

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY APPRAISAL PROGRAMME

### Equality impact assessment – Guidance development

### HST Cerliponase alfa for neuronal ceroid lipofuscinosis type 2

The impact on equality has been assessed during this appraisal 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? |
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<p>During the scoping process, consultees highlighted the following equality issue:</p>
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| <ul style="list-style-type: none"><li>• Patients from ethnic minority backgrounds may access healthcare less well and may be diagnosed later and may therefore be at risk of not qualifying for treatment.</li></ul> |
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<p>The committee noted that implementation issues cannot be addressed by a NICE recommendation. The committee concluded that ideally there would be no starting rules.</p>
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| 2. Have any other potential equality issues been raised in the submissions, expert statements or academic report, and, if so, how has the committee addressed these? |
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<p>Yes it was suggested that some patients who live in remote areas do not have easy access to the treatment centres. The committee noted that access to specialist centres is an implementation issue that cannot be addressed by a NICE evaluation recommendation. The committee also noted that patient</p>
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experts, clinical experts and the company had explained that several additional specialist centres have opened across England since HST12 was published.

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

No issues identified.

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 issues identified.

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 issues identified.

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 issues identified

7. Have the committee's considerations of equality issues been described in the draft guidance, and, if so, where?

Section 3.21 of the draft guidance.

**Approved by Associate Director (name):** ...Richard Diaz.....

**Date:** 28/04/2025

## Final draft guidance

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

- Clinical experts, consultees and stakeholders suggested that the recommendation in the draft guidance constituted indirect disability and age discrimination
- A stakeholder stated that any potential disparities in diagnosis or referral patterns should be addressed to ensure treatments are equally available to all racial groups

The committee noted that age, disability and race are protected characteristics under the Equality Act 2010. The committee concluded the issues raised were not potential equality issues because the recommendation does not restrict access to treatment for some people over others.

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| 1. 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? |
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N/A

2.	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?
	N/A
3.	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?
	N/A
4.	Have the committee's considerations of equality issues been described in the final draft guidance, and, if so, where?
	Section 3.21 of the final draft guidance

**Approved by Associate Director (name):** ...Richard Dlaz.....

**Date:** 07/08/2025