NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Guidance development

HST Patisiran for treating hereditary transthyretin amyloidosis [ID1279]

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?
During the scoping process it was highlighted that one particular mutation, V122I, predominantly affects older people with African-Caribbean family origins. The committee explained that its recommendations apply equally regardless of age or ethnicity, so a difference in disease prevalence, in different age and ethnic groups does not in itself represent an equality issue.	

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?
NICE's guide to the methods of technology appraisal states that in cases when a treatment restores people who would otherwise die or have a very severely impaired life to full or near full health, and when this is sustained over a very long period (normally at least 30 years), cost-effectiveness analyses are very sensitive to the discount rate used. In this circumstance, analyses that use a non-reference-case discount rate for costs and outcomes may be considered. A discount rate of 1.5% for costs and benefits may be considered by the Appraisal Committee if it is highly likely that, on the basis of the evidence presented, the long-term health benefits are likely to be achieved. The company suggested that a 1.5% discount rate should be used because patisiran has shown long-term benefits and shown the ability to halt or reverse disease progression. However, it noted that it is not possible to meet	

the criterion of long-term benefits sustained for 30 years. This is because hereditary transthyretin amyloidosis typically affects older people in the UK, who would have a life expectancy of less than 30 years in the absence of the disease. As such, the company believes that the criteria unfairly penalises people with the disease because they are older. The committee heard from clinical experts that only around half of people remaining on treatment might return to what might be considered near full-health, so the first criteria is not met. The committee noted that the criterion that health benefits must be sustained for 30 years is considered because cost-effectiveness analyses are particularly sensitive to the choice of discount rate when benefits are accrued over a very long period. The criterion does not therefore penalise patients with hATTR because of the age at which they are diagnosed. Furthermore, the treatment is now recommended as a cost-effective use of NHS resources.

3.	Have any other potential equality issues been identified by the Committee, and, if so, how has the Committee addressed these?
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?
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?
Sections 4.16 and 4.23 of the ECD describes the committee's consideration of the equality issues.	

Approved by Associate Director (name): ……

Date: [xx/xx/year]

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?
No additional potential equality issues have been raised during the consultation.	

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. The treatment is recommended for use within its marketing authorisation.	

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.	

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?
No.	

5.	Have the Committee's considerations of equality issues been described in the final evaluation determination, and, if so, where?
Yes. In section 4.25 and 4.33 of the FED.	

Approved by Centre or Programme Director (name): Sheela Upadhyaya

Date: 13/06/2019