

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Guidance development

HST - Ataluren for treating Duchenne muscular dystrophy caused by a nonsense mutation in the dystrophin gene [ID 428]

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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No potential equality issues that needed to be considered by the Committee were raised during scoping.
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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? |
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A potential equality issue was raised in the clinical expert submissions. The clinical expert suggested it could be considered discriminatory to refuse access to treatment on the grounds of cost for such a rare debilitating disease which causes a short life expectancy.

This was not considered to be a potential equality issue. Deciding which treatments to recommend involves balancing the needs and wishes of individuals and the groups representing them against those of the wider population. This sometimes means treatments are not recommended because they do not provide sufficient benefit to justify their cost (Social Value Judgements; 'Principles for the development of NICE guidance', principle 2).

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

No potential equality issues were raised by the Committee.

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?

Not applicable.

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?

Not applicable.

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

Not applicable.

Approved by Associate Director (name): ...Sheela Upadhyaya.....

Date: 7/07/2016

Final evaluation determination

(when an ECD issued)

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

In response to consultation on the evaluation consultation document, patient groups noted that the preliminary recommendations could be considered discriminatory because these:

- ask for long-term evidence base in patients with high unmet medical needs
- fail to recognise the severity of the condition and the benefits of ataluren in the context of a short life on the grounds of costs
- risk discriminating against families in lower socio-economic groups who may need housing adaptations, re-housing after once the patient's ability to walk is lost and are at greater risk of not being able to adjust to the patient's needs. So, if access to ataluren is denied and patients' conditions progress at a faster rate, patients will be exposed to societal prejudice
- are divergent to other commissioning bodies within the UK and internationally.

These were not considered to be potential equality issues. Deciding which treatments to recommend involves balancing the needs and wishes of individuals and the groups representing them against those of the wider population. This sometimes means treatments are not recommended because they do not provide sufficient benefit to justify their cost (Social Value Judgements; 'Principles for the development of NICE guidance', principle 2).

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?

The recommendations do not make it more difficult in practice for a specific group to access the technology compared with other groups.

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?

There is no potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability.

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?

Not applicable.

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

It is noted in the summary table of the FED that no equality issues that needed to be taken into consideration by the committee were identified.

Approved by Centre or Programme Director (name): Meindert Boysen

Date: 7/7/2016