

Understanding the Impact of Equality and Equity Considerations on NICE Highly Specialised Technology (HST) Decision-Making

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Objective

To identify the equality and equity factors that stakeholders consider important for Highly Specialised Technologies (HSTs), and those factors influencing National Institute for Health and Care Excellence (NICE) decision-making.

Background

- Individuals with rare diseases often face inequalities in their care compared to the general population, including delayed diagnosis, poorly coordinated care and limited access to effective treatment.
- The NICE Highly Specialised Technology (HST) programme employs specific considerations and flexibilities to assess treatments for ultra-rare diseases, in recognition of the unique challenges faced when developing and ensuring equitable access to these therapies.¹
- Despite this, the equality and equity factors that are most commonly raised in these appraisals, and the extent to which these factors influence NICE decision making has not been assessed to date.

Methods

- The NICE website was searched for all HST appraisals published between January 2022 and June 2025; the date limit corresponded to the latest NICE methods review.
- Information regarding equality and equity factors was extracted from four source documents: equality impact assessments, committee papers (including company and stakeholder submissions), public committee slides and final guidance.
- Extracted equality/equity considerations were thematically grouped in two ways:
 - Separated into intervention related (driven by characteristics of the technology and associated pathway) or non-intervention related (arising from wider system, service, or societal factors) (Box 1A);
 - Using the principles of the equality staircase (as described by Cookson et al. and also referenced in ISPOR's Health Equity Research Special Interest Group report)^{2,3} (Box 1B).

Results

- Nineteen HSTs were identified; equality/equity considerations were raised in all appraisals, totalling 61 discrete considerations.
- Most equity/equality considerations were initially raised in the committee papers or committee slides (Figure 1).
- Of the identified considerations, 59% (36/61) were related to the intervention (Figure 2A). The remaining factors (41%, 25/61) were either not addressed by or not directly related to the treatment, such as issues regarding diagnosis. Most considerations related to the eligible population and intervention uptake (Figure 2B).
- A key theme across multiple appraisals was considerations relating to access to the intervention (19/61, 31%). This included cultural factors surrounding accessing healthcare, geographical factors such as distance to travel to specialist centres, and socioeconomic factors such as cost of such travel. NICE acknowledged that factors relating to access due to geographic or socioeconomic factors represent equality issues but did not consider that NICE's guidance could resolve them.
- In total, only 15 equity/equality considerations were raised in final guidance; 20% (3/15) were factors addressed by the intervention, 47% (7/15) were factors arising from the introduction of the intervention, and the remainder were broader considerations not directly related to the intervention (e.g. regarding the condition).
- Approximately 50% of the considerations raised in final guidance were said to have influenced decision making or prompted adjustments to the appraisal process (Figure 3). In a small number of cases, NICE explicitly described the adjustments made, such as considering qualitative and proxy data.
- The five factors relating to the eligible population that impacted decision making specifically related to age restrictions within the marketing authorisation.
- In some instances, NICE highlighted limitations in how they can address inequalities within their recommendations (Figure 4).

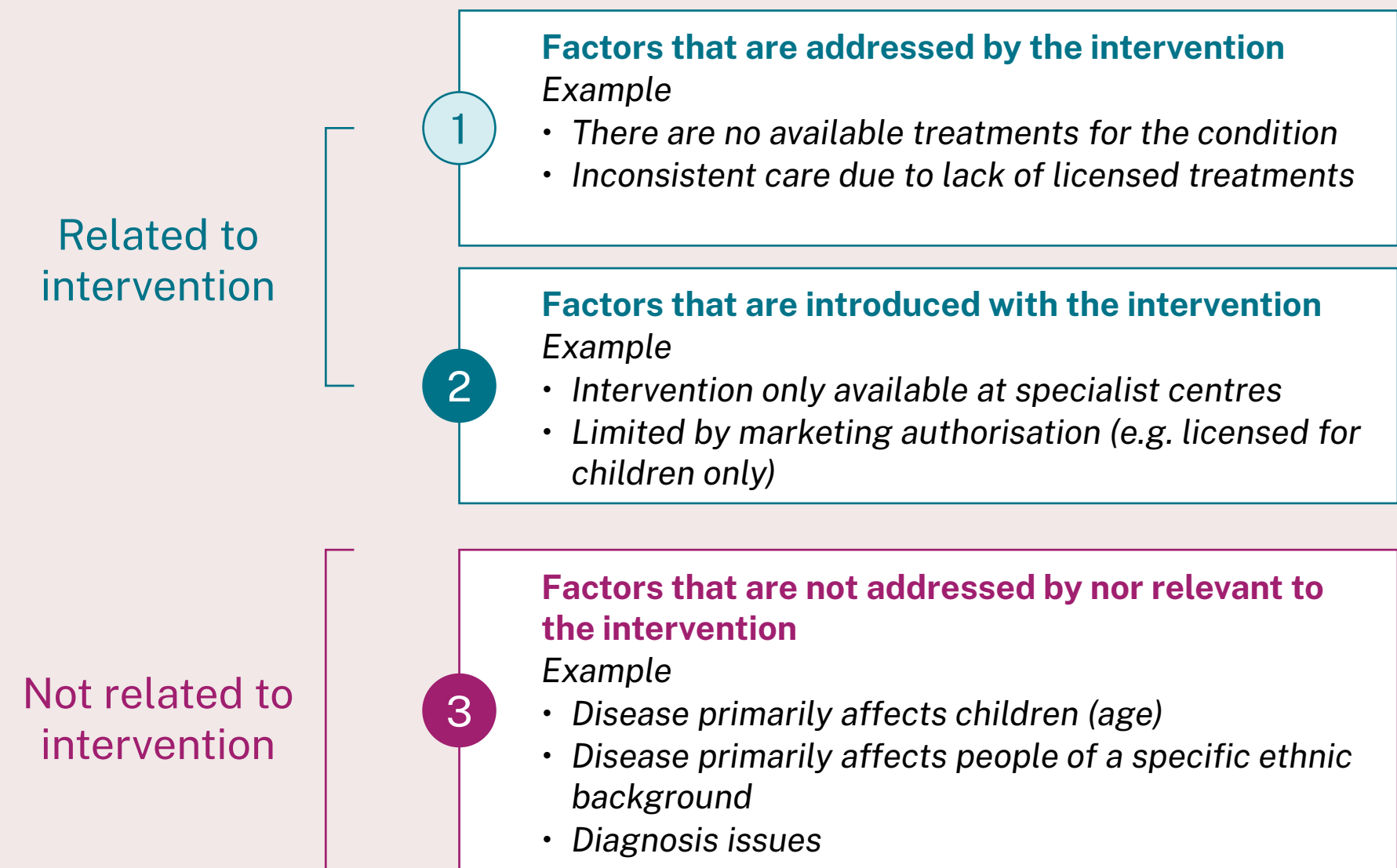
Conclusion

While equality and equity considerations were frequently raised at various stages of HST evaluations, most were not reflected in NICE's final guidance. Many considerations were deemed beyond the scope of the appraisal, or fell outside of the terms of the marketing authorisation for the intervention.

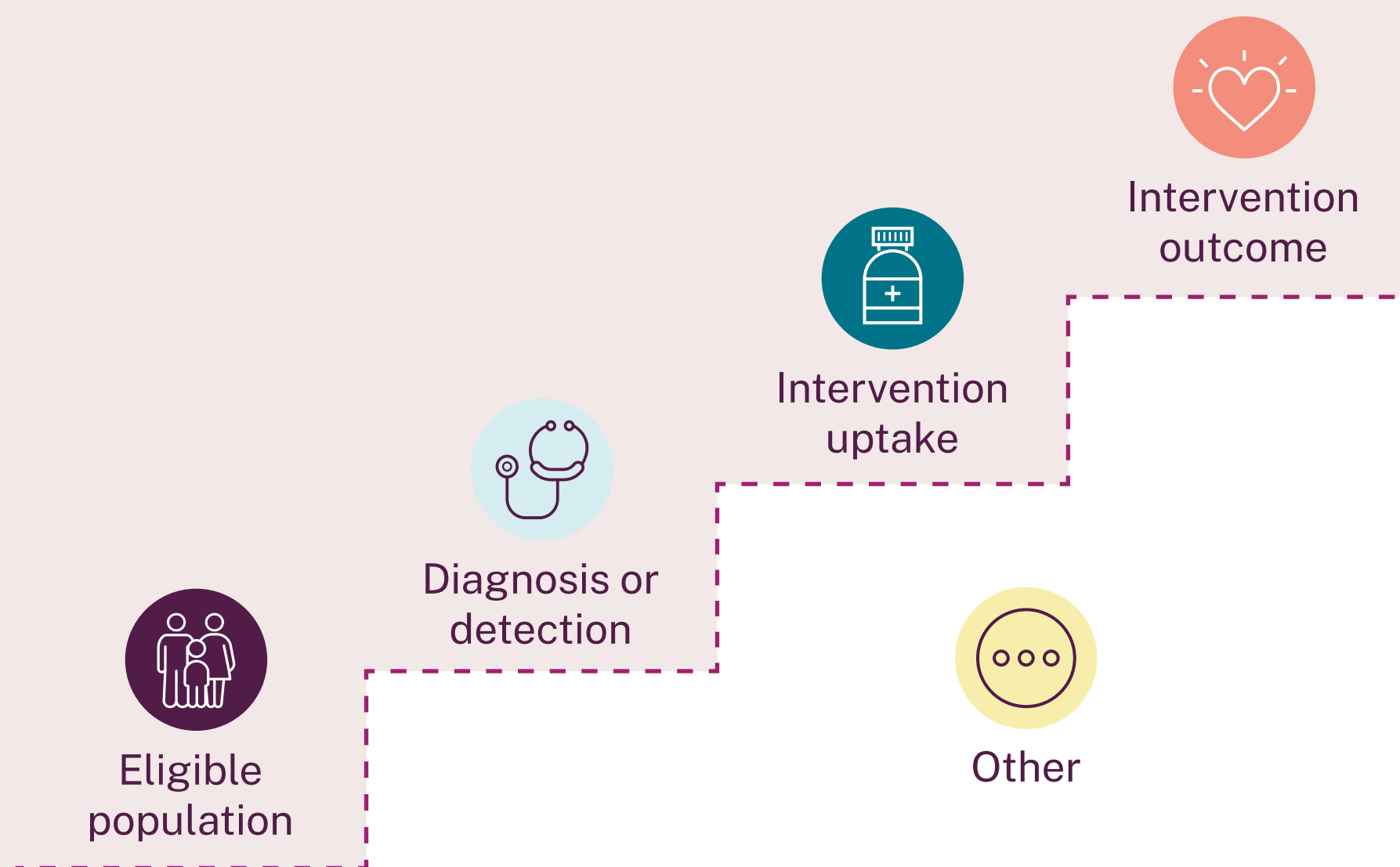
BOX 1

Grouping methods for identified equality/equity considerations

A. Method 1: Relevance to intervention



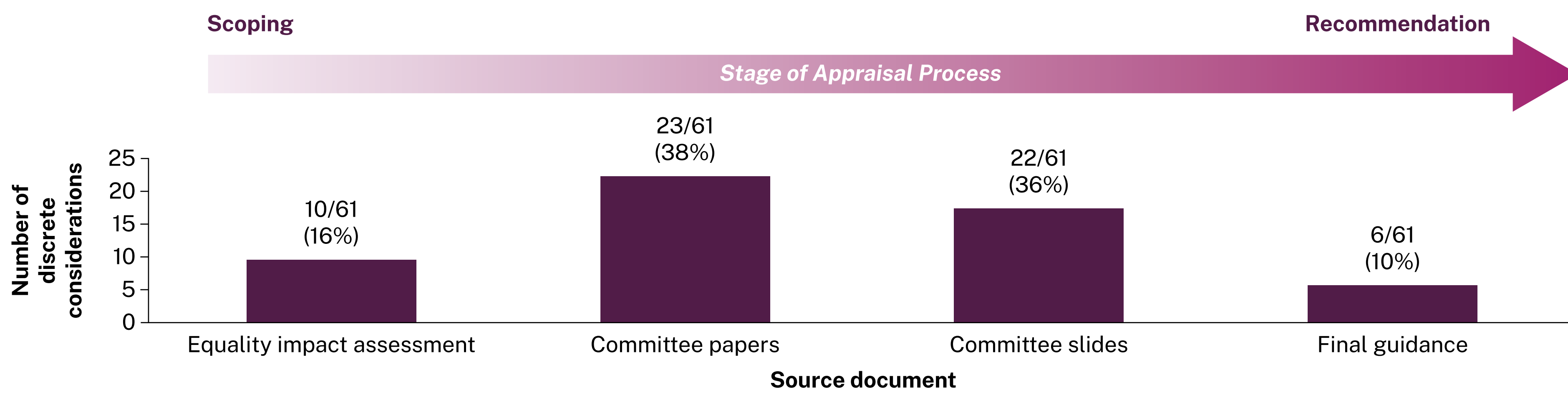
B. Method 2: Equality staircase^a



^aAdapted from Cookson et al.'s staircase of inequality.^{2,3}

FIGURE 1

Initial source documents of equality/equity considerations^a

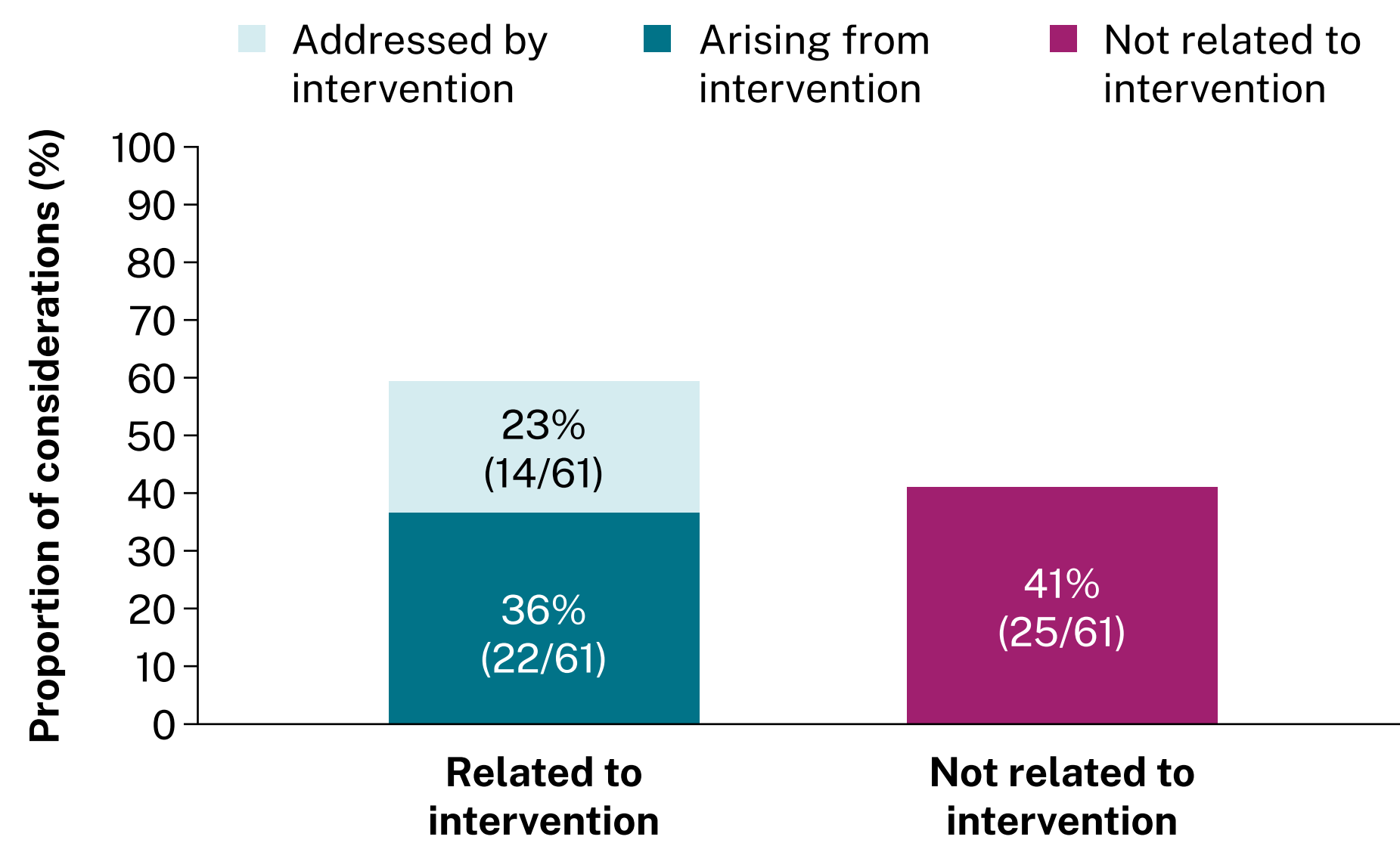


^aNumber refers to the document in which the discrete consideration was first raised during the appraisal process. Considerations may have also featured in subsequent documents.

FIGURE 2

Identified considerations by grouping method

A. Grouping method 1



B. Grouping method 2

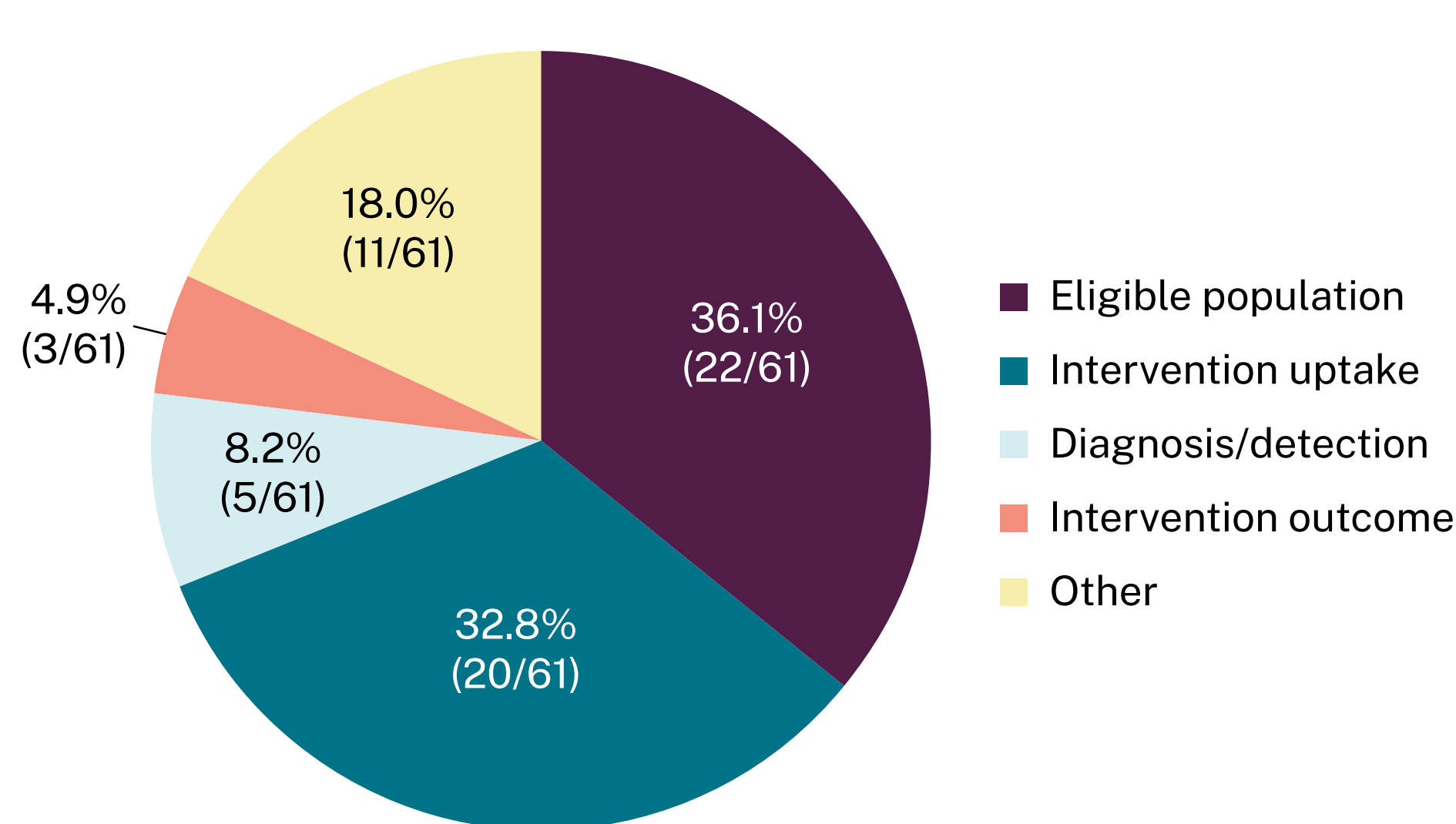
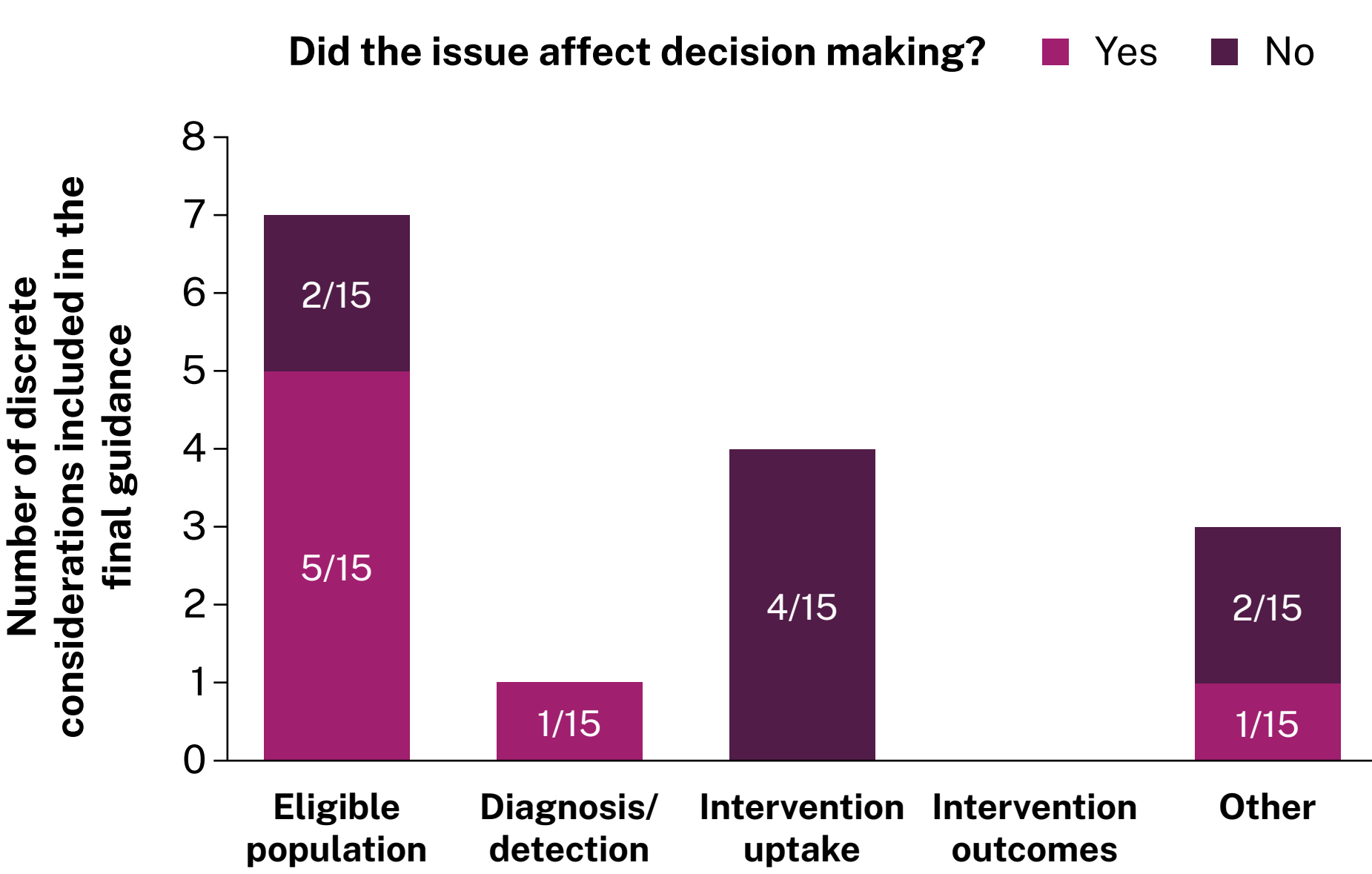


FIGURE 3

Considerations included in the final guidance^a



^aA total of 15 discrete equity/equality considerations featured in the final guidance, some of which may have initially been raised at an earlier stage in the appraisal process.

Abbreviations: HST: Highly Specialised Technology; NICE: National Institute for Health and Care Excellence; UK: United Kingdom.

References: ¹NICE (2025). Highly specialised technologies: NICE prioritisation board routing criteria. Available at: <https://www.nice.org.uk/process/pmg46/resources/highly-specialised-technologies-nice-prioritisation-board-routing-criteria-15301445581/chapter/1-the-vision> [Last accessed 24.09.25]; ²Cookson R. et al. Handbooks in Health Economic Evaluation, Oxford Academic 2020; ³Griffiths MJS. et al. Value Health 2025;28:16–24. Acknowledgements: The authors thank Danielle Kerr, Costello Medical, for graphic design assistance. We also thank Matt Griffiths for his review and editorial assistance in the preparation of this poster.