EQ-5D-Y User Guide

Basic information on how to use the EQ-5D-Y instrument
# Table of contents

1. **INTRODUCTION** .......................................................................................................................... 3  
   1.1. **THE EUROQOL GROUP** ................................................................................................. 3  
   1.2. **EQ-5D** ............................................................................................................................... 3  
      1.2.1. **EQ-5D-3L** ................................................................................................................ 3  
      1.2.2. **EQ-5D-Y** ................................................................................................................ 4  
   1.3. **WHAT IS A HEALTH STATE?** ............................................................................................ 7  

2. **SCORING THE EQ-5D-Y DESCRIPTIVE SYSTEM** ................................................................. 8  

3. **SCORING THE EQ VAS** ............................................................................................................. 9  

4. **CONVERTING EQ-5D STATES TO AN INDEX VALUE** ............................................................ 10  

5. **ORGANISING EQ-5D-Y DATA** ................................................................................................. 11  

6. **PRESENTING EQ-5D-Y RESULTS** ............................................................................................ 12  
   6.1. **HEALTH PROFILES** ........................................................................................................ 12  
   6.2. **EQ VAS** .......................................................................................................................... 14  

7. **EQ-5D PRODUCTS** ..................................................................................................................... 15  
   7.1. **EQ-5D-Y TRANSLATIONS AND OTHER FORMATS** ...................................................... 15  
      7.1.1. **EQ-5D-Y proxy version** ........................................................................................... 15  
   7.2. **OTHER EQ-5D PRODUCTS** .............................................................................................. 15  
      7.2.1. **EQ-5D-3L Translations and other formats** .............................................................. 15  
      7.2.2. **EQ-5D-5L Translations and other formats** .............................................................. 16  
   7.3. **TRANSLATION PROCESS** .............................................................................................. 16  
   7.4. **HOW TO OBTAIN EQ-5D-Y?** .......................................................................................... 16  

8. **FAQS** ....................................................................................................................................... 17  
   8.1. **GENERAL** ...................................................................................................................... 17  
   8.2. **REGISTRATION** .............................................................................................................. 17  
   8.3. **COPYRIGHT** .................................................................................................................... 18  

9. **REFERENCES AND PUBLICATIONS** ..................................................................................... 19  
   9.1. **KEY EUROQOL GROUP REFERENCES** .......................................................................... 19  
   9.2. **REFERRING TO THE EQ-5D-Y INSTRUMENT IN PUBLICATIONS** ............................... 19  
   9.3. **EQ-5D BOOKS** ................................................................................................................ 20
1. Introduction

This guide has been developed in order to give users basic information on how to use the youth version of EQ-5D, the EQ-5D-Y. Topics include administering the instrument, setting up a database for data collected using EQ-5D-Y and suggestions on how to present the data. Also included are several frequently asked questions dealing with common issues regarding the use of EQ-5D-Y and a list of currently available EuroQol Group products.

1.1. The EuroQol Group

- The EuroQol Group is a network of international multidisciplinary researchers devoted to the measurement of health status. Established in 1987, the EuroQol Group originally consisted of researchers from Europe, but nowadays also includes members from North and South America, Asia, Africa, Australia, and New Zealand. The Group is responsible for the development of EQ-5D, a preference based measure of health status that is widely used in clinical trials, observational studies and other health surveys.
- The EuroQol Group has been holding annual scientific meetings since its inception in 1987.
- The EuroQol Group can be justifiably proud of its collective scientific achievements over the last 25 years. Research areas include: valuation, EQ-5D use in clinical studies and in population surveys, experimentation with the EQ-5D descriptive system, computerized applications, interpretation of EQ-5D scores and index values and the role of EQ-5D in measuring social inequalities in self-reported health.

The EuroQol Group’s website (www.euroqol.org) contains detailed information about EQ-5D, guidance for users, a list of available language versions, references and contact details.

1.2. EQ-5D

“EQ-5D is a standardised measure of health status developed by the EuroQol Group in order to provide a simple, generic measure of health for clinical and economic appraisal.”

Applicable to a wide range of health conditions and treatments, EQ-5D provides a simple descriptive profile and a single index value for health status that can be used in clinical and economic evaluation of health care as well as in population health surveys (Figure 1). EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics, and in face-to-face interviews. It is cognitively undemanding, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire.

1.2.1. EQ-5D-3L

The EQ-5D 3 level version (EQ-5D-3L) was introduced in 1990. The EQ-5D-3L essentially consists of 2 pages - the EQ-5D descriptive system (page 2) and the EQ visual analogue scale (EQ VAS) (page 3). The EQ-5D-3L descriptive system comprises the following 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 3 levels: no problems, some problems, problems.

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extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. The EQ VAS records the respondent’s self-rated health on a vertical visual analogue scale, where the endpoints are labelled ‘Best imaginable health state’ and ‘Worst imaginable health state’. This information can be used as a quantitative measure of health outcome as judged by the individual respondents. It should be noted that the numerals 1 to 3 have no arithmetic properties and should not be used as a cardinal score.

1.2.2. EQ-5D-Y

In 2006, a task force was established within the EuroQol Group to develop a child-friendly version of the EQ-5D. The rationale behind it was an increasing demand for a child-friendly EQ-5D-version in general, as well as for country specific child-friendly versions of the EQ-5D. A version that could serve as a template for the development of country specific versions of the EQ-5D-Y did not yet exist. For this reason the working group decided to develop a child-friendly source version (standardized international English) of the EQ-5D-Y, from which all translations could be derived. During the development of this version different terminologies were considered. After much discussion, the working group agreed to use the terminology ‘Youth’ as being adequate for both children and adolescents, therefore naming it, the “EQ-5D-Y” (Figure 1).

The EQ-5D-Y consists of 2 pages – the EQ-5D-Y descriptive system (page 2) and the EQ visual analogue scale (EQ VAS) (page 3). The descriptive system comprises the same 5 dimensions as the EQ-5D-3L, but using a child-friendly wording (mobility, looking after myself, doing usual activities, having pain or discomfort, feeling worried, sad or unhappy). Each dimension has 3 levels: no problems, some problems, a lot of problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. The EQ VAS records the respondent’s self-rated 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’. This information can be used as a quantitative measure of health outcome as judged by the individual respondents. Also, previously published studies by EuroQol Group members showed preliminary evidence of the instrument’s feasibility, reliability and validity.

The age range of users of the EQ-5D-Y version is as follows:

<table>
<thead>
<tr>
<th>Age</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0-7</td>
<td><strong>No EQ-5D-Y for youngest children</strong></td>
</tr>
<tr>
<td></td>
<td><em>NB: For children aged 4-7 a proxy version can be used (see section 7, page 15).</em></td>
</tr>
<tr>
<td>Age 8-11</td>
<td><strong>EQ-5D-Y</strong></td>
</tr>
<tr>
<td></td>
<td><em>NB: A youth version is more understandable for children</em></td>
</tr>
<tr>
<td>Age 12-15</td>
<td><strong>Overlapping area: both Youth and Adult EQ-5D versions can be used</strong></td>
</tr>
<tr>
<td></td>
<td><em>NB: Generally EQ-5D-Y is recommended. However, depending on study design the usage of the EQ-5D adult version might be possible.</em></td>
</tr>
<tr>
<td>Age 16 and older</td>
<td><strong>Adult version</strong></td>
</tr>
<tr>
<td></td>
<td><em>NB: 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. The switch-over to the adult version could bring discontinuity as the adult and child versions are two different instruments.</em></td>
</tr>
</tbody>
</table>

---


Figure 1: EQ-5D-Y (UK English sample version)

<table>
<thead>
<tr>
<th>Describing your health</th>
</tr>
</thead>
</table>

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

**Mobility (walking about)**
I have **no** problems walking about
I have **some** problems walking about
I have **a lot** of problems walking about

**Looking after myself**
I have **no** problems washing or dressing myself
I have **some** problems washing or dressing myself
I have **a lot** of problems washing or dressing myself

**Doing usual activities** *(for example, going to school, hobbies, sports, playing, doing things with family or friends)*
I have **no** problems doing my usual activities
I have **some** problems doing my usual activities
I have **a lot** of problems doing my usual activities

**Having pain or discomfort**
I have **no** pain or discomfort
I have **some** pain or discomfort
I have **a lot** of pain or discomfort

**Feeling worried, sad or unhappy**
I am **not** worried, sad or unhappy
I am **a bit** worried, sad or unhappy
I am **very** worried, sad or unhappy
We would like to know how good or bad your health is TODAY.

This line is numbered from 0 to 100.

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

Please mark an X on the line that shows how good or bad your health is TODAY.
1.3. **What is a health state?**

Each of the 5 dimensions comprising the EQ-5D-Y descriptive system is divided into 3 levels of perceived problems:

- Level 1: indicating no problem
- Level 2: indicating some problems
- Level 3: indicating a lot of problems

A unique health state is defined by combining 1 level from each of the 5 dimensions.

A total of 243 possible health states is defined in this way. Each state is referred to in terms of a 5 digit code. For example, state 11111 indicates no problems on any of the 5 dimensions, while state 11223 indicates no problems with mobility and looking after myself, some problems doing usual activities, having some pain or discomfort and feeling very worried, sad or unhappy.
2. Scoring the EQ-5D-Y descriptive system

The EQ-5D-Y descriptive system should be scored as follows:

<table>
<thead>
<tr>
<th>Describing your health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under each heading, please tick the ONE box that best describes your health TODAY</td>
</tr>
</tbody>
</table>

**Mobility** *(walking about)*
- I have **no** problems walking about ✔
- I have **some** problems walking about □
- I have **a lot** of problems walking about □

**Looking after myself**
- I have **no** problems washing or dressing myself □
- I have **some** problems washing or dressing myself ✔
- I have **a lot** of problems washing or dressing myself □

**Doing usual activities** *(for example, going to school, hobbies, sports, playing, doing things with family or friends)*
- I have **no** problems doing my usual activities □
- I have **some** problems doing my usual activities □
- I have **a lot** of problems doing my usual activities ✔

**Having pain or discomfort**
- I have **no** pain or discomfort □
- I have **some** pain or discomfort □
- I have **a lot of** pain or discomfort ✔

**Feeling worried, sad or unhappy**
- I am **not** worried, sad or unhappy □
- I am a **bit** worried, sad or unhappy □
- I am **very** worried, sad or unhappy ✔

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’

This example identifies the health state ‘12333’.

**NB:** There should be only ONE response for each dimension

**NB:** Missing values can be coded as ‘9’.

**NB:** Ambiguous values *(e.g. 2 boxes are ticked for a single dimension)* should be treated as missing values.
3. Scoring the EQ VAS

The EQ VAS should be scored as follows:

- We would like to know how good or bad your health is TODAY.
- This line is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Please mark an X on the line that shows how good or bad your health is TODAY.

*NB: Missing values should be coded as ‘999’.*
4. Converting EQ-5D states to an index value

EQ-5D health states, defined by the EQ-5D descriptive system, may be converted into a single index value by applying a formula that essentially attaches values (also called weights) to each of the levels in each dimension. The index values, presented in country specific value sets, 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 health care interventions. Information in this format is useful, for example, in cost utility analysis.

At present, a value set for the EQ-5D-Y is not yet available. It is not recommended to use the 3L value set as proxy value set for the EQ-5D-Y. The EuroQol Group is currently working on the development of a protocol for the valuation of the EQ-5D-Y.
5. Organising EQ-5D-Y data

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

<table>
<thead>
<tr>
<th>Variable name</th>
<th>ID</th>
<th>COUNTRY</th>
<th>YEAR</th>
<th>MOBILITY (WALKING ABOUT)</th>
<th>LOOKING AFTER MYSELF</th>
<th>DOING USUAL ACTIVITIES</th>
<th>HAVING PAIN OR DISCOMFORT</th>
<th>FEELING WORRIED, SAD OR UNHAPPY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable description</td>
<td>patient ID number</td>
<td></td>
<td></td>
<td>1=No problems, 2=Some problems, 3=A lot of problems, 9=Missing value</td>
<td>1=No problems, 2=Some problems, 3=A lot of problems, 9=Missing value</td>
<td>1=No problems, 2=Some problems, 3=A lot of problems, 9=Missing value</td>
<td>1=No problems, 2=Some problems, 3=A lot of problems, 9=Missing value</td>
<td>1=Not worried, 2=A bit worried, 3=Very worried, 9=Missing value</td>
</tr>
<tr>
<td>Data row 1</td>
<td>1001</td>
<td>UK</td>
<td>2006</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Data row 2</td>
<td>1002</td>
<td>UK</td>
<td>2006</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable name</th>
<th>STATE</th>
<th>EQ_VAS</th>
<th>SEX</th>
<th>AGE</th>
<th>METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable description</td>
<td>999=Missing value</td>
<td>1=male, 2=female, 9=Missing value</td>
<td>999=Missing value</td>
<td>0=postal, 1=interview, 2=telephone, 9=Missing value</td>
<td></td>
</tr>
<tr>
<td>Data row 1</td>
<td>21221</td>
<td>80</td>
<td>1</td>
<td>43</td>
<td>0</td>
</tr>
<tr>
<td>Data row 2</td>
<td>21111</td>
<td>90</td>
<td>2</td>
<td>24</td>
<td>0</td>
</tr>
</tbody>
</table>
6. Presenting EQ-5D-Y results

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

1. Presenting results from the descriptive system as a health profile
2. Presenting results of the EQ VAS as a measure of overall self-rated health status

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.

6.1. Health profiles
One way of presenting data as a health profile is by making a table with the frequency or the proportion of reported problems for each level for each dimension. These tables can be broken down to include the proportions per subgroup, such as age, before vs. after treatment, treatment vs. comparator, etc.

Sometimes it is more convenient to dichotomise the EQ-5D levels into 'no problems' (i.e. level 1) and 'problems' (i.e. levels 2 and 3), thereby changing the profile into frequencies of reported problems. This can be the case, for example, in a general population survey where the numbers of reported level 3 problems are very low. Tables 2 and 3 are examples of how to present EQ-5D data in tabulated form.

Table 2: Proportion of levels 1, 2 and 3 by dimension and by age group

<table>
<thead>
<tr>
<th>EQ-5D-Y DIMENSION</th>
<th>AGE GROUPS</th>
<th>8-11</th>
<th>12-15</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>MOBILITY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>383</td>
<td>91.8</td>
<td>401</td>
<td>93.9</td>
</tr>
<tr>
<td>Some problems</td>
<td>31</td>
<td>7.4</td>
<td>21</td>
<td>4.9</td>
</tr>
<tr>
<td>A lot of problems</td>
<td>3</td>
<td>0.7</td>
<td>5</td>
<td>1.2</td>
</tr>
<tr>
<td>LOOKING AFTER MYSELF</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>397</td>
<td>95.7</td>
<td>413</td>
<td>97.2</td>
</tr>
<tr>
<td>Some problems</td>
<td>18</td>
<td>4.3</td>
<td>11</td>
<td>2.6</td>
</tr>
<tr>
<td>A lot of problems</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>DOING USUAL ACTIVITIES</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>351</td>
<td>84.6</td>
<td>352</td>
<td>83.4</td>
</tr>
<tr>
<td>Some problems</td>
<td>60</td>
<td>14.5</td>
<td>59</td>
<td>14.0</td>
</tr>
<tr>
<td>A lot of problems</td>
<td>4</td>
<td>1.0</td>
<td>11</td>
<td>2.6</td>
</tr>
<tr>
<td>HAVING PAIN OR DISCOMFORT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>250</td>
<td>60.0</td>
<td>253</td>
<td>59.4</td>
</tr>
<tr>
<td>Some problems</td>
<td>158</td>
<td>37.9</td>
<td>161</td>
<td>37.8</td>
</tr>
<tr>
<td>A lot of problems</td>
<td>9</td>
<td>2.2</td>
<td>12</td>
<td>2.8</td>
</tr>
<tr>
<td>FEELING WORRIED, SAD OR UNHAPPY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not worried, sad...</td>
<td>251</td>
<td>59.9</td>
<td>281</td>
<td>66.3</td>
</tr>
<tr>
<td>A bit worried, sad...</td>
<td>152</td>
<td>36.3</td>
<td>122</td>
<td>28.8</td>
</tr>
<tr>
<td>Very worried, sad...</td>
<td>16</td>
<td>3.8</td>
<td>21</td>
<td>5.0</td>
</tr>
</tbody>
</table>
Table 3: Frequency of reported problems by dimension and age group

<table>
<thead>
<tr>
<th>EQ-5D-Y DIMENSION</th>
<th>AGE GROUPS</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8-11</td>
<td>12-15</td>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>MOBILITY</td>
<td>No problems</td>
<td>383</td>
<td>91.8</td>
<td>401</td>
<td>93.9</td>
</tr>
<tr>
<td></td>
<td>Problems</td>
<td>34</td>
<td>8.2</td>
<td>26</td>
<td>6.1</td>
</tr>
<tr>
<td>LOOKING AFTER MYSELF</td>
<td>No problems</td>
<td>397</td>
<td>95.7</td>
<td>413</td>
<td>97.2</td>
</tr>
<tr>
<td></td>
<td>Problems</td>
<td>18</td>
<td>4.3</td>
<td>12</td>
<td>2.8</td>
</tr>
<tr>
<td>DOING USUAL ACTIVITIES</td>
<td>No problems</td>
<td>351</td>
<td>84.6</td>
<td>352</td>
<td>83.4</td>
</tr>
<tr>
<td></td>
<td>Problems</td>
<td>64</td>
<td>15.4</td>
<td>70</td>
<td>16.6</td>
</tr>
<tr>
<td>HAVING PAIN OR DISCOMFORT</td>
<td>No problems</td>
<td>250</td>
<td>60.0</td>
<td>253</td>
<td>59.4</td>
</tr>
<tr>
<td></td>
<td>Problems</td>
<td>167</td>
<td>40.0</td>
<td>173</td>
<td>40.6</td>
</tr>
<tr>
<td>FEELING WORRIED, SAD OR UNHAPPY</td>
<td>No worried, sad, ..</td>
<td>251</td>
<td>59.9</td>
<td>281</td>
<td>66.3</td>
</tr>
<tr>
<td></td>
<td>Problems</td>
<td>168</td>
<td>40.1</td>
<td>143</td>
<td>33.7</td>
</tr>
</tbody>
</table>

In addition to presenting the results in tabulated form, you can also use graphical presentations. Two or three dimensional bar charts can be used to summarise the results in one graph, (see figure 2). Figure 2 shows the sum of the proportion of reported level 2 and level 3 problems for each of the 5 EQ-5D-Y dimensions for two distinct age groups.

**Figure 2: Profile of the population (% reporting problem)**
6.2. EQ VAS

In order to present all aspects of the EQ VAS data, you should present both a measure of the central tendency and a measure of dispersion. This could be the mean values and the standard deviation or, if the data is skewed, the median values and the 25th and 75th percentiles. An example is presented in table 4.

Table 4: EQ VAS values by age – mean + standard deviation and median + percentiles

<table>
<thead>
<tr>
<th>EQ VAS</th>
<th>AGE GROUPS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8-11</td>
<td>12-15</td>
<td>Total</td>
</tr>
<tr>
<td>N</td>
<td>115</td>
<td>236</td>
<td>351</td>
</tr>
<tr>
<td>Mean</td>
<td>87.3</td>
<td>83.1</td>
<td>84.5</td>
</tr>
<tr>
<td>Standard error</td>
<td>2.2</td>
<td>1.5</td>
<td>1.7</td>
</tr>
<tr>
<td>25th percentile</td>
<td>80</td>
<td>80</td>
<td>80</td>
</tr>
<tr>
<td>50th percentile (median)</td>
<td>90</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td>75th percentile</td>
<td>98</td>
<td>95</td>
<td>95</td>
</tr>
</tbody>
</table>
7. EQ-5D Products

7.1. EQ-5D-Y Translations and other formats
The EQ-5D-Y is an EQ-5D-3L self-complete youth version which has been developed specifically for children and adolescents aged 8-15 years (or respectively 8-18 years; see section 1, page 4). At present, this version is available in more than 25 different languages. Likewise, although the EQ-5D-Y was primarily designed as a pen-and-paper, self-complete instrument, it is now available in the following alternative formats:

- PDA
- Tablet
- Proxy paper

If you want to know if there is an EQ-5D-Y version appropriate for your country, please consult the website.

7.1.1. EQ-5D-Y proxy version
The EQ-5D-Y has two proxy versions (source versions):
- Proxy 1: The proxy rates how he/she rates the health of the child.
- Proxy 2: The proxy rates how he/she thinks the child would rate his/her own state if he/she were asked directly and could communicate it.

It is recommended to use Proxy 1 (if applicable) and can be applied to children from 4-7 years and to children of 8+ who are not able to fill in the EQ-5D-Y themselves.

7.2. Other EQ-5D Products

7.2.1. EQ-5D-3L Translations and other formats
The EQ-5D-3L (EQ-5D 3 level) self-complete paper version is currently translated in more than 170 language versions. Likewise, although the EQ-5D-3L was also primarily designed as a pen-and-paper self-complete instrument, it is now available in alternative formats and modes of administration, and in multiple translations:

- Face-to-face and proxy paper
- Tablet
- Interactive Voice Response
- Telephone
- PDA
- Web

If you want to know whether an EQ-5D-3L language version exists for your country, please consult the EuroQol website.
7.2.2. EQ-5D-5L Translations and other formats

The EQ-5D-5L (EQ-5D 5 level) self-complete adult paper version is currently available in more than 100 different language versions. In order to increase the sensitivity of the EQ-5D-3L an updated version, the EQ-5D-5L was finalised in 2011\(^4\). The EQ-5D-5L is a five level version of EQ-5D, maintaining the dimension format but with new response labels for the five levels. The top label for the mobility domain was changed from “confined to bed” to “unable to walk about”. Likewise, although the EQ-5D-5L was primarily designed as a pen-and-paper, self-complete instrument, it is now available in alternative formats and modes of administration, and in multiple translations:

- PDA
- Telephone
- Proxy paper
- Web
- Tablet

If you want to know whether an EQ-5D-5L version exists for your country, please consult the EuroQol website.

7.3. Translation process

All translations/adaptations of EQ-5D-Y are produced using a standardized translation protocol that conforms to internationally recognized guidelines. These guidelines aim to ensure equivalence to the English ‘source’ version and involve a forward/backward translation process and cognitive debriefing. Only the EuroQol Executive Office can give permission for a translation to be performed and translations can only be stamped as official if they are performed in cooperation with EuroQol Group reviewers.

7.4. How to obtain EQ-5D-Y?

All self-report and alternative modes of self-report versions in different languages must be obtained exclusively from the EuroQol Executive Office. Tablet and PDA versions are exclusively provided via the EuroQol Group’s preferred vendors. Licensing fees are determined by the EuroQol Executive Office on the basis of information provided by the user via the online registration form. Whether a fee is appropriate depends upon the type of study, size and/or number of patients/respondents and requested languages.

8. FAQs

8.1. General

For what period of time does EQ-5D-Y record health status? Self-reported health status captured by EQ-5D-Y relates to the respondent’s situation at the time of completion. No attempt is made to summarise the recalled health status over the preceding days or weeks, although EQ-5D-Y has been tested in recall mode. An early decision taken by the EuroQol Group determined that health status measurement ought to apply to the respondent’s immediate situation - hence the focus on ‘your health today’.

Can I use only the EQ-5D-Y descriptive system or only the EQ VAS? We cannot advise this. EQ-5D-Y is a 2-part instrument so if you only use 1 part you cannot claim to have used EQ-5D-Y in your publications.

How long should the EQ VAS be? Officially, for paper versions, the EQ VAS scale should be 20cms. All methodological and developmental work has been carried using this length. To ensure that you print the correct length, make sure your paper size is set at A4 and the box in your printing instructions labelled ‘scale to paper size’ is set at ‘no scaling’.

Can I publish our study using EQ-5D-Y? Yes, you are free to publish your results. If you are reproducing the EQ-5D-Y in an appendix we request that you use the sample version of EQ-5D-Y and that the following text is included in the footer: © 2008 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.

What is the difference between the EQ-5D-Y descriptive system and the EQ VAS? The descriptive system can be represented as a health state, e.g. health state 11212 represents a patient who indicates some problems on the usual activities and anxiety/depression dimensions. The EQ VAS self-rating records the respondent’s own assessment of their health, including but not limited to the 5 domains of health of the descriptive system. The EQ VAS scores are anchored on 100 = best health you can imagine and 0 = worst health you can imagine.

Is it possible to calculate a single index value out of the descriptive system of the EQ-5D-Y? At present, it is not possible to calculate a single index value for the EQ-5D-Y. A value set for the EQ-5D-Y is not yet available. It is not recommended to use the 3L value set as proxy value set for the EQ-5D-Y. The EuroQol Group is working on a special value set for the EQ-5D-Y at the moment.

8.2. Registration

I am not conducting a study but would like to use the EQ-5D-Y to measure routine clinical outcomes or to set-up a registry. Do I still need to register? Yes. You can only obtain EQ-5D-Y versions by completing the online EQ-5D Registration Form.
8.3. Copyright

Is the EQ-5D-Y a copyrighted instrument?
Yes. Please note that without the prior written consent of the EuroQol Executive Office, you are not permitted to i.e. use, reproduce, alter, amend, convert, translate, publish or make available in whatever way (digital, hard-copy etc.) the EQ-5D-Y and related proprietary materials. The EuroQol Group stresses that any and all copyrights in the EQ-5D-Y, its (digital) representations, and its translations exclusively vest in the EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.
9. References and Publications

9.1. Key EuroQol Group references


9.2. Referring to the EQ-5D-Y instrument in publications

When publishing results obtained with the EQ-5D-Y, the following references can be used:


9.3. EQ-5D Books

This book captures up-to-date and expanded information of EQ-5D self-reported health and index values. EQ-5D population norms and cross-country analyses are provided from representative national surveys of 20 countries and additional regional surveys. The book can be obtained from Springer at www.springeronline.com and is also available as open-access book.

This book describes the history of the institutional and administrative framework within which the EuroQol Group operated. It also presents how the EQ-5D's descriptive system was determined, how translation and language issues were handled, and how valuations were provided. The book and e-book can be obtained from Springer at www.springeronline.com.

This book provides an essential guide to the use of the EuroQol Group’s value sets for anyone working with EQ-5D data and can be obtained from Springer at www.springeronline.com.

This book is a collection of papers representing the collective intellectual enterprise of the EuroQol Group and can be obtained from Springer at www.springeronline.com.

This book reports on the results of the European Union-funded EQ-net project which furthered the development of EQ-5D in the key areas of valuation, application and translation. The book can be obtained from Springer at www.springeronline.com.