ f50.3 + f50.4)/4 .
pfeel = (f4.1 + f4.2 + f4.3 + f4.4)/4 .
cog = (f5.1 + f5.2 + f5.3 + f5.4)/4 .
esteem = (f6.1 + f6.2 + f6.3 + f6.4)/4 .
body = (f7.1 + f7.2 + f7.3 + f7.4)/4 .
nfeel = (f8.1 + f8.2 + f8.3 + f8.4)/4 .
mobil = (f9.1 + f9.2 + f9.3 + f9.4)/4 .
adl = (f10.1 + f10.2 + f10.3 + f10.4)/4 .
depend = (f11.1 + f11.2 + f11.3 + f11.4)/4 .
work = (f12.1 + f12.2 + f12.3 + f12.4)/4 .
relatio = (f13.1 + f13.2 + f13.3 + f13.4)/4 .
support = (f14.1 + f14.2 + f14.3 + f14.4)/4 .
sex = (f15.1 + f15.2 + f15.3 + f15.4)/4 .
inclusi = (f51.1 + f51.2 + f51.3 + f51.4)/4 .
safe = (f16.1 + f16.2 + f16.3 + f16.4)/4 .
home = (f17.1 + f17.2 + f17.3 + f17.4)/4 .
finance = (f18.1 + f18.2 + f18.3 + f18.4)/4 .
care = (f19.1 + f19.2 + f19.3 + f19.4)/4 .
info = (f20.1 + f20.2 + f20.3 + f20.4)/4 .
leisure = (f21.1 + f21.2 + f21.3 + f21.4)/4 .
enviro = (f22.1 + f22.2 + f22.3 + f22.4)/4 .
trans = (f23.1 + f23.2 + f23.3 + f23.4)/4 .
srpb = (f24.1 + f24.2 + f24.3 + f24.4)/4 .
forgive = (f52.1 + f52.2 + f52.3 + f52.4)/4 .
future = (f53.1 + f53.2 + f53.3 + f53.4)/4 .
death = (f54.1 + f54.2 + f54.3 + f54.4)/4 .
general = (g.1 + g.2 + g.3 + g.4)/4 .

CALCULATION OF DOMAIN SCORES

Each facet is taken to contribute equally to the domain score. Domain scores are calculated by computing the mean of the facet score within the domain, according to the following formulae. As negative items have had their scores reversed, the facets are summated according to the procedure given below. Scores are then multiplied by four, so that domain scores range between 4 and 20.

Calculate Domain Scores

Domain1 = (pain + energy + sleep + symptom) / 4 * 4 .

Domain2 = (pfeel + cog + esteem + body + nfeel) / 5 * 4 .

Domain3 = (mobil + adl + depend + work) / 4 * 4 .

Domain4 = (relatio + support + sex + inclusi) / 4 * 4 .

Domain5 = (safe + home + finance + care + info + leisure + enviro + rans) / 8 * 4 .

Domain6 = (forgive + future + death + srpb) / 4 * 4 .

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 An SPSS syntax file that automatically checks, recodes data and computes domain scores may be obtained from:

Coordinator, WHOQOL-HIV Group

Mental Health: Evidence and Research

Department of Mental Health and Substance Dependence

CH-1211 Geneva 27, Switzerland

SCORING OF THE WHOQOL 31-BREF

The WHOQOL-HIV BREF produces six domain scores. Where as the WHOQOL-100 has four items to present each facet, the WHOQOL-HIV BREF has only one item. Included in these, there are two items that examine General quality of life: 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. Hence there are 31 items, representing the 30 facets. Five of these facets are specific to HIV/AIDS.

Like the WHOQOL-100, individual items are rated on a 5 point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. For example, an item in the positive feeling facet asks "How much do you enjoy life?" and the available responses are 1 (not at all), 2 (a little) 3 (a moderate amount), 4 (very much) and 5 (an extreme amount). As such, 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, Death and Dying) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that high scores reflect better QoL. Items are organised by response scale (capacity, frequency, intensity or satisfaction). Instructions for calculation of scores are given below. These follow the syntax file, which can be obtained from the WHOQOL HIV Coordinator, Mental Health: Evidence and Research, Department of Mental Health and Substance Dependence, CH-1211 Geneva 27, Switzerland.

SCORING PROCEDURE

First, all scores need to be checked that they are in the appropriate range (between 1 and 5).

Check all items from assessment have a range of 1-5

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	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 Q27 Q28 Q29 Q30 Q31 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS). (This recodes all data outside the range 1-5 to system missing.)

Domain scores are scaled in a positive direction where higher scores denote higher quality of life. Some items are not scaled in a positive direction (e.g. Pain and Discomfort, Negative Feelings, Dependence on Medication, Death and Dying), meaning that for these facets higher scores do not denote higher quality of

life. These need to be recoded so that high scores reflect better QoL. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). Instructions for calculation of scores are given below.

Reverse negatively phrased items

Reverse 6 negatively phrased items	RECODE Q3 Q4 Q5 Q8 Q9 Q10 Q31 (1=5) (2=4) (3=3) (4=2) (5=1).
	(This transforms negatively framed questions to positively framed questions.)

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, so that scores range between 4 and 20.

Calculate Domain Scores

Compute domain scores	Domain 1 = (Q3 + Q4 + Q14 + Q21)/4 * 4
	Domain 2 = (Q6 + Q11 + Q15 + Q24 + Q31)/5 *4
	Domain 3 = (Q5 + Q22 + Q23 + Q20)/4 * 4
	Domain 4 = (Q27 +Q26 + Q25 + Q17)/4*4
	Domain 5 = (Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30)/8 *4
	Domain6 = (Q7 + Q8 + Q9+ Q10)/4 *4
	(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 WHOQOL-BREF can also be scored by hand. To do this, negative scores must be reversed. Hence the formula 6 - x is used. This will ensure, for example, that if someone reports fearing the future a great deal (5), subtracting the score by six, will automatically recode the item to 1. Instructions for this are provided on the first page of the instrument.

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 An SPSS syntax file that automatically checks, recodes data and computes domain scores may be obtained from:

WHOQOL HIV Coordinator

Mental Health: Evidence and Research

Department of Mental Health and Substance Dependence

CH-1211 Geneva 27, Switzerland

CODING INSTRUCTIONS: WHOQOL-120 HIV and the WHOQOL-HIV BREF INSTRUMENTS

ALL MISSING DATA TO BE ENTERED AS SYTEM MISSING

Variable; fieldid (enter your respondents identity no.)

WHOQOL-HIV 120 ITEMS; (F1.2, F1.3 etc, variable labels correspond directly in the SPSS/EXCEL data file), enter as normal Likert scale with values between 1 - 5

WHOQOL-HIV Importance Items (37 items Imp1.1, Imp2.1 etc., variable labels correspond directly in the SPSS/EXCEL data file), enter as normal Likert scale with values between 1-5

WHOQOL-HIV BREF Items (31 items) (Question 1 (Qu.1) in the instrument responds to the variable label HBREF_1, Question 2 responds to HBREF_2 etc), enter as normal Likert scale with values between 1 – 5

ABOUT YOU:
Item: What is your gender?
Variable name; sex
Values; 1 = male; 2 = female

Item: What is your date of birth?
Variable name; age
Values; please enter age (e.g. 36), NOT date of birth

Item: What is highest education you received?
Variable name; educate
Values; 1 = Primary school , 2 = Secondary school, 3 = University, 4 = Post-graduate

Item: What is your marital status?
Variable name; marital
Values; 1 = Single, 2 = Married, 3 = Living as married, 4 = Separated, 5 = Divorced, 6 = Widowed

Item: How is your health? (G1.2)

Variable name; G5

Values; 1 = very poor, 2 = poor, 3 = neither poor nor good, 4 = good, 5 = very good

Item: Do you consider yourself currently ill?
Variable name; ill_now
Values; 1= yes, 2 = no

Item: What is your HIV serostatus?
Variable name; status
Values;   1= HIV Positive – Asympomatic
                 2 = HIV positive – sympomatic
                 3 = AIDS (AIDS related illnesses)
                 4 = HIV negative
                 5 = don't know

Item: In what year did you first test positive for HIV?
Variable name; year
(enter year e.g. 1996)

Item: In what year do you think you were infected?
Variable name; think
(enter year e.g. 1994)

Item: How do you believe you were infected?
Variable name; infect
Variable name; status
Values;   1= Sex with a man
                2= Sex with a woman
                3= Injecting drugs
                4= Blood products
                5= Other

Once all the variables are entered, the appropriate syntax file can be run to recode all the items and calculate domain scores.