

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Guidance development

HST Ataluren for treating Duchenne muscular dystrophy with a nonsense mutation in the dystrophin gene (review of HST3)

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? |
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Several consultees raised the issue of ease of access for patients from all areas of the country to attend specialist centres for people with Duchenne muscular dystrophy. The committee was aware that the treatment would be offered in a small number of centres as there was a need to concentrate expertise.

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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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1 consultee raised the issue of treatment stopping rules affecting older patients with the condition more. The committee preferred analysis outlined in the evaluation consultation document did not include a formal stopping rule. Therefore, the committee considered that this was not an equality issue.

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

No other potential equality issues have been identified by the committee.

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, as the draft recommendations do not recommend the technology.

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, as the preliminary recommendations do not recommend the technology.

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?

Yes, in section 3.16

Approved by Associate Director (name): Jasdeep Hayre

Date: 22 September 2022

Highly Specialised Technology: Guidance development
Equality impact assessment for the highly specialised technology evaluation of ataluren for treating Duchenne muscular dystrophy with a nonsense mutation in the dystrophin gene (review of HST3)

Final evaluation determination

(when an evaluation consultation document is issued)

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

Some stakeholders said it was important that people with DMD did not have to travel excessive distances for treatment. The committee acknowledged that clinical expertise would usually be concentrated at a small number of centres

One stakeholder also said that the current managed access agreement stopping rules did not allow use in people who could not walk, and that this may discriminate against older DMD patients. The committee noted that it had not included a formal treatment stopping rule in its recommendation.

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.

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 evaluation document, and, if so, where?
Yes, in section 3.17

Approved by Associate Director (name): Jasdeep Hayre

Date: 16 January 2023