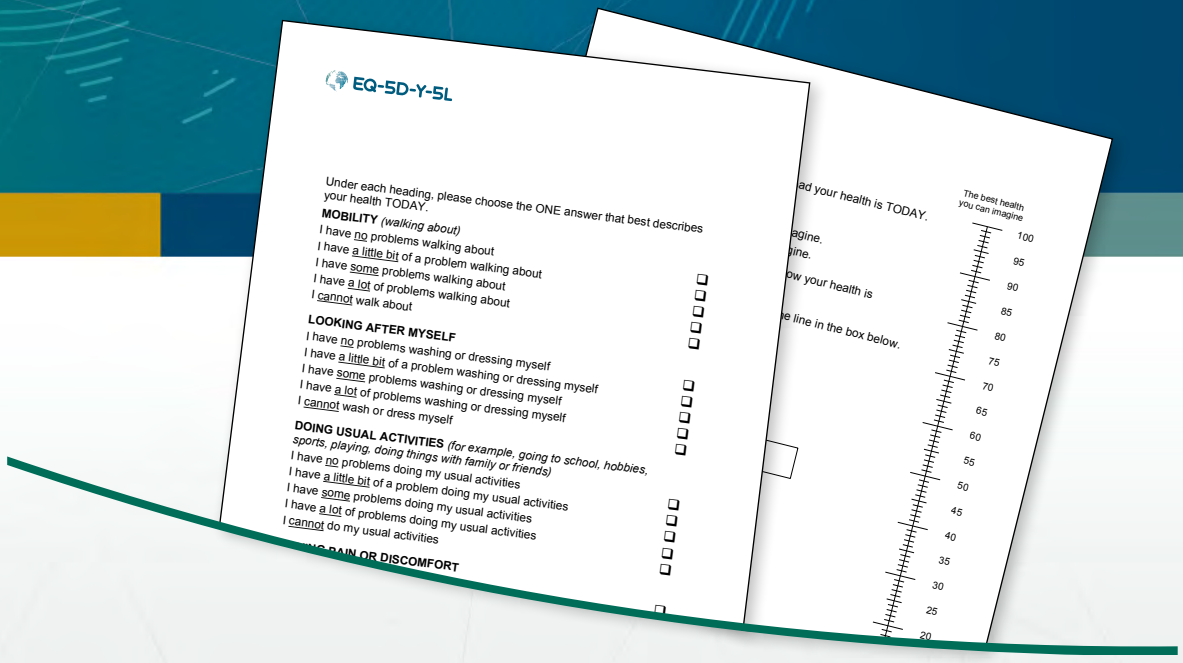
User Guide

EQ-5D-Y-5L

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



Version 1.2
September 2026

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1. Introduction

This guide provides users with basic information on how to use the five-response level youth version of EQ-5D, the EQ-5D-Y-5L. 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-5L. 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-5L, 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 develops, makes available and supports the use of instruments with the widest possible applicability for the measurement and valuation of health. The Foundation is responsible for the development of the EQ-5D family of instruments, 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]

EuroQol is a registered not-for-profit organisation that invests all income into EQ-5D-related 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 Foundation 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 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.

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

For more than 35 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 of different valuation methodologies to generate health state values for use in cost-utility analysis, the development of country-specific value sets for all EQ-5D instruments, analysis of EQ-5D's performance in clinical studies and population surveys, experimentation with the EQ-5D descriptive system and the use of 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 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 over 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) (see Section 1.4).[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, exploring the possibilities for measuring and valuing health in younger children, developing the first EQ-5D-Y-3L valuation protocol[11], and developing and testing the performance of an expanded version of the EQ-5D-Y-3L, the EQ-5D-Y-5L.

The EuroQol website provides detailed information and the latest updates on all versions of EQ-5D including EQ-5D-Y-5L. Materials provided there include guidance for users, a list of available language versions and value sets by country/region, key references, frequently asked questions on using EuroQol instruments, details of the EQ-5D registration process and registration 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 four versions of the instrument: **EQ-5D-3L**, **EQ-5D-5L**, **EQ-5D-Y-3L** and **EQ-5D-Y-5L**.* For over 30 years, EQ-5D instruments have been widely used in clinical trials, population studies and in real-world clinical settings. Given their use worldwide, they have been translated, into numerous languages through a closely monitored translation process.**

* *Other instruments currently in development, with experimental status, include the EQ-TIPS (Toddler and Infant Populations), a new instrument to measure and value health in children aged 0–3 years, and the EQ-HWB (Health and Well-being instrument) which assesses a broader range of dimensions than standard EQ-5D instruments and is intended for use in evaluating interventions in healthcare, public health, and social care.*

** *Please note, users are not permitted to translate EuroQol instruments, such as EQ-5D, without permission. Using tools such as Google Translate or generative artificial intelligence (e.g., ChatGPT) to create a translation is a breach of copyright (see Section 7.1).*

Each EQ-5D instrument comprises a short descriptive system and a visual analogue scale (EQ VAS) that are cognitively undemanding and take 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, while the 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 each EQ-5D health state can be derived for use in in economic evaluations of healthcare. 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 are available for the EQ-5D-5L, EQ-5D-3L and EQ-5D-Y-3L in a number of countries, with more in development around the world.

Designed primarily 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 online/telephone). Proxy versions are also available for populations in which self-completion is not possible (see Section 7.2). Instructions to respondents are included in the questionnaire.

Note: The instrument names (e.g. EQ-5D-Y-5L) are not abbreviations and are the correct terms to use in print or verbally.[13]

1.3 EQ-5D adult versions

EQ-5D-3L

The adult EQ-5D three-level (3L) version was introduced in 1990. The EQ-5D-3L instrument consists of two parts, the EQ-5D-3L 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, unable to/extreme problems. The respondent is asked to indicate his/her health state on the day they complete the questionnaire by checking the box next to the most appropriate response level for 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 and valuing 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.[14]

EQ-5D-5L

The EQ-5D-5L was developed to further improve on the EQ-5D-3L's sensitivity and to provide respondents with a wider range of options to describe their health.[15] Approved as an official EuroQol instrument in 2009, the EQ-5D-5L descriptive system includes five response levels in each dimension: no problems, slight problems, moderate problems, severe problems, unable

* *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.*

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 youth versions

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 hoped that the resulting tool would allow for continuity in the evaluation of health status from paediatric though to adult populations. Two youth versions have been developed, the EQ-5D-Y-3L and the EQ-5D-Y-5L.

The EQ-5D-Y descriptive systems comprise the same five dimensions as the adult EQ-5D instruments, but use more appropriate, child-friendly wording.

EQ-5D-Y-3L

The first youth version, the EQ-5D-Y-3L (formerly EQ-5D-Y), has a descriptive system that comprises the same five dimensions as the EQ-5D-3L and EQ-5D-5L, but uses more appropriate, child-friendly wording (see the EQ-5D-Y-3L User Guide for more information). 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.

The EQ-5D-Y-3L (Paper Self-Complete version) is available in more than 100 language versions for use in over 60 countries and in several modes of administration.

EQ-5D-Y-5L

The five-response level version of the youth instrument, the EQ-5D-Y-5L, has been developed to provide respondents with a wider range of options to describe their health.[16] This newer youth version of EQ-5D includes five response levels in each of the five EQ-5D-Y dimensions.

1.5 EQ-5D-Y-5L

Development History

Development of the EQ-5D-Y-5L was initiated via a multi-country study in Germany, Spain, Sweden and the United Kingdom, between May 2014 and June 2018.[16] The development consisted of two phases, with the first phase aiming to identify severity labels for use in the different countries, and the second phase aiming to test the provisional new version incorporating the expanded level structure.

- **Phase 1:** literature search, synonym search, and focus groups, in four countries, with children and adolescents from the general population to identify potential labels. The identified severity labels were subsequently sorted using the response scaling technique in individual interviews with children and adolescents.

- **Phase 2:** preliminary extended version of the youth instrument was tested in individual or group interviews with children and adolescents.

The preferred labels for the EQ-5D-Y-5L were translated into English to check for equivalence and harmonised between the versions for Germany, Sweden, Spain and the United Kingdom. Subsequent studies have demonstrated the feasibility, validity and reliability of the instrument.[17]

Instrument Characteristics

The EQ-5D-Y-5L consists of two parts, the descriptive system and the EQ VAS. The EQ-5D-Y-5L descriptive system uses the same child-friendly wording as in the EQ-5D-Y-3L with expanded levels of report. The five response levels of severity are:

- no problems/no pain/not worried, sad or unhappy
- a little bit of a problem/a little bit of pain/a little bit worried, sad or unhappy
- some problems/some pain/quite worried, sad or unhappy
- a lot of problems/a lot of pain/really worried, sad or unhappy
- cannot do/extreme pain/extremely worried, sad or unhappy

Respondents are asked to indicate their own health on the day they complete the questionnaire 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, 'a little bit of a problem' (e.g. 'I have a little bit of a problem 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 a little bit of a problem in the Mobility (walking about) dimension and no problems in any of the other dimensions (see Section 2 for further information on how to score the descriptive system).

The EQ VAS records the respondent's overall current health 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.

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 EQ-5D-Y-5L value, an appropriate 'value set' is required (see Section 4).

Table 1 provides broad guidance on how to apply the EQ-5D-Y-5L for children and adolescents in different age ranges. These recommendations are based on the collective research of the EQ-5D-Y-3L across different age groups.

As further research is undertaken within these age groups using the EQ-5D-Y-5L, these recommendations are likely to be refined over time.

Table 1 / **Broad guidance on use of EQ-5D versions by age range**[a]

AGE RANGE	RECOMMENDATION
0–3 years	▪ **There are no versions of EQ-5D currently available for this age range**[b]
4–7 years	▪ **For children aged 4-7, researchers should consider using an interviewer-administered or proxy version of the EQ-5D-Y-5L (or EQ-5D-Y-3L)** See Section 7 and boxes below for more information on proxy versions.
8–11 years	▪ **Use EQ-5D-Y-5L (or 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-5L (or EQ-5D-Y-3L) and adult EQ-5D versions can be used** An overlapping area. Generally, EQ-5D-Y-5L (or 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, including those aged 12-15, for the sake of consistency and ease of administration 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-5L (or EQ-5D-Y-3L) version for the sake of consistency and ease of administration and analysis.

[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 the youth or adult EQ-5D to use, including children's literacy level, age range for inclusion, disease characteristics, etc.

[b] A new instrument, EQ-TIPS, is in development to measure and value health in children aged 0-3 years.

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[18], 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 quite 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.

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 EQ-5D-Y instruments 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.[19] 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.[20] Studies comparing EQ-5D-Y-3L proxy versions have shown mixed results of correlations between self- and proxy-report, but there is insufficient research to be conclusive.[19,21] We recommend caution when comparing or aggregating data obtained using the two different approaches.[22-24] As further research is undertaken using the EQ-5D-Y-5L, these recommendations are likely to be refined over time.

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

In children under 12, it is preferable to use the EQ-5D-Y-5L 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-5L 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-5L 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.

COMPARING the EQ-5D-Y-3L and EQ-5D-Y-5L

The EQ-5D-Y-5L descriptive system comprises the same five dimensions as the EQ-5D-Y-3L but has five response options per dimension instead of three.

A good starting point for an overview of the differences in measurement properties between EQ-5D-Y-3L and EQ-5D-Y-5L is a systematic review of studies comparing the two instruments by Cheng and colleagues (2023).[17] The review concluded by supporting the use of the EQ-5D-Y-3L and EQ-5D-Y-5L in a broad range of patients, populations and countries/regions, while noting that the EQ-5D-Y-5L performed at least as well and sometimes better than the EQ-5D-Y-3L.

An advantage of the EQ-5D-Y-5L is the similarity of its descriptive system with the descriptive system of the EQ-5D-5L. This facilitates transitioning between the two instruments (e.g. when following up children into adulthood or when comparing results in children and adults), in comparison to transitioning between the EQ-5D-Y-3L and either the EQ-5D-3L or EQ-5D-5L, where there is a greater difference in wording.

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

Under each heading, please choose the ONE answer that best describes your health TODAY.

MOBILITY *(walking about)*

I have no problems walking about ❑
I have a little bit of a problem walking about ❑
I have some problems walking about ❑
I have a lot of problems walking about ❑
I cannot walk about ❑

LOOKING AFTER MYSELF

I have no problems washing or dressing myself ❑
I have a little bit of a problem washing or dressing myself ❑
I have some problems washing or dressing myself ❑
I have a lot of problems washing or dressing myself ❑
I cannot wash or dress 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 a little bit of a problem doing my usual activities ❑
I have some problems doing my usual activities ❑
I have a lot of problems doing my usual activities ❑
I cannot do my usual activities ❑

HAVING PAIN OR DISCOMFORT

I have no pain or discomfort ❑
I have a little bit of pain or discomfort ❑
I have some pain or discomfort ❑
I have a lot of pain or discomfort ❑
I have extreme pain or discomfort ❑

FEELING WORRIED, SAD OR UNHAPPY

I am not worried, sad or unhappy ❑
I am a little bit worried, sad or unhappy ❑
I am quite worried, sad or unhappy ❑
I am really worried, sad or unhappy ❑
I am extremely worried, sad or unhappy ❑

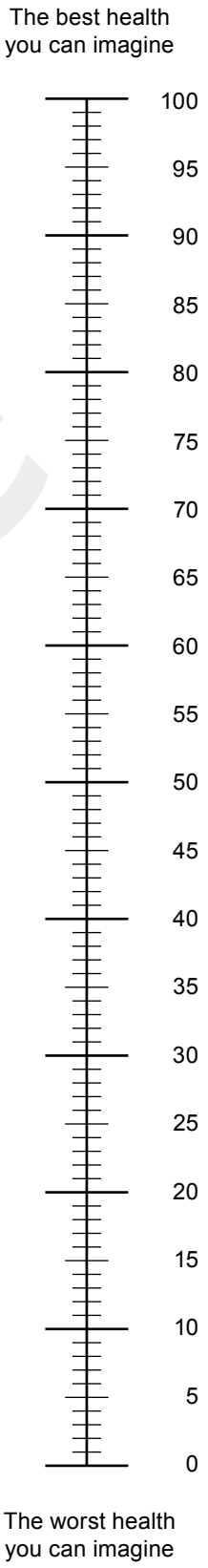
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Note: Making any EQ-5D (sample) version available on a publicly accessible webpage is not allowed. To reproduce or display any EQ-5D sample version, please submit a request for permission by using the EQ-5D **registration form**.

Sample

- 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 to show how your health is TODAY.
- Now, write the number you marked on the line in the box below.

YOUR HEALTH TODAY = ☐



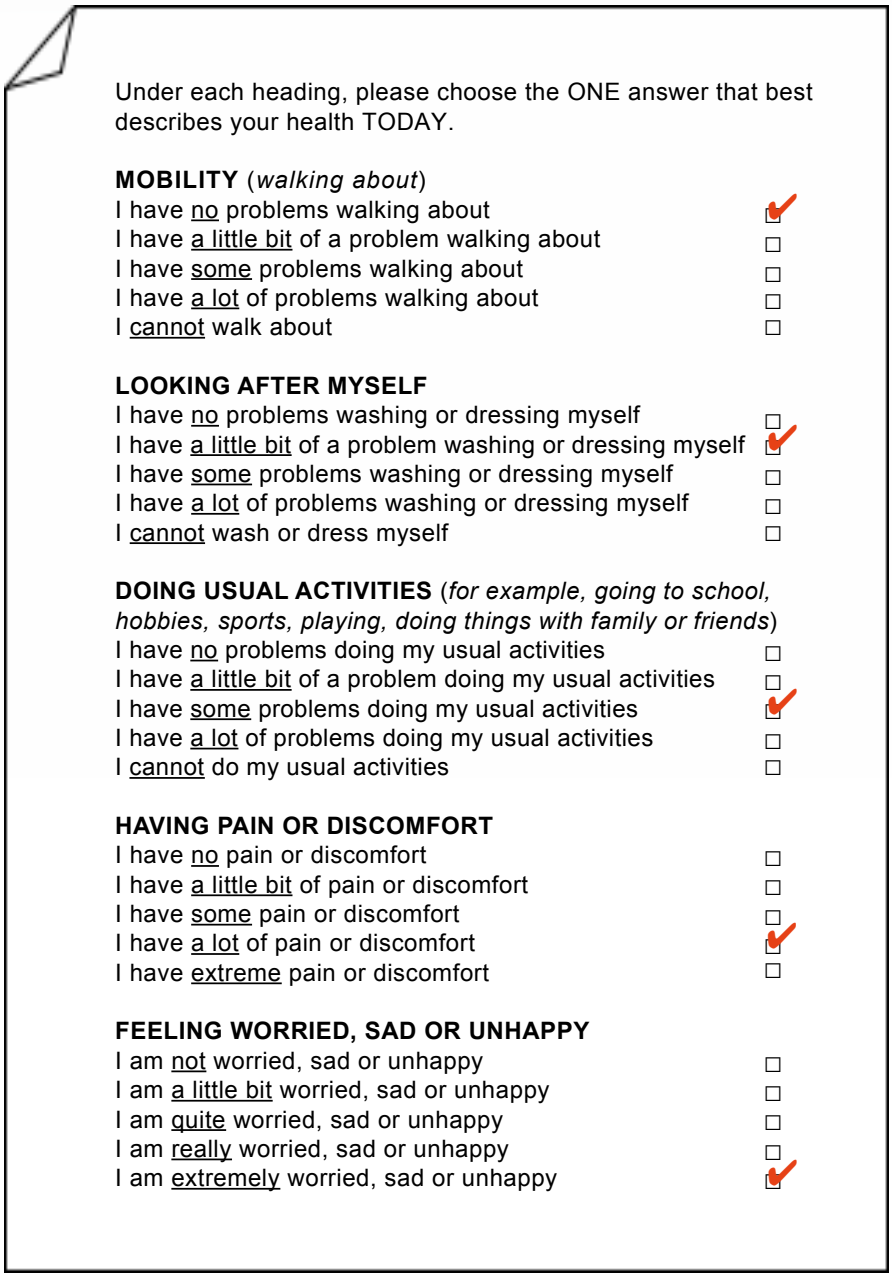
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Sample

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

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



Under each heading, please choose the ONE answer that best describes your health TODAY.

MOBILITY (*walking about*)
I have no problems walking about ☑
I have a little bit of a problem walking about ☐
I have some problems walking about ☐
I have a lot of problems walking about ☐
I cannot walk about ☐

LOOKING AFTER MYSELF
I have no problems washing or dressing myself ☐
I have a little bit of a problem washing or dressing myself ☑
I have some problems washing or dressing myself ☐
I have a lot of problems washing or dressing myself ☐
I cannot wash or dress 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 a little bit of a problem doing my usual activities ☐
I have some problems doing my usual activities ☑
I have a lot of problems doing my usual activities ☐
I cannot do my usual activities ☐

HAVING PAIN OR DISCOMFORT
I have no pain or discomfort ☐
I have a little bit of pain or discomfort ☐
I have some pain or discomfort ☐
I have a lot of pain or discomfort ☑
I have extreme pain or discomfort ☐

FEELING WORRIED, SAD OR UNHAPPY
I am not worried, sad or unhappy ☐
I am a little bit worried, sad or unhappy ☐
I am quite worried, sad or unhappy ☐
I am really worried, sad or unhappy ☐
I am extremely 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'

☐ ☐ ☐ ☑ ☐ Level 4 is coded as a '4'

☐ ☐ ☐ ☐ ☑ Level 5 is coded as a '5'

This example identifies the health state '12345'.

Notes:

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

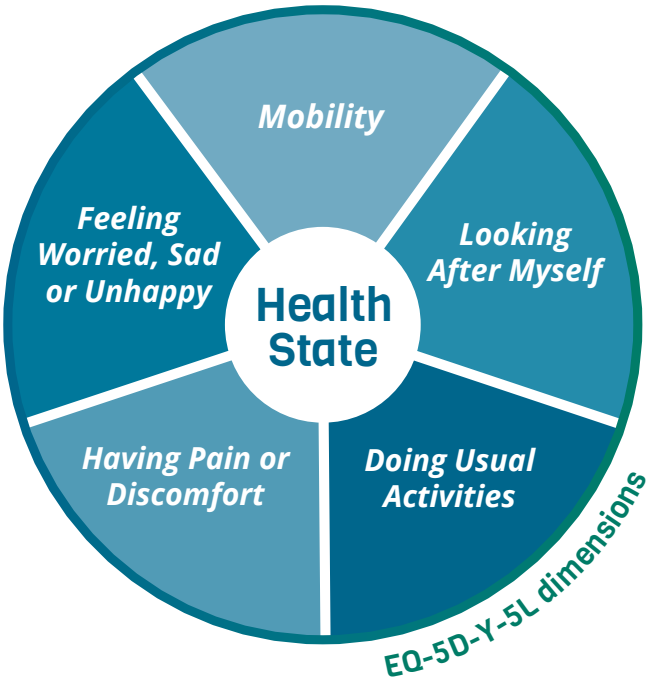
2.1 What is a health state?

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

LEVEL 1: indicating no problem
LEVEL 2: indicating a little bit of a problem
LEVEL 3: indicating some problems
LEVEL 4: indicating a lot of problems
LEVEL 5: indicating cannot/extreme problems

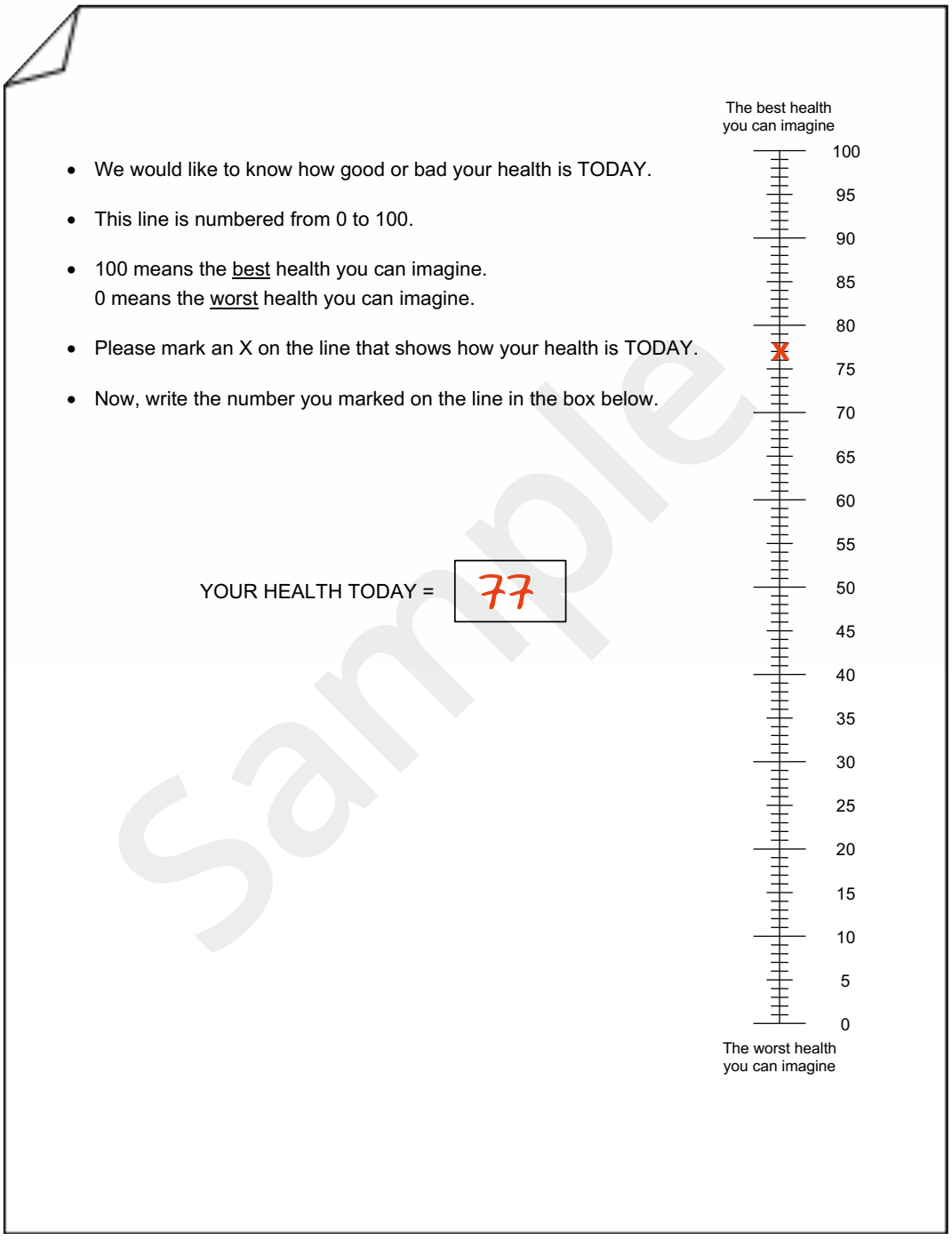
A unique health state is defined by combining one level from each of the five dimensions.

A total of 3125 possible health states is defined in this way. Each state is referred to by a 5-digit code. For example, working clockwise from the top of the diagram, state 12345 indicates no problems with mobility, a little bit of a problem with looking after myself, some problems with doing usual activities, a lot of pain or discomfort and extremely worried, sad or unhappy, while state 11111 indicates no problems on any of the five dimensions.



3. Scoring the EQ VAS

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



Notes:

- Missing values should be coded as '999'.

4. Converting EQ-5D-Y-5L states to a utility value

EQ-5D health states can be described using the 5-digit code (see Section 2.1) 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.[25–27]

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 11111). The collection of EQ-5D values (weights) for all possible EQ-5D health states is called a value set.

At present, value sets for the EQ-5D-Y-5L are not available. The EuroQol Group is currently working on a protocol for the valuation of EQ-5D-Y-5L health states as well as a crosswalk function, which will allow users to link individual responses on the EQ-5D-Y-5L descriptive system with existing EQ-5D-Y-3L value sets.[28] Users are recommended not to use adult EQ-5D-5L value sets to generate values for EQ-5D-Y-5L health states, as societal preferences for adult (5L) health states may differ considerably from societal preferences for child/adolescent (Y) health states.

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

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

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

Table 2 / **Example illustration of one way of organising EQ-5D-Y-5L data in a database**

VARIABLE NAME	ID	COUNTRY	YEAR	MOBILITY	LOOK-ING AFTER MYSELF	DOING USUAL ACTIVITIES	HAVING PAIN OR DISCOMFORT	FEELING WORRIED, SAD OR UNHAPPY
Variable description	Patient ID number			1 = No problems 2 = A little bit of a problem 3 = Some problems 4 = A lot of problems 5 = Cannot 9 = Missing value	1 = No problems 2 = A little bit of a problem 3 = Some problems 4 = A lot of problems 5 = Cannot 9 = Missing value	1 = No problems 2 = A little bit of a problem 3 = Some problems 4 = A lot of problems 5 = Cannot 9 = Missing value	1 = No pain/ discomfort 2 = A little bit of pain/ discomfort 3 = Some pain/ discomfort 4 = A lot of pain/ discomfort 5 = Extreme pain/ discomfort 9 = Missing value	1 = Not worried/ sad/unhappy 2 = A little bit worried/sad/ unhappy 3 = Quite worried/ sad/unhappy 4 = Really worried/ sad/unhappy 5 = Extremely worried/sad/ unhappy 9 = Missing value
Data row 1	1001	Spain	2020	4	1	3	2	5
Data row 2	1002	UK	2020	2	1	1	1	1

Table continued on next page... >>

Table continued >>

VARIABLE NAME	HEALTH STATE	EQ VAS	EQ-5D VALUE	SEX	AGE	MODE OF ADMINISTRATION
Variable description	5-digit code for EQ-5D-Y-5L	999 = Missing value		1 = Male 2 = Female 9 = Missing value	999 = Missing value	1 = Paper self-complete 2 = Digital self-complete 3 = Interviewer-administered (face to face)
Data row 1	41325	63		1	10	2
Data row 2	21111	90		2	12	2

Notes:

- The variable names are just examples. However, the variables for the five dimensions of the EQ-5D-Y-5L 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-5L results

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

1. **Presenting results from the EQ-5D-Y-5L 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-5L values (currently EQ-5D-Y-5L values cannot be derived, but are considered in this section in anticipation of the forthcoming availability of value sets for the instrument).**

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-Y-5L data. A comprehensive methodological guide to analysing and reporting EQ-5D data by Devlin and colleagues is also available.[29]

6.1 Descriptive system

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.

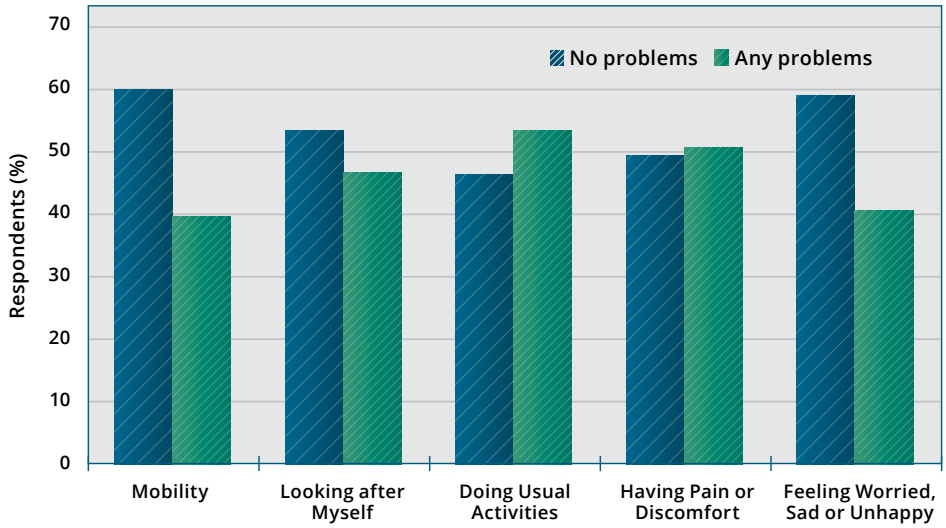
When reporting data, it is important to begin by describing the number and percentage of respondents reporting each level of problem on each dimension of the EQ-5D-Y-5L. In Table 3, results from a study of the Spanish version of the EQ-5D-Y-5L in children aged 6-14 years with cancer are displayed showing frequencies and proportions by EQ-5D-Y-5L dimension and severity level.[30] Sometimes it is more convenient to split the EQ-5D-Y-5L levels into 'no problems' (level 1) and 'any problems' (levels 2, 3, 4 and 5 combined), thereby changing the profile into frequencies of reported problems. In this study, problems were most often reported in the EQ-5D-Y-5L Doing Usual Activities dimension (53.4%). A higher rate of problems were reported in Having Pain or Discomfort (50.7%) compared to Looking After Myself (46.6%). The dimensions Feeling Worried, Sad or Unhappy (41.1%) and Mobility (39.7%) had the lowest rates of problems.

Table 3 / **EQ-5D-Y-5L data, showing frequencies and proportions by dimension and severity level, derived from a study of children aged 6-14 years with a diagnosis of cancer.**[30]

EQ-5D-Y-5L DIMENSION		RESPONSES N (%)
Mobility (Walking about)	No problems	44 (60.3)
	A little bit of a problem	12 (16.4)
	Some problems	11 (15.1)
	A lot of problems	5 (6.8)
	Cannot	1 (1.4)
Looking After Myself	No problems	39 (53.4)
	A little bit of a problem	15 (20.5)
	Some problems	11 (15.1)
	A lot of problems	8 (11.0)
	Cannot	0 (0.0)
Doing Usual Activities	No problems	34 (46.6)
	A little bit of a problem	26 (35.6)
	Some problems	9 (12.3)
	A lot of problems	3 (4.1)
	Cannot	1 (1.4)
Having Pain or Discomfort	No pain or discomfort	36 (49.3)
	A little bit of pain or discomfort	21 (28.8)
	Some pain or discomfort	12 (16.4)
	A lot of pain or discomfort	4 (5.5)
	Extreme pain or discomfort	0 (0.0)
Feeling Worried, Sad or Unhappy	Not worried, sad or unhappy	43 (58.9)
	A little bit worried, sad or unhappy	15 (20.5)
	Quite worried, sad or unhappy	11 (15.1)
	Really worried, sad or unhappy	4 (5.5)
	Extremely worried, sad or unhappy	0 (0.0)

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, 3 ,4 and 5 combined) for each of the five EQ-5D-Y-5L dimensions.

Figure 2 / **Proportion of respondents reporting no problems or any problems (levels 2, 3, 4 and 5 combined) by EQ-5D-Y-5L dimension, derived from a study of children aged 6–14 years with a diagnosis of cancer.**[30]



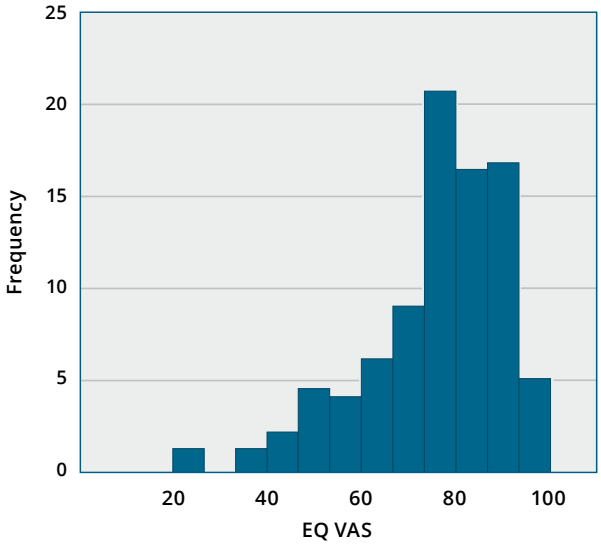
6.2 EQ VAS

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 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-5D values represent the value (or utility) which a society attaches to a given EQ-5D-Y-5L 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 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, a study aimed to establish the population norm of HRQoL in children and adolescents aged 6–17 years in Hong Kong and examine the associations of screen time, sleep duration, and physical activity with HRQoL in this population.[31] Using the EQ-5D-Y-5L, the study found that the mean (SD) EQ VAS in this population was 82.7 (18.5), 82.8 in boys and 82.6 in girls. There were significant differences in the EQ VAS scores among the three age groups: age 6–8, age 9–11, and age 12–17 (mean 88.9 (18.5), 85.2 (17.6), 77.1 (17.5), $p < 0.001$). In this study population, EQ VAS scores were found to be positively correlated with sleep duration and moderate/vigorous activity but was negatively correlated with screen time.

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

Figure 3 / **EQ VAS frequency distribution (hypothetical data)**



6.3 EQ-5D-Y-5L values

At present, value sets for the EQ-5D-Y-5L are not available which means that values (utilities, societal weights) for EQ-5D-Y-5L health states cannot currently be derived. A protocol to value EQ-5D-Y-5L health states is currently in development and a 'crosswalk' function which can link EQ-5D-Y-5L health states to EQ-5D-Y-3L value sets will also be provided in the future. In anticipation of these developments, an introductory subsection on how to present EQ-5D-Y-5L values is provided below.

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-5L descriptive system. EQ-5D-Y-5L 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-5L values, a maximum of three decimal places is usually sufficient.

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

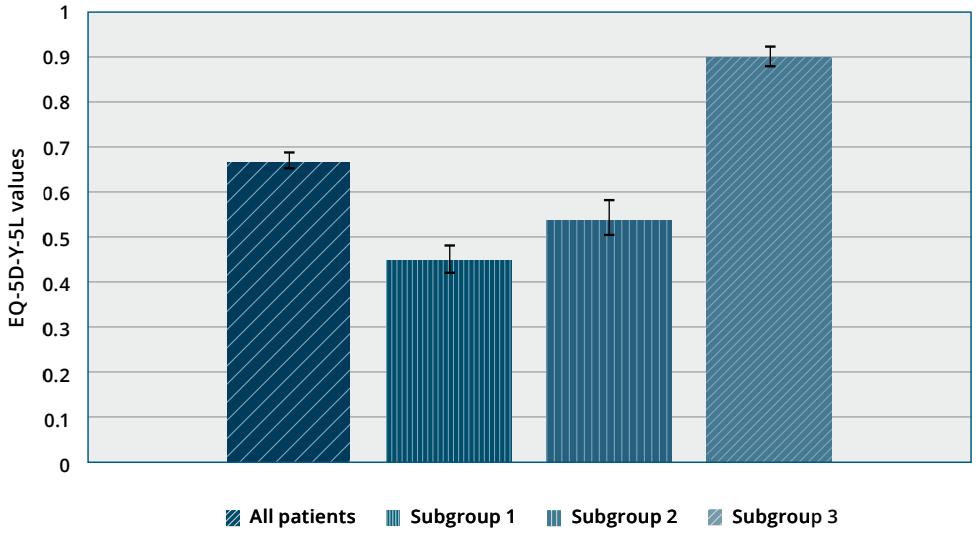
Table 4 / **Impact of treatment on EQ-5D-Y-5L values (hypothetical data)**

VISIT	INTERVENTION A		INTERVENTION B		P-VALUE [a]
	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-5L 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-5L 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).[32]

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

>>

About the EQ-5D-Y-5L

- The EQ-5D-Y-5L 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 five response levels of severity. This part of the EQ-5D-Y-5L 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 11234 would have no problems with mobility or looking after him/herself, a little bit of a problem with doing usual activities, some pain or discomfort, and would feel really worried, sad or unhappy. The second part of the questionnaire consists of a visual analogue scale (EQ 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-5L 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-5L should be applied in different age ranges. Between the ages of 4 and 7 years, researchers should consider using an interview-administered or proxy-version. In children aged 8–11 years, the self-complete version of EQ-5D-Y-5L is generally recommended. Between 12-15 years, generally, EQ-5D-Y-5L is recommended in this age group, however, depending on study design, it might be preferable to use one of the EQ-5D adult versions. 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-5L dimension in each visit.
- The EQ VAS score (between 0 and 100) will be summarised using mean, SD, minimum, median and maximum scores by visit and by treatment.
- 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.
- If value sets are available and 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-5L value will be calculated from individual health profiles. Mean, SD, minimum, median, and maximum EQ-5D values will be provided for the study population and relevant subgroups by visit and by treatment.

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

7.1 EQ-5D-Y-5L translations

A number of EQ-5D-Y-5L paper self-complete and digital versions are available, with more in development. Please check the EuroQol website for the latest list of available language versions.

All translations/adaptations of EQ-5D, including EQ-5D-Y-5L, 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.[33] New translations can be produced on request by submitting a new request to use/registration form on the EuroQol website. The EuroQol Office manages the production of new translations and in general, translation costs are covered by the user 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.

Table 5 / **Digital and paper self-complete language versions of EQ-5D-Y-5L that are either available or at an advanced stage of development.**

COUNTRY	LANGUAGE
Australia	English
Canada	English
Canada	French
China	Simplified Chinese
France	French
Germany	German
Hungary	Hungarian
Italy	Italian
Japan	Japanese
Mexico	Spanish
Netherlands	Dutch
Puerto Rico	Spanish
Spain	Spanish
United Kingdom	English
USA	English
USA	Spanish

Note: You can also check using the EQ-5D registration process on the EuroQol website to see whether the language version you need is available. If it is not available, you will be provided with a quote and timelines for producing the translation.

Developing unofficial translations of EuroQol instruments
Users are not permitted to translate EuroQol instruments, such as EQ-5D, without permission. Using tools such as Google Translate or generative artificial intelligence (e.g., ChatGPT) to create a translation is a breach of copyright. It may also jeopardise the quality and compromise publication of any resulting research. If you need a language version that is not currently available (see website for available versions), you can request a new translation by submitting a new registration on the EuroQol website.

7.2 Modes of administration

The EQ-5D-Y-5L is available in several modes of administration including:

- Self-complete versions (*paper and digital*)
- Proxy versions (*paper and digital*)
- Interviewer-administered versions (*paper and digital, including proxy interviewer-administered versions*)

Please check the EuroQol website for the latest list of modes of administration available for different language versions.

Note: Digital versions of EQ-5D

The digital format of EQ-5D-Y-5L can be used on any digital device. A library of EQ-5D representations are available, consisting of EuroQol Office–approved EQ-5D screenshots of the digital EQ-5D versions. These enable customers and vendors to check that their digital implementation of EQ-5D conforms to EuroQol's Digital Representation Design Guidelines. This means that customers are solely responsible for checking the correctness of all digital EQ-5D implementations and screenshot review. However, as a service, the Office team will do screenshot reviews on request.

8. Other EuroQol Group instruments

8.1 EQ-5D-Y-3L

The EQ-5D-Y-3L (formerly EQ-5D-Y) was the first EQ-5D version developed specifically for children and adolescents. The EQ-5D-Y-3L has a descriptive system that comprises the same five dimensions as the EQ-5D-3L, but uses more appropriate, child-friendly wording. The EQ-5D-Y-3L (Paper Self-Complete version) is available in more than 100 language versions for use in over 60 countries. EQ-5D-Y-3L is available in several modes of administration (Table 6). Please check the EuroQol website for the latest list of available language versions and modes of administration.

A valuation protocol is now available for the EQ-5D-Y-3L for use by research teams to generate value sets. A number of EQ-5D-Y-3L value sets have already been published, with more in development around the world. For a list of available EQ-5D-Y-3L value sets, please see 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-Y-5L and each dimension has five levels: no problems, slight problems, moderate problems, severe problems and extreme problems. Implicitly designed to be used by adults, the wording used in the descriptive system questionnaire is slightly different from the EQ-5D-Y-5L. 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). Please check the EuroQol website for the latest list of available language versions and modes of administration.

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.

8.3 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. 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). Please check the EuroQol website for the latest list of available language versions and modes of administration.

Table 6 / **Available EQ-5D modes of administration.**

MODES OF ADMINISTRATION	EQ-5D-3L	EQ-5D-5L	EQ-5D-Y-3L	EQ-5D-Y-5L
SELF-COMPLETE VERSIONS				
• Paper Self-Complete	✔	✔	✔	✔
• Digital Self-Complete	✔	✔	✔	✔
• Digital survey platforms[a]	✔	✔	✔	
• British Sign Language version (for use in REDCap)		✔		
PROXY VERSIONS				
• Paper Proxy 1	✔	✔	✔	✔
• Digital Proxy 1	✔	✔	✔	✔
• Digital survey platforms[a], Proxy 1		✔	✔	
INTERVIEWER-ADMINISTERED VERSIONS				
• Paper Interviewer Administration	✔	✔	✔	✔
• Digital Interviewer Administration	✔	✔	✔	✔
• Paper Proxy 1 Interviewer Administration	✔	✔	✔	✔
• Digital Proxy1 Interviewer Administration	✔	✔	✔	✔
• Digital survey platforms[a], Interviewer Administration & Proxy Interviewer Administration	✔	✔	✔	

[a] Digital survey platforms include REDCap, Qualtrics and LimeSurvey. More information is available on the EuroQol website.

Note: Digital platforms

The ready-to-use modules for the digital supported platforms are for non-commercial use only. If a commercial user would like to use one of these platforms, they will receive the regular Digital version and should arrange their own permissions to use the platform and create their own reproduction on the platform.

*Information about available versions of these digital platforms can be found on the **EuroQol website**.*

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

- The EuroQol Research Foundation is a registered charity in the Netherlands and serves as the single point of distribution for the EQ-5D family of instruments.
- If you would like to use EQ-5D-Y-5L in your study/trial/project, you must first complete the registration form on the EuroQol website. Registering does not commit you to purchasing a license.
- After your request to use EQ-5D-Y-5L 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 vision and mission.
- The EQ-5D licensing policy and standard timelines for licensing and receiving the instrument are available on the EuroQol website.
- 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-5L references
- EQ-5D books
- EQ-5D working papers
- Explanation of EQ-5D version numbering and quality control
- Further information and support

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EQ-5D-Y-5L

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