



# EQ-5D

## EQ-5D-Y User Guide

How to apply, score, and present results from the EQ-5D-Y

**EQ-5D-Y**

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 ☐

**WORRIED, SAD OR UNHAPPY**

I have no problems ☐

I have some problems ☐

I have a lot of problems ☐

The best health you can imagine

100

95

90

85

80

75

70

65

60

55

50

45

40

35

30

25

20

The worst health you can imagine

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

- Updates have been made to nearly all sections of the User Guide, including: a revised section on converting EQ-5D-Y states to an index value – now that a standard EuroQol valuation protocol has been developed specifically for the EQ-5D-Y; a revised section on how to present results; expanded descriptions of available modes of administration and translations; inclusion of information boxes throughout (e.g. about sources for further background reading; research into a five-level version of the EQ-5D-Y; example text for study protocols).
- Following the launch of the new [EuroQol website](#) – which contains regularly updated, detailed information about EQ-5D – this update of the User Guide uses hyperlinks to refer users to relevant webpages for the latest information on a given topic.

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**How to obtain the EQ-5D-Y:** To register your interest in using the EQ-5D-Y for your study/trial/project, please complete the registration form on the [EuroQol website](#). The EuroQol office will then contact you by e-mail and inform you about the terms and conditions that apply to your use of the EQ-5D, including licensing fees (if applicable).

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# 1. Introduction

This guide provides users with basic information on how to use the youth version of EQ-5D, the EQ-5D-Y. Topics include administering the instrument, deriving the index value, value sets, setting up a database for data collected using EQ-5D-Y, presentation of EQ-5D-Y results, modes of administration and translations. The guide should be used in conjunction with the **EuroQol website**, which contains regularly updated, detailed information about all EQ-5D versions, including EQ-5D-Y (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.<sup>1</sup>

*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 consisted of researchers from Europe. Today, it is a global network of more than 100 members from Africa, Asia, Europe, North America, Oceania and South America.

For 30 years EuroQol has funded or co-funded research and development into standardised non-disease-specific instruments to describe

\* The organisational structure is provided on the **EuroQol website**.

and value health-related quality of life. Research areas include: the investigation and application of different valuation methodologies to obtain health state values for use in cost-utility analysis, development of value sets for health states, EQ-5D use in clinical studies and in population surveys, experimentation with the EQ-5D descriptive 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.

Measurement of health-related quality of life in children and adolescents has been a focus of research by the EuroQol Research Foundation for at least two decades. Initial research assessed the performance of EQ-5D in adolescents and then in younger age groups.<sup>2-8</sup> This evolved into an international task force, formed to develop a well-validated version of the EQ-5D for younger respondents, the EQ-5D-Y (see [Section 1.4](#)).<sup>9,10</sup>

Research into the EQ-5D-Y by the Foundation has continued apace over the past decade, facilitated by the EQ-5D in Younger Populations Working Group and other EuroQol Working Groups.

Research has focused on further testing the instrument's measurement properties in a range of populations and settings, developing and testing the performance of an expanded version of the EQ-5D-Y, exploring the possibilities for measuring and valuing health in younger children, and most recently developing the first EQ-5D-Y valuation protocol.

*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 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 latest developments about 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®

*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>11</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 30 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 numerous 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 (see [Section 4](#)). 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 EQ-5D 3L versions are available in a large and growing number of countries.

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

## 1.3/EQ-5D adult versions

### EQ-5D-3L

The EQ-5D three-level (3L) version was introduced in 1990. The EQ-5D descriptive system questionnaire is on page 2 and the EQ VAS is on page 3 of the instrument:

- 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 that ranges from 'The best health you can imagine' to 'The worst health you can imagine'. This information can be used as a quantitative measure of health outcome as judged by 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>12</sup>

### EQ-5D-5L

The EQ-5D-5L was developed to further improve the EQ-5D-3L's sensitivity and to provide respondents with a wider range of options to describe their health.<sup>13</sup> This newer version of EQ-5D includes five response levels in each of the five EQ-5D dimensions: no problems, slight problems, moderate problems, severe problems, 'unable to'/extreme problems. In addition, the most severe label for the mobility dimension was changed from 'I am confined to bed' in the EQ-5D-3L to 'I am unable to walk about', enhancing its applicability and increasing the sensitivity of this dimension. The EQ-5D-5L is currently available in more than 150 different languages (for the self-complete versions) and in several modes of administration.



## 1.4/EQ-5D-Y

### Development history

In 2006, an international task force was established within the EuroQol Group to develop a child-friendly version of the EQ-5D. The rationale behind this development was an increasing demand for a version of EQ-5D that would allow younger respondents to directly self-report their health, without having to rely on reports from intermediaries (e.g. through adult proxies). By developing a version of EQ-5D that was suitable for younger respondents, but which would adhere as far as possible to the content and structure of the standard EQ-5D, it was also hoped that the resulting tool would allow for continuity in the evaluation of health status from paediatric age through to adult populations. The task force focused initially on developing a child-friendly source version in standardised international English from which translated versions could then be derived.<sup>9</sup> During the development of this version, it was agreed to use the terminology 'Youth version' to describe the new variant of EQ-5D, as 'youth' was considered to cover both children and adolescents. The instrument was therefore named 'EQ-5D-Y' (Figure 1).

Development and initial testing of the EQ-5D-Y was overseen by the task force and consisted of six steps:

1. Review of the adult version's five domain definitions by the task force to determine their applicability to a younger age group.
2. Revision of questionnaire wording to optimise item comprehension for younger respondents.
3. Translation of the standardised source version.
4. Cognitive interviews in Germany, Italy, Spain and Sweden in samples of healthy and chronically ill young people aged 8–18 to assess item comprehension, acceptability and interpretation.
5. Integration of results and decision-making on harmonisation into a provisional new questionnaire.
6. Comparison of results between the new EQ-5D-Y and the standard adult EQ-5D.

Subsequent studies have demonstrated the feasibility, validity and reliability of the instrument.<sup>10,14–16</sup>

### Instrument characteristics

*The EQ-5D-Y descriptive system comprises the same five dimensions as the EQ-5D-3L and EQ-5D-5L, but uses more appropriate, child-friendly wording.*

The EQ-5D-Y consists of three pages: the title page, the EQ-5D-Y descriptive system (page 2) and the EQ VAS (page 3).

The descriptive system comprises the same five dimensions as the EQ-5D-3L and EQ-5D-5L, but uses more appropriate, child-friendly wording. The most relevant differences with the adult EQ-5D-3L are:

- The 'Mobility' dimension header now includes '(walking about)' to facilitate understanding.
- The title of the second dimension was changed from 'Self-Care' to 'Looking After Myself'.
- The 'Usual Activities' dimension is now more child relevant: the new title, 'Doing Usual Activities', is followed by '(for example, going to school, hobbies, sports, playing, doing things with family or friends)'.
- For the fifth dimension, 'Anxiety/Depression' was replaced with 'Feeling Worried, Sad or Unhappy'.
- The wording of the items representing the highest level of severity were changed in all dimensions, from 'confined to bed' to 'a lot of problems walking about', in the first dimension, and from 'being unable to' to

‘having a lot of problems’ (with washing or dressing myself, or doing usual activities) in the second and third dimensions. In the Pain/Discomfort dimension, the upper (worst) level was changed from ‘I have extreme pain or discomfort’ in the adult 3L version to ‘I have a lot of pain or discomfort’ in the Y version; in the final dimension, the upper level was changed from ‘I am extremely anxious or depressed’ to ‘I am very worried, sad or unhappy’.

- The wording of the first response level in the Looking after Myself dimension was also changed from ‘I have no problems with self-care’ to ‘I have no problems washing or dressing myself’.

Each dimension has three levels: no problems/no pain/not worried, some problems/some pain/a bit worried, a lot of problems/a lot of pain/very worried. Respondents are asked to indicate their own health state by checking the box next to the most appropriate response level for each of the five dimensions. Responses are coded as single-digit numbers expressing the severity level selected in each dimension. For instance, ‘some problems’ (e.g. ‘I have some problems 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 some 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).

### 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, based on just the numbers one cannot assume that a state 21111 is better than 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](#)).

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 respondent’s perception of their overall health.

Table 1 provides recommendations on how to apply the EQ-5D-Y for children and adolescents in different age ranges. For children aged 4–7 years, a proxy version should be used – i.e. a version of the questionnaire that is suitable for completion by a third party (e.g. a parent, caregiver or health professional), on the child’s behalf. In children aged 8–15 years, the EQ-5D-Y is generally recommended. However, depending on the study design, for older adolescents it may be more appropriate to use one of the adult versions.



Table 1 / Recommended age range of users of the EQ-5D-Y version

Age range	Recommendation
0–3 years	<ul style="list-style-type: none"> <li><b>No EQ-5D-Y version is available for this age range</b></li> </ul>
4–7 years	<ul style="list-style-type: none"> <li><b>For children aged 4–7, a proxy version should be used</b> No self-reported EQ-5D-Y is available for this age range at present. See <a href="#">Section 7</a> and boxes below for more information on proxy versions</li> </ul>
8–11 years	<ul style="list-style-type: none"> <li><b>Use EQ-5D-Y</b> The EQ-5D-Y is more understandable for children in this age range than an adult version of the EQ-5D</li> </ul>
12–15 years	<ul style="list-style-type: none"> <li><b>Both the EQ-5D-Y and adult EQ-5D versions can be used</b> An overlapping area. Generally, EQ-5D-Y is recommended. However, depending on study design, it might also be appropriate to use one of the EQ-5D adult versions. For example, if a study includes both adult respondents and respondents between the ages of 12 and 15, the study team might prefer to use just one version of EQ-5D across the whole study population</li> </ul>
16 years and older	<ul style="list-style-type: none"> <li><b>Use an adult version (EQ-5D-3L or EQ-5D-5L)</b> A possible exception would be a study that only includes children up to age 18. In this case, it may be preferable to use EQ-5D-Y across the full age range to avoid using two different versions of EQ-5D</li> </ul>

## EQ-5D-Y: USE OF PROXY VERSIONS

When responses cannot be obtained directly from an individual (e.g. if they are too young or too ill to complete a questionnaire themselves), a third party can be asked to complete the questionnaire on their behalf. With paediatric-age populations, these 'proxy respondents' are usually parents.

As pointed out in recent guidelines,<sup>17</sup> obtaining responses directly from children themselves (self-report) is the ideal approach to patient-reported outcomes (PRO) data collection, whenever feasible. However, the use of proxy respondents is fairly common in the field of PRO research in children, since it can be the only means of obtaining reliable PRO data, especially in young children (under the age of about 7–8 years) who would have difficulty completing a questionnaire themselves. The use of proxy measures can also be useful or essential in some older paediatric age groups, such as those with learning or behavioural disorders, or neurocognitive conditions.

Study teams with research aims that require a proxy version of the EQ-5D-Y can choose from two options:

- In **proxy version 1**, the proxy (parent, other caregiver or informant) is asked to respond to the questionnaire by providing their own impression of the child or adolescent's health status on the day of administration.
- In **proxy version 2**, the proxy is asked to rate how they think the child or adolescent would rate his/her own health on the day if he/she was able to complete the questionnaire.

When self-report is not feasible, collecting proxy data is clearly better than collecting none at all. However, research in this area suggests that agreement between self-report and proxy responses using EQ-5D-Y is variable and could be influenced by factors such as the type of patient population. One study carried out by EuroQol Group members<sup>18</sup> showed higher correlations between self- and proxy-report when proxy version 1 was used, but there is insufficient research to be conclusive. We recommend caution when comparing or aggregating data obtained using the two different approaches.<sup>19–21</sup>

## EQ-5D-Y: USE OF PROXY VERSIONS IN A MIXED-AGE POPULATION

In children under 12, it is preferable to use the EQ-5D-Y self-complete or proxy version – rather than an adult version – as the wording is more suitable for that age group. However, if proxy versions are to be used in a mixed age population, e.g. in children under 12 and in adults, *and* if the priority is to be able to compare or aggregate results between children and adults, then users could consider using the proxy version of the standard (adult) EQ-5D-3L or EQ-5D-5L for both age groups. Using the same proxy version will facilitate the comparison / aggregation of results and the wording should not cause problems of comprehension, as those responding in both cases will be adults.

On the other hand, if some children in the under 12 group use the self-complete version of the EQ-5D-Y while proxy responses are obtained for others in that group, *and* if the research priority is to be able to compare/aggregate self-complete and proxy responses for the under 12's, then it is preferable to use the EQ-5D-Y version in both cases (self-complete and proxy).

The choice of which version to use in this situation will depend on each study's individual characteristics and objectives. General recommendations on which version to use are outlined in Table 1, but do contact the EuroQol office if your research team would like further advice based on your specific requirements.

## FURTHER BACKGROUND INFORMATION ON THE EQ-5D-Y

An article by Kreimeier et al.<sup>22</sup> brings together the experiences of members of the research team that developed and validated the EQ-5D-Y instrument. The paper summarises the EQ-5D-Y's characteristics, its development and current use, as well as discussing methodological and conceptual issues related to the valuation of child health and the development of an EQ-5D-Y value set.

## IN DEVELOPMENT: EQ-5D-Y version with five severity levels (EQ-5D-Y-5L)

A **five-level version** of the EQ-5D-Y has been developed and is being studied to determine whether it can improve on the psychometric performance of the current youth instrument. A small number of studies have been published to date, and further testing of the five-level version's psychometric properties is underway.<sup>23–26</sup>

## Figure 1/ UK (English) EQ-5D-Y Paper Self-Complete (sample version, v2.1)

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 ☐

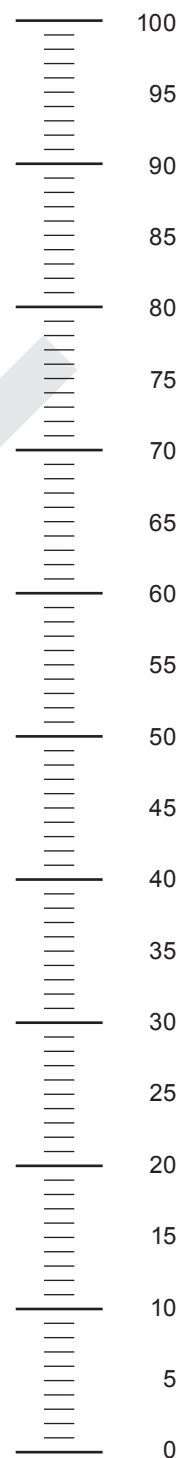
### **FEELING WORRIED, SAD OR UNHAPPY**

- I am not worried, sad or unhappy ☐
- I am a bit worried, sad or unhappy ☐
- I am very worried, sad or unhappy ☐

**Note:** Making any EQ-5D (sample) version available on a publicly accessible webpage is **not allowed**. For reproduction / displaying any EQ-5D sample version, please submit a request for permission by using the EQ-5D registration form.

- 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 your health is TODAY.

The best health  
you can imagine



The worst health  
you can imagine

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

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

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 ☒

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'.

### Notes:

- There should be only ONE response for each dimension.
- Missing values are preferably coded as '9'.
- Ambiguous values (e.g. two boxes ticked for a single dimension) should be treated as missing values.
- This example is for the EQ-5D-Y Paper Self-Complete. Instructions for the 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 three 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 one level from each of the five dimensions.

A total of 243 possible health states is defined in this way. For example, working clockwise from the top of the diagram, state 11223 indicates no problems with mobility or looking after myself, some problems doing usual activities, having some pain or discomfort and feeling very worried, sad or unhappy. State 11111 indicates no problems on any of the five dimensions.



### 3. Scoring the EQ VAS

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

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

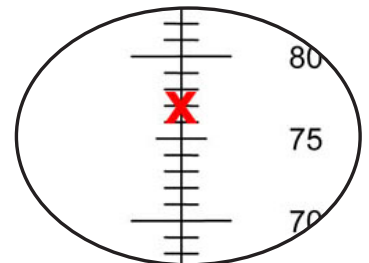
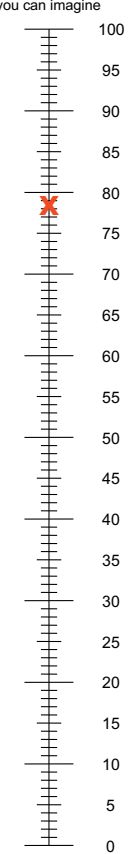
• This line is numbered from 0 to 100.

• 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 your health is 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:

- Missing values should be coded as '999'.



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

EQ-5D-Y health states can be described 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>27-29</sup>

A summary index for the EQ-5D-Y 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. EQ-5D value sets are obtained using 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. Until recently, no value sets were available for EQ-5D-Y because research showed that the approach used to value EQ-5D-3L health states for use in adult populations was not appropriate when valuing EQ-5D-Y health states for use in economic evaluations of healthcare interventions for paediatric-age populations.<sup>30,31</sup> Evidence showed that health states are valued differently when used to describe an adult or a child, that valuation

techniques suitable for valuing ‘adult’ health states may be unsuitable for valuing ‘youth’ health states, and that health state values are affected by the wording used in the instrument (EQ-5D-Y vs EQ-5D-3L). Consequently, EQ-5D-3L value sets should not be used to assign values to EQ-5D-Y health states.

*EQ-5D-3L value sets should not be used to assign values to EQ-5D-Y health states.*

Following an international methodological research programme, led by the EuroQol Group, an evidence-based protocol has been developed to value EQ-5D-Y health states and create standard value sets for the instrument.<sup>31</sup> The protocol for valuing EQ-5D-Y health states uses online discrete choice experiments (DCE) to define the relative importance of dimensions/

\* 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’.

levels and face-to-face composite time-trade-off (cTTO)\* to anchor the DCE values at 1 (full health) and 0 (dead). This new standard protocol is now available for use by research teams to generate EQ-5D-Y value sets for countries around the world.

Using value sets produced with the EuroQol Group's standardised valuation technology, known as EQ-VT, ensures that results are derived using a tried and tested methodology,

which provides robust results and facilitates international comparisons. At the time of publication of this User Guide (September 2020), standard EQ-5D-Y valuation studies have completed data collection in Germany, Indonesia, Japan, Slovenia and Spain; and planning is underway for valuation studies in Australia, Belgium, China, Hong Kong and the Netherlands. Once published, EQ-5D-Y valuation studies will be listed on the [EuroQol website](#).

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

**Note:** As EQ-5D-Y value sets become available, documents containing the scoring algorithms, information on the valuation studies, tables of values for all 243 health states and syntax files\*\* may be requested from the EuroQol office.

*\*\* 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.*

\* cTTO is a TTO variant that adopts conventional TTO for the valuation of better than dead states and lead time TTO for the valuation of worse than dead states. See the FAQ section of the [EuroQol website](#) for more information about TTO.

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

Data collected using EQ-5D-Y is entered in a database, as illustrated in the example below:

Variable Name	ID	Country	Year	Mobility	Looking after Myself	Doing Usual Activities	Having Pain or Discomfort	Feeling Worried, Sad or Unhappy
<b>Variable description</b>	Patient ID number				See table note <sup>a</sup>	See table note <sup>a</sup>	See table note <sup>b</sup>	See table note <sup>c</sup>
<b>Data row 1</b>	1001	UK	2020	2	1	2	2	1
<b>Data row 2</b>	1002	UK	2020	2	1	1	1	1

Variable Name	State	EQ VAS	Index score	Sex	Age	Mode of administration
<b>Variable description</b>	5-digit code for EQ-5D-Y	999 = Missing value		1 = Male 2 = Female 9 = Missing value	999 = Missing value	See table note <sup>d</sup>
<b>Data row 1</b>	21221	80		1	10	2
<b>Data row 2</b>	21111	90		2	12	2

Table notes:

- <sup>a</sup> 1 = No problems, 2 = Some problems, 3 = A lot of problems, 9 = Missing value.  
<sup>b</sup> 1 = No pain / discomfort; 2 = Some pain / discomfort; 3 = A lot of pain / discomfort; 9 = Missing value.  
<sup>c</sup> 1 = Not worried / sad / unhappy; 2 = A bit worried / sad / unhappy; 3 = Very worried / sad / unhappy.  
<sup>d</sup> 1 = Paper self-complete; 2 = Digital self-complete; 3 = Interviewer administered (face to face).

### Notes:

- The variable names are just examples. However, the variables for the five dimensions of the EQ-5D-Y descriptive system should be 'Mobility', 'Looking After Myself', 'Doing Usual Activities', 'Having Pain or Discomfort' and 'Feeling Worried, Sad or Unhappy'.
- A respondent's rating on EQ VAS is to the nearest whole number.



## 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 EQ-5D-Y 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-Y 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. The following subsection illustrates some of the basic ways of presenting EQ-5D data. A comprehensive methodological guide to analysing and reporting EQ-5D data by Devlin and colleagues is also available.<sup>32</sup>

### 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 respondents reporting each level of problem on each dimension of the EQ-5D-Y. In Table 2, results from a cross-sectional study of children aged 8–15 years with juvenile idiopathic arthritis are displayed showing frequencies and propor-

tions by EQ-5D-Y dimension and severity level.<sup>33</sup> Sometimes it is more convenient to split the EQ-5D-Y levels into ‘no problems’ (level 1) and ‘any problems’ (levels 2 and 3), thereby changing the profile into frequencies of reported problems. In this study, problems were most often reported in the EQ-5D-Y Pain/Discomfort dimension (54.7%). A slightly higher rate of problems were reported in Mobility (40.6%) compared to Usual Activities (37.5%) and Worried, Sad or Unhappy (34.4%); Looking After Myself (15.6%) had the lowest rate of problems.

Results can also be broken down for other relevant subgroups in a study – for example, by treatment arm, age group or sex – and/or by study visit, e.g. before/after treatment.



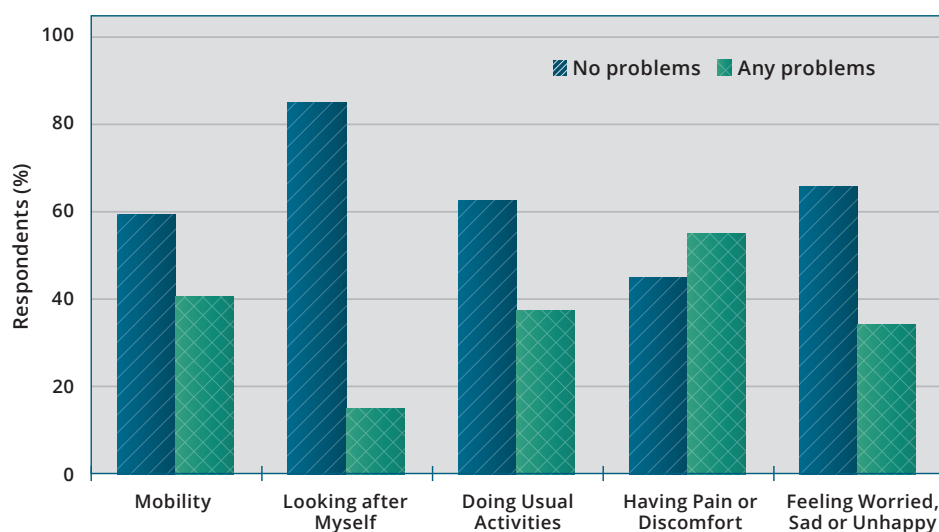
**Table 2 / EQ-5D-Y data, showing frequencies and proportions by dimension and severity level, derived from a study of children aged 8–15 years with juvenile idiopathic arthritis<sup>33</sup>**

EQ-5D-Y dimension		Responses n (%)
<b>Mobility</b>	No problems	38 (59.4)
	Some problems	23 (35.9)
	A lot of problems	3 (4.7)
<b>Looking After Myself</b>	No problems	54 (84.4)
	Some problems	9 (14.1)
	A lot of problems	1 (1.6)
<b>Doing Usual Activities</b>	No problems	40 (62.5)
	Some problems	18 (28.1)
	A lot of problems	6 (9.4)
<b>Having Pain or Discomfort</b>	No problems	29 (45.3)
	Some problems	30 (46.9)
	A lot of problems	5 (7.8)
<b>Feeling Worried, Sad or Unhappy</b>	Not worried, sad or unhappy	42 (65.6)
	A bit worried, sad or unhappy	18 (28.1)
	Very worried, sad or unhappy	4 (6.3)

In addition to presenting the results in tabulated form, you can use graphical presentations. Bar charts can be used to summarise the results in one graph; for example, Figure 2 shows the

proportion of reported problems (levels 2 and 3 combined) for each of the five EQ-5D-Y dimensions.

**Figure 2 / Proportion of respondents reporting no problems or any problems (levels 2 and 3 combined) by EQ-5D-Y dimension, derived from a study of children aged 8–15 years with juvenile idiopathic arthritis<sup>33</sup>**



## 6.2/EQ VAS

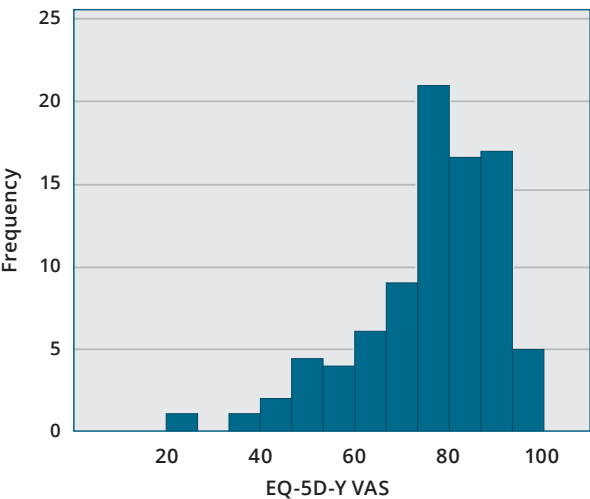
As described earlier, the EQ VAS is a 0–100 scale where respondents are asked to indicate their overall health on the day of questionnaire completion. It is conceptually different from the EQ-5D index, which is a value attached to an EQ-5D profile according to a set of weights that reflect, on average, people’s preferences about how good or bad the state is. The EQ VAS represents the respondent’s perspective, whereas most value sets represent the societal perspective (i.e. what the general population thinks about the value of the health state). Choosing the most relevant perspective depends on the research question. As a rule of thumb, the societal perspective is mostly used in health economics; the respondent’s perspective is more relevant in clinical settings, as well as in population studies and surveys, where economic outcomes are not of interest.

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). For example, in a large cross-sectional survey<sup>34</sup> among students in Sweden (aged 13–18 years; n=6574), girls reported a lower mean VAS score than boys, with a mean VAS (SD) of 71.8 (18.3) versus 78.9 (16.9), respectively.

Respondents with one or both parents unemployed reported a lower mean VAS score compared with respondents where both parents were working; mean (SD) scores were 72.3 (18.8) versus 76.1 (17.3), respectively. In the study of children (aged 8–15) with juvenile idiopathic arthritis, the mean EQ-5D-Y VAS score was 77.8 (23.2).<sup>33</sup>

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

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



## 6.3/EQ-5D-Y index

Value sets for the EQ-5D-Y are now being developed, based on a new standard valuation study protocol. Information about the EQ-5D-Y index, derived using a value set, can be presented in much the same way as the EQ VAS data. Sample mean and standard deviation (or standard error) can be estimated, or medians and interquartile ranges if data is skewed. Note, when reporting index values, a maximum of three decimal places is usually sufficient.

Table 3 gives a hypothetical example of how to present EQ-5D-Y index results for an intervention study. Intervention B improves health status by 0.05 points compared to a reduction in health status of –0.02 points for Intervention A, giving a new overall gain in health status of 0.07 points for Intervention B versus Intervention A (p<0.05) at Week 12.

Table 3 / Impact of treatment on EQ-5D-Y index score (hypothetical data)

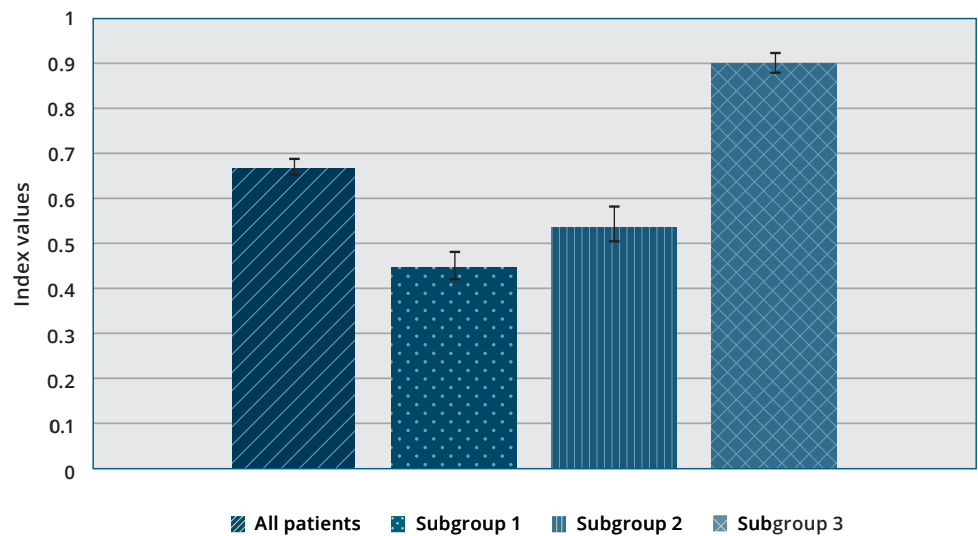
Visit	Intervention A		Intervention B		p-value <sup>a</sup>
	N	Mean (SD)	N	Mean (SD)	
Baseline	229	0.59 (0.30)	227	0.60 (0.28)	0.6345
Week 12	194	0.57 (0.32)	186	0.65 (0.29)	0.0149

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

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-Y index, is subgroup 3.

Subgroup 1 reported the worst health. The differences between all subgroups were statistically significant ( $p<0.05$ ).

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



## ANALYSIS OF INDEX 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 fall with injury 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' (2016).<sup>35</sup>

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

Study protocols and project proposals often need to include a description of EQ-5D and how the results will be reported and analysed. Below is an example of the kind of information that could be provided on EQ-5D-Y for an intervention study.

#### **About the EQ-5D-Y**

- The EQ-5D-Y is a child-friendly version of the widely used EQ-5D generic measure of health status. It consists of two parts. The first part (the descriptive system) assesses health in five dimensions (Mobility; Looking After Myself; Doing Usual Activities; Having Pain or Discomfort; Feeling Worried, Sad or Unhappy), each of which has three levels of response (no problems/no pain/not worried, some problems/some pain/a bit worried, a lot of problems/a lot of pain/very worried). This part of the EQ-5D-Y questionnaire provides a description of the respondent's health that can be used to generate a health state profile. For example, a patient in health state 11223 would have no problems with mobility or looking after him/herself, some problems doing usual activities, some pain or discomfort, and would feel very worried, sad or unhappy. 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 <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 respondent rates his/her perceived health from 0 (the worst imaginable health) to 100 (the best imaginable health). The EQ-5D-Y

questionnaire is cognitively undemanding, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire.

- Guidance is provided by EuroQol on how the EQ-5D-Y should be applied in different age ranges. Between the ages of 4 and 7 years, a proxy-completed version should be used. In children aged 8–15 years, the EQ-5D-Y is generally recommended. Depending on the study design, in older adolescents the use of an adult version may be appropriate. See Table 1 for typical recommendations.

## Reporting and analysis of results

- A health profile will be generated for each patient by visit and by study arm. Summary statistics will be derived, including numbers and proportions of patients reporting each level of severity in each EQ-5D-Y dimension in each visit.
- If relevant (i.e. if results are to be used in an economic evaluation of the intervention[s] under investigation), a health state index value 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<sup>a</sup>]. Mean, SD, minimum, median, and maximum EQ-5D-Y index scores will be provided for the study population and relevant subgroups 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.
- Mean, SD, minimum, median and maximum changes on the EQ-5D-Y index and VAS will be provided 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, vary depending on the study. 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-Y translations and modes of administration

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

The EQ-5D-Y (Paper Self-Complete version) is available in more than 90 languages for use in over 60 countries. All translations/adaptations of EQ-5D, including EQ-5D-Y, are produced using a standardised translation protocol that conforms to internationally recognised guidelines. The guidelines aim to ensure equivalence of the translated version to any of the English (UK), German (Germany), Italian (Italy), Spanish (Spain) and Swedish (Sweden) 'source' versions which are used as the starting point for translation. The translation process itself is based on forward and back translation, and in-depth

cognitive debriefing.<sup>36</sup> New translations can be produced on request by submitting a new registration on the [EuroQol website](#). 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-Y translations for different modes of administration.



## 7.2 / Modes of administration

The EQ-5D-Y is available in several modes of administration (Table 4).

Table 4 / Language versions available for various modes of administration of the EQ-5D-Y

Modes of administration	Total number of languages versions available
SELF-COMPLETE VERSIONS	
Paper	>90
PDA/Smartphone	>30
Tablet	>70
Laptop/Desktop	>10
PROXY VERSIONS	
Proxy version 1 (Paper) <sup>a</sup>	>70
Proxy version 2 (Paper) <sup>b</sup>	>15

<sup>a</sup> Proxy version 1: The proxy (parent, other caregiver or informant) is asked to respond to the questionnaire by providing their own impression of the child or adolescent's health status on the day of administration.

<sup>b</sup> Proxy version 2: The proxy is asked to rate how they think the child or adolescent would rate his/her own health on the day if s/he was able to complete the questionnaire.

Note: Further information is provided about proxy versions of the EQ-5D-Y in [Section 1.4](#).

**Note:** To find out whether an EQ-5D-Y 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](#).

## 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-Y and also has three severity levels: no problems, some problems, extreme problems. Implicitly designed to be used by adults, the wording used in the descriptive system questionnaire and EQ VAS is slightly different from the EQ-5D-Y. The EQ-5D-3L is the original EQ-5D

instrument 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 190 different language versions (for the self-complete versions), across several modes of administration (Table 5).

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

EQ-5D-3L available modes of administration	
Self-complete versions	Interview versions
• Paper	• Face-to-face
• PDA/Smartphone	• Telephone
• Tablet	• Interviewer administration
• Laptop/Desktop	<b>Proxy versions</b>
• REDCap platform <sup>a</sup>	<b>Interactive Voice Response system version</b>
• Limesurvey platform <sup>b</sup>	
• Castor EDC platform <sup>c</sup>	

<sup>a</sup> REDCap is a secure web application for building and managing online surveys and databases. It is specifically geared to support data capture for research studies. More information on the REDCap project and available EQ-5D-3L versions for REDCap can be found on the [EuroQol REDCap webpage](#).

<sup>b</sup> LimeSurvey is an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system. More information on LimeSurvey and available EQ-5D-3L versions for LimeSurvey can be found on the [EuroQol LimeSurvey webpage](#).

<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. More information on Castor EDC and available EQ-5D-3L versions for Castor EDC can be found on the [EuroQol Castor EDC webpage](#).

**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-5L

The EQ-5D-5L has a descriptive system that comprises the same five health dimensions as in the EQ-5D-3L, but each dimension has five levels: no problems, slight problems, moderate problems, severe problems and extreme

problems. The EQ-5D-5L is currently available in more than 150 different language versions (for the self-complete versions), across several modes of administration (Table 6).

Table 6 / EQ-5D-5L available modes of administration

EQ-5D-5L available modes of administration	
Self-complete versions	Interview versions
• Paper	• Face-to-face
• PDA/Smartphone	• Telephone
• Tablet	• Interviewer administration
• Laptop / Desktop	<b>Proxy versions</b>
• REDCap platform <sup>a</sup>	<b>Interactive Voice Response system version</b>
• Limesurvey platform <sup>b</sup>	
• Castor EDC platform <sup>c</sup>	
• British Sign Language version (for use in REDCap)	

<sup>a</sup> REDCap is a secure web application for building and managing online surveys and databases. It is specifically geared to support data capture for research studies. More informatio on the REDCap project and available EQ-5D-5L versions for REDCap can be found on the [EuroQol REDCap webpage](#).

<sup>b</sup> LimeSurvey is an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system. More information on LimeSurvey and available EQ-5D-5L versions for LimeSurvey can be found on the [EuroQol LimeSurvey webpage](#).

<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. More information on Castor EDC and available EQ-5D-5L versions for Castor EDC can be found on the [EuroQol Castor EDC webpage](#).

A growing number of value sets are available for the EQ-5D-5L, derived using a standardised valuation study protocol. The status of all valuation research for the EQ-5D-5L is available on the [EuroQol website](#) (ongoing and completed), along with references for published value sets.

A list of publications that have compared the EQ-5D-3L with the EQ-5D-5L has also been compiled on the [EuroQol website](#).

**Note:** For more information on the EQ-5D-5L and whether an EQ-5D-5L version exists for your country/region, please consult the [EuroQol website](#).



## 9. How to obtain the EQ-5D-Y

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 EQ-5D-Y in your study/trial/project, please complete the registration form on the [EuroQol website](#). Note, you are not obliged to purchase EQ-5D-Y 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 amount 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-Y references</b>	<a href="https://euroqol.org/publications/key-euroqol-references/eq-5d-y/">https://euroqol.org/publications/key-euroqol-references/eq-5d-y/</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>





## 11. References

1. Kennedy-Martin M, Slaap B, Herdman M, van Reenen M, Kennedy-Martin T, Greiner W, Busschbach J, Boye KS. Which multi-attribute utility instruments are recommended for use in cost-utility analysis? A review of national health technology assessment (HTA) guidelines [published online ahead of print, 2020 Jun 8]. *Eur J Health Econ*. 2020;10.1007/s10198-020-01195-8.
2. Hennessy S, Kind P. Measuring health status in children: developing and testing a child-friendly version of EQ-5D. 19th Plenary Meeting of the EuroQol Group, York, UK, 2002.
3. Stolk EA, Busschbach JJ, Vogels T. Performance of the EuroQol in children with imperforate anus. *Qual Life Res* 2000;9:29–38.
4. Badia X, Gracia-Hernandez G, Cobos N, López-David C, Nocea G, Roset M; Grupo VALAIR. Validity of the Spanish version of the Pediatric Quality of Life Questionnaire for evaluating quality of life in asthmatic children. *Clin Med* 2001;116:565–572.
5. Burström K, Egmar AC, Eriksson M, Lugnér A, Svartengren M. Development of a Swedish child-friendly version of the EQ-5D. 20th Plenary Meeting of the EuroQol Group, Bled, Slovenia, 2003.
6. Burström K, Egmar A-C, Eriksson M, Svartengren M. EQ-5D in a Swedish representative population survey of children aged 8 and 12 years: a child-friendly version used in a clinical examination. 22nd Plenary Meeting of the EuroQol Group, Oslo, Norway, 2005.
7. Jelsma J, Knight F, Meyer L, McNaughton S, Smith C, Venning K, Wicks L. The validity of the UK 'child friendly' version of the EQ-5D in South African children aged 9 to 12 years. 22nd Plenary Meeting of the EuroQol Group, Oslo, Norway, 2005.
8. Jelsma J, Coppez P, Jehosofat T, Lenders C, Millet Clay S, Voights A. The concurrent validity of the child friendly version of the EQ-5D when used with high school English speaking children in South Africa. 23rd Plenary Meeting of the EuroQol Group, Barcelona, Spain, 2006.
9. Wille N, Badia X, Bonsel G, Burström K, Cavrini G, Devlin N, Egmar AC, Greiner W, Gusi N, Herdman M, Jelsma J, Kind P, Scalone L, Ravens-Sieberer U. Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. *Qual Life Res* 2010;19:875–886.
10. Ravens-Sieberer U, Wille N, Badia X, Bonsel G, Burström K, Cavrini G, Devlin N, Egmar AC, Gusi N, Herdman M, Jelsma J, Kind P, Olivares PR, Scalone L, Greiner W. Feasibility, reliability, and validity of the EQ-5D-Y: results from a multinational study. *Qual Life Res* 2010;19:887–897.
11. EuroQol Group. EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199–208.
12. Finch AP, Brazier JE, Mukuria C. What is the evidence for the performance of generic preference-based measures? A systematic overview of reviews. *Eur J Health Econ* 2018;19:557.
13. Devlin NJ, Brooks R. EQ-5D and the EuroQol Group: past, present and future. *Appl Health Econ Health Policy* 2017;15:127–137.

14. Bergfors S, Åström M, Burström K, Egmar A-C. Measuring health-related quality of life with the EQ-5D-Y instrument in children and adolescents with asthma. *Acta Paediatr* 2015;104:167–173.
15. Burström K, Bartonek A, Brostrom EW, Sun S, Egmar A-C. EQ-5D-Y as a health-related quality of life measure in children and adolescents with functional disability in Sweden: testing feasibility and validity. *Acta Paediatr* 2014;103:426–435.
16. Chen G, Flynn T, Stevens K, Brazier J, Huynh E, Sawyer M, Roberts R, Ratcliffe J. Assessing the health-related quality of life of Australian adolescents: an empirical comparison of the Child Health Utility 9D and EQ-5D-Y instruments. *Value Health* 2015;18:432–438.
17. Matza LS, Patrick DL, Riley AW, Alexander JJ, Rajmil L, Pleil AM, Bullinger M. Pediatric patient-reported outcome instruments for research to support medical product labeling: report of the ISPOR PRO good research practices for the assessment of children and adolescents task force. *Value Health* 2013;16:461–479.
18. Scott D, Jelsma J. A comparison of the validity of the two EQ-5D-Y proxy versions in acutely and chronically ill children in South Africa. A cross sectional analytical descriptive study – preliminary results. Poster presented 33rd EuroQol Group Scientific Plenary meeting, Berlin, 2016.
19. Perez Sousa MÁ, Olivares Sánchez-Toledo PR, Gusi Fuerte N. Parent-child discrepancy in the assessment of health-related quality of life using the EQ-5D-Y questionnaire. *Arch Argent Pediatr*. 2017;115:541–546.
20. Bray N, Noyes J, Harris N, Edwards RT. Measuring the health-related quality of life of children with impaired mobility: examining correlation and agreement between children and parent proxies. *BMC Res Notes* 2017;10:377.
21. Shirowa T, Fukuda T, Shimosuma K. Psychometric properties of the Japanese version of the EQ-5D-Y by self-report and proxy-report: reliability and construct validity. *Qual Life Res* 2019;28:3093–3105.
22. Kreimeier S, Greiner W. EQ-5D-Y as a health related quality of life instrument for children and adolescents: the instrument's characteristics, development, current use, and challenges of developing its value set. *Value Health* 2019;22:31–37.
23. Kreimeier S, Greiner W. Development of the German version of EQ-5D-Y-5L to measure health-related quality of life in children and adolescents: identification of response labels and pilot testing. *Z Evid Fortbild Qual Gesundheitswes* 2019;144–145:24–34.
24. Kreimeier S, Åström M, Burström K, Egmar AC, Gusi N, Herdman M, Kind P, Perez-Sousa MA, Greiner W. EQ-5D-Y-5L: developing a revised EQ-5D-Y with increased response categories. *Qual Life Res* 2019;28:1951–1961.
25. Wong CKH, Cheung PWH, Luo N, Lin J, Cheung JPY. Responsiveness of EQ-5D Youth version 5-level (EQ-5D-5L-Y) and 3-level (EQ-5D-3L-Y) in patients with idiopathic scoliosis. *Spine* 2019;44:1507–1514.
26. Wong CKH, Cheung PWH, Luo N, Cheung JPY. A head-to-head comparison of five-level (EQ-5D-5L-Y) and three level EQ-5D-Y questionnaires in paediatric patients. *Eur J Health Econ* 2019;20:647–656.
27. Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW. *Methods for the Economic Evaluation of Health Care Programmes*, 4th ed. Oxford: Oxford University Press, 2015.
28. Jonsson B. Ten arguments for a societal perspective in the economic evaluation of medical innovations. *Eur J Health Econ* 2009;10:357–359.
29. Neumann PJ, Sanders GD, Russell LB, Siegel JE, Ganiats TG, eds. *Cost-Effectiveness in Health and Medicine*. Oxford: Oxford University Press, 2016.
30. Kind P, Klose K, Gusi N, Olivares PR, Greiner W. Can adult weights be used to value child health states? Testing the influence of perspective in valuing EQ-5D-Y. *Qual Life Res* 2015;24:2519–2539.
31. Ramos-Goñi JM, Oppe M, Stolk E, Shah K, Kreimeier S, Rivero-Arias O, Devlin N. The international valuation protocol for the EQ-5D-Y-3L. *Pharmacoeconomics* 2020;38:653–663.

32. Devlin N, Parkin D, Janssen B. Methods for Analysing and Reporting EQ-5D Data. Springer International Publishing. 2020. (ebook ISBN: 978-3-030-47622-9; hardcover ISBN: 978-3-030-47621-2).
33. Scott D, Scott C, Jelsma J, Abraham D, Verstraete J. Validity and feasibility of the self-report EQ-5D-Y as a generic Health-Related Quality of Life outcome measure in children and adolescents with juvenile idiopathic arthritis in Western Cape, South Africa. *S Afr J Physiother* 2019;75:1335.
34. Åström M, Persson C, Lindén-Boström M, Rolfson O, Burström K. Population health status based on the EQ-5D-Y-3L among adolescents in Sweden: results by socio-demographic factors and self-reported comorbidity. *Qual Life Res* 2018;27:2859–2871.
35. Wolowacz SE, Briggs A, Belozeroff V, Clarke P, Doward L, Goeree R, Lloyd A, Norman R. Estimating health-state utility for economic models in clinical studies: an ISPOR Good Research Practices Task Force report. *Value Health* 2016;19:704–719.
36. Rabin R, Gudex C, Selai C, Herdman M. From translation to version management: a history and review of methods for the cultural adaptation of the EuroQol five-dimensional questionnaire. *Value Health* 2014;17:70–76.







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