

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health Technology Evaluation

Equality impact assessment – Scoping

Givinostat for treating Duchenne muscular dystrophy in people 6 years and over [ID6323]

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?
<p>Yes. Stakeholders noted the following:</p> <ul style="list-style-type: none">• A significant proportion of people with Duchenne muscular dystrophy (DMD) have poor outcomes because of learning or behavioural difficulties, ADHD, autism, and pre-existing psychiatric difficulties, making up around 30% of the adult population. A significant proportion of people with DMD cannot have corticosteroids because of these issues and have worse outcomes. The randomised controlled trial uses givinostat as an add on treatment to standard corticosteroid treatment. Therefore, this subgroup is excluded may not have access to givinostat if it is approved, increasing inequality of access to care.• DMD is a rare condition and there is limited access to comprehensive studies and inclusion in novel therapeutic randomised controlled trials and the impact on equity of care.• As people with DMD have varying levels of disability and so, should not have to travel excessive distances to have treatment.
2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

The committee can only evaluate a technology within its marketing authorisation. The committee can consider the difficulties in evidence generation associated with DMD as a rare condition. It should consider that many people with DMD have learning or behavioural difficulties and the impact of this on the evidence base. It will consider issues around access to treatment, if appropriate.

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 stakeholder list been made?

No.

Approved by Associate Director (name): Ian Watson

Date: 12/06/2024