Carer health-related quality of life in National Institute for Health and Care Excellence (NICE) appraisals: an update of the Pennington review

Valérie van Hezik-Wester[1,2], Holly Cranmer[3], Ingelin Kvamme[1,2], Andy Boateng[3], Irene Santi[1,2], Job van Exel[2], Tim Kanters[1,2]

[1]Institute for Medical Technology assessment, Rotterdam; [2]Erasmus School of Health Policy & Management, Rotterdam; [3]Takeda UK Ltd

✉ wester@eshpm.eur.nl

This research was funded by Takeda UK Ltd
Holly Cranmer and Andy Boateng are employees of Takeda UK Ltd

Background

While health technologies are targeted at improving patient health-related quality of life (HRQoL), it is increasingly acknowledged that treatments can also benefit individuals within the patient's network, such as caring and non-caring family members. The 2022 National Institute for Health and Care Excellence (NICE) methods guide[1] states that health effects in others, particularly carers, should be considered when relevant. A review of NICE appraisals by Pennington (2020) [2] showed that in practice the inclusion of carer HRQoL in cost-utility analysis (CUA) is rare. We aimed to establish the use of carer HRQoL in NICE appraisals since 2019.

The NICE 2022 methods guide[1]

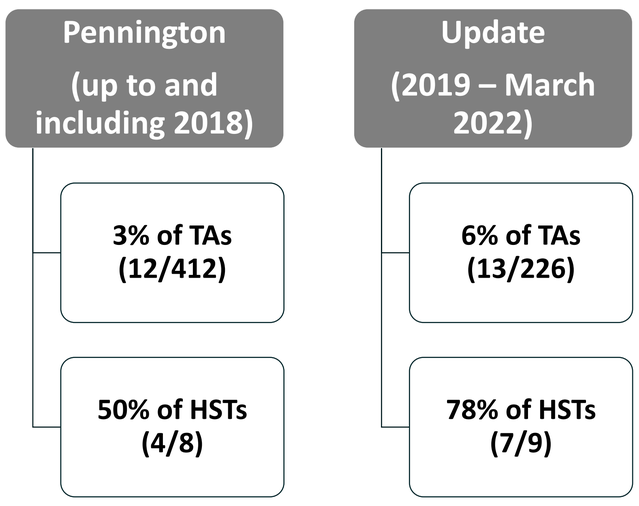
*"Evaluations should consider **all health effects**, whether for patients or, when relevant, other people **(mainly carers)**"*

*"When presenting health effects for carers, **evidence** should be provided to show that the condition is associated with a **substantial effect** on carer's health-related quality of life and **how the technology affects carers**."*

Methods

Technology appraisals (TAs) and highly specialized technologies (HSTs) published between January 2019 and March 2022 were screened for the inclusion of carer HRQoL, following the approach described in the article by Pennington[2]. Justification, methods and data sources for the inclusion of carer HRQoL were extracted and analysed.

Figure 1: Inclusion of carer utilities in CUAs



Results

In the Pennington review[2], 3% (12/414) of TAs and 50% (4/8) of HSTs included carer HRQoL in the CUA, this increased to 6% (13/226) of TAs and 78% (7/9) of HSTs in our update. The conduct of de-novo HRQoL studies as opposed to the use of HRQoL estimates from published sources became more prevalent (7/20). Moreover, inclusion of carer HRQoL is more frequently seen in the base-case (19/20) than in scenario analysis only. HRQoL was most frequently measured using EQ-5D weights (16/20) and less often with EQ-VAS, time trade-off (TTO) or HUI derived values. Carer HRQoL was often modelled as a function of a patient's disease severity, other methods included linking carer HRQoL to treatment arm or treatment response, clinical event, patient's death or a combination of methods. Whether NICE accepts the inclusion of carer HRQoL often hinges on the perceived credibility of the input parameters and assumptions.

Main findings of the updated review

- **The proportion of TA company submissions including carer HRQoL increased since the Pennington review but remained small (13/226)**
- **The majority of HST company submissions includes carer HRQoL (7/9)**
- **In our updated review, carer HRQoL is more often included in the company's base-case analysis (19/20) as opposed to scenario analysis only**
- **For justification of including carer HRQoL, company submissions generally relied on a qualitative description of carer burden based on literature or carer testimonials**
- **Appropriateness of considering carer HRQoL was acknowledged by the committee in all but one appraisal (19/20)**
- **Inclusion of carer HRQoL in the base-case analysis was accepted in all HSTs (7/7), but in approximately half of TAs (7/13)**
- **Uncertainty introduced by low quality evidence, assumptions and modelling techniques were reasons for rejecting the inclusion of carer utilities**
- **Other considerations for rejecting were no inclusion of carer HRQoL in previous appraisals in the indication area and a substantial size of carer HRQoL impact relative to patient HRQoL impact**

Figure 2: Methods for including carer HRQoL in CUAs in the updated review

Sources of carer HRQoL	• De-novo HRQoL study (n=7) • Published sources (n=13)
Measurement of carer HRQoL	• EQ-5D was the most used instrument (n=16) • Other methods included EQ-VAS, TTO, HUI (n=4)
Modelling of carer HRQoL	• Most often as a function of a patient's disease severity (n=13) • Less frequently linked to treatment, clinical event, death or a combination of techniques (n=7)
Number of carers included	• One carer (n=8) • More than one carer (n=9) • Not reported (n=3)

Conclusions

The inclusion of carer HRQoL is becoming increasingly prevalent in NICE appraisals, but is still uncommon in TAs. The robustness of the evidence on carer HRQoL values and the prevalence of informal care use is pivotal for inclusion in the base-case analysis.

References

1. National Institute for Health and Care Excellence (NICE) (2021). Methods, processes and topic selection for health technology evaluation: proposals for change. Accessed May 2022. Available at: https://www.nice.org.uk/process/pmg36/chapter/introduction-to-health-technology-evaluation
2. Pennington BM (2020) Inclusion of Carer Health-Related Quality of Life in National Institute for Health and Care Excellence Appraisals. Value Health 10: 1349-1357

Erasmus University Rotterdam
Make it happen.

institute for
Medical
Technology
Assessment