

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

HST Sebelipase alfa for treating Wolman disease

The impact on equality has been assessed during this appraisal 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?

During scoping, stakeholders raised that the population in this evaluation should include all people with lysosomal acid lipase (LAL) deficiency rather than focusing on Wolman disease. They stated that older children, adolescents and adults with LAL deficiency, may be negatively impacted by not having access to treatment with sebelipase alfa.

The final scope and draft guidance specifies that this evaluation is for Wolman disease only.

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?

One stakeholder commented that people from a South Asian family background can have a genetic deletion which compasses the entire LIPA gene, causing increased disease severity. The committee considered this issue and noted that the recommendations for sebelipase alfa would not affect people from South Asian family backgrounds differently. This is noted in section 3.16 of the draft guidance.

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?
N/A.	

7.	Have the committee's considerations of equality issues been described in the appraisal consultation document, and, if so, where?
Yes, in section 3.16.	

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

Date: 25 May 2023

Technology appraisals: Guidance development

Equality impact assessment for the highly specialised technology evaluation of sebelipase alfa for Wolman disease

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