User Guide

EQ-5D-Y-3L

How to apply, score, and present results from the EQ-5D-Y-3L (formerly EQ-5D-Y)

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Version 2.1

Updated April 2024

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CHANGES INCLUDED in this update of the EQ-5D-Y-3L User Guide

- Updates have been made to nearly all sections of the User Guide, including:
 - EQ-5D-Y instrument renamed EQ-5D-Y-3L throughout this document. This is due to the launch of a new version of the EQ-5D-Y instrument (EQ-5D-Y-5L) during 2024, which provides five response levels of severity to questions in the descriptive system
 - Revisions to Table 1 to clarify recommended age ranges of users for different EQ-5D versions
 - Updating the sample instrument (Paper Self-Complete) to version 2.3
 - Updating the status of EQ-5D-Y-3L valuation studies
 - New note that EuroQol does not charge a licence fee for non-commercial uses of EQ-5D of any scale, large or small
 - Changing term EQ-5D Index to EQ-5D values throughout to reflect preferred EuroQol terminology
 - Updating the modes of administration tables
- Please note, this update of the User Guide uses hyperlinks to refer users to relevant webpages on the <u>EuroQol website</u> for the latest information on a given topic.

EQ-5D-Y-3L NAME CHANGE TRANSITION PERIOD

Please note, there will be a period of transition when both the EQ-5D-Y and EQ-5D-Y-3L name will be used in documents. Moreover, EQ-5D versions, obtained by registering with the EuroQol Research Foundation, may still use the old name, "EQ-5D-Y". Both the -Y and -Y-3L versions can be used in the same project, as the content of the instrument has not changed, only its name. Publications about the instrument released before 2024 will most often refer to the EQ-5D-Y.

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How to obtain the EQ-5D-Y-3L: To register your interest in using the EQ-5D-Y-3L for your study/ trial/project, please complete the registration form on the **EuroQol website**. No license fee will be charged for non-commercial use of any scale. For simple non-commercial studies, applicants are asked to agree to EuroQol's Terms of Use. For all other applications, the EuroQol Office will 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-3L. Topics include administering the instrument, deriving a value for EQ-5D-Y-3L health states, value sets, setting up a database for data collected using EQ-5D-Y-3L, presentation of 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-3L. 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-Y-3L, 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 standardised preference-based measure of health-related quality of life (HRQoL) 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.¹ The EuroQol Research Foundation is a registered not-for-profit organisation that invests all income into EQ-5D research, education and user support.

EUROQOI

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 its income into EQ-5D research, education and user support.

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 organisational structure is provided on the <u>EuroQol website</u>.

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 more than 30 years EuroQol has funded or co-funded research and development into standardised non-disease-specific instruments to describe and value HRQoL. 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 selfreported health, and the measurement and valuation of HRQoL in younger populations. The EuroQol Group Association has been holding annual scientific meetings since its inception in 1987.

Measurement of HRQoL 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.²⁻⁸ This work led to the establishment of an international task force, which was formed to develop and validate a version of the EQ-5D for younger respondents, the EQ-5D-Y-3L (initially named the EQ-5D-Y; '3L' indicates the number of response levels to each question) (see <u>Section 1.4</u>).^{9,10}

Research into the EQ-5D-Y-3L by the Foundation has continued apace over the past decade, facilitated by the Younger Populations Working Group and other EuroQol Working Groups.

Research has focused on further testing the EQ-5D-Y-3L's measurement properties in a range of populations and settings, developing and testing the performance of an expanded version of the EQ-5D-Y-3L (the EQ-5D-Y-5L), exploring the possibilities for measuring and valuing health in younger children, and developing the first EQ-5D-Y-3L valuation protocol.¹¹

The EuroQol website provides detailed information and latest developments about all versions of EQ-5D including EQ-5D-Y-3L, guidance for users, a list of available language versions and value sets by country/region, key references, frequently asked questions regarding the use of EuroQol instruments, EQ-5D registration process and forms, information about the EuroQol Group organisation and contact details.

1.2 The EQ-5D[®] family of instruments

EQ-5D is a standardised measure of HRQoL developed by the EuroQol Group to provide a simple, generic questionnaire for use in clinical and economic appraisal.¹²

The EQ-5D[®] family of instruments has been developed to describe and value HRQoL across a wide range of disease areas, settings, and

populations. They are also frequently used in research into health in the general population. There are currently three approved versions of the instrument: **EQ-5D-5L**, **EQ-5D-3L** and **EQ-5D-Y-3L**.* 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.

* A fourth version of the EQ-5D, the EQ-5D-Y-5L, is due to be released during 2024. Further instruments are in development, with the aim of ensuring that the whole lifespan of a person can be covered with different EQ-5D questionnaires, as well as instruments for measuring health and well-being in health and social care.

Each EQ-5D instrument comprises a short descriptive system and a visual analogue scale (EQ VAS) that are cognitively undemanding, taking only a few minutes to complete. The descriptive system provides a simple profile of the respondent's health state on the day they complete the questionnaire. The EQ VAS provides the respondent's rating of their own overall current health status. When the descriptive system profile is linked to a value set, a single summary EQ-5D value* for health status is derived that can be used in economic evaluations of healthcare (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. A number of value sets for the EQ-5D-Y-3L have recently been published, with more in development around the world (see <u>Section 4</u>).

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 <u>Section 7.2</u>). Instructions to respondents are included in the questionnaire.

Note: The instrument names (e.g. EQ-5D-5L, EQ-5D-Y-3L) are not abbreviations and are the correct terms 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-3L consists of two parts, the descriptive system questionnaire and the EQ VAS:

- 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 selfrated 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.¹³

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.¹⁴ This newer version of EQ-5D includes five response levels in each of the five EQ-5D dimensions: no problems, slight

* An EQ-5D value is also sometimes referred to as an index, score, utility, preference weight, preference-based value, or QALY (quality-adjusted life year) weight.

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 180 different languages (for the self-complete versions) and in several modes of administration.

1.4 EQ-5D-Y-3L

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 HRQoL, 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 though 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.9 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' (EQ-5D-Y-3L) (Figure 1).

Development and initial testing of the EQ-5D-Y (EQ-5D-Y-3L) was overseen by the task force and consisted of six steps:

- Review of the adult version's five domain definitions by the task force to determine their applicability to a younger age group.
- 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.

- Integration of results and decision-making on harmonisation into a provisional new questionnaire.
- Comparison of results between the new EQ-5D-Y and the standard adult EQ-5D.

Subsequent studies have demonstrated the instrument's feasibility, validity and reliability.¹⁵

A new 5-level version of the instrument has now been developed. As a consequence, the original 3-level version of the EQ-5D-Y was renamed the EQ-5D-Y-3L in 2023.

Instrument characteristics

The EQ-5D-Y-3L 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-3L consists of two parts, the EQ-5D-Y-3L descriptive system and the EQ VAS.

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 <u>Section 2.1</u>). 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 EQ-5D-Y-3L value, an appropriate 'value set' is required (see <u>Section 4</u>).

The EQ VAS records the respondent's overall current health status on a vertical visual analogue scale between 0-100, 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-3L for children and adolescents in different age ranges. For children aged 4–7 years, a proxy version can 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. An interviewer-administered version is also available for younger children and preliminary studies have shown it to be reliable and valid in the 5–7 years age range.¹⁶ In children aged 8–15 years, the EQ-5D-Y-3L is generally recommended. However, depending on the study design, for older adolescents it may be more appropriate to use one of the adult versions.

AGE RANGE	RECOMMENDATION
0–3 years	 There are no versions of EQ-5D currently available for this age range
4–7 years	 For children aged 4-7, researchers should consider using an interviewer-administered or proxy version of the EQ-5D-Y-3L See <u>Section 7</u> and boxes below for more information on proxy versions
8–11 years	 Use EQ-5D-Y-3L The self-complete version is recommended in this age group. If a child or children in a study are expected to have difficulty responding to the self-complete version, researchers should consider using an interviewer-administered or proxy version.
12–15 years	 Both the EQ-5D-Y-3L and adult EQ-5D versions can be used An overlapping area. Generally, EQ-5D-Y-3L is recommended in this age group. However, depending on study design, it might be preferable to use one of the EQ-5D adult versions. For example, if a study includes a mix of adult respondents and respondents between the ages of 12 and 15 it may be preferable to use an adult version of EQ-5D (EQ-5D-3L or EQ-5D-5L) for all respondents, for the sake of consistency, ease of adminstration and analysis.
16 years and older	 Adult version (EQ-5D-3L or EQ-5D-5L) may be preferred Although it is generally recommended to use an adult version of EQ-5D in respondents aged 16 and over, in studies where all respondents are 18 or under it may be preferable to only use an EQ-5D-Y version for the sake of consistency and ease of administration and analysis.

Table 1 / Recommendations for use of EQ-5D versions by age range^a

^a It is important to note that this table only provides general recommendations and that various factors need to be taken into account when deciding which version (self-complete, interviewer-administered, proxy) of EQ-5D-Y, or adult EQ-5D, to use, including children's literacy level, age range for inclusion, disease characteristics, etc. 9

EQ-5D-Y-3L: 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,¹⁷ 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-3L 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-3L is variable and could be influenced by factors such as the type of patient population. One study carried out by EuroQol Group members¹⁸ 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.¹⁹⁻²¹

EQ-5D-Y-3L: USE OF PROXY VERSIONS IN A MIXED-AGE POPULATION

In children under 12, it is preferable to use the EQ-5D-Y-3L 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-3L 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-3L 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 <u>EuroQol office</u> if your research team would like further advice based on your specific requirements.

FURTHER BACKGROUND INFORMATION ON THE EQ-5D-Y-3L

An article by Kreimeier et al.²² brings together the experiences of members of the research team that developed and validated the EQ-5D-Y-3L instrument. The paper summarises the EQ-5D-Y-3L'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-3L value set. A paper by Devlin et al.²³ provides the current state of play on EQ-5D-Y-3L valuation research.

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 its psychometric properties evaluated in an increasing number of studies. Studies have found that it is a valid and reliable version of EQ-5D-Y, and additional studies are on-going. An approved version of the EQ-5D-Y-5L will be released in 2024.^{15,24-26}

Figure 1 / UK (English) EQ-5D-Y-3L Paper Self-Complete

(sample version, v2.3)

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 <u>a lot</u> 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 <u>a lot</u> 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 <u>a lot</u> of problems doing my usual activities	
HAVING PAIN OR DISCOMFORT	
I have <u>no</u> pain or discomfort	
I have <u>some</u> pain or discomfort	
I have a lot of pain or discomfort	
FEELING WORRIED, SAD OR UNHAPPY	
I am <u>not</u> worried, sad or unhappy	
I am <u>a bit</u> worried, sad or unhappy	
I am <u>very</u> 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**.





2. Scoring the EQ-5D-Y-3L descriptive system

This example shows how a health state is described using the EQ-5D-Y-3L descriptive system:

1		
Δ	Under each heading, please tick the ONE box that best	
	describes your health TODAY.	Levels of perceived
		problems are coded
	MOBILITY (walking about)	as follows:
	l have <u>no</u> problems walking about	
	I have some problems walking about	
	I have <u>a lot</u> of problems walking about	
		└ coded as
	LOOKING AFTER MYSELF	a '1' □
	I have <u>no</u> problems washing or dressing myself	
	I have <u>some</u> problems washing or dressing myself	
	I have <u>a lot</u> of problems washing or dressing myself	
		Coded as
	DOING USUAL ACTIVITIES (for example, going to school,	a '2'
	hobbies, sports, playing, doing things with family or friends)	
	I have <u>no</u> problems doing my usual activities	
	I have some problems doing my usual activities	
	I have <u>a lot</u> of problems doing my usual activities	Level 3 is
		a '3'
	HAVING PAIN OR DISCOMFORT	
	I have <u>no</u> pain or discomfort	
	I have <u>some</u> pain or discomfort	
	I have <u>a lot</u> of pain or discomfort	
	FEELING WORRIED, SAD OR UNHAPPY	
	I am <u>not</u> worried, sad or unhappy	
	I am <u>a bit</u> worried, sad or unhappy	
	I am <u>very</u> worried, sad or unhappy	

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-3L 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-3L Paper Self-Complete version shows how the EQ VAS is scored.



Notes:

• Missing values should be coded as '999'.

4. Converting EQ-5D-Y-3L states to an EQ-5D-Y-3L value

EQ-5D health states can be described using the 5-digit code (see <u>Section 2.1</u>) or represented by a single summary number (**EQ-5D value**),* which reflects how good or bad a health state is according to the preferences of the general population of a country/ region. EQ-5D 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.²⁷⁻²⁹

EQ-5D values for EQ-5D health states are derived by applying a formula that attaches values (weights) to each of the levels in each dimension. The EQ-5D value is calculated by deducting the appropriate weights from 1, the value for full health (i.e. state 1111). The collection of EQ-5D 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-3L 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-3L health states for use in economic evaluations of healthcare interventions for paediatric-age populations.^{11,30} 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-3L vs EQ-5D-3L). Consequently, EQ-5D-3L value sets should not be used to assign values to EQ-5D-Y-3L health states.

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

Following an international methodological research programme led by the EuroQol Group, an evidence-based protocol was developed to value EQ-5D-Y-3L health states and create standard value sets for the instrument.¹¹ The protocol for valuing EQ-5D-Y-3L health states

* An EQ-5D value is also sometimes referred to as an index, score, utility, preference weight, preference-based value, or QALY weight.

uses online discrete choice experiments (DCE) to define the relative importance of dimensions/ levels and face-to-face composite time-trade-off (cTTO)* to anchor the DCE values at 1 (full health) and 0 (dead). The EQ-5D-Y-3L valuation protocol is now available for use by research teams to generate EQ-5D-Y-3L 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 (April 2024), standard EQ-5D-Y-3L valuation studies have been published ³¹ for Belgium, China (mainland), Germany, Hungary, Indonesia, Japan, Netherlands, Slovenia and Spain; are underway or have completed in Australia, Brazil, Hong Kong, Malaysia, Pakistan, Singapore, Taiwan, US and Vietnam. Preparatory work has started for studies in Poland, Saudi Arabia and the United Kingdom. Once published, EQ-5D-Y-3L valuation studies will be listed on the <u>EuroQol website</u>.

Note: It is advisable to contact the relevant national or regional authorities regarding any requirements for national value sets.

Note: As more EQ-5D-Y-3L value sets become available, 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-3L data

Table 2 / Illustration of how to organise EQ-5D-Y-3L data in a database

					LOOKING	DOING	HAVING	FEELING
VARIABLE NAME	ID	COUNTRY	YEAR	MOBILITY	AFTER MYSELF		PAIN OR DISCOMFORT	WORRIED, SAD OR UNHAPPY
Variable description	Patient ID number			1 = No problems, 2 = Some problems, 3 = A lot of problems, 9 = Missing value	1 = No problems, 2 = Some problems, 3 = A lot of problems, 9 = Missing value	1 = No problems, 2 = Some problems, 3 = A lot of problems, 9 = Missing value	1 = No pain / discomfort; 2 = Some pain /discomfort; 3 = A lot of pain /discomfort; 9 = Missing value	1 = Not worried/sad / unhappy; 2 = A bit worried/sad / unhappy; 3 = Very worried/sad / unhappy
Data row 1	1001	Spain	2020	2	1	2	2	1
Data row 2	1002	UK	2020	2	1	1	1	1

VARIABLE NAME	HEALTH STATE	EQ VAS	EQ-5D VALUE	SEX	AGE	MODE OF ADMINISTRATION
Variable description	5-digit code for EQ-5D-Y-3L	999 = Missing value		1 = Male 2 = Female 9 = Missing value	999 = Missing value	1 = Paper self-complete; 2 = Digital self-complete; 3 = Interviewer admin- istered (face to face)
Data row 1	21221	80	0.624	1	10	2
Data row 2	21111	90	0.896	2	12	2

Notes:

- The variable names are included by way of example. However, the variables for the five dimensions of the EQ-5D-Y-3L descriptive system should always be labelled '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-3L results

Data collected using EQ-5D-Y-3L can be presented in various ways. A basic subdivision can be made according to the structure of the EQ-5D-Y-3L:

- 1. Presenting results from the EQ-5D-Y-3L descriptive system.
- 2. Presenting results of the EQ VAS as a measure of overall self-rated health status.
- **3.** Presenting results for EQ-5D-Y-3L values.

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.³²

6.1 Descriptive system

Reporting descriptive statistics on patientreported 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-3L. In Table 3, results from a cross-sectional study of children aged 8–15 years with juvenile idiopathic arthritis are displayed showing frequencies and proportions by EQ-5D-Y-3L dimension and severity level.³³ Sometimes it is more convenient to split the EQ-5D-Y-3L 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-3L Having Pain or Discomfort dimension (54.7%). A slightly higher rate of problems were reported in Mobility (40.6%) compared to Doing Usual Activities (37.5%) and Feeling 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 3 / EQ-5D-Y-3L data, showing frequencies and proportions by dimension and severity level,derived from a study of children aged 8-15 years with juvenile idiopathic arthritis³³

EQ-5D-Y-3L DIMENSION		RESPONSES N (%)
Mobility	No problems	38 (59.4)
	Some problems	23 (35.9)
	A lot of problems	3 (4.7)
Looking After Myself	No problems	54 (84.4)
	Some problems	9 (14.1)
	A lot of problems	1 (1.6)
Doing Usual Activities	No problems	40 (62.5)
	Some problems	18 (28.1)
	A lot of problems	6 (9.4)
Having Pain or	No problems	29 (45.3)
Discomfort	Some problems	30 (46.9)
	A lot of problems	5 (7.8)
Feeling Worried,	Not worried, sad or unhappy	42 (65.6)
Sad or Unhappy	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-3L dimensions.

Figure 2 / Proportion of respondents reporting no problems or any problems (levels 2 and 3 combined) by EQ-5D-Y-3L dimension, derived from a study of children aged 8–15 years with juvenile idiopathic arthritis³³



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 they complete the questionnaire. EQ VAS scores are conceptually different to EQ-5D-Y-3L values, or Index scores, which are described in the next section. EQ VAS scores represent the individual respondent's perception of their current overall health, while EQ values represent the value (or utility) which a society attaches to a given EQ-5D-Y-3L health state. Whether to use one or the other, or both, when presenting study results depends on the aim of the study. EQ VAS data may be more relevant in clinic settings, or population studies and surveys, when self-reported descriptive data are required, whereas EQ-5D-Y-3L values may be more relevant in economic assessments of health care, when perceived benefits at a societal level are relevant.

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-setional survey³⁴ 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.

6.3 EQ-5D-Y-3L values

Value sets for the EQ-5D-Y-3L are now available, based on the EuroQol Group's standard valuation protocol for the instrument. These value sets are used to assign a value (also known as an index, score, utility, preference weight, or QALY weight) to each health state generated by the EQ-5D-Y-3L descriptive system. EQ-5D-Y-3L values 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 EQ-5D-Y-3L values, a maximum of three decimal places is usually sufficient. 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-3L VAS score was 77.8 (23.2).³³

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



Figure 3 / EQ VAS frequency distribution (hypothetical data)

Table 4 gives a hypothetical example of how to present EQ-5D-Y-3L value 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.

VIOIT	INTERVENTION A		INTERVENTION A INTERVENTION B		P-VALUE ^a
VISIT	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

^a Using *t*-test.

Data can also be presented graphically; a hypothetical example is presented in Figure 4 where the group with the highest mean health status, using EQ-5D-Y-3L values, 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-3L values and 95% confidence intervals for the total patient population and three subgroups (hypothetical data)



ANALYSIS OF EQ-5D VALUES 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).³⁵

EXAMPLE TEXT FOR DESCRIBING THE EQ-5D-Y-3L AND REPORTING AND ANALYSING EQ-5D-Y-3L 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-3L for an intervention study.

About the EQ-5D-Y-3L

The EQ-5D-Y-3L is a child-friendly version of the widely used EQ-5D generic measure of HRQoL. 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-3L 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 EQ-5D-Y-3L value 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 EQ-5D values 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 values 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-3L

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-3L should be applied in different age ranges. Between the ages of 4 and 7 years, a proxy-completed version can be used. In children aged 8–15 years, the self-complete version of EQ-5D-Y-3L 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-3L dimension in each visit.
- If relevant (i.e. if results are to be used in an economic evaluation of the intevention[s] under investigation), a health state EQ-5D-Y-3L 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^a]. Mean, SD, minimum, median, and maximum EQ-5D values 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 in EQ-5D-Y-3L values and on the EQ 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.
- ^a See <u>FAQs</u> section on choosing a value set, for more information.

7. EQ-5D-Y-3L translations and modes of administration

7.1 EQ-5D-Y-3L translations

The EQ-5D-Y-3L (Paper Self-Complete version) is available in more than 100 language versions for use in over 60 countries. All translations/ adaptations of EQ-5D, including EQ-5D-Y-3L, are produced using a standardised translation protocol that conforms to internationally recognised guidelines. The translation process itself is based on forward and back translation, and in-depth cognitive debriefing.³⁶ New translations can be produced on request by submitting a new registration on the <u>EuroQol website</u>. 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 <u>EuroQol website</u> or contact the <u>EuroQol office</u>. See the next section regarding the availability of EQ-5D-Y translations for different modes of administration.

Note: New digital versions of EQ-5D

In April 2022, the three previous digital formats of EQ-5D (smartphone, tablet, laptop/desktop) were replaced by one new digital format that can be used on any digital device. As part of the introduction of the new digital format, a library of EQ-5D Representations was also rolled out, consisting of EuroQol Office–approved EQ-5D screenshots of the new digital EQ-5D versions. These will enable customers and vendors to check that their digital implementation of EQ-5D conforms to EuroQol's Digital Representation Design Guidelines. This means that from 6 April 2022, customers are solely responsible for checking the correctness of all digital EQ-5D implementations and screenshot review by the EuroQol Office team is no longer mandatory. However, as a service, the Office team will continue to do screenshot reviews on request.

Note: Renaming of EQ-5D-Y to EQ-5D-Y-3L

EQ-5D-Y was renamed EQ-5D-Y-3L in 2023. It should be noted that, apart from the name, the content of the instrument is identical. The renaming process across all our documents will take time and during this period users should expect to see the old name on some versions of the instrument received from EuroQol.

7.2 Modes of administration

The EQ-5D-Y-3L is available in several modes of administration (Table 5).

Table 5 / Language	versions available	for various mode	s of administration	of the EO-5D-Y-3L
		iei faileas illeas		0.0.0 = 0

MODES OF ADMINISTRATION	TOTAL NUMBER OF LANGUAGES VERSIONS AVAILABLE			
SELF-COMPLE	ETE VERSIONS			
Paper	>110			
Digital devices	>75			
for use in REDCap ^a	>15			
for use in Qualtrics ^b	4			
INTERVIEWER ADMINISTERED				
Interviewer Administered	9			
Interviewer Administered Proxy version 1	1			
Interviewer Administered Proxy version 2	1			
PROXY VERSIONS				
Proxy version 1 (Paper) ^c	>90			
Proxy version 2 (Paper) ^d	>15			

- ^a 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 available EQ-5D-Y-3L versions for REDCap can be found on the <u>EuroQol website</u>.
- ^b Qualtrics is a survey platform that is used by commercial and non-commercial researchers to manage everything from simple questionnaires to detailed research projects. More information on Qualtrics can be found on the <u>EuroQol website</u>.
- ^c 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.

^d 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-3L in Section 1.4.

Note: To find out whether an EQ-5D-Y-3L language version is available for your country/region, please consult the relevant mode of administration section of the <u>EuroQol website</u>. If a language version is not currently available, please contact the <u>EuroQol office</u>.

8. Other EuroQol Group instruments

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-3L 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-3L. The EQ-5D-3L is the original EQ-5D instrument and was introduced in 1990. The EQ-5D-3L is a widely used instrument for measuring health status; it is currently available in more than 180 different language versions (for the self-complete versions), across several modes of administration (Table 6).

Table 6 / EQ-5D-3L available modes of administration

INTERVIEW VERSIONS
• Face-to-face
• Telephone
Interviewer administration
PROXY VERSIONS
INTERACTIVE VOICE RESPONSE SYSTEM VERSION

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**.

Note: Digital platforms

- Qualtrics is a survey platform that is used by commercial and non-commercial researchers to manage everything from simple questionnaires to detailed research projects.
- 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.
- LimeSurvey is an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system.

Information about available versions of these digital platforms can be found 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 7).

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

SELF-COMPLETE VERSIONS	INTERVIEW VERSIONS
• Paper	• Face-to-face
Digital devices	• Telephone
Qualtrics platform	Interviewer administration
REDCap platform	PROXYVERSIONS
Limesurvey platform	INTERACTIVE VOICE RESPONSE SYSTEM VERSION
British Sign Language version (for use in REDCap)	

A growing number of value sets are available for the EQ-5D-5L, derived using a standardised valuation study protocol. A list of published value sets for the EQ-5D-5L is available 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-3L

- The EuroQol Research Foundation is a registered charity in the Netherlands and serves as the single point of distribution for the EQ family of instruments.
- If you would like to use EQ-5D-Y-3L in your study/trial/project, you must first complete the registration form on the <u>EuroQol website</u>. Registering does not commit you to purchasing a license.
- After your registration to use EQ-5D-Y-3L has been approved, it can be used free of charge for academic, educational, public health, and other non-commercial purposes.
- Commercial users are charged a license fee, which is calculated by the EuroQol office based on the user information provided in the registration form. Fees charged are used to fund the activities of the EuroQol Research Foundation in line with its <u>vision and mission</u>.
- The <u>EQ-5D licensing policy</u> and standard timelines for licensing and receiving the instrument are available on the <u>EuroQol website</u>.
- For more information on how to obtain the EQ-5D is available 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:

- Answers to frequently asked questions
- EQ-5D terms explained
- Key EQ-5D-Y-3L references
- EQ-5D books
- EQ-5D working papers
- Explanation of EQ-5D version numbering and quality control

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