Inclusion of Carer Health-Related Quality of Life (HRQoL) in National Institute for Health and Care Excellence (NICE) Appraisals Published Since 2019

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Introduction

- The NICE reference case states that the perspective on outcomes should be 'all relevant health effects, whether for patients or, when relevant, other people (mainly carers)' (1)
- Inclusion of health effects for carers should be supported by evidence showing that the condition is associated with 'a substantial effect on carer's HRQoL' (1)
- Pennington (2020) (2) reviewed the methods for including carer HRQoL in NICE technology (TA) and highly specialised technology (HST) appraisals published up to 2019
- This review reported two sources of carer HRQoL estimates used in appraisals of adult populations – Acaster et al (2013) (3) and Neumann et al (2000) (4)
- A total of 10 appraisals, mostly for multiple sclerosis, used the data from Neumann et al (2000) (4) looking at informal carers of patients with Alzheimer's disease in the United States (US). HRQoL estimates were obtained using the Health Utility Index (HUI) 2 or HUI3 measures
- The carer utility value from Neumann et al (2000) (4) was used for the first time in TA111 published in 2006 (superseded by TA217 in 2011)
- The maximum carer disutility of 0.14, calculated by subtracting the lowest HUI3 global utility score in Neumann et al (2000) (4) from a score of full health, was accepted by NICE for the first time in TA127 (Gani et al [2008] (5))

Objectives

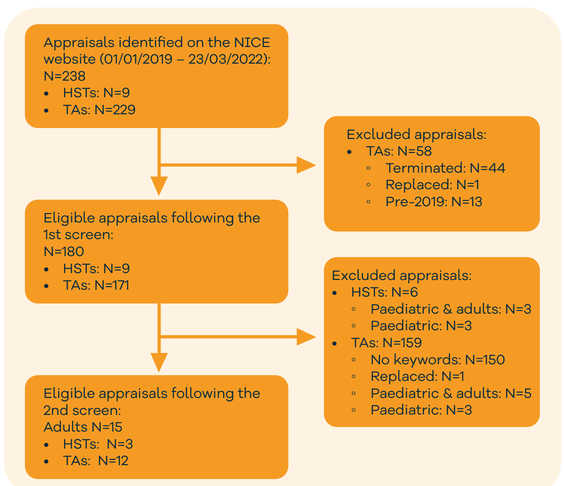
The research objectives were to:

- Review TAs and HSTs published since 2019 to determine the total number of appraisals that considered carer HRQoL in the economic submissions focused on adult populations
- Review the source of carer HRQoL estimates to highlight whether any new sources of data, other than those identified by the review carried out by Pennington (2020) (2), were used in these appraisals

Methods

- The NICE website was searched to identify all HSTs or TAs published between 01/01/2019 and 23/03/2022 (6)
- Appraisals that were terminated, or replaced by more recent TAs, were not considered in the review (1st screen)
- For each HST and TA, the final evaluation determination document (FED) or final appraisal document (FAD) was downloaded and searched for the terms 'carer', 'caregiver' or 'informal care'
- Only FEDs and FADs where the above terms were used in the context of carer HRQoL in the company's economic submission were considered further. Appraisals in paediatric or mixed adult/paediatric populations were also excluded at this stage (2nd screen)
- The following data from each eligible HST and TA were extracted:
  - Medical condition
  - NICE committee's decision regarding the inclusion of carer HRQoL in the economic analysis
  - Methods of including carer HRQoL data in the economic analysis

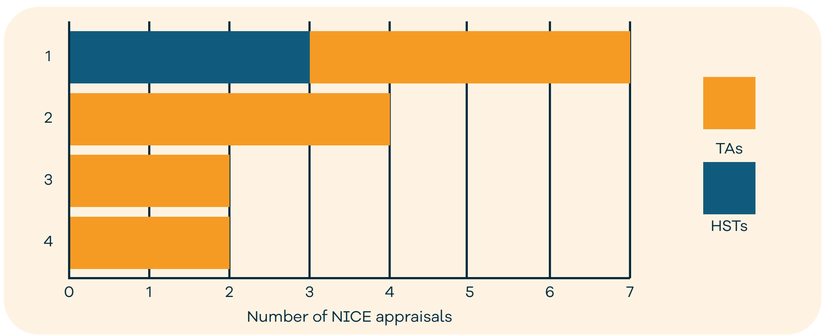
Figure 1: Flowchart of the screening process of the eligible NICE Appraisals



Results

- A total of 238 appraisals were downloaded from the NICE website including 9 (3.8%) HSTs and 229 (96.2%) TAs (Figure 1)
- During the screening, a total of 58 TAs were excluded after the 1st screening. A total of 6 HSTs and 159 TAs were excluded after the 2nd screening
- Nine HSTs and 20 TAs mentioned the terms 'carer', 'caregiver' or 'informal care' in the context of carer HRQoL
- Overall, three HSTs and 12 TAs published after 2019 considered carer HRQoL in adult populations
- Inclusion of carer HRQoL was accepted in all three identified HSTs; in the TAs, HRQoL was accepted as part of the base case analysis in only four appraisals (33.3%; Figure 2, group 1)

Figure 2: The NICE Committee decision regarding inclusion of carer HRQoL in the economic submissions of HSTs and TAs (N=15) focused on adult populations



Legend:
1. Carer HRQoL accepted by the NICE committee and included in the base case.
2. Carer HRQoL acknowledged as important for the appraisal, but not included in the manufacturer's base case.
3. Carer HRQoL estimates provided in the manufacturer's submission, but removed by the NICE committee.
4. Carer HRQoL estimates not provided in the manufacturer's submission and considered by the NICE committee as not relevant for the appraisal

- Considering the appraisals where carer HRQoL was accepted, five (HST9, HST10, TA585, TA624, TA656) evaluated treatments for conditions affecting the patient's nervous system (transthyretin amyloidosis or multiple sclerosis). In these appraisals carer HRQoL was modelled as a function of the patient's health state (Table 1)
- All five appraisals (HST9, HST10, TA585, TA624, TA656) used Gani et al (2008) (5) as the source of carer HRQoL estimates
- Gani et al (2008) (5) derived the carer disutility values per each Expanded Disability Status Scale score from a maximum disutility of 0.14, derived from Neumann et al (2000) (4), and the UK MS Survey (7) reporting the percentage of time spent caring
- One HST (HST13) in which carer HRQoL was accepted evaluated treatment for metabolic disorder. A family utility decrement was applied in the base case of the economic analysis. The value was an assumption agreed during the NICE committee discussion (Table 1)
- One TA (TA759) in which carer HRQoL was accepted evaluated treatment for an autoimmune disorder. Utility decrements for carer HRQoL were applied in the economic model only for post-intra-cranial haemorrhage (ICH) health states. The literature source was not reported in the committee papers or the FAD (Table 1)
- Therefore, no new literature sources reporting carer HRQoL were identified in the eligible economic submissions
- The NICE committee acknowledged the importance of carer HRQoL in four TAs (33.3%); however, the manufacturer did not include carer HRQoL evidence in the base case (Figure 2, group 2)
- The NICE committee did not accept carer HRQoL in the economic analyses of two TAs (16.7%; Figure 2, group 3). The reasons included poor modelling methodology and lack of face validity of the HRQoL estimates
- Carer HRQoL was considered as not relevant for inclusion in the economic submission in two TAs (16.7%; Figure 2, group 4) as the NICE committee agreed that all HRQoL benefits were already captured by the submission

Table 1: Methods of inclusion of carer HRQoL accepted by NICE in the economic submissions focused on adult populations

NICE Appraisal	Condition	Inclusion of carer HRQoL	Source of HRQoL data
HST9 HST10	Hereditary transthyretin amyloidosis	Utility decrements as a function of patient's health state	Gani et al (2008) (5)
HST13	Familial chylomicronaemia syndrome	Annual family utility decrement	Assumption agreed following the discussion with NICE Committee
TA585	Primary progressive multiple sclerosis	Utility decrements as a function of patient's health state	Gani et al (2008) (5)
TA624	Relapsing–remitting multiple sclerosis		
TA656	Secondary progressive multiple sclerosis		
TA759†	Refractory chronic immune thrombocytopenia		Literature source with the full reference not reported in the FAD

†Utility decrements applied only for post-ICH health states

Conclusion

- Only a small proportion of all TAs and HSTs published after 2019 considered carer HRQoL in the economic submissions focused on adult populations
- No new literature sources for carer HRQoL estimates in adult populations were identified in this review
- Most appraisals reviewed relied on values derived from a HUI3 utility measure and a US value set; NICE prefers the EQ-5D valued by a UK population for evaluations of treatments for adults
- Lack of new literature reporting estimates of carer HRQoL highlights the need for more sources of carer HRQoL data to support NICE submissions focusing on a variety of diseases and capture the indirect disease impact

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Abbreviations

FAD, final appraisal document; FED, final evaluation determination; HRQoL, health-related quality of life; HST, highly specialised technology; HUI, Health Utility Index; ICH, intra-cranial haemorrhage; NICE, National Institute for Health and Care Excellence; TA, technology appraisal.