

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Scoping

STA Idebenone 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?

A couple of potential equality issues are raised by stakeholders:

First:

- One stakeholder noted that the scope remit could be considered discriminatory if access to an effective treatment is refused on grounds of cost for a life-limiting condition for which there is no cure. It explained that It's important that the scope does not just consider costs, but also looks at the possibility and importance of extra time for families and people living with Duchenne, which Puldysa (idebenone) could potentially provide.

Second:

- Another stakeholder noted that given the nature of the disease, all Duchenne muscular dystrophy (DMD) patients should be considered to have disability(ies). And that society has the obligation to look after this disadvantaged population and provide them with licensed treatments that can enable people with Duchenne muscular dystrophy to have a better quality of life for longer.

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

With regards to the first: NICE is required to make decisions based on the

evidence available. When deciding whether or not to recommend a technology, the committee will take into account both the relative benefits and costs associated with it (its clinical – and cost-effectiveness). However, decisions are not based on the evidence alone, where appropriate, other factors, such as wider benefits not captured in QALY may be considered. Recommendations are not made on grounds of costs alone therefore this does not in itself represent an equality issue.

Regarding the second: if appropriate, consideration may be given to characteristics that are shared by people with DMD and are protected under equality legislation (including disability).

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

Not applicable.

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): Nicole Elliott

Date: 30/03/2020