NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

Setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome (review of HST31)

The impact on equality has been assessed during this appraisal 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?
Yes, during consultation, one stakeholder highlighted that adults with BBS experience multiple overlapping inequalities, including learning difficulties, visual impairment, disability and significant stigma related to obesity. Poor mental health, including low mood, depression and emotional dysregulation, is also common and can further affect quality of life and access to support. Access to specialist care varies geographically, which may widen inequalities. • Please see section 3.33 for committee discussion and consideration. .

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?
Yes. Several potential equality issues were raised in the submissions and consultation comments. • The company stated in its submission that the whole-population co-base case, including both children and adults, provided context for the adult base-case population and helped to address potential inequity concerns. This was because starting semblative later in life does not

capture the full potential lifetime benefits of treatment through undiscounted QALY gains.

- The EAG highlighted a potential inequity for people with BBS who were already adults, aged 18 years or over, before the HST31 recommendations were published and therefore were not able to start treatment during childhood.
- Another stakeholder also raised other potential equality issues discussed in HST31, including age, disability, race and ethnicity, socioeconomic context, and geographic variation in access to specialist care.

The committee considered these issues.

Regarding the first 2 points relating to adults:

- The committee concluded that adults with BBS and a BMI of 30 kg/m^2 or more was the population that should be considered for decision making in this review.
- The committee was unable to determine a preferred cost-effectiveness estimate for people starting treatment as adults. This meant that it was unclear whether the cost-effectiveness estimate was below the threshold normally considered an acceptable use of NHS resources for a highly specialised technology when applying a QALY weighting.
- The committee concluded that a negative recommendation for people starting treatment as adults would be proportionate to NICE's legitimate aim to recommend clinically and cost-effective technologies. Please see sections 3.7 and 3.33 of the draft guidance for the committee's discussion and consideration.

Regarding the 3rd point concerning other potential equality issues:

- The committee considered the equality issues raised during HST31, including age, disability, race and ethnicity, socioeconomic context, and geographic variation in access to specialist care. It noted that

	these issues had been considered in the original appraisal and remained relevant to this review. Please see section 3.32 of the draft guidance for the committee's discussion and consideration.

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?
N/A	

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?
N/A	

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 appraisal consultation document/draft guidance, and, if so, where?

Yes, please see section 3.32 and section 3.33 of the draft guidance.

Approved by Associate Director (name): …Richard Diaz……

Date: 10 July 2026