

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HIGHLY SPECIALISED TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

#### HST Elosulfase alfa for treating mucopolysaccharidosis type 4A

The impact on equality has been assessed during this evaluation according to the principles of the NICE equality scheme.

#### Consultation

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|---|
| 1. Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how? |
| N/A   |

- |  |
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| 2. Have any other potential equality issues been raised in the submissions, expert statements or independent academic report, and, if so, how has the Committee addressed these?   |
| <p>At technical engagement, patient expert submissions raised potential equality issues around the significant cost of elosulfase alfa and difficulties in demonstrating benefit due to the very small number of patients with mucopolysaccharidosis type 4A.</p> <p>The methods and processes for highly specialised technologies allow the committee to apply variations for very rare diseases. As part of this process the committee consider a range of other factors including the nature of the disease and the impact of the technology beyond direct health benefits. The threshold for a cost-effective technology is higher compared with the single technology appraisal process. Also, for treatments that are above a most plausible ICER of £100,000 per QALY and where there is compelling evidence that the treatment offers significant gains in health-related quality of life, the committee are able to apply QALY weighting. For more details please see the <a href="#">Interim Process and Methods of the Highly Specialised</a></p> |

[Technologies Programme.](#)

The committee did not consider these to be equality issues because the recommendation applies to all people with mucopolysaccharidosis type 4A within the marketing authorisation for elosulfase alfa.

3. Have any other potential equality issues been identified by the Committee, and, if so, how has the Committee addressed these?

No

4. Do the preliminary recommendations make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

5. Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

6. Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 4 or 5, or otherwise fulfil NICE's obligations to promote equality?

No

7. Have the Committee's considerations of equality issues been described in the evaluation consultation document, and, if so, where?

See section 3.19 of the Evaluation Consultation Document

**Approved by Associate Director (name):** Jasdeep Hayre

**Date:** 1 November 2021

## Final appraisal determination

(when an ACD issued)

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the committee addressed these?

At consultation, a stakeholder raised a potential equality issue because people with disabilities were excluded from fully contributing to the consultation process. This was discussed at the second appraisal committee meeting and it was noted that during the consultation period, NICE was not informed of any issues with documents or asked to make any adjustments. The committee did not consider this to be an equality issue specific to elosulfase alfa.

2. If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, the recommendation applies to the full population in the marketing authorisation

3. If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

4. If the recommendations have changed after consultation, are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality?

No

5. Have the committee's considerations of equality issues been described in the final appraisal determination, and, if so, where?

See section 3.20 of the Final Evaluation Document

**Approved by Associate Director (name):** Jasdeep Hayre

**Date:** 10 March 2022