References for all chapters


Cohen J. Weighted kappa: nominal agreement with provision for scaled disagreement or partial credit. Psychological Bulletin 1968;70:213-220.


References for all chapters


Health Funding Authority. How shall we prioritise health and disability services? Discussion paper. Wellington: Health Funding Authority, 1998.


References for all chapters


Johnson J A, Pickard S. Comparison of the EQ-5D and the SF-12 health surveys in a general population survey in Alberta, Canada. Medical Care 2000b;38:115-121.


References for all chapters


References for all chapters


Health Questionnaire

We are trying to find out what people think about health. We are going to describe a few health states that people can be in. We want you to indicate how good or bad each of these states would be for a person like you. There are no right or wrong answers. Here we are interested only in your personal view.

But first of all we would like you to indicate (on the next page) the state of your own health today.
By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** *(e.g. work, study, housework, family or leisure activities)*
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.
• We now want you to consider some other health states.

• Remember, we want you to indicate how good or bad each of these states would be for a person like you.

• They are described, on either side of the scale, on the page opposite.

• When thinking about each health state imagine that it will last for one year. What happens after that is not known and should not be taken into account.

• Please draw **one line from each box** to whichever point on the scale indicates how good or bad the state described in that box is.

• It does not matter if your lines cross each other.
Best imaginable health state

No problems in walking about
No problems with self-care
Some problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
No pain or discomfort
Not anxious or depressed

No problems in walking about
No problems with self-care
No problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
Moderate pain or discomfort
Not anxious or depressed

Some problems in walking about
No problems with washing or dressing self
Some problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
Extreme pain or discomfort
Extremely anxious or depressed

Confined to bed
Unable to wash or dress self
Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
Extreme pain or discomfort
Extremely anxious or depressed

Worst imaginable health state

No problems in walking about
No problems with self-care
No problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
Moderate pain or discomfort
Moderately anxious or depressed

Confined to bed
Unable to wash or dress self
Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
Moderate pain or discomfort
Not anxious or depressed

PLEASE CHECK THAT YOU HAVE DRAWN ONE LINE FROM EACH BOX (THAT IS, 8 LINES IN ALL)
In the same way as on the previous page, please indicate how good or bad these additional states are, by drawing a line from each box to a point on the scale.

You will find that 2 of these states (marked *) are repeated from the previous page.

Best imaginable health state

- Some problems in walking about
- No problems with self-care
- No problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
- No pain or discomfort
- Not anxious or depressed

100

- No problems in walking about
- No problems with self-care
- No problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
- No pain or discomfort
- Moderately anxious or depressed

90

- Confined to bed
- Some problems with washing or dressing self
- Some problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
- No pain or discomfort
- Not anxious or depressed

80

- Unconscious

70

- Confined to bed
- Unable to wash or dress self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Extreme pain or discomfort
- Extremely anxious or depressed

60

Worst imaginable health state

- Some problems in walking about
- Some problems with washing or dressing self
- No problems with performing usual activities (e.g. work, study, housework, family or leisure activities)
- No pain or discomfort
- Not anxious or depressed

50

- Some problems in walking about
- Some problems with washing or dressing self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Moderate pain or discomfort
- Extremely anxious or depressed

40

- Some problems in walking about
- Some problems with washing or dressing self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Extremely anxious or depressed

30

- Some problems in walking about
- Some problems with washing or dressing self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Extremely anxious or depressed

20

- Some problems in walking about
- Some problems with washing or dressing self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Extremely anxious or depressed

10

- Some problems in walking about
- Some problems with washing or dressing self
- Unable to perform usual activities (e.g. work, study, housework, family or leisure activities)
- Extremely anxious or depressed

0

Please check that you have drawn one line from each box (that is, 8 lines in all).
• In the previous pages we asked you to say how good or bad various health states are in your view.

• We would now like you to tell us how good or bad you feel the state ‘dead’ is, compared with being in the other states for one year.

• Please turn back to pages 5 and 6 and draw one line across the thermometer at the point you would locate the state ‘dead’.

• Remember we would like you to do this on both pages 5 and 6.
Because all replies are anonymous, it will help us to understand your answers better if we have a little background data from everyone, as covered in the following questions. (At the end there is space to add anything else you think may be helpful to us).

1. Have you experienced serious illness?  
   - in yourself  
   - in your family  
   - in caring for others

2. What is your age in years?

3. Are you:  
   - Male  
   - Female

4. Are you:  
   - a current smoker  
   - an ex-smoker  
   - a never smoker

5. Do you now, or did you ever, work in health or social services?  
   If so, in what capacity?

6. Which of the following best describes your main activity?  
   - in employment or self employment  
   - retired  
   - household  
   - student  
   - seeking work  
   - other (please specify)

7. Did your education continue after the minimum school leaving age?

8. Do you have a Degree or equivalent professional qualification?
9. Please add here any comments you may wish to make which might help us to understand your answers better:

10. Did you find filling in this questionnaire:
    
    very difficult [ ]
    fairly difficult [ ]
    fairly easy [ ]
    very easy [ ]

11. Could you please let us know roughly how long it took you to complete (in minutes):
    
    [ ]

12. If you know your postcode, would you please write it here:
    
    [ ]

Thank you for being so helpful
APPENDIX 2

SUGGESTIONS FOR EQ-5D TELEPHONE ADMINISTRATION

GENERAL INSTRUCTION

It is suggested that the telephone administrator follows the script of the EQ-5D. Although allowance should be made for the interviewer's particular style of speaking, the wording of the questionnaire instructions should be followed as closely as possible. In the case of the EQ-5D descriptive system on page 2, the precise wording must be followed.

It is recommended that the administrator has a copy of the EQ-5D in front of him or her as it is administered over the telephone. This enables the respondent's answers to be entered directly on the EQ-5D by the administrator on behalf of the respondent (i.e. the appropriate boxes on page 2 are marked and the scale on page 3 is marked at the point indicating the respondent's 'own health state today'). If the respondent asks for clarification, the administrator can help by re-reading the question verbatim. The administrator should not try to offer his or her own explanation but suggest that the respondent uses his or her own interpretation.

If the respondent has difficulty with regard to which box to mark, the administrator should repeat the question verbatim and ask the respondent to answer in a way that most closely resembles his or her thoughts about his or her health state today.

INTRODUCTION TO EQ-5D

We are trying to find out what you think about your health. I will first ask you a few brief and simple questions about your own health state today. I will then ask you to do a rather different task that involves rating your health on a measuring scale. I will explain the tasks fully as I go along but please interrupt me if you do not understand something or if things are not clear to you. Please also remember that there are no right or wrong answers. We are interested here only in your personal view.
First I am going to read out some questions. Each question has a choice of three answers. Please tell me which answer best describes your own health state today.

Do not choose more than one answer in each group of questions.

(Note for administrator: it may be necessary to remind the respondent regularly that the timeframe is today.)

Mobility

First I'd like to ask you about mobility.

Question 1: Would you say you have…

1. No problems in walking about?
2. Some problems in walking about?
3. Are you confined to bed?

So, would you say you have no problems in walking about, some problems in walking about or are you confined to bed?

(Note for administrator: mark the appropriate box on EQ-5D)

Self-Care

Next I'd like to ask you about self-care.

Question 2: Would you say you have…

1. No problems with self-care?
2. Some problems washing or dressing yourself?
3. Are you unable to wash or dress yourself?

So, would you say you have no problems with self-care, some problems washing or dressing yourself or are you unable to wash or dress yourself?

(Note for administrator: mark the appropriate box on EQ-5D)
Usual Activities

Next I'd like to ask you about usual activities, for example work, study, housework, family or leisure activities.

Question 3: Would you say you have…

1. No problems with performing your usual activities?
2. Some problems with performing your usual activities?
3. Are you unable to perform your usual activities?

So, would you say you have no problems performing your usual activities, some problems performing your usual activities or are you unable to perform your usual activities?

(Note for administrator: mark the appropriate box on EQ-5D)

Pain/Discomfort

Next I'd like to ask you about pain or discomfort.

Question 4: Would you say you have…

1. No pain or discomfort?
2. Moderate pain or discomfort?
3. Extreme pain or discomfort?

So, would you say you have no pain or discomfort, moderate pain or discomfort or extreme pain or discomfort?

(Note for administrator: mark the appropriate box on the EQ-5D questionnaire)

Anxiety/Depression

Finally I'd like to ask you about anxiety or depression.

Question 5: Would you say you are…

1. Not anxious or depressed?
2. Moderately anxious or depressed?
3. Extremely anxious or depressed?

So, would you are not anxious or depressed, moderately anxious or depressed or extremely anxious or depressed?

(Note for administrator: mark the appropriate box on the EQ-5D questionnaire)
I would now like to ask you to do a rather different task.

To help you say how good or bad your health state is, I'd like you to try to picture in your mind a scale that looks a bit like a thermometer. Can you do that? The best health state you can imagine is marked 100 (one hundred) at the top of the scale and the worst state you can imagine is marked 0 (zero) at the bottom.

EQ VAS - PAGE 3: TASK

I would now like you to tell me the point on this scale where you would put your own health state today.

Thank you for taking the time to answer these questions.
APPENDIX 3

SUGGESTIONS FOR SELF-COMPLETION OF THE EQ-5D IN THE PRESENCE OF AN INTERVIEWER

The EQ-5D may be completed alone or it may be completed in the presence of an interviewer. When an interviewer is present, he or she can either give the EQ-5D to the respondent for self-completion or read out the questions. If the respondent asks for clarification, the administrator can re-read the question verbatim. The administrator should not try to offer his or her own explanation but should suggest that the respondent uses his or her own interpretation.

If the respondent has difficulty choosing which box to mark, the interviewer should repeat the question verbatim. He or she should not offer any suggestions or advice but should ask the respondent to answer in a way that most closely resembles his or her thoughts about his or her health state today.
It is suggested that the interviewer follows the script of the telephone administration of the EQ-5D. Although allowance should be made for the interviewer’s particular style of speaking, the wording of the questionnaire instructions should be followed as closely as possible. In the case of the EQ-5D dimensions on page 2, the precise wording must be followed.

It is recommended that the interviewer gives a copy of the EQ-5D to the respondent. This enables the respondent’s answers to be entered directly on the EQ-5D by the administrator on behalf of the respondent (i.e. the appropriate boxes on page 2 are marked and the scale on page 3 is marked at the point indicating the respondent’s ‘own health state today’).

If the respondent asks for clarification, the interviewer can help by re-reading the question verbatim. The interviewer should not try to offer his or her own explanation but suggest that the respondent uses his or her own interpretation.

If the respondent has difficulty with regard to which box to mark, the administrator should repeat the question verbatim and ask the respondent to answer in a way that most closely resembles his or her thoughts about his or her health state today.
Appendices

APPENDIX 5

SCRIPT FOR PROXY VERSION OF THE EQ-5D: VERSION 1

(asking the proxy to rate how he or she (i.e. the proxy) would rate the subject’s health)

Proxy version of the EQ-5D: 1

By placing a tick in one box in each group below, please indicate which statement best describes (insert name of person whose health is being assessed e.g. Mr. Smith's or John's) health state today.

Do not tick more than one box in each group

**Mobility**
- No problems in walking about [☐]
- Some problems in walking about [☐]
- Confined to bed [☐]

**Self-Care**
- No problems with self-care [☐]
- Some problems washing or dressing myself [☐]
- Unable to wash or dress myself [☐]

**Usual Activities** (e.g. work, study, housework, family or leisure activities)
- No problems with performing usual activities [☐]
- Some problems with performing usual activities [☐]
- Unable to perform usual activities [☐]

**Pain/Discomfort**
- No pain or discomfort [☐]
- Moderate pain or discomfort [☐]
- Extreme pain or discomfort [☐]

**Anxiety/Depression**
- Not anxious or depressed [☐]
- Moderately anxious or depressed [☐]
- Extremely anxious or depressed [☐]
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad the subject’s health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad you think the subject’s health is today.

\[\text{Best imaginable health state} \quad 100 \quad \text{Worst imaginable health state}\]

(N.B: “The subject’s health” may be replaced by e.g. “Mrs. Smith’s health”)
APPENDIX 6

SCRIPT FOR PROXY VERSION OF THE EQ-5D: VERSION 2

(asking the proxy to rate how he or she, (i.e. the proxy), thinks the subject would rate his or her own health if he or she could communicate it).

Proxy version of the EQ-5D: 2

By placing a tick in one box in each group below, please indicate which statement (insert name of person whose health is being assessed e.g. Mr. Smith or John) would choose to describe his or her health state today if he or she were able to tell us.

Do not tick more than one box in each group

**Mobility**
- No problems in walking about
- Some problems in walking about
- Confined to bed

**Self-Care**
- No problems with self-care
- Some problems washing or dressing myself
- Unable to wash or dress myself

**Usual Activities** (e.g. work, study, housework, family or leisure activities)
- No problems with performing usual activities
- Some problems with performing usual activities
- Unable to perform usual activities

**Pain/Discomfort**
- No pain or discomfort
- Moderate pain or discomfort
- Extreme pain or discomfort

**Anxiety/Depression**
- Not anxious or depressed
- Moderately anxious or depressed
- Extremely anxious or depressed
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad the subject would say his or her health is today, if he or she was able to tell us. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad you think the subject would say his or her health is today.

(N.B: "The subject's health" may be replaced by e.g. "Mrs. Smith's health")
APPENDIX 7

DEFINITION OF EQ-5D CONCEPTS
EQ-5D DESCRIPTIVE SYSTEM, EQ-VAS AND EQ-5D VAS

Health

A general term relating to physical, emotional and social functioning; is wider than a strict medical interpretation (e.g. absence of illness), as it also includes emotional and social well-being. Includes both negative aspects of health (illness) as well as positive aspects (well-being).

Your own health state

Emphasis on the respondent's own judgement of his/her health state; relates to the individual and depends on the respondent's own situation.

Today

The day of completing the questionnaire (this particular calendar day).

Mobility

This refers to the physical ability to walk or move about, both inside and outside. It does not refer to the use of bicycle, car or public transport.

1. Walking about: The ability to walk or move about independently from one place to another, both inside and outside. It does not refer to walking about an object such as a building. In some languages, where the concept of walking ‘about’ does not exist, the translation of simply ‘walking’ has been accepted. ‘Walking about’ does not refer to running, strenuous activities, country walks or sport.

2. Confined to bed: Restricted to staying in bed (except to use the toilet). It includes being confined to a chair (but not wheelchair) all day (e.g. where someone is moved from bed to a chair and returned to bed at the end of the day). This can be a long-term condition or short term (e.g. in bed because of influenza). What is important is that the subject is confined to bed on the day the EQ-5D questionnaire is administered.
Thus, the 3 levels of mobility could be interpreted as:

Level 1: Can walk (about) without help or aids.
Level 2: Needs to use stick, crutches, walking frame, when walking. Would include people in a wheelchair (although they may not classify themselves in level 2).
Level 3: Confined to bed or chair all of the day (except to use the toilet). Excludes people in a wheelchair.

**Self-Care**

The term self-care refers to independence in daily personal care. It specifically covers washing and dressing, but also includes feeding oneself, personal hygiene, brushing teeth, grooming and going to the toilet. It does not include social or role activities, or the ability to manage personal finances or household affairs.

**Washing self**

Ability to take a bath or shower without help from someone else; washing whole body and not just face and hands.

**Usual activities**

This refers to activities such as work (paid and unpaid), study, housework, leisure and social activities. ‘Usual’ means activities carried out on a regular basis, but not necessarily on a daily basis. The activities should be ‘usual for you’, i.e. the respondent personally. The ability to perform usual activities refers to the ability to be able to participate in these activities today, rather than to accomplish or complete them.

**Pain/Discomfort**

1. *Pain:* Physical or bodily hurt. Does not refer to psychological or mental suffering.

2. *Discomfort:* Uncomfortable physical sensation, of a lower grade of intensity than pain. Includes ache(s), breathlessness, itching, palpitations, nausea, tiredness, dizziness, bloatedness, pins and needles, ringing in the ears. Does not include psychological or mental disturbance.
Appendices

Anxiety/Depression

1. Anxiety: Psychological sensation relating to ‘worry’; covers general feelings of feeling tense, troubled, nervous, apprehensive, fearful. An example of extreme anxiety may be panic or dread.

2. Depression: Psychological sensation relating to lowness of spirit. Does not refer only to clinical depression; covers feeling cheerless, gloomy, dejected, down, sad, miserable, unhappy. No inherent time element i.e. not defined by length of time for which it has been experienced.

Some/moderate problems

Ranges from a small number or a small degree of difficulty to many problems or difficulties. Should indicate a middle level between no problems and extreme problems. More severe than mild.

Extreme

Indicating a very severe or very bad level - the highest (outermost) level.

Best imaginable health state

The most optimal, desirable, ideal health state a person can imagine.

Worst imaginable health state

The most bad, undesirable health state a person can imagine. Unable to function independently in all areas of life.

A person like you

The respondent personally in terms of his/her characteristics (may include socio-demographic factors).

Personal view

The respondent’s own subjective opinion or perception.
When thinking about each health state imagine that it will last for one year. What happens after that is not known and should not be taken into account.

The respondent should think about the particular health state for a period of a year. He/she should not think about what happens after the year (i.e. getting better, worse, same, die) because this is uncertain. It is important that when judging the health state, the respondent should not take prognosis into account.

Unconscious

Being alive but not awake or aware of surroundings.

The state dead

Deprived of life. All functions have ceased and are incapable of being restored or revived. Does not include the process of dying.
APPENDIX 8

TRANSLATION GUIDELINES FOR THE EQ-5D DEVELOPED BY THE EUROQOL GROUP

Before beginning the process of translating the EQ-5D, the Project Manager in the country where the EQ-5D is being translated should contact the Business Manager of the EuroQol Group, Dr. Frank de Charro, who will ensure that he/she receives all of the relevant materials and information. These include a copy of the official English version of the EQ-5D, definitions of key words and phrases contained in the EQ-5D, as well as these guidelines which should be read carefully. The EuroQol Business Manager is also responsible for organising the communication procedure between the Project Manager and EuroQol Group members during the process. This involves an on-going communication with members of a translation review team within the EuroQol Group who will be continually involved in the process. Time should be allowed at each stage for the EuroQol review team to provide feedback and comments on the reports they receive.

If these guidelines are not followed, the EuroQol Group will not be able to approve translations.

The process of translation should consist of the following steps:

Forward Translation

*Two forward translations into the target language by qualified and/or experienced translators who should be native speakers of the target language, and fluent in English.

*The production of a first consensus version from the two forward translations in a meeting with the Project Manager.

*The production of a report on the forward translation process.

*Submission of full report on the process to the EuroQol Business Management before proceeding to the next stage.
Appendices

Back translation

*Two back translations of the consensus version into English.

*Comparison of the back translations with the original version.

*Production of a report on the back translation process.

*Production of a second consensus version, incorporating changes decided upon after comparison between the back translations and the original version.

*Submission of a full report on the process to the EuroQol Business Management before proceeding to the next stage.

Respondent testing

*Testing of the second consensus version on a sample of lay respondents, native speakers of the target language. The lay respondents should include healthy individuals as well as patients.

*Production of third consensus version based on comments from lay subjects.

*Production of final version incorporating comments from the EuroQol translation review team.

It is important to realise that these instructions are designed to ensure that the version of the EQ-5D for use in your country will be as semantically equivalent as possible to other language versions used around the world (in other words that the meaning of individual words and phrases is similar to that used in other language versions). These guidelines cannot ensure that the questionnaire per se will be appropriate in terms of its content and purpose. That is matter for your judgement, and should be determined before undertaking the translation exercise.

In order to help you achieve an operationally equivalent version of the questionnaire, you will be provided with an electronic format of the EQ-5D which you should use to ensure an identical layout and style.

References are available on request from the EuroQol Business Management which should be helpful in understanding the aims and problems of the translation process.
Forward translations into the target language

The first stage in the translation process is to produce 2 *forward* translations, i.e. translations from English into the ‘target’ language. These 2 forward translations (from the official EQ-5D English version), should be carried out independently by 2 qualified and/or experienced translators who are native speakers of the target language, and fluent in English. At least one of the translators should be someone unconnected with the health field. Details of translators' qualifications and/or experience should be provided in the report.

The forward translators should be briefed on the nature of the task by the Project Manager. The aim is to produce clear and natural-sounding translations which are acceptable to respondents in the target language, but which transmit the meaning of the original. Care should be taken to ensure the use of simple, non-technical language. Translators should note alternative wordings and difficulties encountered.

Production of first consensus version

Once the 2 forward translations are completed, the 2 forward translators should meet with the Project Manager to produce the *first consensus version* of the EQ-5D in the target language.

The questionnaire should be reviewed sentence by sentence to produce a single version in the target language on which all participants agree. The criteria of simplicity, clarity, and natural language should guide decision-making, particularly as the EQ-5D is used by a wide variety of respondents, some of whom may have only a low level of education. Alternatives and difficulties noted by the translators should be taken into account.

Report on the forward translation process

Details of the forward translation meeting should be included in a report produced for the EuroQol translation review team. The report should include:

i) Copies of the 2 forward translations (clearly indicated).

ii) Copies of the final consensus version (clearly indicated).

iii) Qualifications and/or experience of translators.

iv) Problematic words, phrases or items encountered.

v) Points of disagreement.

vi) Alternatives considered.

vii) Solutions/consensus items.
Appendices

It should be remembered that those reviewing the process will normally not understand the target language, and that the quality of translated versions will be judged largely on the reports produced.

The report should be sent to the EuroQol Business Management who will distribute copies to members of the EuroQol translation review team, who will then comment on the process and ask for clarification where necessary. Their comments and queries should be answered by the Project Manager before moving onto the next stage.

*Back translations of the consensus version into English*

Once the first consensus version has been agreed upon, 2 back translations of that version should be produced by 2 qualified and/or experienced translators whose native language is English, but who are bilingual in the target language. The 2 back translators should work independently.

One back translator should be asked to produce a relatively literal translation, the other a more polished version. Translators should note any difficulties encountered, as well as formulations which sound unnatural in the target language.

*Back translation meeting*

Once the back translations are completed, the Project Manager should meet with the back translators to discuss the process. The aim of this meeting is to produce a report on the back translation process.

At the meeting the Project Manager and the back translator should:

i) Discuss problems the translators had in translating the questionnaire.

ii) Compare the back translations with the original English version of the questionnaire, noting any discrepancies. The translators should also be asked to comment on their perceptions of the first consensus version of the questionnaire in the target language.

*Report on the back translation process*

The report should therefore mention:

i) Differences between the original version and the back translations, or between the 2 back translations.

ii) The quality and adequacy of the first consensus version.
The Project Manager should produce a report of the meeting which will include:

i) Copies of the 2 back translations (clearly indicated).
ii) Copies of the final consensus version (clearly indicated).
iii) Qualifications and/or experience of translators.
iv) Differences with original English version.
v) Differences between back translations.
vi) Comments on first consensus version.

The report should be sent to the EuroQol Business Management who will distribute copies to members of the EuroQol translation review team. They will comment on the process and ask for clarification where necessary. Their comments and queries should be answered by the Project Manager before moving onto the next stage. Suggestions made by the Project Manager and the EuroQol translation review team may lead to changes to the first consensus version. The version produced after back translation is the second consensus version.

Respondent testing

There are separate guidelines for respondent testing (Appendix 9).

The report on respondent testing should be sent to the EuroQol Business Management. They will distribute the report to members of the EuroQol translation review team, who will comment on the process and ask for clarification where necessary. They will liaise with the Project Manager, and final changes will be agreed upon, taking into account comments and queries made at earlier stages in the process. The version produced at this stage will be the final version, and should be proof-read by at least 2 native speakers of the target language.

Translated versions of the EQ-5D are given the official seal of approval by the EuroQol Translation Committee based on the recommendations of members of the EuroQol translation review team who carried out the work. Recommendation for official approval is based on the quality of the process followed, particularly the quality and detail of the reports provided to the EuroQol Translation Committee (Examples of previous reports are available on request from the EuroQol Business Management). Please follow guidelines and recommendations as closely as possible, and make reports as detailed as possible.
If you wish to carry out a translation of the EQ-5D, please contact the EuroQol Business Manager. His details are:

Dr. Frank de Charro
EuroQol Business Manager
PO Box 4443
3006 AK Rotterdam
The Netherlands
Tel: +31 10 4081545
Fax: +31 10 4525303
E-mail: fdecharro@compuserve.com
APPENDIX 9

RESPONDENT TESTING OF EQ-5D

The second consensus version of the EQ-5D should be tested on 8 respondents, who are native speakers of the target language. The questionnaire should be self-administered in the presence of the Project Manager or other members of the research team. The aim of respondent testing is to evaluate the clarity, understandability, naturalness and adequacy of wording. Respondents should represent a range of socio-demographic and health characteristics, and should include healthy individuals as well as patients, with a bias towards those in lower educational categories. Respondents should not have seen the questionnaire before, and should not be connected with the health professions.

The aim of this testing is to identify any items which respondents: have difficulty understanding; think are inappropriate for any reason. Where respondents have difficulties understanding, it is important to determine what the problems are and how he/she would word the question.

The interview should be conducted as follows:

(i) First ask the respondent to complete the EQ-5D. Explain that it is a brief questionnaire on health that has been translated from English, and that you want to check that it is clear and well-written in his/her language.

Ask the respondent to answer the questions as carefully as possible, but remind him/her that there are no right or wrong answers, and that you are primarily interested in the respondent’s opinions regarding the quality of the questionnaire. Explain that when the respondent has completed the questionnaire you will ask some further questions regarding the respondent’s impression of the questionnaire.

(ii) Once the respondent has completed the questionnaire, record his/her age and the time it took to complete the questionnaire.

Record the respondent’s general impression about the EQ-5D as follows:

- Is it clear, easy to understand, easy to answer?
- Is it too long?
- Are the instructions clear?
Once you have recorded the respondent’s general impression you should go through the whole questionnaire item by item (including response options and instructions) and check whether:

- The question/instruction was difficult to understand or answer. If so, why?
- Wording was ambiguous.
- The language used was easy to understand and colloquial.
- The respondent would ask the question or formulate the instruction in another way.

It is helpful to standardise questioning as follows: For each instruction in the EQ-5D, you should ask respondents:

- Are there words that you find difficult to understand?
- Would you change anything in the instructions?
- Would you add anything to the instructions?

To get a better understanding of respondents’ interpretation of key words and concepts in the instructions, the following questions can be used.

- What does [INSERT WORD] mean for you?
- What were you thinking about when you read the instructions?

In the instructions, key words tested should include ‘health status’ and ‘today’

For each question, you should ask the respondents:

- Do you understand the question?
- What does it mean for you?
- What were you thinking about when you answered the question? Were you thinking about any particular aspect of your health or your current situation?
- Would you make any changes to the question? If so, what?

To get a better understanding of respondents’ interpretation of key words and concepts in the questions, the following questions can be used:

- What does [INSERT WORD] mean for you?
- What were you thinking about when you answered this question? Were you thinking about any particular aspect of your health or your current situation when you answered this question
- What does the word [INSERT WORD] make you think of?
Key words tested should include 'mobility', 'walking about', 'confined to bed', 'self-care' 'wash', 'discomfort' 'moderate' 'extreme' 'anxious' 'depressed'.

(iv) The aim of respondent testing is to make any final adjustments to the translated version of the EQ-5D so that it is clear and acceptable to respondents.

Once the 8 respondents have been interviewed, their comments should be summarised in a report in English and returned to the Business Management of the EuroQol Group. The report should be approximately 2-3 pages long and should give a brief summary of the comments of the respondents in relation to each question and instruction text in the EQ-5D. The report should be accompanied by a summary of the demographic characteristics of the respondents (see summary form).

Wherever possible, it would be helpful for future analysis of respondents' impressions of the EQ-5D, to record the respondent testing interviews on cassette or video recorder. Copies of the tapes should be provided to the EuroQol Business Management, and respondents' permission to record the interview should be sought.
Below is an example of a patient testing report. This form is available from the EuroQol Business Management on request.

**Cognitive Debriefing**

**Data summary**

**Questionnaire:** EQ-5D developed by the EuroQol Group

**Country:**

**Language:**

Specify age, sex, profession and time taken to complete the EQ-5D of each respondent

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Sex</th>
<th>Profession</th>
<th>Time needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>R 1</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 2</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 3</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 4</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 5</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 6</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 7</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R 8</td>
<td></td>
<td>☐ male ☐ female</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mean age .........

Mean time .........

Median age .........

Median time .........
APPENDIX 10

GUIDELINES FOR EQ-5D LANGUAGE ADAPTATIONS

These guidelines apply to situations where it may be unnecessary to perform a complete translation process, due to the similarities between the language spoken in a given country and an existing EQ-5D language version. This applies for example to South America where the Spanish spoken in Spain is similar to that spoken in countries like Venezuela and Peru or where the French spoken in Quebec, Canada is similar to the French spoken in France.

Before beginning the process of adapting EQ-5D, the Project Manager in the country where the EQ-5D is being adapted should contact the Business Manager of the EuroQol Group, who will ensure that he/she receives all of the relevant materials and information. Together with these guidelines, these include:

i) A copy of the official English version of the EQ-5D.
ii) A copy of the ‘mother’ language version to be adapted. This should also be used as a ‘template’ for changes (if any) so that the standard format of the questionnaire can be maintained.
iii) Definitions of key words and phrases contained in the EQ-5D.
iv) An example of a report on a previous EQ-5D language adaptation.

The EuroQol Business Manager is also responsible for organising the communication procedure between the Project Manager and EuroQol Group members during the process. This involves an on-going communication with a translation review team member within the EuroQol Group who will be continually involved in the process. Time should be allowed at each stage for the EuroQol Group reviewer to provide feedback and comments on the reports he/she receives.

If these guidelines are not followed, the EuroQol Group will not be able to approve language adaptation.

References are available on request from the EuroQol Business Management which should be helpful in understanding the aims and problems of the translation process.

The process of adapting EQ-5D language versions should consist of the following steps:
Appendices

Review by a translation consultant

The translation consultant should be a qualified and/or experienced translator who is a native speaker of the target language, and fluent in English.

He/she should be briefed on the nature of the task by the Project Manager. The aim is to produce a clear and natural-sounding version that is acceptable to respondents in the target language. This is especially important as EQ-5D is used by a wide variety of respondents some of whom may have only a low level of education. Alternatives and difficulties noted by the translators should be taken into account.

First consensus version

When the consultant has reviewed the existing “mother” version he/she should meet with the Project Manager to produce a first consensus version of EQ-5D in the target language.

Report on the review of the mother version by the consultant.

A full report on the review process of the mother version outlining the suggested changes should be submitted to the EuroQol Business Management.

The report should include.

(i) Copy of the first consensus version (using the standard layout of EQ-5D).
(ii) Names, qualifications and/or experience of consultant.
(iii) Problematic words, phrases or items encountered.
(iv) Alternatives considered.
(v) Solutions offered.

It should be remembered that those reviewing the process from the EuroQol Group will normally not understand the target language, and that the quality of translated versions will be judged largely on the reports produced.

The report should be sent to the EuroQol Business Management who will distribute copies to a member of the EuroQol translation review team. He/she will comment on the process and ask for clarification where necessary. Comments and queries from the EuroQol reviewer should be answered by the Project Manager before moving onto the next stage. Suggestions made by the Project Manager and the EuroQol translation reviewer may lead to changes to the first consensus version.
Respondent testing

Guidelines for respondent testing for language adaptations are the same as for full translations except that the number of participants is less (5).

The report on respondent testing should be sent to the EuroQol Group Business Management. They will distribute the report to a member of the EuroQol translation review team, who will comment on the process and ask for clarification where necessary. He/she will liaise with the Project Manager, and final changes will be agreed upon, taking into account comments and queries made at earlier stages in the process. The version produced at this stage will be the final version, and should be proof-read by at least two native speakers of the target language.

All translations and adaptations of EQ-5D are given the official seal of approval by the EuroQol Translation Committee based on the recommendations of members of the EuroQol translation review team who carried out the work. Recommendation for official approval is based on the quality of the process followed, particularly the quality and detail of the reports provided to the EuroQol Translation Committee. Please follow guidelines and recommendations as closely as possible, and make reports as detailed as possible.

If you wish to carry out a translation or adaptation of EQ-5D, please contact the EuroQol Business Manager. His details are:

Dr. Frank de Charro  
EuroQol Business Manager  
PO Box 4443  
3006 AK Rotterdam  
The Netherlands  
Tel: +31 10 4081545  
Fax:+31 10 4525303  
E-mail:fdecharro@compuserve.com
Index

Africa 167, 186
Age 4, 32, 44, 48, 58, 59, 61, 62, 66, 68, 70, 75, 77, 78, 83, 85, 86, 87, 89, 90, 92, 94, 100, 130, 144, 149, 210, 231
Aggregation 33, 34
Application 1, 4, 7, 8, 11, 29, 33, 34, 39, 95, 106, 172, 229
Asia 167
Australasia 167
Back translation 183, 184, 185, 191, 192, 193, 195, 201, 203
Background variables 24, 55, 56, 57, 63, 66, 75, 77, 78, 79, 81, 82, 84, 85, 91, 99, 103, 113, 117, 129, 130, 144, 148, 231, 232, 233, 235
Best imaginable health state 3, 10, 30, 176, 177, 188
Biomed II 4, 229
Canada 40, 167, 186, 208
CANALS 117, 118, 119, 120, 121, 122, 123, 233
Cardinal index 1
Catalonia 58, 62, 71, 78, 82, 83, 85, 112
Clinical decision-making 38
Clinical studies 7, 8, 9, 12, 13, 14, 32, 38, 39, 195
Cognitive debriefing 172
Communication 4, 5, 229
Computer-assisted methods 4, 23
Cornella de Llobregat 58, 62, 83, 112, 146
Cost-benefit analysis 8
Cost-effectiveness analysis 8
Cost-utility analysis 8, 35, 41, 211
Cross-cultural measurement 183
Dementia 9, 24, 25, 173, 174, 176
Denmark 40, 177, 179, 197
Descriptive system 3, 7, 10, 11, 12, 14, 15, 21, 22, 24, 29, 30, 43, 44, 55, 59, 63, 67, 81, 93, 103, 107, 108, 112, 114, 125, 131, 145, 148, 167, 173, 176, 192, 193, 195, 210, 230, 231, 235
Disease-specific 1, 2, 8, 143
Economic evaluation 2, 8, 10, 34, 130, 131, 231, 234
Education 4, 13, 14, 56, 66, 67, 69, 70, 75, 76, 77, 78, 83, 85, 87, 91, 93, 100, 113, 129, 149, 179, 197, 199, 210, 212, 231, 232, 235
England 59, 146
Epilepsy 173, 174, 175, 176
EQ SDQ 4, 197
EQ-5D index 10, 11, 14, 31, 230
EQ-net 4, 5, 37, 39, 55, 63, 64, 66, 78, 191, 192, 198, 202, 204, 205, 207, 229, 230, 231
EQ-net TTO 57, 62, 63, 71, 74, 77, 79
EQ-net VAS 38, 39, 41, 55, 57, 58, 59, 63, 68, 71, 72, 75, 78, 79, 103, 199
Equivalence 5, 172, 180, 183, 188, 191, 205
Europe 167, 177, 192, 207
European Union 4
European VAS-based health state valuations 99
EuroQol Business Management 23, 299
Exclusion criteria 57, 83, 99, 100, 104, 147, 231, 235
Exclusions 55, 57, 71, 72, 73, 74, 75, 77, 78
Experience of illness 66, 212, 231
Experimental 7, 9, 11, 13, 14, 22, 25
Face-to-face 2, 22, 61, 145, 229, 277
Finland 40, 56, 59, 64, 65, 68, 69, 71, 72, 73, 82, 85, 87, 94, 95, 96, 112, 113, 115, 129, 132, 133, 184, 197, 199, 218
Forward translation 183, 184, 185, 191
Framing effects 23
Freme IV 59
Generic 1, 2, 7, 10, 29, 31, 54, 167, 180, 191, 230
Generic instrument 8, 167, 188, 208, 229
Germany 40, 56, 60
Guidelines 4, 5, 7, 143, 183, 185, 186, 187, 189, 191, 192, 205, 229
Health profile 3
Health states 1, 2, 3, 5, 8, 10, 11, 13, 27, 29, 30, 31, 33, 34, 35, 37, 39, 41, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 78, 81, 82, 83, 85,
<table>
<thead>
<tr>
<th>Index</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health status index</td>
<td>10, 11</td>
</tr>
<tr>
<td>Health status measurement</td>
<td>2, 38</td>
</tr>
<tr>
<td>Health-related quality of life (HRQoL)</td>
<td>1, 2, 5, 7, 8, 9, 10, 12, 13, 25, 26, 29, 30, 31, 32, 34, 81, 101, 103, 143, 167, 168, 176, 180, 183, 184, 188, 189, 191, 192, 203, 208, 209, 229, 230, 233</td>
</tr>
<tr>
<td>Inconsistencies</td>
<td>55, 57, 58, 62, 71, 72, 73, 74, 78, 83, 85, 100, 104, 109, 110, 111, 112, 113, 130, 147, 170, 172, 181, 211, 212, 231, 233</td>
</tr>
<tr>
<td>Interpretation</td>
<td>13, 25, 26, 27, 31, 53, 148, 149, 167, 168, 172, 177, 178, 179, 180, 181, 186, 205, 271, 275, 277</td>
</tr>
<tr>
<td>Intra-class correlation coefficient (ICC)</td>
<td>43</td>
</tr>
<tr>
<td>Japan</td>
<td>40, 186, 207, 208, 209, 210</td>
</tr>
<tr>
<td>l'Hospitalet del Llobregat</td>
<td>58, 64, 65, 71, 82, 83, 112</td>
</tr>
<tr>
<td>Language versions</td>
<td>5, 167, 180, 183, 184, 185, 186, 187, 189, 191, 192, 193, 201, 203, 205</td>
</tr>
<tr>
<td>Latin America</td>
<td>167</td>
</tr>
<tr>
<td>Maori</td>
<td>207, 212, 213</td>
</tr>
<tr>
<td>Meaning</td>
<td>1, 47, 168, 170, 171, 172, 175, 179, 180, 188, 189, 194, 195, 196, 203, 204</td>
</tr>
<tr>
<td>Medical effectiveness</td>
<td>4</td>
</tr>
<tr>
<td>Missing data</td>
<td>11, 12, 13</td>
</tr>
<tr>
<td>Mode of administration</td>
<td>2, 21, 22, 23, 27, 31</td>
</tr>
<tr>
<td>Modelling</td>
<td>1, 14, 33, 34, 57, 106, 147, 175, 233, 234</td>
</tr>
<tr>
<td>Multi-level model</td>
<td>107, 148</td>
</tr>
<tr>
<td>N2 variable</td>
<td>125</td>
</tr>
<tr>
<td>N3 variable</td>
<td>107, 109, 122, 125</td>
</tr>
<tr>
<td>Navarra</td>
<td>40, 61, 64, 65, 68, 69, 71, 72, 73, 82, 83, 85, 87, 93, 94, 95, 96, 97, 98, 99, 100, 113, 115, 132, 133, 198, 200</td>
</tr>
<tr>
<td>Netherlands</td>
<td>40, 56, 61, 62, 65, 71, 81, 82, 85, 112, 113, 129, 177, 179, 184, 186, 197, 199, 204</td>
</tr>
<tr>
<td>New Zealand</td>
<td>40, 186, 207, 211, 212, 213</td>
</tr>
<tr>
<td>Non-linear regression analysis</td>
<td>117, 129, 233</td>
</tr>
<tr>
<td>Norway</td>
<td>184, 204</td>
</tr>
<tr>
<td>Nottingham Health Profile (NHP)</td>
<td>2</td>
</tr>
<tr>
<td>Observational</td>
<td>8, 9, 11, 14</td>
</tr>
<tr>
<td>Observer</td>
<td>2, 4, 29</td>
</tr>
<tr>
<td>OLS regression</td>
<td>12, 107, 113, 114, 116, 117, 118, 119, 129, 233</td>
</tr>
<tr>
<td>Outcomes</td>
<td>3, 7, 8, 12, 13, 14, 32, 34, 39, 95, 99, 113, 114, 118, 122, 130, 183, 191, 229, 233, 234</td>
</tr>
<tr>
<td>Pacific Islands</td>
<td>207, 212</td>
</tr>
<tr>
<td>Paired comparisons</td>
<td>33</td>
</tr>
<tr>
<td>Pakeha</td>
<td>212</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>22, 26, 173, 175, 210</td>
</tr>
<tr>
<td>Patient</td>
<td>4, 5, 7, 9, 11, 13, 14, 22, 24, 25, 26, 27, 29, 32, 35, 37, 38, 40, 44, 54, 58, 167, 173, 174, 175, 176, 183, 210, 212, 214, 230</td>
</tr>
<tr>
<td>Person Trade-Off (PTO)</td>
<td>33, 180</td>
</tr>
<tr>
<td>Perspective</td>
<td>11, 35, 37, 164</td>
</tr>
<tr>
<td>Population health</td>
<td>2, 4, 7, 8, 9, 10, 14</td>
</tr>
<tr>
<td>Population studies</td>
<td>3</td>
</tr>
<tr>
<td>Preference weights</td>
<td>11</td>
</tr>
<tr>
<td>Proxies</td>
<td>2, 22, 24, 25, 27</td>
</tr>
<tr>
<td>Proxy report</td>
<td>23, 24, 229</td>
</tr>
<tr>
<td>Quality-adjusted life-year (QALY)</td>
<td>1, 10, 11, 35, 214, 231</td>
</tr>
<tr>
<td>Quasi-experimental</td>
<td>9, 10, 11</td>
</tr>
<tr>
<td>Ranking</td>
<td>33, 59, 61, 64, 83, 85, 130, 131, 145, 204, 209, 214, 234, 235</td>
</tr>
<tr>
<td>RCTs</td>
<td>7, 8, 9, 11</td>
</tr>
<tr>
<td>Reliability</td>
<td>1, 4, 43, 44, 45, 46, 48, 50, 51, 53, 54, 189, 230</td>
</tr>
<tr>
<td>Reproducibility</td>
<td>43, 53, 230</td>
</tr>
<tr>
<td>Rescaling</td>
<td>106, 114, 127, 130, 131, 233, 234</td>
</tr>
</tbody>
</table>
Resource allocation 4, 32
Respondent characteristics 55, 56, 57, 63, 66, 67, 68, 70, 75, 77, 78, 82, 83, 84, 85, 86, 87, 99, 100, 113, 205, 231, 232
Rheumatoid arthritis 9, 44, 48, 49, 50, 51, 52, 54, 176, 230

Sample features 55, 63, 64, 65, 78, 231
Scotland 44, 59, 146, 230
Self-completion 2, 22, 23, 29, 31, 172, 229, 275
Self-report 2, 3, 4, 21, 22, 23, 24, 26, 52, 53, 54, 209, 212
Self-reported problems 3, 41
Semantic 5, 168, 172, 179, 180, 185, 188, 189, 191, 204, 205
Sex 4, 32, 58, 61, 62, 68, 75, 84, 86, 87, 146, 148, 149, 210, 231
SF-36 2, 210
Sickness Impact Profile (SIP) 2
Singular value decomposition (SVD) 84
Spain 40, 56, 100, 101, 143, 144, 148, 184, 186, 195, 200, 202, 204, 232, 235
Standard Gamble (SG) 33
Statistical models 12, 14
Stroke 24, 209
Study designs 8, 14, 58
Sweden 40, 56, 62, 64, 65, 68, 69, 71, 72, 73, 81, 82, 84, 85, 87, 95, 96, 99, 112, 113, 115, 132, 133, 184, 204
Telephone 2, 4, 21, 22, 23, 32, 60, 61, 62, 147, 229, 271, 274, 277
Test-retest 4, 43, 44, 45, 49, 53, 54, 229, 230
Time trade-off (TTO) 33, 143, 204
Transformation 30, 33, 34, 104, 105, 114, 117, 118, 120, 122, 123, 129, 233
Translation 4, 5, 100, 112, 167, 168, 170, 172, 173, 177, 179, 180, 183, 184, 185, 186, 187, 188, 189, 191, 192, 193, 194, 195, 196, 197, 198, 201, 202, 203, 204, 205
Treatments 2
TTO database 55, 57, 62, 63, 65, 66, 67, 70, 71, 74, 77, 78, 79, 231, 235

UK MVH 37, 44, 45, 46, 47, 48, 49, 50, 51, 53, 58, 59, 62, 63, 65, 68, 69, 70, 71, 72, 73,
74, 82, 85, 87, 95, 96, 97, 99, 100, 108, 112, 115, 132, 133, 144, 145, 146, 147, 199, 201, 202, 208, 210, 213, 230, 236
UK TTO A1 37, 38, 41
UK VAS A3 39, 41
Unconscious 3, 29, 55, 56, 58, 59, 60, 61, 62, 63, 105, 112, 129, 146, 147, 169, 170, 199, 202, 231
United Kingdom 56, 59, 143, 172
United States 40, 101, 167, 186, 204, 208, 232
Utility weights 35, 37, 41, 81
Valuation 1, 2, 3, 39, 40, 78, 112, 176, 230
Value sets 3, 29, 31, 35, 39, 40, 41, 143, 144, 212, 213, 214, 229, 230
VAS database 55, 57, 58, 59, 63, 64, 65, 66, 67, 68, 71, 72, 75, 78, 79, 103, 199
Wales 59, 146
Weighted health state index 3
working 231
Working status 56, 66, 75, 76, 78, 231
World Health Organisation 183
Worst imaginable health state 3, 10, 169, 171, 172, 176

Zimbabwe 40, 186, 188, 207, 208