



# EQ-5D

## EQ-5D-5L User Guide

Basic information on how to use the EQ-5D-5L instrument

**EQ-5D-5L**

Under each heading, please tick the ONE box that best describes your health TODAY.

**MOBILITY**

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

**SELF-CARE**

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe 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 doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

**PAIN/DISCOMFORT**

How your health is TODAY.

The best health you can imagine 100

How your health is TODAY. 95

90

85

80

75

70

65

60

55

50

45

40

35

30

25

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## CHANGES INCLUDED in this update of the EQ-5D-5L User Guide

Updates have been made to nearly all sections of the User Guide, including: a significantly revised section on how to present results; inclusion of a list of available standard value sets and ongoing EQ-5D-5L valuation studies; expanded descriptions of available modes of administration and translations; inclusion of information boxes (e.g. about publications comparing the EQ-5D-3L and EQ-5D-5L; example text for study protocols). Following the launch of the new EuroQol website – which contains regularly updated, detailed information about the EQ-5D – this update of the User Guide also refers the user to relevant webpages, using hyperlinks, for the latest information on a given topic.

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# 1. Introduction

This guide provides users with basic information on how to use the EQ-5D questionnaire. Topics include administering the instrument, deriving the summary index, value sets, setting up a database for data collected using EQ-5D, presentation of EQ-5D results, modes of administration and translations. The guide should be used in conjunction with the EuroQol website, which contains regularly updated, detailed information about the EQ-5D (see below). Where appropriate, weblinks to relevant resources on the EuroQol website are provided in this guide. For further information or assistance regarding the use of the EQ-5D, you can also contact the **EuroQol office** directly.

## 1.1/EUROQOL

EuroQol\* consists of a Research Foundation and a Group Association. The EuroQol Research Foundation is a not-for-profit organisation that supports, initiates and performs scientific research and development of instruments that describe and value health. The Foundation is responsible for the development of the EQ-5D, a preference-based measure of health status that is widely used around the world in clinical trials, population studies and real-world clinical settings. The EQ-5D is recommended by several health technology assessment bodies internationally as a key component of cost-utility analysis.

*The EuroQol Group Association consists of a large global network of experts, from a wide range of academic disciplines and countries, who are committed to ongoing research on the EQ-5D family of instruments.*

The scientific expertise behind EuroQol is the EuroQol Group Association, an international network of multidisciplinary researchers dedicated to the measurement of health status. When established in 1987, the EuroQol Group Association originally consisted of researchers from Europe. Today, it is a global network of more than 90 members from Africa, Asia, Europe, North America, Oceania and South America.

EuroQol can be justifiably proud of its collective scientific achievements over the last 30 years. Research areas include: the investigation and application of different valuation methodologies to obtain health state values for use in cost-effectiveness analysis, development of value sets for health states, EQ-5D use in clinical studies and in population surveys, experimentation with the EQ-5D descriptive

\* The organisational structure is provided on the [EuroQol website](#).

system, computerised applications, interpretation of EQ-5D responses, the role of EQ-5D in measuring social inequalities in self-reported health, and the measurement and valuation of health in younger populations. The EuroQol Group Association has been holding annual scientific meetings since its inception in 1987.

*EuroQol is a registered not-for-profit organisation that invests all income into EQ-5D research, education and user support.*

The EuroQol Research Foundation is a registered not-for-profit organisation in the Netherlands and the single organisation that manages the distribution and licensing of the EQ-5D family of instruments worldwide. The EuroQol Group invests all income into EQ-5D research, education and user support.

The [EuroQol website](#) provides detailed information and updates on the EQ-5D, guidance for users, a list of available language versions and value sets by country/region, key EQ-5D references, frequently asked questions regarding the use of EQ-5D, EQ-5D registration process and forms, information about the EuroQol Group organisation and contact details.

## 1.2/EQ-5D<sup>®</sup>

*EQ-5D is a standardised measure of health status developed by the EuroQol Group to provide a simple, generic measure of health for clinical and economic appraisal.<sup>1</sup>*

The EQ-5D family of instruments has been developed to describe and value health across a wide range of disease areas. They are also frequently used in research into health in the general population. There are three versions of the instrument: **EQ-5D-5L**, **EQ-5D-3L** and **EQ-5D-Y**. For over 25 years, they have been widely used in clinical trials, population studies and in real-world clinical settings. The EQ-5D is used worldwide and has been translated into most major languages through a closely monitored translation process.

Each EQ-5D instrument comprises a short **descriptive system** questionnaire and a **visual analogue scale (EQ VAS)** that are cognitively undemanding, taking only a few minutes to complete. The questionnaire provides a simple descriptive profile of a respondent's health state. The EQ VAS provides an alternative way to

elicit an individual's rating of their own overall current health. When the descriptive system profile is linked to a **'value set'**, a single summary index value for health status is derived that can be used in economic evaluations of health-care interventions. A value set provides values (weights) for each health state description according to the preferences of the general population of a country/region. Value sets for the EQ-5D-5L and 3L versions are available in a large and growing number of countries (see [Section 4](#)).

Designed for self-completion by respondents and available in both paper and digital versions, the EQ-5D is ideally suited for use in online or postal surveys, in clinics and in interviews (face-to-face or telephone). Proxy versions are also available for populations in which self-completion is not possible (see [Section 7.2](#)). Instructions to respondents are included in the questionnaire.

**Note:** The EQ-5D is not an abbreviation and is the correct term to use in print or verbally.

## 1.3/EQ-5D-3L

The EQ-5D three-level (3L) version was introduced in 1990. The standard paper-based, self-complete version consists of a title page, the descriptive system (on page 2), and the EQ VAS (on page 3).

- The EQ-5D-3L descriptive system comprises the following five dimensions, each describing a different aspect of health: **MOBILITY, SELF-CARE, USUAL ACTIVITIES, PAIN / DISCOMFORT** and **ANXIETY / DEPRESSION**. Each dimension has three response levels of severity: no problems, some problems, extreme problems. The respondent is asked to indicate his/her health state by checking the box next to the most appropriate response level of each of the five dimensions.

- The EQ VAS records the respondent's self-rated health on a vertical VAS where the endpoints are labelled 'The best health you can imagine' and 'The worst health you can imagine'. This information can be used as a quantitative measure of health outcome as judged by the individual respondents.

The EQ-5D-3L is one of the most widely used instruments worldwide for measuring health status and the self-complete language version has been translated into over 180 languages. The EQ-5D-3L has been proven to be valid, reliable and responsive in numerous conditions and populations.<sup>2</sup>

## 1.4/EQ-5D-5L

In 2005, a research programme was implemented to investigate methods to further improve the EQ-5D-3L's sensitivity.<sup>3</sup> After much deliberation, it was decided that there should be no change in the number of dimensions for a new version of EQ-5D. However, previously published studies by EuroQol Group members showed that experimental five-level (5L) versions of EQ-5D could significantly increase reliability and sensitivity (discriminatory power) while maintaining feasibility and potentially reducing ceiling effects.<sup>4-7</sup> The Group therefore decided that the new version of the EQ-5D should include five levels of severity in each of the existing five EQ-5D dimensions and that it would be called the EQ-5D-5L (Figure 1). In addition, the most severe label for the mobility dimension was changed from 'I am confined to bed' to 'I am unable to walk about', enhancing its applicability and increasing the sensitivity of the mobility dimension. The EQ VAS layout, method for marking a response and instructions were simplified in the EQ-5D-5L, compared with the

original VAS used in the EQ-5D-3L, making the task easier to complete and easier to score.\* The existing EQ-5D was renamed the EQ-5D-3L. The research underpinning the development and preliminary testing of the EQ-5D-5L is summarised on the [EuroQol website](#).<sup>8</sup>

As with the 3L version, the standard paper-based, self-complete version of the EQ-5D-5L still consists of three pages – the title page, the EQ-5D-5L descriptive system (on page 2) and the EQ VAS (page 3).

The EQ-5D-5L descriptive system comprises the same five dimensions as the EQ-5D-3L (MOBILITY, SELF-CARE, USUAL ACTIVITIES, PAIN / DISCOMFORT and ANXIETY / DEPRESSION), but each dimension now has five response levels: no problems, slight problems, moderate problems, severe problems, unable to/extreme problems. The respondent is asked to indicate his/her health state by checking the box next to the most appropriate response level for each

\* As of 2018, the EQ VAS in all versions of the EQ-5D-3L has been updated to match the VAS format used in the EQ-5D-5L.



of the five dimensions. Responses are coded as single-digit numbers expressing the severity level selected in each dimension. For instance, 'slight problems' (e.g. 'I have slight problems in walking about') is always coded as '2'. The digits for the five dimensions can be combined in a 5-digit code that describes the respondent's health state; for instance, 21111 means slight problems in the mobility dimension and no problems in any of the other dimensions

(see [Section 2](#) for further information on how to score the descriptive system).

The EQ VAS records the respondent's overall current health on a vertical visual analogue scale, where the endpoints are labelled 'The best health you can imagine' and 'The worst health you can imagine'. The EQ VAS provides a quantitative measure of the patient's perception of their overall health.

### SEVERITY LEVELS for dimensions in the descriptive system

The numbers representing the five severity levels of a dimension are labels used in the numerical description of a health state (see [Section 2.1](#)). They have no arithmetic properties. For instance, on the basis of just the numbers one cannot assume that a state 21111 is better 13111. Therefore, these numbers should not be used to derive a summary score. To derive the summary index score, an appropriate 'value set' is required (see [Section 4](#)).

### PUBLICATIONS COMPARING the EQ-5D-3L and EQ-5D-5L

The EuroQol website includes a continuously updated section on publications comparing the EQ-5D-3L and EQ-5D-5L. The section is subdivided into publications comparing the [descriptive systems](#), [value sets](#), [implications for cost effectiveness analysis](#), [commentaries](#), [editorials](#) and [institutional guidance documents](#). Please note that comparative performance across patient groups is driven by differences in the descriptive systems **and** the associated value sets. Since countries use different value sets, the differences between EQ-5D-3L and EQ-5D-5L can be country/region-specific.

A good starting point for an overview of the differences in measurement properties between EQ-5D-3L and EQ-5D-5L is:

- A systematic review of studies comparing the two instruments by [Buchholz and colleagues \(2018\)](#).<sup>9</sup> The review concluded by supporting the use of the EQ-5D-3L and EQ-5D-5L in a broad range of patients, populations and countries/regions, while noting that the EQ-5D-5L showed better or at least similar measurement properties to the EQ-5D-3L.
- A head-to-head comparison of descriptive systems and value sets across seven countries (Canada, China, England/UK, Japan, Netherlands, South Korea and Spain) by [Janssen and colleagues \(2018\)](#).<sup>10</sup> The study found that the EQ-5D-5L is superior to the EQ-5D-3L with respect to various measurement properties, enabling improvements in sensitivity and precision in health status measurement. It recommends the EQ-5D-5L for use across applications, including economic evaluation, clinical studies, quality of care and in public health studies.

## Figure 1/UK (English) EQ-5D-5L Paper Self-Complete (sample version)

Under each heading, please tick the ONE box that best describes your health TODAY.

### MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

### SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe 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 doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

### PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

### ANXIETY / DEPRESSION

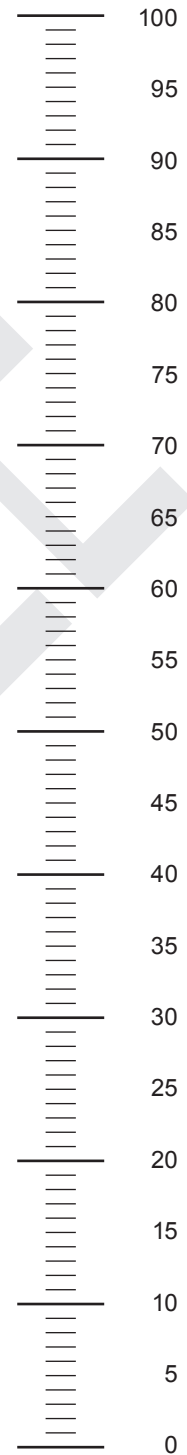
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed



- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.  
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health  
you can imagine



The worst health  
you can imagine

## 2. Scoring the EQ-5D-5L descriptive system

This example shows how a health state is described using the EQ-5D-5L descriptive system:

Under each heading, please tick the ONE box that best describes your health TODAY.

**MOBILITY**

I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

**SELF-CARE**

I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe 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 doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

**PAIN/DISCOMFORT**

I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

**ANXIETY/DEPRESSION**

I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

I am severely anxious or depressed

I am extremely anxious or depressed

Levels of perceived problems are coded as follows:

Level 1 is coded as a '1'

Level 2 is coded as a '2'

Level 3 is coded as a '3'

Level 4 is coded as a '4'

Level 5 is coded as a '5'

This example identifies the health state '12345'.

### Notes:

- There should be only ONE response for each dimension
- Missing values are preferably coded as '9'.
- Ambiguous values (e.g. two boxes are ticked for a single dimension) should be treated as missing values.
- This example is for the EQ-5D-5L Paper Self-Complete. Instructions for the interview and proxy versions are provided with those instruments.

## 2.1 / What is a health state?

Each of the five dimensions comprising the EQ-5D descriptive system is divided into five levels of perceived problems:

- LEVEL 1: indicating no problem
- LEVEL 2: indicating slight problems
- LEVEL 3: indicating moderate problems
- LEVEL 4: indicating severe problems
- LEVEL 5: indicating unable to/extreme problems

A total of 3125 possible health states is defined in this way. Each state is referred to by a 5-digit code. For example, working clockwise from the top of the diagram, state 12345 indicates no problems with mobility, slight problems with washing or dressing, moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression, while state 11111 indicates no problems on any of the five dimensions.

A unique health state is defined by combining one level from each of the five dimensions.



### 3. Scoring the EQ VAS

This example from the EQ-5D-5L Paper Self-Complete version shows how the EQ VAS is scored.

• We would like to know how good or bad your health is TODAY.

• This scale is numbered from 0 to 100.

• 100 means the best health you can imagine.  
0 means the worst health you can imagine.

• Mark an X on the scale to indicate how your health is TODAY.

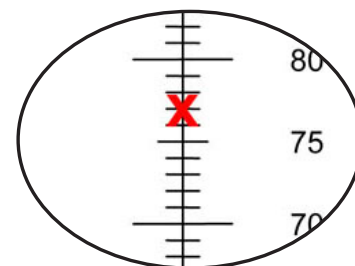
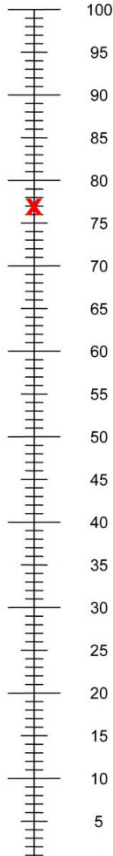
• Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health you can imagine

100  
95  
90  
85  
80  
75  
70  
65  
60  
55  
50  
45  
40  
35  
30  
25  
20  
15  
10  
5  
0

The worst health you can imagine



For example, the response above should be coded as 77

#### Notes:

- For this example, the response should be coded as 77
- Missing values should be coded as '999'.
- If there is a discrepancy between where the respondent has placed the X and the number he/she has written in the box, administrators should use the number in the box (this is only relevant for the Paper Self-Complete version).

## 4. Converting EQ-5D-5L states to an index value

### 4.1 / Deriving an EQ-5D index value

EQ-5D-5L health states can be summarised using the 5-digit code (see [Section 2.1](#)) or represented by a single summary number (**index value**)\*, which reflects how good or bad a health state is according to the preferences of the general population of a country/region. Index values are a major feature of the EQ-5D instrument, facilitating the calculation of quality-adjusted life years (QALYs) that are used to inform economic evaluations of healthcare interventions. The preferences of the general population of a country/region for different health states represent the societal perspective which, in general, is considered the preferred perspective in health economic analysis.<sup>11-13</sup>

An EQ-5D summary index is derived by applying a formula that attaches values (weights) to each of the levels in each dimension. The index is calculated by deducting the appropriate weights from 1, the value for full health (i.e. state 11111). The collection of index values (weights) for all possible EQ-5D health states is called a **value**

**set**. Most EQ-5D value sets have been obtained from a standardised valuation exercise, in which a representative sample of the general population in a country/region is asked to place a value on EQ-5D health states. The standardised valuation study protocol, **EQ-VT**, was developed by the EuroQol Group to create standard value sets for the EQ-5D-5L. This protocol is based on the use of the composite time trade-off (cTTO) valuation technique, supplemented by a discrete-choice experiment (DCE). Using value sets produced with the EuroQol Group's standardised valuation technology, EQ-VT ensures that results are derived using the most state-of-the-art valuation techniques while also facilitating international comparability.

**Note:** It is advisable to contact authorities about national value set requirements.

### 4.2 / Standard EQ-5D-5L value sets

At the time of publication (September 2019), EQ-5D-5L valuation research using EQ-VT has been undertaken in 34 countries around the world. The latest status of the EQ-5D-5L valuation studies can be viewed on the [EuroQol website](#) and a list of value sets published as of September 2019 is provided in Table 1. An updated list of available value sets can be found on the [EuroQol website](#). Note, to obtain a value set please contact the valuation study authors.

If a standard EQ-5D-5L value set is not available for your country, an option may be to select an EQ-5D-5L value set for a country/region that most closely approximates yours. Alternatively, if an EQ-5D-3L value set is available, you can choose to use a so-called 'crosswalk' value set — a value set created for the EQ-5D-3L and then adapted to fit the EQ-5D-5L descriptive system. More information about crosswalk value sets can be found on the [EuroQol website](#) and a brief overview of the crosswalk project is provided in the following sections.

\* Many different terms are in use for these index values, such as preference weights, preference-based values, utilities, QALY weights, etc. Here, we use the term 'index value'.

**Table 1 / List of available (published) standard EQ-5D-5L value sets and status of ongoing valuation studies by country (as of September 2019)**

Country/ Region	Valuation study status	Year of data Collection	N	Valuation Method
<b>AFRICA</b>				
Egypt	Ongoing	2019		EQ-VT v2.0
Ethiopia	Completed <sup>a</sup>	2018	1050	EQ-VT v2.0
<b>ASIA</b>				
China <sup>14</sup>	Published	2012	1271	EQ-VT v1.0
Hong Kong <sup>15</sup>	Published	2014	1033	EQ-VT v1.1
India	Ongoing	2019		EQ-VT v2.1 <sup>b</sup>
Indonesia <sup>16</sup>	Published	2015	1054	EQ-VT v2.0
Japan <sup>17</sup>	Published	2013	1026	EQ-VT v1.1
Malaysia <sup>18</sup>	Published	2016	1137	EQ-VT v2.0
Philippines	Completed	2017		EQ-VT v2.1
Singapore	Completed	2014-2015		EQ-VT v2.0
South Korea <sup>19</sup>	Published	2013	1080	EQ-VT v2.0
Taiwan <sup>20</sup>	Published	2017	1000	EQ-VT v2.0
Thailand <sup>21</sup>	Published	2014	1207	EQ-VT v1.1
Vietnam	Completed			EQ-VT v2.1
<b>EUROPE</b>				
Belgium	Ongoing	2018-2019		EQ-VT v2.1
Denmark	Ongoing	2018-2019		EQ-VT v2.1
England <sup>22</sup>	Published	2012	996	EQ-VT v1.0
France	Completed	2018		EQ-VT v2.1
Germany <sup>23</sup>	Published	2015	1158	EQ-VT v2.0
Hungary	Completed	2018		EQ-VT v2.1
Ireland <sup>24</sup>	Published	2015-2016	1160	EQ-VT v2.0
Netherlands <sup>25</sup>	Published	2012	1003	EQ-VT v1.0
Norway	Ongoing			
Poland <sup>26</sup>	Published	2016	1252	EQ-VT v2.0
Portugal <sup>27</sup>	Published	2015-2016	1451	EQ-VT v2.0
Romania	Ongoing	2018-2019		EQ-VT v2.1
Spain <sup>28</sup>	Published	2012	1000	EQ-VT v1.0
Sweden	Ongoing			
<b>NORTH AND SOUTH AMERICA</b>				
Canada <sup>29</sup>	Published	2012	1073	EQ-VT v1.0
Mexico	Ongoing	2019		EQ-VT v2.1
Peru	Completed	2018-2018	1000 (DCE=1000; TTO=300) <sup>b</sup>	EQ-VT v2.1 'light'
Uruguay <sup>30</sup>	Published	2013	794	EQ-VT v1.1
USA <sup>31</sup>	Published	2017	1062	EQ-VT v2.0
<b>OCEANIA</b>				
Australia	Completed	2017	300 <sup>b</sup>	EQ-VT v2.0 'light'



- <sup>a</sup> Results for 'completed' studies were not available at the time of publication of this User Guide; please check the [EuroQol website](#) for the latest status of these studies.
- <sup>b</sup> The experimental design of the valuation study was modified to be optimal for the amended sample size. Further details can be obtained from the [EuroQol office](#).  
*DCE, discrete-choice experiment; EQ-VT, standardised valuation study protocol; TTO, time trade-off.*

### 4.3 / The EQ-5D-5L crosswalk project

The EuroQol Group coordinated a study that administered both the 3L and 5L versions of the EQ-5D, in order to develop a 'crosswalk' between the EQ-5D-3L value sets and the new EQ-5D-5L descriptive system, resulting in crosswalk value sets for the EQ-5D-5L. A total of 3691 respondents completed both the EQ-5D-3L and EQ-5D-5L across six countries: Denmark, England, Italy, the Netherlands, Poland and Scotland. Different subgroups were targeted, and in most countries, a screening protocol was implemented to ensure

that a broad spectrum of levels of health would be captured across the dimensions of EQ-5D for both the 5L and 3L descriptive systems. Several methods were consequently tested to optimise the link function between the two descriptive systems. A scientific report by van Hout and colleagues (2012) describing the mapping methodology behind the study in detail has been published.<sup>32</sup> A more detailed description of the crosswalk model and methodology also can be downloaded from the [EuroQol website](#).

### 4.4 / Crosswalk value sets for the EQ-5D-5L

The crosswalk link function resulting from the research by van Hout and colleagues (2012)<sup>32</sup> can be used to calculate index values for EQ-5D-5L, using the individual responses to the EQ-5D-5L descriptive system and the existing value sets for the EQ-5D-3L. Value sets have been derived for EQ-5D-3L in a number of countries using either the visual analogue scale technique or the time trade-off valuation techniques. The list of currently available EQ-5D-3L value sets is presented on the [EuroQol website](#). Most of the EQ-5D-3L value sets have been obtained using a representative sample of the general population,

thereby ensuring that they represent the societal perspective. A tool, the 'EQ-5D-5L Crosswalk Index Value Calculator', that calculates the crosswalk index values for the EQ-5D-5L dimension scores is available for download on the [EuroQol website](#).

Crosswalk value sets for the EQ-5D-5L are currently available for the following countries: Denmark, France, Germany, Japan, the Netherlands, Spain, Thailand, UK, USA and Zimbabwe. The actual index values can be downloaded from the [EuroQol website](#).

#### FURTHER INFORMATION ON VALUE SETS

- For more information on how to choose a value set, see the [EuroQol website](#).
- For anyone working with EQ-5D data, an essential guide to the use of the EuroQol Group's value sets can be found in Vol. 2 of the EuroQol Group Monograph series, *EQ-5D Value Sets: Inventory, Comparative Review and User Guide* (Springer, 2006), available at <https://euroqol.org/publications/books>.
- Documents containing the scoring algorithms, information on the valuation studies, tables of values for all 3125 health states and syntax files<sup>a</sup> may be requested from the [EuroQol office](#).

<sup>a</sup> A syntax file is a computer program that can be run using statistical software to automatically calculate the values for the EQ-5D health states stored in a database.

## 5. Organising EQ-5D-5L data

Data collected using EQ-5D-5L can be entered in a database according to the following schema:

Variable Name	ID	Sex	Age	EDU	Country	Year	Mobility
<b>Variable description</b>	Patient ID number	1 = Male 2 = Female 9 = Missing value	999 = Missing value	1 = Low 2 = Medium 3 = High 9 = Missing value	Country where data was collected	Year in which data was collected	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value
<b>Data row 1</b>	1001	1	43	1	UK	2011	4
<b>Data row 2</b>	1002	2	24	2	UK	2011	2

Variable Name	Self-care	Activity	Pain	Anxiety	State	EQ_VAS
<b>Variable description</b>	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value	1 = No pain 2 = Slight pain 3 = Moderately pain 4 = Severe pain 5 = Extreme pain 9 = Missing value	1 = Not anxious 2 = Slightly anxious 3 = Moderately anxious 4 = Severely anxious 5 = Extremely anxious 9 = Missing value	5-digit code for EQ-5D-5L	999 = Missing value
<b>Data row 1</b>	1	3	2	5	41325	63
<b>Data row 2</b>	1	1	1	1	21111	90

### Notes:

- The variable names are just examples. However, the variables for the five dimensions of the EQ-5D descriptive system should be named 'mobility', 'self-care', 'activity', 'pain' and 'anxiety'.
- A respondent's rating on EQ VAS is to the nearest whole number.



## 6. Presenting EQ-5D-5L results

Data collected using EQ-5D-5L can be presented in various ways. A basic subdivision can be made according to the structure of the EQ-5D-5L:

1. Presenting results from the EQ-5D-5L descriptive system as a health profile
2. Presenting results of the EQ VAS as a measure of overall self-rated health status
3. Presenting results from the EQ-5D-5L index value.

The way results can be presented is determined both by the data and by what message you, as a researcher, wish to convey to your audience. The following subsection illustrates some of the basic ways of presenting EQ-5D data.

### 6.1/Health profiles

Reporting descriptive statistics on patient-reported outcomes (PRO) data can be very insightful. In patient samples, it can identify which dimensions of health are most affected by a given condition or treatment; in population health surveys, it can provide an overview of the frequency of problems across dimensions and, in repeated surveys, show their evolution over time.

When reporting data, it is important to begin by describing the number and percentage of patients reporting each level of problem on each dimension of the EQ-5D. For example, Table 2

shows EQ-5D-5L data from a recent survey of 6800 individuals who were representative of the Lombardy (Italy) general adult population for age, gender and geographic distribution.<sup>33</sup> The study authors also reported the proportion of patients with a full health state of 11111 (38.0%), as well as stratifying the results by age and gender (data not presented here). Tables can also be broken down for other relevant subgroups — for example, by treatment arm, age group or sex — and/or by study visit, e.g. before/after treatment.

Table 2 / EQ-5D-5L frequencies and proportions reported by dimension and level<sup>33</sup>

	MOBILITY n (%)	SELF-CARE n (%)	USUAL ACTIVITIES n (%)	PAIN / DISCOMFORT n (%)	ANXIETY / DEPRESSION n (%)
<b>Level 1</b> (No problems)	5727 (84.2)	6406 (94.2)	5770 (84.9)	3592 (52.8)	4196 (61.7)
<b>Level 2</b> (Slight problems)	614 (9.0)	214 (3.1)	626 (9.2)	2046 (30.1)	1747 (25.7)
<b>Level 3</b> (Moderate problems)	353 (5.2)	132 (1.9)	311 (4.6)	1018 (15.0)	757 (11.1)
<b>Level 4</b> (Severe problems)	86 (1.3)	31 (0.5)	65 (1.0)	123 (1.8)	56 (0.8)
<b>Level 5</b> (Extreme problems/ unable to do)	20 (0.3)	17 (0.3)	28 (0.4)	21 (0.3)	44 (0.6)
<b>Total</b>	6800 (100)	6800 (100)	6800 (100)	6800 (100)	6800 (100)

**Note:** Sometimes it is more convenient to dichotomise the EQ-5D levels into 'no problems' (level 1) and 'any problems' (levels 2, 3, 4 and 5), thereby changing the profile into frequencies of reported problems.

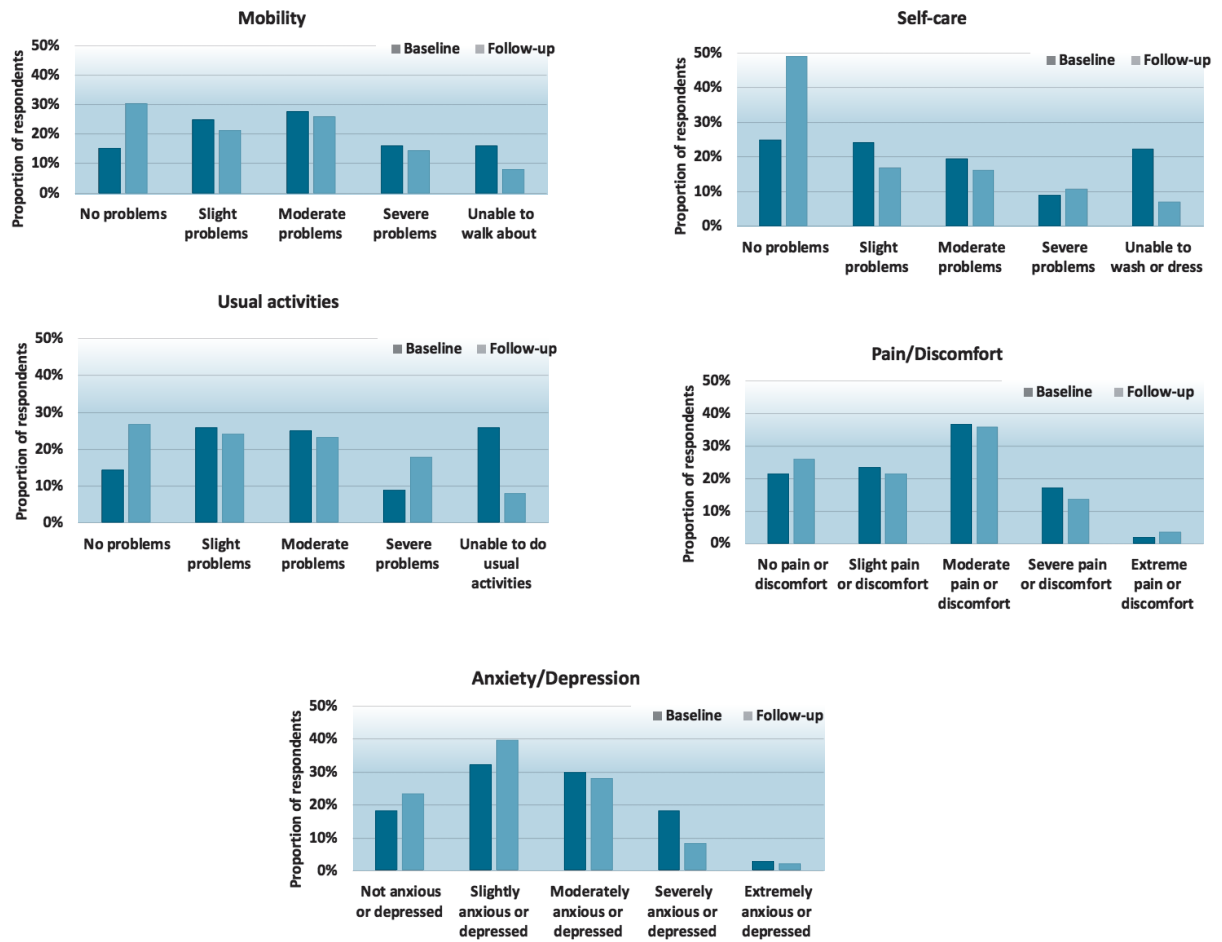
Data can also be presented to show changes in health over time. For example, in a single-centre observational longitudinal cohort study of patients (n=112) with stroke in Poland, the EQ-5D-5L was administered on two separate occasions.<sup>34</sup> The initial survey took place during index hospitalisation, before discharge. The second survey was conducted after an initial post-stroke recovery phase about

4 months later, in outpatient clinics, neurological rehabilitation departments or the patients' own homes. Table 3 shows significant differences in the distribution of responses to the self-care and usual activities dimensions of the EQ-5D-5L (p<0.001 and 0.001, respectively). It can also be helpful to report this information graphically (Figure 2).

**Table 3 / Distribution of EQ-5D-5L dimension responses at baseline and at follow-up<sup>34</sup>**

Dimension	Baseline n (%)	Follow-up n (%)	P Value
<b>Mobility</b>			
No problems	17 (15.2)	34 (30.4)	<b>0.057</b>
Slight problems	28 (25.0)	24 (21.4)	
Moderate problems	31 (27.7)	29 (25.9)	
Severe problems	18 (16.1)	16 (14.3)	
Unable to walk about	18 (16.1)	9 (8.0)	
<b>Self-care</b>			
No problems	28 (25.0)	55 (49.1)	<b>&lt; 0.001</b>
Slight problems	27 (24.1)	19 (17.0)	
Moderate problems	22 (19.62)	18 (16.1)	
Severe problems	10 (8.9)	12 (10.7)	
Unable to wash or dress	25 (22.3)	8 (7.1)	
<b>Usual activities</b>			
No problems	16 (14.3)	30 (26.8)	<b>0.001</b>
Slight problems	29 (25.9)	27 (24.1)	
Moderate problems	28 (25.0)	26 (23.2)	
Severe problems	10 (8.9)	20 (17.9)	
Unable to do usual activities	29 (25.9)	9 (8.0)	
<b>Pain/discomfort</b>			
No pain/discomfort	24 (15.2)	29 (25.9)	<b>NS</b>
Slight pain/discomfort	26 (23.2)	24 (21.4)	
Moderate pain/discomfort	41 (36.6)	40 (35.7)	
Severe pain/discomfort	19 (17.0)	15 (13.4)	
Extreme pain/discomfort	2 (1.8)	4 (3.6)	
<b>Anxiety/depression</b>			
Not anxious/depressed	20 (17.9)	26 (23.2)	<b>NS</b>
Slightly anxious/depressed	36 (32.1)	44 (39.3)	
Moderately anxious/depressed	33 (29.5)	31 (27.7)	
Severely anxious/depressed	20 (17.9)	9 (8.0)	
Extremely anxious/depressed	3 (2.7)	2 (1.8)	

Figure 2 / Proportion of responses by level of severity for EQ-5D-5L dimensions at baseline and at follow-up<sup>34</sup>



Although very useful information is contained in tables like Table 3, they can be hard to read; an overall summary is sometimes helpful. One way of simplifying the information is based on the principles of a Pareto improvement in Welfare Economics — the Pareto Classification of Health Change (PCHC).<sup>35</sup> With this approach, an EQ-5D health state is deemed to be ‘better’ than another if it is better on at least one dimension and is no worse in any other dimension. An EQ-5D health state is deemed to be ‘worse’ than

another if it is worse in at least one dimension and is no better in any other dimension. Using that principle to compare a patient’s EQ-5D health states between any two time periods, there are only four possibilities:

- Their health state is better
- Their health state is worse
- Their health state is exactly the same
- The changes in health are ‘mixed’: better on one dimension, but worse on another.



## 6.2/EQ VAS

As described earlier, the EQ VAS is a 0—100 scale where patients are asked to indicate their overall health on the day of questionnaire completion. It is conceptually different from the EQ-5D index which is a value attached to an EQ-5D profile according to a set of weights that reflect, on average, people's preferences about how good or bad the state is. The EQ VAS represents the patient perspective, whereas most values sets

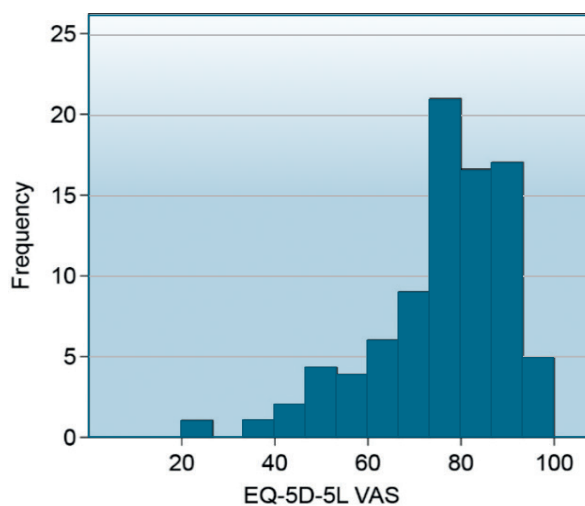
represent the societal perspective (i.e., what the general population thinks about the value of the health state). Choosing which perspective is most relevant depends on the research question. As a rule of thumb, the societal perspective is mostly used in health economics, while the respondent's perspective is used in clinical assessment of the patient and population surveys.

EQ VAS data should be presented using a measure of central tendency and a measure of dispersion. This could be the mean value and the standard deviation (SD) or, if the data are skewed, the median values and the interquartile range (IQR). A couple of examples are given below.

- In a large (n=1296) EQ-5D-5L valuation study in China, the mean (SD) EQ VAS was reported as 86.0 (11.4).<sup>36</sup>
- In an e-survey of patients (n=337) across 30 countries with tenosynovial giant cell tumour, it was reported that the median (IQR) was 75 (65–85) for localised and 75 (56.5–85) for diffuse type tumours.<sup>37</sup>

EQ VAS data can also be presented graphically, such as in frequency charts (Figure 3).

**Figure 3 / EQ-5D-5L VAS frequency distribution (hypothetical data)**



## 6.3/EQ-5D index

Information about the EQ-5D index, derived using a value set, can be presented in much the same way as the EQ VAS data, i.e. using measures of central tendency and dispersion, such as mean values and the SD (or standard error). If the data are skewed, the median values and the 25th and 75th percentiles could be presented. Note, when reporting index values, a maximum of three decimal places is usually sufficient.

Table 4 provides an example where index values are reported for a representative sample of the Spanish general population (n=21,007) using data from the Spanish National Health Survey 2011–2012.<sup>38</sup> The index values are reported by various sociodemographic factors and clinical characteristics in the paper.

Table 4 / Selected study sample characteristics, EQ-5D-5L male and female population norms<sup>38</sup>

EQ-5D-5L INDEX		
	Mean	SD
<b>Overall</b>	0.897	0.212
GENDER		
<b>Female</b>	0.867	0.238
<b>Male</b>	0.931	0.171
AGE GROUP		
<b>15-17</b>	0.983	0.115
<b>18-29</b>	0.978	0.101
<b>30-39</b>	0.971	0.110
<b>40-49</b>	0.959	0.111
<b>50-59</b>	0.930	0.166
<b>60-69</b>	0.922	0.172
<b>70-79</b>	0.871	0.214
<b>80-89</b>	0.744	0.315
<b>≥90</b>	0.645	0.304
MARITAL STATUS		
<b>Single</b>	0.952	0.150
<b>Married</b>	0.928	0.174
<b>Divorced/separated</b>	0.930	0.165
<b>Widowed</b>	0.836	0.239
SMOKING STATUS		
<b>Yes</b>	0.903	0.199
<b>No</b>	0.991	0.050
NET MONTHLY INCOME OF HOUSEHOLD (€)		
<b>&lt;550</b>	0.897	0.209
<b>551-1300</b>	0.903	0.195
<b>1301-2250</b>	0.947	0.151
<b>2251-3450</b>	0.961	0.146
<b>≥3451</b>	0.972	0.093

Table 5 gives a hypothetical example of how to present EQ-5D index results for an intervention study. The improvement in health state utility associated with treatment with Drug A versus Drug B was 0.08 ( $p < 0.05$ ) at Week 12.

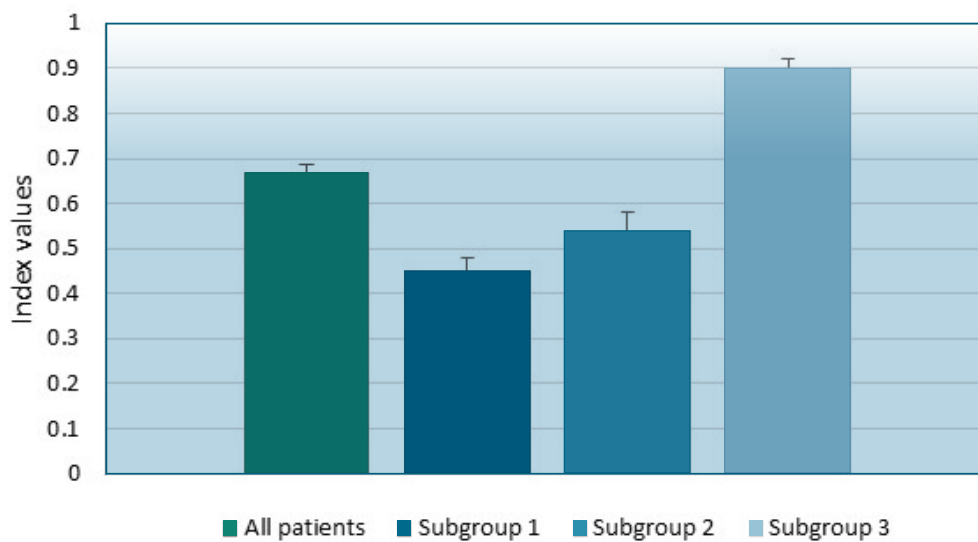
Data can also be presented graphically; a hypothetical example is presented in Figure 4 where the group highest mean health status, using the EQ-5D-5L index, is subgroup 3. Subgroup 1 reported the worst health. The differences between all subgroups were statistically significant ( $p < 0.05$ ).

Table 5 / Impact of treatment on EQ-5D-5L index score (hypothetical data)

Visit	Drug A		Drug B		p-value <sup>a</sup>
	N	Mean (SD)	N	Mean (SD)	
Baseline	229	0.59 (0.30)	227	0.60 (0.28)	0.6345
Week 12	194	0.57 (0.32)	186	0.65 (0.29)	0.0149

<sup>a</sup> Using t-test.

Figure 4 / Mean EQ-5D-5L index values and 95% confidence intervals for the total patient population and three subgroups (hypothetical data)



## ANALYSIS OF UTILITY DATA FOR ECONOMIC EVALUATION

When analysing data to inform an economic evaluation, the approach will generally need to be different from an analysis that has been undertaken for regulatory purposes – i.e. which reports a comparison between treatment arms. Typically, EQ-5D data will be analysed to estimate the difference between health states (defined in an economic model) or the effect of specific events (e.g. a stroke, exacerbation or relapse). Such an analysis should also control for the effect of treatment arm, but the treatment arm may not be the primary focus of the analysis. For further insight on this topic, please refer to the ISPOR Good Research Practices Task Force report on ‘Estimating Health-State Utility for Economic Models in Clinical Studies’ by Wolowacz et al, 2016.<sup>39</sup>

## Example text for describing the EQ-5D and reporting and analysing EQ-5D data for study protocols/proposals

Study protocols and project proposals often require information to be included describing the EQ-5D instrument and how the results will be reported and analysed. Below is an example outline of the kind of information that could be provided on the EQ-5D-5L for an intervention study.

### About the EQ-5D

- The EQ-5D-5L<sup>1</sup> is a widely used generic measure of health status consisting of two parts. The first part (the descriptive system) assesses health in five dimensions (MOBILITY, SELF-CARE, USUAL ACTIVITIES, PAIN / DISCOMFORT, ANXIETY / DEPRESSION), each of which has five levels of response (no problems, slight problems, moderate problems, severe problems, extreme problems/unable to). This part of the EQ-5D questionnaire provides a descriptive profile that can be used to generate a health state profile. For example, a patient in health state 12345 would have no problems with mobility, slight problems with self-care (washing or dressing), moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression. Each health state can potentially be assigned a summary index score based on societal preference weights for the health state. These weights, sometimes referred to as 'utilities', are often used to compute QALYs for use in health economic analyses. Health state index scores generally range from less than 0 (where 0 is the value of a health state equivalent to dead; negative values representing values as worse than dead) to 1 (the value of full health), with higher scores indicating higher health utility. The health state preferences often represent national or regional values and can therefore differ between countries/regions. The second part of the questionnaire consists of a visual analogue scale (VAS) on which the patient rates his/her perceived health from 0 (the worst imaginable health) to 100 (the best imaginable health). The EQ-5D questionnaire is cognitively undemanding, taking only a few minutes to complete. Instructions to patients are included in the questionnaire.

### Reporting and analysis of results

- A health profile will be generated by visit and by treatment. Summary statistics will be derived, including numbers of patients and proportions of categorical responses for the five EQ-5D dimensions.
- A health state index score will be calculated from individual health profiles using [insert country/region specific value set and reference here – where a value set is not available for your country/region, it may be possible to use a value set for a country/region that most closely approximates yours or use a crosswalk value set<sup>a</sup>]. Mean, standard deviation (SD), minimum, median, and maximum scores will be provided for the study population by visit and by treatment.
- The EQ VAS score (between 0 and 100) will be summarised using mean, SD, minimum, median and maximum scores by visit and by treatment.
- For the health state index and EQ VAS scores, mean, SD, minimum, median and maximum will be provided for change from baseline to [enter questionnaire assessment time points here, e.g. Week 12, Week 24] and [final study assessment, e.g. Week 52].
- The type of model used and the covariates and fixed effects will be study-dependent. As an example, an ANCOVA model could be conducted for the changes from baseline to [assessment time points], with country and treatment as fixed effects and baseline as a covariate. In this example, significance of change within each treatment group and significance of the difference between the treatment groups would be reported.

<sup>a</sup> See [EuroQol website](#) section on choosing a value set, for more information.



## 7. EQ-5D-5L translations and modes of administration

### 7.1/EQ-5D-5L translations

The EQ-5D-5L (Paper Self-Complete version) is available in more than 150 languages. All translation / adaptations of EQ-5D are produced using a standardised translation protocol that conforms to internationally recognised guidelines. These guidelines aim to ensure equivalence to the English 'source' version and involve a forward/backward translation process and cognitive debriefing.<sup>40</sup> New translations can be produced on request.

The EuroQol office manages the production of new translations and in general, translation costs are covered by the client requesting a translation.

For more information on the EQ-5D translation process, consult the [EuroQol website](#) or contact the [EuroQol office](#). See the next section regarding the availability of EQ-5D-5L translations for different modes of administration.

## 7.2 / Modes of administration

The EQ-5D-5L is available in a wide range of modes of administration (Table 6).

**Table 6 / Language versions available for various modes of administration of the EQ-5D-5L**

Modes of administration	Total number of languages versions available
<b>SELF-COMPLETE VERSIONS</b>	
Paper	>170
PDA/Smartphone	>200
Tablet	>110
Laptop/Desktop	>150
REDCap Platform <sup>a</sup>	>40
Limesurvey Platform <sup>b</sup>	>5
Castor EDC Platform <sup>c</sup>	>2
<b>INTERVIEW VERSIONS</b>	
Interviewer Administration <sup>d</sup>	>3
Face-to-face	>6
Telephone	>90
<b>PROXY VERSIONS</b>	
Proxy version 1 <sup>e</sup>	>150
Proxy version 2 <sup>f</sup>	>40
<b>INTERACTIVE VOICE RESPONSE SYSTEM VERSION</b>	
IVR system version	>30

<sup>a</sup> REDCap is a secure web application for building and managing online surveys and databases.

<sup>b</sup> LimeSurvey is an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system.

<sup>c</sup> Castor EDC is a cloud-based Electronic Data Capture platform that enables commercial and non-commercial researchers to easily capture high quality, reusable data from any source in real-time.

<sup>d</sup> Interviewer Administered (IA) version was developed for use either in face-to-face or telephone/computer interviews when participants are either unable to read or write or unable to be physically present for the interview. May be used interchangeably with existing Telephone and Face-to-face versions.

<sup>e</sup> Proxy version 1: The caregiver (the proxy) is asked to rate the patient's health in their (the proxy's) opinion.

<sup>f</sup> Proxy version 2: The caregiver (the proxy) is asked to rate how they (the proxy) think the patient would rate his/her own health, if the patient were able to communicate it.

**Note:** To find out whether an EQ-5D-5L language version is available for your country / region, please consult the relevant mode of administration section of the **EuroQol website**. If a language version is not currently available, please contact the **EuroQol office**.



## EQ-5D MODULAR VERSIONS

Previously, EQ-5D would have to be hosted on EuroQol's dedicated server. EQ-5D can now also be hosted on your own server, the REDCap, the LimeSurvey or the Castor EDC platform. These EQ-5D modular versions are now available as ready-to-use surveys that do not require screenshot review by EuroQol.

- **REDCap:** a web application for building and managing online surveys and databases. It is mainly used in academic research.
- **LimeSurvey:** an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system.
- **Castor EDC:** a cloud-based Electronic Data Capture platform that enables commercial and non-commercial researchers to easily capture high-quality, reusable data from any source in real time.

For further information, please see the [website](#) or contact the [EuroQol office](#).

## 8. Other EQ-5D products

### 8.1 / EQ-5D-3L

The EQ-5D-3L has a descriptive system that comprises the same five health dimensions as in the EQ-5D-5L, but each dimension has three levels: no problems, some problems, extreme problems. The EQ-5D-3L preceded the 5L version of the EQ-5D and was introduced in 1990.

The EQ-5D-3L is still one of the most widely used instruments for measuring health status; it is currently available in more than 180 different language versions (for the self-complete versions), across several modes of administration (Table 7).

Table 7 / EQ-5D-3L available modes of administration

Self-complete versions	Interview versions
<ul style="list-style-type: none"><li>• Paper</li></ul>	<ul style="list-style-type: none"><li>• Interviewer Administered (IA)</li></ul>
<ul style="list-style-type: none"><li>• PDA/Smartphone</li></ul>	<ul style="list-style-type: none"><li>• Face-to-face</li></ul>
<ul style="list-style-type: none"><li>• Tablet</li></ul>	<ul style="list-style-type: none"><li>• Telephone</li></ul>
<ul style="list-style-type: none"><li>• Laptop/Desktop</li></ul>	<b>Proxy versions</b>
<ul style="list-style-type: none"><li>• REDCap platform</li></ul>	<b>Interactive Voice Response system version</b>
<ul style="list-style-type: none"><li>• LimeSurvey platform</li></ul>	
<ul style="list-style-type: none"><li>• Castor EDC platform</li></ul>	

**Note:** For more information on the EQ-5D-3L and to see whether an EQ-5D-3L version exists for your country/region, please consult the [EuroQol website](#). An EQ-5D-3L user guide is also available on the [EuroQol website](#).

## 8.2 / EQ-5D-Y (Youth)

The EQ-5D-Y is a child-friendly version of the EQ-5D-3L questionnaire that was developed specifically for children and adolescents aged 8–15 years (Table 8). It can also be used in

paediatric studies that include respondents up to 18 years, if it is preferred to just use a single EQ-5D version in the study.

**Table 8 / The age range of users of the EQ-5D-Y version**

<b>Age 0–7</b>	<b>No EQ-5D-Y for youngest children</b> For children aged 4–7, a proxy version can be used.
<b>Age 8–11</b>	<b>EQ-5D-Y</b> A youth version is more understandable for children.
<b>Age 12–15</b>	<b>Overlapping area: both Youth and Adult EQ-5D versions can be used</b> Generally, EQ-5D-Y is recommended. However, depending on study design, using the EQ-5D adult version might be possible.
<b>Age 16 and older</b>	<b>Adult version</b> Possible exception: a study only with children up to 18 years; in this case EQ-5D-Y for older children would be recommended in order to have only one EQ-5D version in the study. Switching to the adult version could disrupt continuity, as the adult and child versions are two different instruments.

Self-complete and proxy versions of the EQ-5D-Y are available (Table 9). The self-complete version is now available in more than 50 language versions. Research is ongoing, partly funded by the EuroQol

Research Foundation, to derive EQ-5D-Y value sets for use in children and adolescents. Please consult the [EuroQol website](#) for the latest developments on EQ-5D-Y valuation research.

**Table 9 / EQ-5D-Y available modes of administration**

<b>Self-complete versions</b>	<b>Proxy versions</b>
• Paper	• Face-to-face
• PDA/Smartphone	• Telephone
• Tablet	

**Note:** If you would like to know whether there is an EQ-5D-Y version appropriate for your country/region, please consult the [EuroQol website](#). A user guide for the EQ-5D-Y is also available on the [EuroQol website](#).



## 9. How to obtain EQ-5D-5L

The EuroQol Research Foundation is a registered charity in the Netherlands and serves as the single point of distribution for the family of EQ-5D instruments. If you would like to use the EQ-5D in your study/trial/project, please complete the registration form on the [EuroQol website](#). Note, you are not obliged to purchase the EQ-5D by registering. The EuroQol office will then e-mail you with details of the terms and conditions for use, including licensing fees if applicable. Default timelines for EuroQol business processes for different elements of the licensing process are provided on the [EuroQol website](#).

Licensing fees are determined by the EuroQol office based on the user information provided in the registration form. If applicable, the size of the licence fee depends on the type of study, funding source, sample size and number of requested EQ-5D versions and languages. The EQ-5D user licence policy is available on the [EuroQol website](#). Please note that where fees are charged, these allow the EuroQol Research Foundation to fund activities in line with its vision and mission as described on the [EuroQol website](#).



## 10. Additional resources on the EuroQol website

Throughout this User Guide, weblinks to relevant resources on the EuroQol website have been provided. Here is a selection of additional web resources that the reader may find useful:

<b>Answers to frequently asked questions</b>	<a href="https://euroqol.org/support/faqs/">https://euroqol.org/support/faqs/</a>
<b>EQ-5D terms explained</b>	<a href="https://euroqol.org/support/terminology/">https://euroqol.org/support/terminology/</a>
<b>Key EQ-5D-5L references</b>	<a href="https://euroqol.org/publications/key-euroqol-references/eq-5d-5l/">https://euroqol.org/publications/key-euroqol-references/eq-5d-5l/</a>
<b>EQ-5D books</b>	<a href="https://euroqol.org/publications/books/">https://euroqol.org/publications/books/</a>
<b>EQ-5D working papers</b>	<a href="https://euroqol.org/publications/working-papers/">https://euroqol.org/publications/working-papers/</a>
<b>Explanation of EQ-5D version numbering and quality control</b>	<a href="https://euroqol.org/support/quality-control/">https://euroqol.org/support/quality-control/</a>



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