

Mapping patient involvement in NICE appraisals of oncology products

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Objective

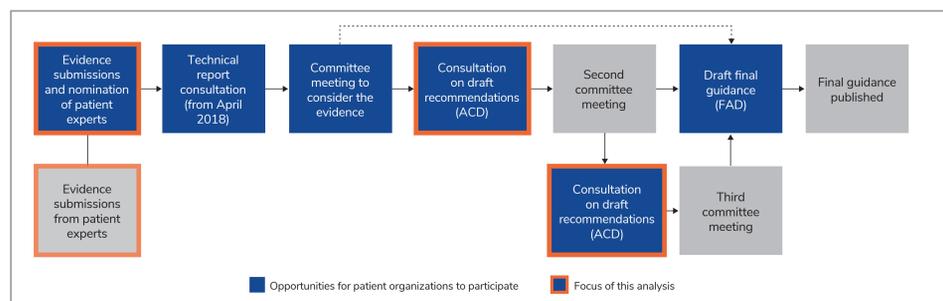
- Understanding the value of patient involvement is crucial for efforts to encourage patients and their representatives to participate in health technology assessment (HTA).
- This study sought to understand the extent of patient involvement in guidance development for single technology appraisals (STAs) by the UK National Institute for Health and Care Excellence (NICE), and the type of information contributed by patient stakeholders.

Background

During guidance development:

- Multiple patient organizations may register as consultees and submit statements for the NICE evidence review. The submission form asks for views on the advantages and disadvantages of the new technology compared with current options, and views on how the condition affects patients and carers.
- Up to two patient experts are also selected from patient organization nominations: they can submit a personal statement, or simply 'agree with' the statement from the nominating organization.
- Patient organization consultees may also provide comments in response to consultations on draft recommendations (Appraisal Consultation Documents, ACDs).

Figure 1: Opportunities for patient organizations to participate during guidance development phase of NICE technology appraisals. The highlighted stages were included in the scope of this study as the written submissions enable a consistent analysis across the appraisals.



ACD, Appraisal Consultation Document; FAD, Final Appraisal Determination
Source: NICE guide to the processes of technology appraisals. May 2018

Methods

We reviewed committee papers for all oncology STAs (completed April 2018-April 2019) to establish:

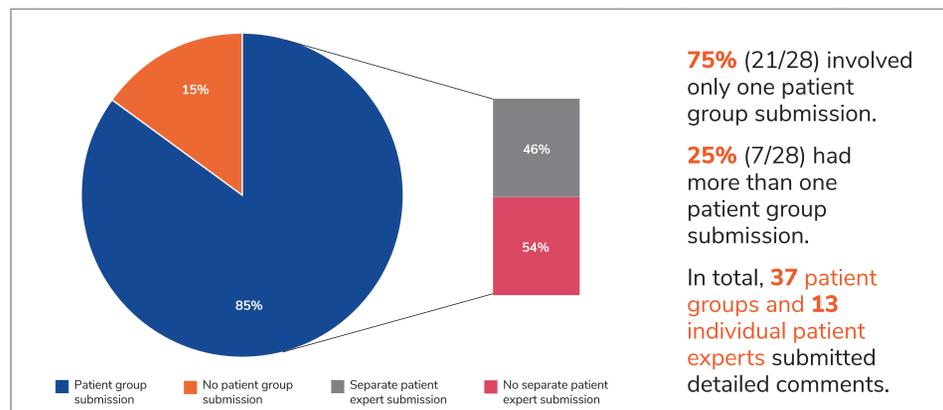
- the number of patient stakeholders providing written comments within each appraisal
- the issues raised by patient stakeholders via thematic analysis of written comments.

Results

Involvement in the evidence review

- Thirty-three STAs of oncology treatments were completed during 2018–19.
- Submissions to the evidence review were made by patient stakeholders in 85% (28/33) of the appraisals.
- In 46% of these (13/28), individual patient experts submitted independent comments alongside comments from their nominating organization.

Figure 2: Patient stakeholder involvement in STA evidence reviews (oncology STAs 2018/19)



Key topics raised during the evidence review

82% included detailed comments on the burden of the condition or symptoms on patients.

82% included comments on the advantages of the new technology over current options (e.g., providing a more effective or convenient option).

79% specifically described the limitations of current treatments.

79% included comments on the disadvantages of the new treatment; however, they commonly stressed that the potential benefits outweighed the risks.

64% described a practical, financial, or emotional burden on carers, explaining that more convenient or effective treatment options are of particular value to carers.

61% outlined the most important goals of treatment (e.g., from surveys or personal testimonies), often highlighting the importance to patients of improving survival or quality of life and preventing disease recurrence.

46% contained descriptions of how new treatments brought hope of longer survival or remission, better quality of life, or a bridge to further treatments that may be available in the future.

A small number of comments related to:

- a need for patients to be better informed about their choices
- a need for counselling provision to accompany new treatments
- a concern about a postcode lottery of access to the new treatment if it is not recommended.



Involvement in ACDs

- 18/22 STAs with an ACD involved one or more formal consultation response from patient groups.
- Of the two STAs with a second ACD, one received a patient stakeholder response.

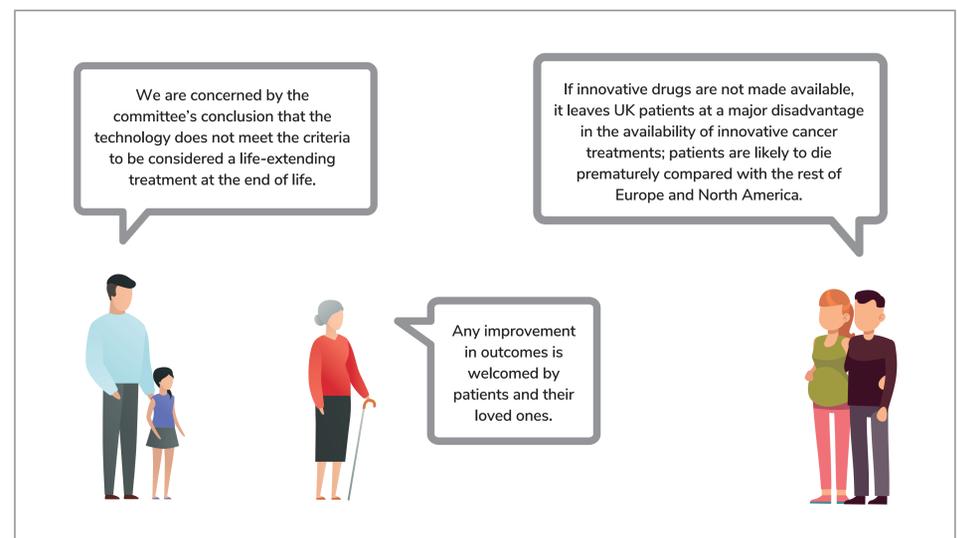
Key topics raised in response to ACDs

67% included concerns about the impact of the draft recommendation on access to the medicine.

50% included concerns that the assessment had undervalued or misunderstood aspects of the technology or the disease.

To support their responses, patient stakeholders often re-stated key messages from their earlier submissions relating to:

- the value of incremental improvements to patients
- patients' willingness to accept inconvenience or risks
- concerns about a postcode lottery of access if the treatment is not recommended.



Conclusions

- Patient stakeholders are involved in the majority of oncology appraisals, and are an important stakeholder group within the NICE STA process.
- They contribute both insights into the value new cancer treatments have for patients and carers and commentary on the assessment process/outcome.
- Assessing the impact of a single stakeholder group in HTA is challenging due to the complex decision-making framework involved in each appraisal.
- Further research evaluating the impact of patient involvement in NICE STAs would help ensure continued advocacy of role of the patient voice in HTA.

References

NICE guide to the processes of technology appraisals. May 2018.
STA committee papers accessed from the NICE website on 6 May 2019 www.nice.org.uk.

Acknowledgments

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