Integrating Patient Perspectives in HTA: What Can We Learn to Inform HTA-Focused Value Communications?

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Summary

+ Patient perspectives are increasingly recognised as an important element of health technology assessment (HTA), but the extent of their integration in appraisal processes and their potential influence on final recommendations by HTA bodies remains unclear.
+ This study aimed to examine whether HTA bodies mention patient input in their methodological guidelines and to assess whether patient input was explicitly present and considered in single technology appraisals (STAs) conducted by the National Institute for Health and Care Excellence (NICE).
+ Our results show that:
  - All 17 HTA bodies assessed referenced patient input, but less than two-thirds outlined specific engagement methodologies, mostly involving consultations.
  - 70 of 88 (79.5%) eligible NICE appraisals included explicit patient input, and this was almost always explicitly considered by the committee.
  - Patient contributions most often mentioned were related to unmet need (60/68) and quality of life (QoL) (42/68), with appraisals for blood/immune system, diabetes/metabolic, and neurological conditions generally covering more domains of patient input.

Background

In recent years, patient perspectives have been recognised as essential in HTA[1,2], helping ensure that the lived experience of disease and treatment informs decision-making[3,4,5]. Despite this, the extent to which patient input is formally integrated and influences final decisions remains unclear[6,7]. Research shows a lack of standardised approaches across HTA bodies[6,8], with varying methods and limited evidence on how consistently patient input is captured or used[9]. This suggests a need for greater clarity on how patient input is weighed in practice and how it can best contribute to strengthening decision-making.

In the UK, NICE follows the principle of involving patients, service users, carers, and the public in HTA[10]. While these groups are invited to submit evidence and engage with committees, this input is not always explicitly reported in final guidance, making it difficult to assess its impact in practice.

In this context, our study reviewed HTA body guidelines to identify if patient input is referenced and then focused on NICE STAs as a case example. Our aim was to determine whether patient input was explicitly mentioned in the final appraisal guidance and whether it was explicitly considered by the committee. We further examined which aspects of patient input were most frequently reported and how this may differ across therapeutic areas to better understand how patient perspectives are considered in practice and what this means for both HTA bodies and manufacturers.

Methods

Methodological guidance for patient input in HTA

We conducted a targeted review of 17 publicly-available English-language HTA methodological guidelines to assess whether and how they described methodologies for incorporating patient input. Documents were reviewed to identify explicit references to methods for including patient input in HTA processes. Identified methodologies were classified into categories: 1) consultation (e.g., interviews/testimonies by patient experts and representatives); 2) written submissions (e.g., structured forms and letters); 3) literature review of published qualitative/quantitative evidence; and 4) capacity building in the form of training, guidance and resources.

Mapping patient input in NICE STAs

We reviewed NICE STAs published between January 2024 and April 2025 for patient input evidence. Excluding terminated and updated appraisals, 88 STAs were shortlisted. We then scanned the STAs for explicit evidence of patient input across four domains: unmet need, QoL, caregiver/family impact and health equity.

We then examined committee considerations and/or recommendations to assess whether patient perspectives were explicitly acknowledged. When this was the case, we applied a 0–4 patient input score: a score of 0 indicated that no domains were explicitly considered, while a score of 4 indicated that all four domains were explicitly acknowledged by NICE. We then calculated mean patient input scores by therapeutic area.

Results

All HTA bodies analysed mentioned patient input, but fewer than two-thirds had specific engagement methodologies.

Table 1. References to patient input (or perspective/voice) and presence of specific engagement methodologies in the guidelines of 17 HTA bodies.

Country	Name of HTA Body	Specific patient input methodologies	Methodologies specified
Australia	Pharmaceutical Benefits Advisory Committee (PBAC)	Yes	Consultation
Belgium	Belgian Health Care Knowledge Centre (KCE)	Yes	Consultation, Capacity Building
Canada	Canadian Agency for Drugs and Technologies in Health (CADTH)	Yes	Consultation, Written Submissions, Literature Review, Capacity Building
Denmark	Danish Health Technology Council (DHTC)	Yes	Consultation, Literature Review
Estonia	Estonian Health Insurance Fund (EHIF)	No	-
Germany	Institute for Quality and Efficiency in Health Care (IQWiG)	No	-
Ghana	Ghana Health Service (GHS)	No	-
Ireland	Health Information and Quality Authority (HIQA)	No	-
Malaysia	Malaysian Health Technology Assessment Section (MaHTAS)	No	-
Philippines	Health Technology Assessment Council (HTAC)	Yes	Consultation, Written Submissions
South Africa	National Department of Health (NDoH)	Yes	Consultation, Literature Review
Sweden	Swedish Agency for HTA and Assessment of Social Services (SBU)	Yes	Literature Review
Switzerland	Federal Office of Public Health (FOPH)	No	-
Thailand	Health Intervention and Technology Assessment Program (HITAP)	No	-
Ukraine	State Expert Center of the Ministry of Health (SECMOH)	Yes	Consultation, Literature Review, Capacity Building
United Kingdom	National Institute for Health and Care Excellence (NICE)	Yes	Consultation, Written Submissions
United States	Institute for Clinical and Economic Review (ICER)	Yes	Consultation, Written Submissions

Figure 1. Proportion of NICE appraisals including patient input and where input was explicitly considered by the committee.

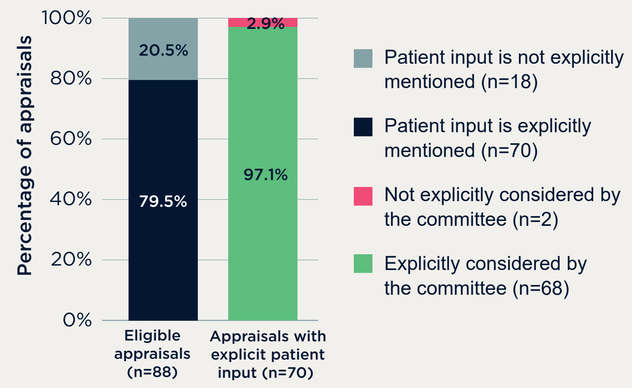

Figure 2. Distribution of patient input across four domains in the 68 NICE appraisals where patient input was explicitly considered by the committee.

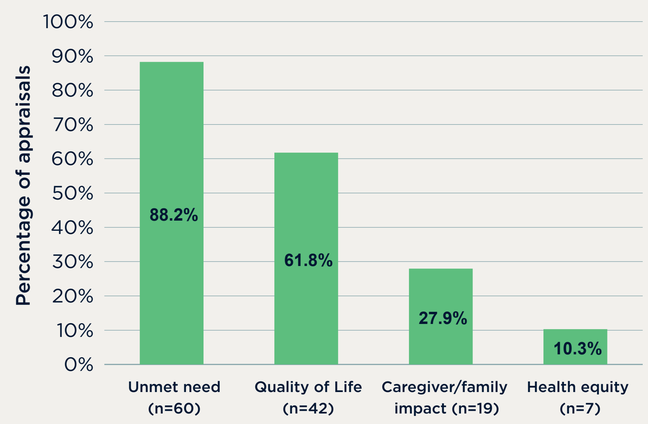

Table 2. Number of appraisals and mean patient input scores by therapeutic area in recommended and optimised appraisals (including Cancer drugs Fund) with patient input explicitly considered by the committee.

Therapeutic area	Number of appraisals	Mean patient input score
Blood and immune system conditions	24	2
Cancer	23	1.7
Diabetes and other endocrinal/ metabolic conditions	4	2
Neurological conditions	2	2
Cardiovascular conditions	2	1.5
Other (non-rare)*	6	1.8
Other (rare)*	1	3.0†
All conditions	**62**	**1.9**

*Therapeutic areas with only 1 appraisal (eye conditions; gynaecological conditions; infectious diseases; liver conditions; skin conditions; other conditions) were pooled into "Other", depending on whether these were rare diseases or not. †Other (rare)" had one appraisal for Duchenne muscular dystrophy.

Higher patient input scores were observed in blood/immune system, diabetes/metabolic, and neurology technology appraisals

Conclusions

Our review found that while all analysed HTA bodies reference patient input, not all outline clear methodologies for engaging patients, which may limit the consistency and extent to which the patient voice is incorporated into appraisal processes. In NICE STAs, patient input was frequently captured and explicitly acknowledged by the committees, particularly regarding unmet need and quality of life.

These findings suggest that systematically identifying and presenting patient perspectives can help ensure they are visible to committees. Incorporating patient perspectives early in product development, and aligning evidence generation with domains most relevant to patients may enhance the clarity and relevance of value communication to HTA bodies and contribute to a more informed decision-making.

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