

## 4. EQ-5D in Children

### 4.1. *Validation of the EQ-5D-Y-5L*

As in earlier calls, the Younger Populations Working Group (YPWG) calls again for proposals to carry out validation studies for the newly developed, extended version of the EQ-5D-Y in non-English speaking countries. Over recent years, a YPWG study team has developed an extended 5L version of the EQ-5D-Y. There are currently a few validation studies underway, mainly using the English version, but we are interested in receiving further proposals to test the measurement properties of the extended version (e.g. its sensitivity, validity, feasibility) in populations of children and adolescents in non-English speaking countries. We would particularly welcome proposals that aim to:

- Test the psychometric properties and performance of the extended EQ-5D-Y-5L in disease areas that cover the whole range of possible health impairments
- Compare the EQ-5D-Y-3L to the extended EQ-5D-Y-5L and therefore help to show whether instrument validity and sensitivity are improved in the extended version

Further, it will be relevant to conduct reviews, secondary data analysis and – if needed and not too expensive – studies that aim for primary data collection (also in English-speaking countries) that compare the EQ-5D-Y instruments (-3L and/or -5L) with other child-specific instruments to gain information on the psychometric performance of the EQ-5D-Y instruments. Especially, comparisons of EQ-5D-Y and CHU9D are very welcome.

*Note: Please be aware that the Office needs some time (at least 6-9 months) to produce a new language version of EQ-5D-Y-5L (where that version is not already available) to support research. This should be considered when planning a project. Further, currently all EQ-5D-Y-5L versions are beta versions. If the English source version changes, amendments to the language versions might be necessary as well.*

### 4.2. *Valuation of EQ-5D-Y-3L*

A valuation protocol for the EQ-5D-Y has been agreed. The YPWG welcomes proposals for EQ-5D-Y-3L valuation studies. If EuroQol members are interested in conducting a national valuation study for the EQ-5D-Y-3L, they should contact Elly Stolk at the Office (stolk@euroqol.org). If a large number of applications are received, the YPWG and the Office

will prioritise the requests. Requests for funding for valuation studies should also include a further (explorative) research question, in addition to the standard protocol. Candidate topics for consideration as research questions include:

- Framing/Wording of the valuation tasks which require respondents to take a ‘child health perspective’ (e.g. descriptor term, “a hypothetical child”, “a child you know”, “you as a child”, etc.)
- Whether and how the age of the child/adolescent described within the task affects valuations
- Impact of respondent background characteristics on the valuation of younger people’s health
- Impact of time/duration on the valuation of child health states
- Whether people’s valuation of child health states (vs. adult health states) reflects their wider views about how health care resources should be prioritized
- People’s priorities for children vs. adults
- Whether and how adult preferences for children and adolescent preferences differ
- Feasibility of TTO to obtain adolescent preferences

#### *Conceptual work on youth valuation*

The YPWG would like to invite proposals for conceptual work about the implications of the common finding of the first valuation studies that the value range of EQ-5D-Y is narrower than the value range of EQ-5D (adult version). These findings likely reflect that for adult and children, people calibrate their time trade-offs differently (i.e. for the same quality of life improvement, they would sacrifice greater proportion of remaining lifespan in adults than in children). What does this mean for the comparability of TTO values of adult and child health states? If a child and an adult both report a health state that has been valued at 0.7, do they have the same quality of life? What are the consequences for cost-effectiveness analysis? Is it possible to compare or aggregate QALY gains incurred in different age groups?

#### *Assessing the appropriateness of the descriptive system*

There is some debate about whether the EQ-5D-Y covers the appropriate domains for assessing the health status of younger populations. Therefore, proposals for research on the relevance of the descriptive system would be welcome, including the relevance of the current dimensions and the wording of dimension headers.

### *Application of EQ-5D-Y (Y-3L/Y-5L)*

Based on PubMed data, EQ-5D-Y seems to be used relatively rarely. The YPWG would like to encourage expanded use. It would be important to learn more about the usefulness and usability of EQ-5D-Y (Y-3L and/or Y-5L) in specific clinical areas/conditions. Studies of the most prevalent conditions are likely to be prioritised, however, studies of other relevant conditions would also be welcomed.

Further, in line with the research initiatives for adults, the use of the youth instruments in routine clinical practice should also be a focus for research. Therefore, the YPWG calls for research on the usefulness and usability of EQ-5D-Y (Y-3L &/or Y-5L) as an outcome measure in routine clinical practice.

### *Testing an interviewer-administered version of the EQ-5D-Y for children aged about 5 to 7 years old*

Lastly, the YPWG is interested in a specific topic: an interviewer-administered version of the EQ-5D-Y is available which can be used in children who are able to report their health state by themselves but are unable or unwilling to self-complete the EQ-5D-Y, e.g. children aged 5-7 years. This version contains some guidance/information for an interviewer (how to use the version, how to ask, etc.). The YPWG calls for proposals to test the use of the interviewer-administered EQ-5D-Y version and the appropriate lower cut-off age. Further, a comparison to the self-report version will be interesting. The aim of this version would be to enable self-report by children at age 7 and maybe below.