

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE
HIGHLY SPECIALISED TECHNOLOGIES PROGRAMME

Equality impact assessment – Scoping

**HST Ataluren for treating Duchenne muscular dystrophy with a
nonsense mutation in the dystrophin gene**

Batch 41

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?

The scoping workshop attendees raised 2 potential equality issues:

1) They noted that age is a potential equality issue because if an evaluation does not take place and guidance is not issued as soon as possible, many children will be discriminated as they will lose their ambulation and will not be eligible to have ataluren.

2) The scoping workshop attendees also noted that because disability is a protected characteristic, given the nature of Duchenne muscular dystrophy all patients will be considered to have disability(ies) and therefore not recommending the drug could be considered discriminatory.

2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

1) The referral process has been expedited for this topic and the evaluation will be started shortly. This was not considered to be a potential equality issue because the consideration relevant to Committee was whether its recommendations have a different impact on people protected by the equalities legislation than the wider population.

2) This was not considered to be a potential equality issue because the

disability in this instance is a consequence of the condition.

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

There is no need to change the draft scope to highlight these potential equality issues.

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 additional stakeholders related to potential equality issues have been identified during the scoping process

Approved by Associate Director (name):Josie Godfrey.....

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