

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Scoping

HST: Setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome

Batch 82

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?

3 points were raised:

1. A consultee, Bardet-Biedl Syndrome UK, noted that the means of delivery – daily sub-cutaneous injection – may exclude some from accessing treatment, for example those living independently with visual impairment would not be able to safely self-administer a sub-cutaneous injection. A clinician at the workshop noted that this is particularly important for the adult patients as it requires that another adult they live with or someone else to administer the injection daily. As living independently is a particular source of pride in these patients, this is very important.
2. The company, Rhythm Pharmaceuticals, considered that appraisal via the STA route (originally proposed) would compromise ability of the small number of patients with these rare conditions (with range of severe disabilities and significant burden on families and caregivers) to access this new technology
3. A consultee, NHSE, noted that the condition is an autosomal recessive condition and likely to be more common in communities where there is consanguinity (i.e. having blood relations).

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

1. The extent to which this constitutes an issue of equality of access to care in

the context of any appraisal is currently unclear. Where appropriate, the committee will consider any potential equality issues identified throughout the evaluation and whether the recommendations make it more difficult for a particular group to access treatment.

2. This topic has been routed to HST as it met the HST criteria.
3. The extent to which this constitutes an issue of equality of access to care in the context of any appraisal is currently unclear. Where appropriate, the committee will consider any potential equality issues identified throughout the evaluation and whether the recommendations make it more difficult for a particular group to access treatment.

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): ...Richard Diaz

Date: 8 Nov 2022