

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technologies (HST)

Re-evaluation following a period of managed access

Equality impact assessment – Scoping

HST: elosulfase alfa for treating mucopolysaccharidosis type IVA (re-evaluation of highly specialised technologies guidance 2)

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

1. Have any potential equality issues been identified during the scoping process (draft scope consultation and scoping workshop discussion), and, if so, what are they?

Equality issues were raised by a number of consultees during the consultation period.

A consultee noted that if subgroups of patients with MPS IVa are analysed for differences in their response to elosulfase alfa, this may have a disproportionate effect on certain ethnicities. For example, patients homozygous for the G116V mutation tend to have a more severe phenotype and these patients all originate from the Kashmir area of Pakistan. The consultee suggests that any separate consideration should address this as a genotype-based analysis (which may be lawful and scientific) and not a purely ethnicity-based one (which could be unlawful).

There were also several comments from consultee about age impacting the benefit of treatment. A consultee suggested that a subgroup of people less than 5 years old would potentially benefit more from treatment with elosulfase alfa compared with older children.

2. What is the preliminary view as to what extent these potential equality

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Issue date: December 2019

issues need addressing by the Committee?

The committee will consider whether its recommendations could have a differential impact on people with protected characteristics covered by equality legislation (that is patients homozygous for the G116V mutation and age).

3. Has any change to the draft scope been agreed to highlight potential equality issues?

Yes. If evidence allows subgroup analysis by age and genotype should be considered.

4. Have any additional stakeholders related to potential equality issues been identified during the scoping process, and, if so, have changes to the matrix been made?

No.

Approved by Associate Director (name): Jasdeep Hayre

Date: 12/12/2019