

## 2.4. EQ-5D in Children

The YGWP calls for proposals in 3 main areas of research interest: measurement properties and applications, value sets and valuation methods, and use of EuroQol instruments in the youngest populations.

### *2.4.1. Measurement properties, and applications*

Several priorities for research are identified below in relation to the application and assessment of measurement properties of EQ-5D-Y (Y-3L and Y-5L).

#### *Psychometric properties of EQ-5D-Y values/value sets*

Assessing the psychometric properties of EQ-5D-Y profile data summarised by EQ-5D-Y values as these values become available from a variety of value sets is of particular interest, including analyses of the similarities and differences in psychometric performance between values using self-complete versus proxy reporting of EQ-5D-Y, i.e. how the use of self- vs proxy-reports impacts on utility losses and gains when applying value sets. Research could use new or existing EQ-5D-Y databases. Comparison and sensitivity of results using different value sets with different properties is also of interest.

#### *Applications*

The YPWG particularly encourages research using EQ-5D-Y to assess the impact of **COVID19** and any COVID-related public health measures on health outcomes in children and adolescents. The research could focus on children and adolescents who have had (or have) the condition (in that sense, follow-up of children with 'long' COVID could be of particular interest), or it could focus on the effects on children of lockdown and other measures intended to limit social interaction, though other types of proposal will be considered as well. This area of application seems particularly suitable for large-scale collaborative initiatives between research teams in different countries and we encourage that type of approach.

#### *Assessing measurement properties*

A NICE Decision Support Unit (DSU) document published early last year<sup>1</sup> reported on the results from a systematic review of the psychometric performance of AQoL-6D, CHU9D, EQ-

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<sup>1</sup> Available in Value in Health: <https://doi.org/10.1016/j.jval.2020.09.012>

5D-Y, HUI2 and HUI3. The review covered literature up to March 2019 and focused on publications assessing known-groups validity, convergent validity, responsiveness, reliability, acceptability and feasibility.

The authors concluded that there is a paucity of studies assessing the psychometric properties of EQ-5D-Y instruments (only n=20 studies). Although it is arguable that some relevant studies were not included, the results suggest there is definitely room for more research investigating the Y's psychometric properties, acceptability, and content validity in patient, and other populations. Even in some of the most common chronic childhood conditions (cancer, diabetes, obesity/overweight, ADHD, epilepsy, autism, etc), research into the psychometric performance of EQ-5D-Y is relatively sparse, or non-existent. The YPWG therefore encourages research into the instrument's psychometric performance and content validity in these and other childhood conditions, including acute infectious conditions. Research that can shed light on specific areas of instrument performance where the DSU report suggested evidence is lacking or unclear will be especially welcome, i.e. research covering:

- test-retest reliability
- inter-rater reliability/agreement
- responsiveness
- content validity.

Research into these specific aspects of psychometric performance, and the Y's content validity, will be particularly welcome, both for the EQ-5D-Y-3L and the Y-5L. From psychometric research, we are also keen to learn if systematic differences exist in the psychometrics of the EQ-5D-Y instruments across administration conditions (e.g. Self-report, proxy, interviewer administered). Studies (or analyses of existing databases) which allow assessment of responsiveness after a health care or other intervention (e.g. behavioural interventions for children with ADHD) are especially encouraged.

In addition to the priority areas of application and validation noted above, we also encourage proposals on the following:

- Comparing distributions, agreement, and psychometric performance of the EQ-5D adult and youth versions in age ranges where either an adult or youth version can be used (ages 13 – 18)
- Usefulness and usability of EQ-5D-Y (Y-3L &/or Y-5L) as a routine outcome measure in clinical, or other settings

- Results from representative samples of the general population can provide a useful benchmark when interpreting outcomes on the EQ-5D-Y. The YPWG would like to encourage proposals aiming to provide such population reference data<sup>2</sup>.

Note: if your study will be conducted in a country where the relevant EQ-5D-Y translation is available yet, please be aware that the Office requires at least 6-9 months to produce a new language version of EQ-5D-Y-5L to support research. This should be considered when planning a project. You also need to incorporate the costs for the translation process into the budget of your proposal. Further, please note that all EQ-5D-Y-5L versions are experimental versions. If the English source version changes, amendments to other language versions might be necessary as well.

#### ***2.4.2. Value sets for EQ-5D-3L and research on methods for valuing Y instrument***

A valuation protocol for the EQ-5D-Y-3L is now available (Ramos-Goni et al 2020). Seven EQ-5D-Y-3L value set studies have completed data collection with a further three underway and still others planned. Producing more value sets for EQ-5D-Y-3L therefore is no longer a top priority. Although researchers are welcome to submit proposals for new EQ-5D-Y-3L value sets, to be eligible for funding by the EuroQol research foundation, proposed EQ-5D-Y-3L value set studies must contain a strong methodological element alongside use of the standardized protocol. Please note that proposed EQ-5D-Y-3L value set studies will be more likely to be well received if they (a) are co-funded by local organisations, and (b) indicate clear plans for consultation and engagement with and involvement of local HTA bodies and other key decision makers and advisors. EuroQol members interested in conducting a national valuation study for the EQ-5D-Y-3L are encouraged to contact members of the YPWG ([mikeherdman.insight@gmail.com](mailto:mikeherdman.insight@gmail.com), [nancy.devlin@unimelb.edu.au](mailto:nancy.devlin@unimelb.edu.au)) or Elly Stolk at the Office ([stolk@euroqol.org](mailto:stolk@euroqol.org)) to discuss their plans.

The focus of the EuroQol Group is currently on testing and strengthening the valuation protocol in the context of EQ-5D-Y-3L; proposals for EQ-5D-Y-5L value sets are not invited at present. Direct valuation of EQ-5D-Y-5L will only be invited after we have extracted lessons learned from EQ-5D-Y-3L valuation and developed a protocol for valuing EQ-5D-Y-5L. Consequentially, it may be the case that when the EQ-5D-Y-5L is approved, users need to rely on mapping from the EQ-5D-Y-5L to the EQ-5D-Y-3L to attach values to the EQ-5D-Y-5L health states. Research aimed at facilitating mapping is welcome.

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<sup>2</sup> e.g. see Åström M, et al. Population health status based on the EQ-5D-Y-3L among adolescents in Sweden: Results by sociodemographic factors and self-reported comorbidity. Qual Life Res. 2018 Nov;27(11):2859-2871

### ***2.4.3. EuroQol instruments in younger children and infants***

Interest in assessing health outcomes of young children is growing and this raises new questions about optimal administration conditions. Our guidelines currently recommend using the self-complete version of EQ-5D-Y from age 8 years and up, and proxy versions from 4 – 7 yrs. However, in a sense, these are somewhat arbitrary cut-off points and data collection will be complicated when other instruments need to be administered that use other cut-off points for their proxy or self-complete versions. We could potentially improve guidance for users by providing more information on how well children in that age range are able to self-complete the instrument. There has been relatively little research into the feasibility of self-completion of EQ-5D-Y above and below the 8-year threshold, say in the 6 – 9-year age range. We could also improve guidance by investigating the feasibility and validity of different modes of administration of EQ-5D-Y in that age range, as self-complete (or self-response) versions are now available in paper, digital, and Interviewer administered (IA) formats. Such research could furthermore highlight areas for improvements/modifications to the instrument and/or administration procedures.

### ***2.4.4. Other research***

As always, we are open to receiving proposals describing innovative research focusing on the EQ-5D-Y that falls outside of the research themes described above. Before sending a full proposal, it is advisable to contact a member of the WG to discuss the possible interest for the WG of the intended research.