

gNATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Guidance development HST Velmanase alfa for treating alpha-mannosidosis [ID800]

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

Consultation

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

None identified.

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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None identified.

3. Have any other potential equality issues been identified by the Committee, and, if so, how has the Committee addressed these?
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None 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?
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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?

N/A

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

Section 4.26 of the ECD specifies that no equality issues have been identified.

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

Date: 10/05/2018

Consultation 2

(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?

None identified during consultation.

The committee recognised that alpha-mannosidosis can have a substantial effect on people's lives, and many people with alpha-mannosidosis have a disability within the provision of the Equality Act. It discussed whether the disability might cause people to be disadvantaged within the evaluation. The committee considered that the impact of the disability and the technology had been fully captured in the evidence, economic modelling and committee considerations, and that it had considered and all of the available evidence, including patient testimony, indirect evidence and small studies, in the appropriate context. The committee concluded that it had taken into account the disability associated with this condition when developing its recommendations. See section 4.34 of the FED.

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?

N/A – recommendations have not changed.

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?

N/A – recommendations have not changed.

The committee recognised that alpha-mannosidosis can have a substantial effect on people's lives, and that some people with alpha-mannosidosis have a disability within the provision of the Equality Act. It discussed whether the disability might cause people to be disadvantaged within the evaluation. The committee concluded that it had taken into account the disability associated with this condition when developing its recommendations. See section 4.34 of the FED.

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?

N/A – recommendations have not changed.

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

Section 4.37 of the FED specifies that no further equality issues have been identified.

Approved by Centre or Programme Director (name): ...Richard Diaz...

Date: 27/09/23

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?

During consultation the company identified that guidance may be discriminatory against people with a disability and children, that committee may be discriminatory by not considering inherent uncertainties with evidence due to the very small patient population, and Committee did not consider difficulties in demonstrating cost-effectiveness where there are no recommended treatment options.

The committee recognised that alpha-mannosidosis can have a substantial effect on people's lives, and many people with alpha-mannosidosis are considered to be disabled in the Equality Act 2010. It discussed whether the evaluation might disadvantage disabled people. It felt that the effect of the

disability associated with this condition and the benefits of the technology had been fully captured in the evidence, economic modelling and committee considerations. The committee highlighted that it had fully considered all available evidence including case studies, clinical expert opinion and patient testimony. It concluded that it had taken into account the disability associated with this condition when developing its recommendations.

The committee carefully considered whether this topic warranted any additional considerations and reasonable adjustments over and above what is normally afforded to topics in the highly specialised technologies programme due to equalities issues. It also considered the comments on these factors received during consultation and at resubmission. It concluded that all relevant factors had already been taken into account, and that no additional considerations were needed regarding equalities concerns.

The committee also allowed additional flexibility recognising the difficulties with evidence generation for this ultra-rare condition and in children.

See section 4.22 and 4.23 of the FED.

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 specific group was identified.

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, committee considered that all relevant factors had already been taken into account, and that no additional considerations were needed regarding equalities concerns.

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?

N/A – no issues identified.

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

Section 4.22 of the FED.

Approved by Centre or Programme Director (name):Richard Diaz

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Date: 2/11/2023