

## EQ-5D in Children

### Validation of the EQ-5D-Y-5L

The Younger Populations Working Group (YPWG) calls for proposals to carry out validation studies for the newly developed, extended version/versions 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. Two proposals for validation studies using the English version have been approved 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

### Valuation

A valuation protocol for the EQ-5D-Y will be agreed and published soon. If EuroQol members are interested in a national valuation study for the EQ-5D-Y-3L, they should contact Elly Stolk at the Office ([stolk@euroqol.org](mailto:stolk@euroqol.org)). If a large number of applications are received, the Younger Population Working Group 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
- 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

## **Proxy version for very young populations**

The YPWG is also interested in studies around the development of a version of EQ-5D-Y for very young populations, i.e. those under approximately 5 years of age. There might be an investigation of new versions of the tool or of new aspects which are relevant in younger age-groups, e.g. additional domains, changes in the instructions or language etc.).

We welcome both proposals to undertake primary data collection and proposals to analyse existing datasets. We also welcome both qualitative and quantitative research.

## **Further specific research questions**

There are further specific research questions in which the Younger Population Working Groups is interested and would like to receive proposals.

### ***Testing an interviewer-led version of the EQ-5D-Y for children aged 5 or 6 to 7 years old***

During a past validation study of the EQ-5D-Y proxy version, the Italian team studied some properties of a slightly modified version of the EQ-5D-Y to be used in children who are still able to report their state by themselves but who not able or not willing to self-complete the EQ-5D-Y, e.g. children aged 6-8 years. This version contains some guidance /information for an interviewer (how to use the version, how to ask, etc.). The Working Group calls for proposals to test such an interviewer-led EQ-5D-Y version. The aim of this version would be to enable self-report by children below the age of 8.

- *Exploration of the feasibility and “improvability” of the instructions in the EQ-5D-Y*

### ***Testing the VAS instructions and maybe two different VAS versions in children and adolescents aged 8-15 years.***

During a harmonisation process, the Younger Population Working Group and the Version Management Committee discussed changes in the VAS of the EQ-5D-Y. The instruction ‘Write the number you marked on the line in the box below’ in the EQ-5D-Y self-complete paper versions (as in the adult version EQ-5D-5L) was added. After some explorative pilot testing, there is doubt about whether younger children could actually understand or do this task. For now, it was agreed to just retain the instruction to mark the line. However, it might be aimed for a harmonized solution with the adult version, and also with the Y digital version, where such a box is used. Overall, evidence is needed whether all age groups between 8 and 15 years are able to understand all instructions given for the VAS and especially if they are able to use the “box” version of the VAS or whether we should stick to the original version, “Mark an X on the line”. If EuroQol members are interested, the Version Management Committee needs to be contacted to get information about the wording that needs to be tested.

***Testing whether the instructions of the descriptive system are appropriate for children aged from 8 years***

Past observations of data and discussions with colleagues developing and using the EQ-5D-Y have suggested that the instructions included in the descriptive system (heading, domains label, levels) in the might not be always appropriate and might need to be adjusted. For instance, a better explanation, in the heading, about what is mentioned in the questionnaire and how to answer it, or a more clear explanation of the meaning “problems” might improve the validity of the tool. Research focusing on investigating whether a different wording of the descriptive system should help to ensure the comprehensibility for the target children.