



# EUROQOL

Using HRQoL data from children and youth to strengthen HTA.  
What are the barriers? How can we improve current practice?

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# Declarations

- I am a member of the Euroqol Group.
- I am the PI on research projects closely related to this symposium, including QUOKKA, funded by the Australian Government Medical Future Fund, and multiple projects funded the EuroQol Research Foundation.
- My attendance at ISPOR Europe 2024 is funded by ISPOR, in my capacity as Editor in Chief of *Value in Health*

# 1. Tools and evidence on measuring pediatric HRQoL

- Over a decade ago, an ISPOR Taskforce report on PRO Good Research Practices for the Assessment of Children and Adolescents ([Matza et al 2013](#)), noted gaps in methods and evidence concerning development and validation of age-appropriate PROs
- Research undertaken since then has improved evidence available on:
  - the nature of differences between self- and proxy-report
  - the comparative performance of disease-specific and generic PROs for pediatric populations (e.g. QUOKKA P-MIC study)
- Increased availability of instruments
  - e.g., EQ-5D-Y-5L; IQI; HUPs; EQ-TIPS
- Systematic reviews e.g. [Kwon et al 2022](#); [Kwon et al 2023](#).

## 2. Growing evidence to support preference-weighting pediatric PROs

- Since 2020, 17 value sets for EQ-5D-Y-3L available or close to completion
- HUPs linked to HUI3 preference weights
- Preference weights for PedsQL close to completion
- Evidence has grown on the methods issues unique to valuing child HRQoL:
  - Whose preferences? What methods? What 'perspective'? What age of child?
- Systematic reviews of methods used to value child HRQoL e.g. [Bailey et al \(2022\)](#)
- An ISPOR Good Practices Taskforce on Pediatric Utilities due for publication early 2025.
- Research questions remain, some of which relate to value judgements required by decision makers

### 3. Gaps & weaknesses in evidence on pediatric HRQoL submitted to HTA.

- Despite the progress in tools and evidence on measuring and valuing pediatric HRQoL, use of available tools lags behind
- Considerable gaps and weaknesses noted in reviews of evidence available for decision making

*PBAC:*  
*“Submissions involved inconsistent approaches, use of adult measures and weights, and substantial gaps in evidence”*  
*(Bailey et al 2021)*

*NICE: “...most used generic HRQoL measures designed for adults. Measures were usually completed by adult patients or clinical experts. Committees frequently commented on limitations in the HRQoL data” (Lamb et al 2021)*  
*Just 25% of assessments used child and adolescent population-specific measures (Hill et al, 2020)*

*“...we found considerable gaps and weaknesses in the current evidence base for utilities used in economic evaluations of pediatric vaccines.” (Herdman et al 2016)*

*“...considerable gaps in the way (pediatric) valuation weights are used and reported in CEA”*  
*Neppelenbroek et al 2023)*

- Growing awareness by HTA bodies – e.g. CADTH (2024), but just one HTA body (Netherlands) provides methods guidance on pediatric HRQoL

## 4. The questions we will address in this symposium

- What are the barriers to using existing age-appropriate HRQoL tools – and what methods gaps remain?
- What can we do to strengthen the use of age-appropriate PROs?
- How can we improve the evidence on HRQoL used to inform decision making concerning resource allocation child health?

**This symposium will present a range of perspectives on these questions, including reflections from HTA agencies, industry and methodological research.**

## Our speakers



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National Health  
Care Institute, the  
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Wendy Ungar  
The Hospital for Sick  
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