

# Using health-related quality of life data from children and youth to strengthen HTA

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Science Policy and Research

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**NICE** National Institute for  
Health and Care Excellence



# Declarations

I am an employee of NICE, and a EuroQol member.

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The views expressed do not necessarily reflect the views of NICE or of EuroQol.

# About NICE

NICE helps practitioners and commissioners get the best care to people, fast, while ensuring value for the taxpayer.

We do this by:



Producing useful and usable guidance for health and care practitioners.



Focusing on what matters most by prioritising topics that are most important to the health and care system or address an unmet need.



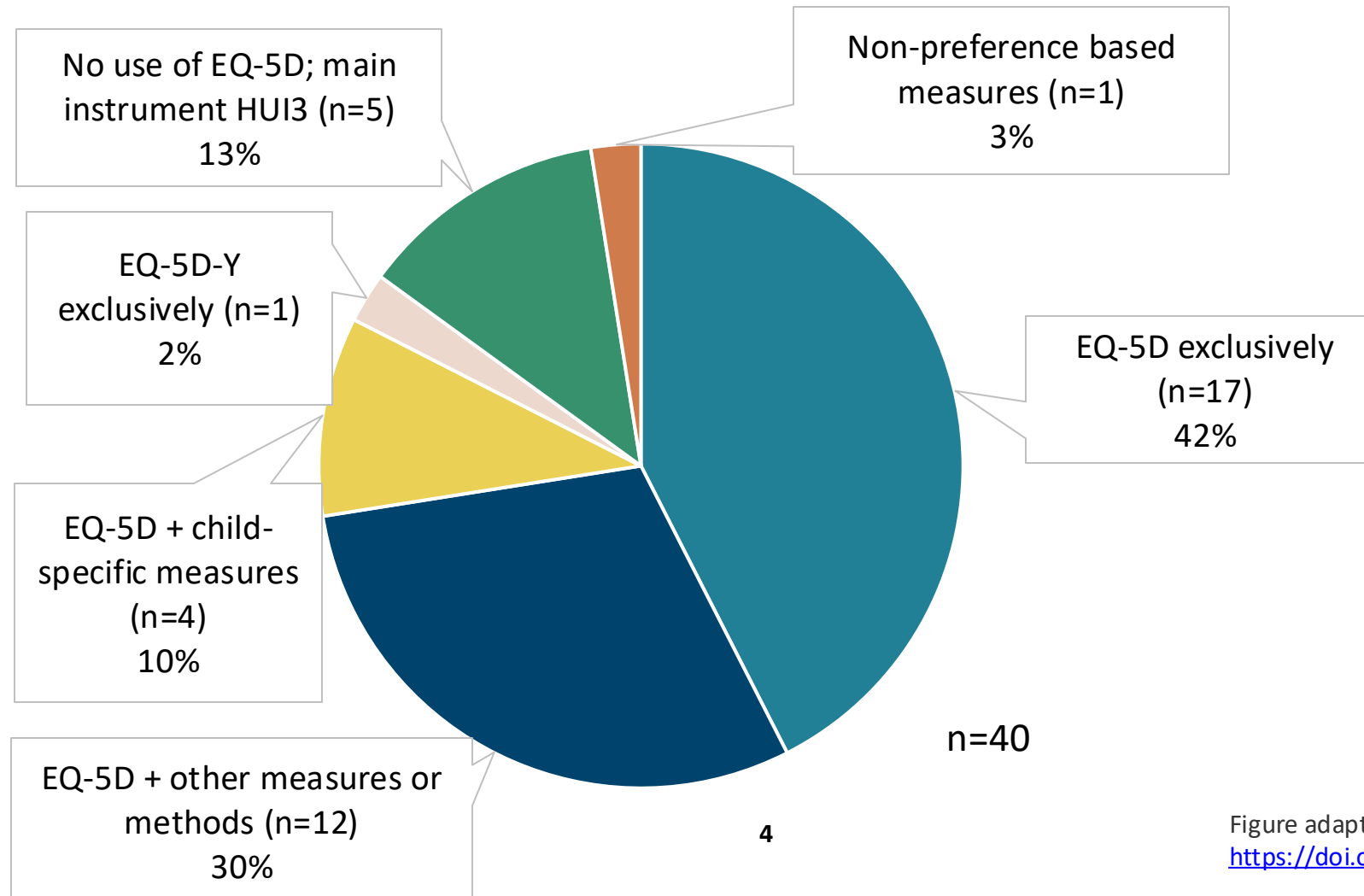
Providing rigorous, independent assessment of complex evidence for new health technologies.



Encouraging the uptake of best practice to improve outcomes for everyone.

# Instruments used in NICE technology evaluations

## Generating utilities for children and young people

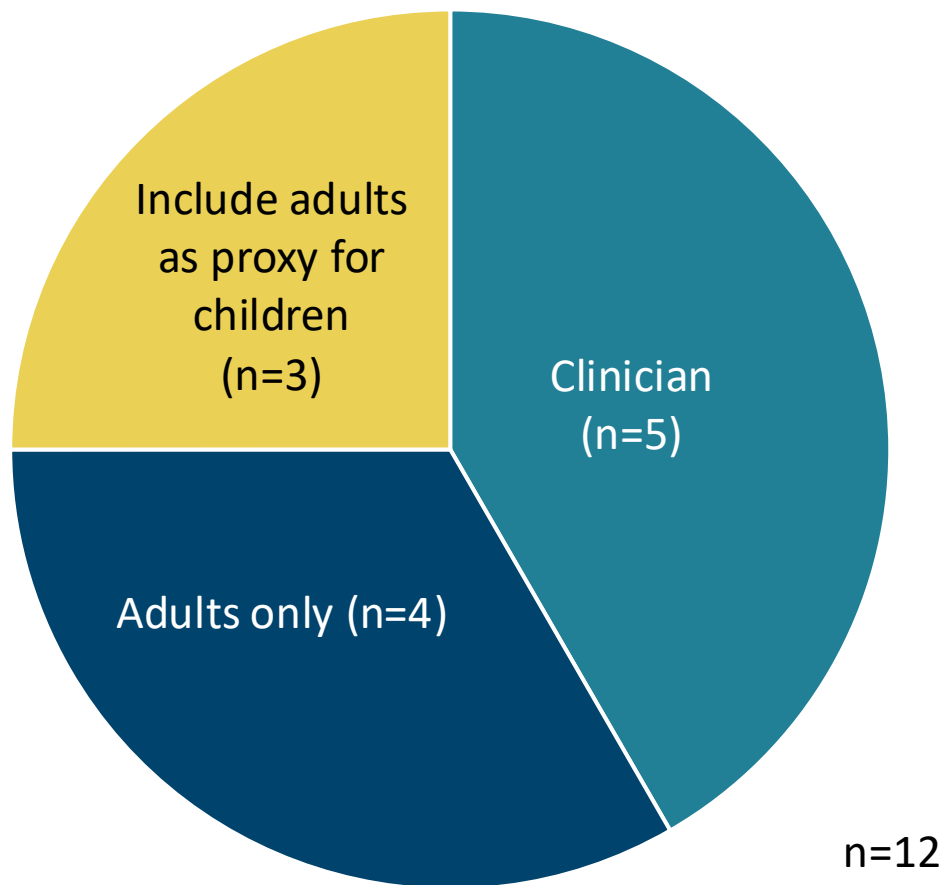


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Figure adapted from Hill et al. (2020)  
<https://doi.org/10.1016/j.jval.2020.02.011>

# Focus on pre-school children (under 5s)

## Source of utility values in NICE evaluations



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# NICE methods update (2022)

- Academic literature was not deemed mature enough to recommend specific measure(s) and value set(s) for children and young people
- The chosen measure should
  - be a generic measure
  - have good psychometric performance in the relevant age ranges
- Important to report who completed the measure
  - adults / children and young people / on behalf of children

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# Challenges and barriers for NICE

## **Which instrument & completed by whom?**

More age-appropriate evidence on psychometric performance

More age-appropriate evidence on content validity

Head-to-head comparisons

## **Valuation**

Population – whose preferences?

Perspective – whose health?

Methods – which valuation technique?

## **Consistency**

Consistency within models

Consistency in decision making



Canadian Journal of Health Technologies

September 2024 Volume 4 Issue 9

CADTH Health Technology Review

# Measuring and Valuing Health for Children: A Review of the Evidence



# Common challenges in child health technology evaluations

- No health-related quality of life data collected in trials
- Or if data was collected, an unsuitable instrument was used
- Patient population spans childhood and adulthood
- Learning difficulties or cognitive impairment can make measurement of health states directly from patients difficult or impossible
- Data quality is inevitably poorer, so resulting estimates are more uncertain



# Common enquiries to NICE

- Availability of EQ-5D-Y utility values for England
- Proxy measurement by carers / parents
- How to measure health-related quality of life in very young ages
- How to account for issues not captured by instruments, e.g. ability to socialise and engage with other children
- Assessment of carer quality of life (children typically require full time care when sick)
- Issues associated with trial design
  - Wide age range of the patient population
  - Learning disabilities





# Assessing the content validity of child and adolescent-specific preference-based measures with potential to inform UK policy

June 2024

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PREFERENCE-BASED ASSESSMENTS · [Articles in Press](#), October 09, 2024 · [Open Access](#)

## Practicality, Validity and Responsiveness of Using the Proxy Version of the CHU-9D with Children Aged 2 to 5 Years

[Tracey H. Sach, PhD](#) <sup>1,2</sup>   · [Hywel C. Williams, DSc](#) <sup>3</sup> on behalf of the [BEEP study team](#) \* · ... · [Hywel Williams](#) <sup>15</sup> · [Joanne Chalmers](#) <sup>15</sup> · [Susan Davies-Jones](#) <sup>15</sup>... [Show more](#)

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Show Outline

### Highlights:

- Measuring child utility in health economic evaluations is challenging. The Child Health Utility – 9 dimension (CHU-9D) is a generic preference-based measure with 9 dimensions each with 5 levels that has been used with children aged  $\geq 5$  years. Few studies have examined the psychometric properties of CHU-9D in the under 5's.
- This paper explores the practicality, validity (construct and convergent), and responsiveness of the proxy CHU-9D in children aged 2 to 5 years using data collected as part of a previously reported clinical trial.
- The practicality of the proxy CHU-9D improved with age. In terms of validity and responsiveness only small changes and responsiveness were observed for the relatively healthy children aged under 5 years in this study. A small proportion found the 'School Work/Homework' question difficult particularly at the lower age range despite additional guidance. Further research is needed to corroborate these findings, examine other measurement properties, and consider the appropriateness of the value set for younger children.



Contents lists available at [ScienceDirect](#)

## Social Science & Medicine

journal homepage: [www.elsevier.com/locate/socscimed](http://www.elsevier.com/locate/socscimed)



# Who should value children's health and how? An international Delphi study

Philip A. Powell<sup>a,\*</sup>, Donna Rowen<sup>a</sup>, Anju Keetharuth<sup>a</sup>, Clara Mukuria<sup>a</sup>, Koonal Shah<sup>b</sup>

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# Valuation of the Child Health Utility 9D Index

Original Research Article | Published: 23 December 2012

Volume 30, pages 729–747, (2012) [Cite this article](#)

[Katherine Stevens](#) 





Social Science & Medicine

Volume 157, May 2016, Pages 48–59



## Valuing the Child Health Utility 9D: Using profile case best worst scaling methods to develop a new adolescent specific scoring algorithm

[Julie Ratcliffe](#)<sup>a</sup>  , [Elisabeth Huynh](#)<sup>b</sup>, [Gang Chen](#)<sup>a</sup>, [Katherine Stevens](#)<sup>c</sup>, [Joffre Swait](#)<sup>b</sup>, [John Brazier](#)<sup>c</sup>, [Michael Sawyer](#)<sup>d</sup>, [Rachel Roberts](#)<sup>e</sup>, [Terry Flynn](#)<sup>f</sup>



Value in Health

Available online 27 September 2024

In Press, Journal Pre-proof  [What's this?](#)



## Development of a health state classification system for the PedsQL™ 4.0 Generic Core Scales for preference-based valuation in Australia


[Joseph Kwon](#) PhD<sup>1</sup>, [Rakhee Raghunandan](#) PhD<sup>2</sup>, [Son Hong Nghiem](#) PhD<sup>3</sup>, [Kirsten Howard](#) PhD<sup>2</sup>, [Emily Lancsar](#) PhD<sup>3</sup>, [Elisabeth Huynh](#) PhD<sup>3</sup>, [Martin Howell](#) PhD<sup>2</sup>, [Stavros Petrou](#) PhD<sup>1</sup>  , [Sarah Smith](#) PhD<sup>4</sup>

## EQ-5D-Y-3L Value Sets, Valuation Methods and Conceptual Questions

Editorial | [Open access](#) | Published: 12 December 2022

Volume 40, pages 123–127, (2022) [Cite this article](#)

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[Nancy Devlin](#) , [Bram Roudijk](#), [Rosalie Viney](#) & [Elly Stolk](#)

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