

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

HST Pegzilarginase for treating arginase-1 deficiency

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 consultation, it was noted that the scope should take into account the ethnicity of the UK patient population with arginase deficiency and the economic and quality of life impact of being a patient or carer of a patient with intellectual and physical disabilities. The appraisal committee took this issue into account in its's decision making.

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?

Clinical expert and patient carer organisation submission stated that ARG1-D is a genetic condition with a reported higher prevalence in communities where consanguineous marriage is more prevalent. It highlighted that special consideration must be given to communities where consanguineous marriage is common.

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?

No.

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 Have the committee's considerations of equality issues been described in the draft guidance, and, if so, where?

Yes, section 3.21 of the draft guidance.

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

Date: 29/08/2024