HTA367

What Is the Impact of Patient Voice on NICE Recommendations for Drugs Assessed in 2024?

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1 OBJECTIVES

NICE has a clear pathway for how patient organisations and experts can be involved in the appraisal process-with patients joining consultations to determine scoping areas at the beginning of a health technology assessment (HTA), submitting patient evidence for consideration, and being recruited as committee members to jointly develop National Institute for Health and Care Excellence (NICE) guidance. However, the degree to which these inputs influence final recommendations is not consistently clear. This study aims to examine how patient voices, both individual and organisational, shaped committee deliberations and final recommendations in recent appraisals.

2 METHODS

Technology appraisals (TAs) published in 2024/25 were identified using the TA Recommendations (Excel) dataset from the NICE website. As shown in **Figure 1**, appraisals were excluded if they were: **(a)** terminated due to non-submission, **(b)** multiple technology appraisals (MTAs), or **(c)** oncology-related products. All records were downloaded directly from the NICE website into an Excel spreadsheet for extraction. For each, the 'Final Draft Guidance' and 'Committee Papers' were reviewed and data were extracted on: **(1)** presence and role of patient organisations and experts; **(2)** type of contributions; **(3)** key themes raised; (4) whether input was discussed in committee deliberations and **(5)** whether it was reflected in final guidance.

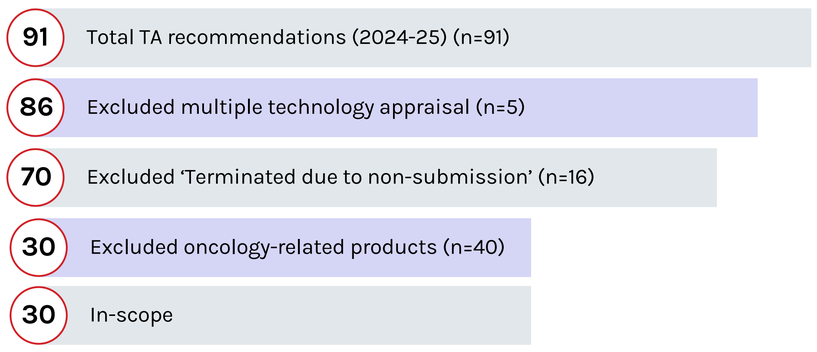

Fig.1 Methodology to select technology appraisals analysed

3 RESULTS

Of the 30 TAs assessed, patient involvement was observed in 90% of the committee papers with variable impact on the final recommendation by NICE. The number of patient experts participating ranged from 0–2 along with representation from 0–3 relevant patient organisations. The patient experts are individuals with lived experience of the condition and/or technology and do not represent the manufacturer. The forms of patient contribution in committee papers included a written 'patient expert statement' and verbal input from patient experts during committee meetings, with written submissions being used more.

Key themes raised: Key themes raised included descriptions of quality of life, unmet needs and treatment burden reflected in words like burden, impact, need and access as shown in Figure 2. Emotional and psychological effects were also mentioned (e.g., anxiety, fatigue, emotional).

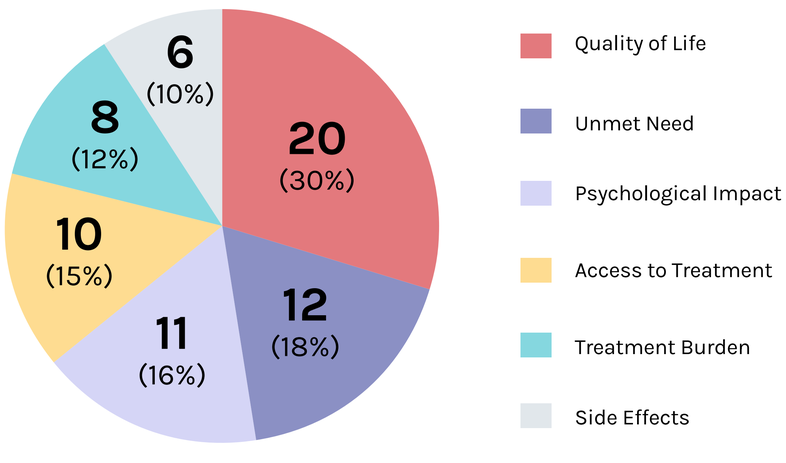

Fig.2 Count of mentions of the key themes raised by patient experts

Patient input mention and final recommendation: Technologies with appraisals where patient input was explicitly mentioned in the final recommendation were more often "Recommended" (recommended in line with marketing authorization) or "Optimised" (access is restricted to a narrower population than the one described in the medicine's marketing authorization), while those without explicit mention were more likely "Not recommended" (technology was not considered to be an appropriate use of NHS resources based on the data available) **(Figure 3)**. However, the association is not statistically significant (p=0.34), suggesting that although mention of patient opinion could correlate positively, it does not strongly determine the outcome.

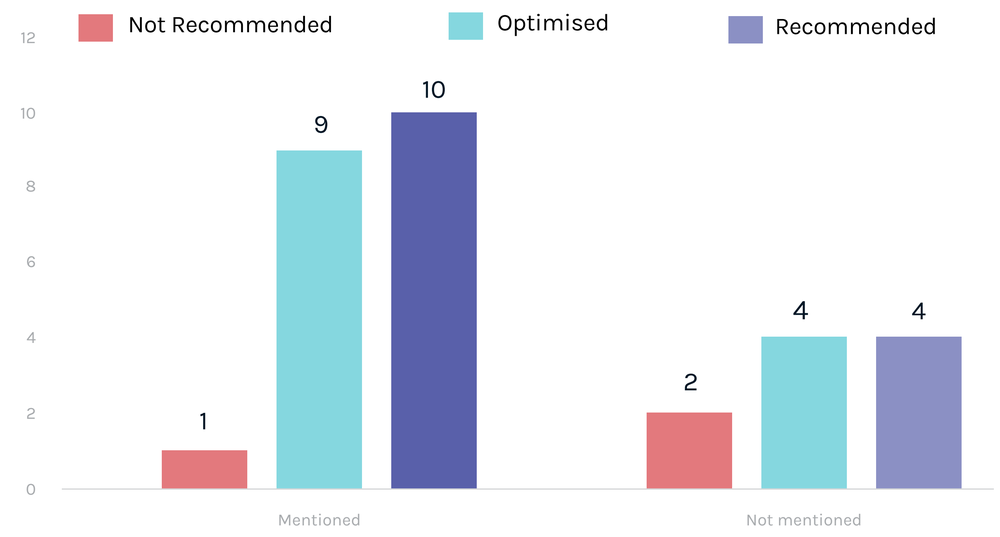

Fig.3 Mention of patient input in the final guidance document and the NICE final recommendation

Patient involvement and disease area: No clear patterns were found between the importance of patient input and disease area. However, the sample size studied in this research is narrow, and further studies could be conducted to verify this.

4 CONCLUSIONS

In most cases, patient input has primarily been considered as contextual information, helping to frame the lived experience of the condition and the acceptability of treatment. Uncertainty remains regarding the extent to which patient contributions influence the final recommendations, with clinical and economic evidence continuing to be the predominant drivers of decision-making.

These findings align with other published literature which also found that patient input did not explicitly shape recommendations.[1,2,3] A study analysing NICE ultra-rare disease appraisals also found that most reference to patient input is for disease-specific themes such as carer burden, unmet need, and symptoms, but did not find conclusive evidence that patient input holds more weight where uncertainty around clinical evidence is highest. [3]

Enhancing the consistency, timing, and visibility of patient involvement will be essential to support transparent and robust decision-making in the UK. It would also be interesting to see how NICE compares to other international HTA bodies in integrating patient voices and their input in final decisions.

5 REFERENCES

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