

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HIGHLY SPECIALISED TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

#### **HST Voretigene neparvovec for treating inherited retinal dystrophies caused by RPE65 gene mutations [ID1054]**

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

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

Stakeholders noted that because this is an autosomal recessive disease, specific mutations were more common in some ethnic groups in the UK (in cultures in which it is more common to marry a family member, for example, first cousins). The committee considered this and concluded that its recommendations applied equally regardless of ethnicity, so a difference in disease prevalence in different ethnic groups did not in itself represent an equality issue, and no additional amendments were required.

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?

Stakeholders noted that people with RPE65-mediated inherited retinal dystrophies (IRD) share protected characteristics of disability as defined by the Equality Act 2010 and, therefore, consideration was given to whether further adjustment should be made to the process and methods. The committee considered that the methodology employed did not disadvantage people with RPE65-mediated IRD therefore no further adjustments were required to its decision-making process.

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

The committee noted that the population for which voretigene neparvovec is indicated includes children and young people. It was aware that there were considerable uncaptured benefits related to sustaining vision in children, and these had been considered qualitatively in its decision-making.

4. Do the 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 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 final evaluation determination, and, if so, where?

Please see 'Other factors' section (4.42 to 4.44) in the FED

**Approved by Programme Director:** Helen Knight

**Date:** 09/10/2019