

The Australian paediatric multi-instrument comparison (P-MIC) study: data quality, feasibility, acceptability, and construct validity of the EQ-5D-Y-3L, EQ-5D-Y-5L, TANDI and PedsQL.

Renee Jones^{1,2}, Brendan Mulhern³, Nancy Devlin¹, Rachel O'Loughlin¹, Xiuqin Xiong¹, Mina Bahrapour³, Kristy McGregor², Shilana Yip², Harriet Hiscock^{2,4,5}, Kim Dalziel^{1,2} on behalf of QUOKKA (Quality of Life in Kids: Key Evidence for Decision Makers in Australia)

1. Health Economics Unit, The University of Melbourne, Melbourne, Australia
2. Health Services and Economics, Murdoch Children's Research Institute, Melbourne, Australia
3. Centre for Health Economics Research and Evaluation, University of Technology Sydney, Australia
4. Health Services Research Unit, The Royal Children's Hospital, Melbourne, Australia
5. Department of Paediatric, The University of Melbourne, Melbourne, Australia

Abstract

Objectives: There is a lack of evidence on the performance of paediatric Health-related quality of life (HRQoL) instruments. Feasibility, acceptability, and construct validity are core aspects of the overall performance of a HRQoL instrument. Additionally, understanding the quality of paediatric HRQoL data collected using different administration modes is crucial. The paediatric multi-instrument comparison (P-MIC) study is the first of its kind: it uses concurrent measurement of common generic and condition-specific paediatric HRQoL instruments to facilitate comparisons of instrument performance. This paper aims to explore the quality of data collected in the P-MIC study, as well as present initial results on the feasibility, acceptability, and psychometric performance of the EQ-5D-Y-3L, EQ-5D-Y-5L, TANDI and PedsQL.

Methods: Data from the P-MIC study data cut 1, dated 6th May 2022, were used. The P-MIC study is collecting survey data on Australian children aged 2 to 18 years via The Royal Children's Hospital Melbourne Australia and online Australian survey panels, including a general population and health condition samples. Participants complete two surveys, an initial survey and follow-up survey, both involving the concurrent collection of PedsQL, EQ-5D-Y-3L, EQ-5D-Y-5L and TANDI, alongside other generic and condition-specific instruments. As PedsQL is a commonly used instrument validated in children aged 2 to 18 years it was chosen as the comparator instrument. To assess data quality, participant demographics, dropout rates, and quality checks were analysed descriptively. To assess feasibility and acceptability, self-reported difficulty completing each instrument, time to complete each instrument, and instrument response patterns were analysed descriptively. To assess construct validity, known group and convergent validity were assessed. Where appropriate, sub-group analysis was undertaken by child age, report type (proxy vs self-report), child health status, and recruitment method.

Results: More participants from the online panel sample were removed for not meeting minimum quality criteria (33.9%) compared to those recruited via hospital (2%). After their removal, the quality of the data, based on frequency of inconsistent responses to similar items, was similarly good across samples. A total of the 6,247 participants who completed the initial survey remained in the dataset for analysis, of these 2,142 (34.3%) completed the follow-up survey. Higher follow-up rates were found in the hospital sample (79.8%) compared to online panel samples (25.3%). Of the children recruited via the hospital, 76.4% had a chronic condition lasting at least 6 months, compared to 46.5% of the online panel condition groups sample. EuroQol instruments were quicker and participants reported they were easier to complete, however, had greater ceiling effect issues compared to PedsQL. All instruments demonstrated known group validity and correlations were generally in the directions expected.

Conclusion: PedsQL is widely used and accepted by clinicians in paediatrics. However, EuroQol's paediatric instruments have the advantage of being quicker and easier to complete. A disadvantage of EuroQol's paediatric instruments is their ceiling effects. The P-MIC study has shown that data collected in hospital settings is of better quality and includes more chronically unwell children than online panel settings. This can help to guide future multi-instrument comparison studies.