NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Scoping

HST eteplirsen for treating Duchenne muscular dystrophy

The impact on equality has been assessed during this appraisal 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?

Two potential equality issues were raised during the scoping process:

- Issue 1 (identified in consultation comments on the scope): People
 who have participated in clinical trials of drisapersen should be
 allowed to receive eteplirsen. Both drisapersen and eteplirsen are
 exon 51 skipping treatments. According to the clinical trial protocols,
 people who have received drisapersen are not allowed to participate
 in clinical trials of eteplirsen.
- Issue 2 (identified at scoping workshop): Clinical experts at the scoping workshop suggested that, based on current data, eteplirsen might be more effective in people who are able to walk than in people who cannot walk. Scoping workshop attendees considered that it would be discriminatory to restrict access to treatment based on walking ability.
- 2. What is the preliminary view as to what extent these potential equality issues need addressing by the committee?

Issue 1: Issues relating to clinical trial enrolment cannot be addressed in a NICE evaluation of a highly specialised technology. Accordingly, this is not viewed as an equality issue that needs to be discussed by the committee

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Issue 2: This, and all other potential equality issues, will be considered during the course of the evaluation and the committee will consider whether its recommendations could have a different impact on people protected by the equality legislation than on the wider population.

3.	Has any change to the draft scope been agreed to highlight potential equality issues?
No.	
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): Sheela Upadhyaya

Date: 4/10/2017

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