

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

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

The impact on equality has been assessed during this evaluation according to the principles of the NICE equality scheme.

#### Consultation

1. Have the potential equality issues identified during the scoping process been addressed by the committee, and, if so, how?

Equality issues identified at scoping included:

1. 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. The committee discussed this in the meeting. However, clinical experts highlighted that the burden of administration would reduce significantly with the new weekly formulation in a pre-filled injector.
2. That 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. This topic was routed as a HST so this potential issue is not applicable.
3. 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). The committee considered that, because setmelanotide is not recommended in the full licenced population, its recommendation did not made it more difficult for a particular group to access treatment.

2. Have any other potential equality issues been raised in the submissions, expert statements or academic report, and, if so, how has the committee addressed these?

One stakeholder highlighted that 20% of people with BBS do not have identifiable pathogenic variants on testing and are identified clinically. The committee noted that genetic confirmation was a requirement in the marketing authorisation for setmelanotide. So, some people with the condition would not be able to access the treatment. The committee considered that its recommendation applies to the full licenced population, and it could not make a recommendation outside of this.

3. Have any other potential equality issues been identified by the committee, and, if so, how has the committee addressed these?

No

4. Do the preliminary recommendations make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

5. Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

6. Are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with,

access identified in questions 4 or 5, or otherwise fulfil NICE's obligations to promote equality?
N/A

7. Have the committee's considerations of equality issues been described in the draft guidance, and, if so, where?
Yes, see section 3.28 of the draft guidance

**Approved by Associate Director (name):** Jasdeep Hayre

**Date:** 25 July 2023