

Values for child health related quality of life: a checklist for studies reporting the elicitation of stated preferences.

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Abstract

Background: A systematic review of measures of child Health Related Quality-of-Life (HRQoL) and their accompanying value sets (Kwon et al., 2022) shows widely varying methods for eliciting and modelling value sets for child HRQoL, and very different characteristics of the resulting value sets e.g., some contain no values < 0; others contain very high proportions of negative values. That paper, and a follow-on review of the methods used in valuing pediatric HRQoL to date (Bailey et al., 2022), encountered poor and incomplete reporting in many studies. Checklists can play an important role in improving standards of reporting and in helping users to interpret and assess available values. Existing checklists for HRQoL utilities tend to be focussed on valuation of adult HRQoL instruments, and do not include checklist items addressing the methods issues specific to valuing child HRQoL. Further, existing checklists do not address how users should judge the validity of reported values.

Objectives: Our aim was to develop a checklist for studies generating values for child HRQoL. The values used in cost effectiveness models of pediatric interventions often include values directly elicited for disease-specific states or vignettes for children as well as those from value sets for childhood HRQoL instruments; our checklist was developed with the aim of being able to be applied to either.

Methods: A conceptual model was developed that provides a modular structure for the checklist. The modules are grouped by (i) methods (modules A-D) and (ii) values (module E). A longlist of potential items for each 'method' module was obtained from a recent review of checklists for adult HRQoL values (Zoratti. et al 2021), complemented by generation of additional items specific to child HRQoL values, extracted from recent reviews of the relevant methods literature. Checklist items relating to the characteristics of the 'values' were based on theoretical papers on external validity of stated preference data (e.g., Lancsar and Swait 2014) and papers reporting methods for examining the distribution of 'theoretical' values in value sets (e.g., Pan et al 2021). The long list of items in each module was reduced by eliminating duplication and overlap; and then refined to strengthen relevance and clarity via an iterative process. The resulting checklist was tested by applying it to a range of papers selected from those reported in Kwon et al (2022) and Bailey et al (2022), including recently published EQ-5D-Y value sets.

Results: The resulting checklist contains modules aimed at reporting methods (A-D) and the characteristics of values (E). These modules are populated with a total of 81 items; which modules and sub-set of these items are relevant to use depends on the type of valuation study to which the checklist is applied. Its application to a selection of papers reporting child HRQoL value suggests it is feasible to use. Illustrative examples of its application to an EQ-5D-Y-3L value set and a CHU9D value set are provided.

Conclusions: This is the first checklist for child HRQoL values. Its modular structure means that in principle it can be applied to assessing value sets as well as values generated from other types of studies eliciting values for child health states. The inclusion of items relating to characteristics of values is novel and potentially has broader relevance (e.g., to future checklists for adult utilities). The checklist has the potential to improve completeness in the reporting of pediatric values, as well as helping users compare and assess the characteristics of available value sets. This is work in progress: we plan a consultative process to finalise the checklist, and to improve its useability.