

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HIGHLY SPECIALISED TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

#### HST Onasemnogene Abeparvovec for treating SMA [ID1473]

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

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

During scoping consultees highlighted that, because onasemnogene abeparvovec would be provided at a limited number of highly specialist centres, there was the potential for issues of equity of access based on geographic location.

Consultees also commented during scoping that using spinal muscular atrophy (SMA) 'type' to define the population may be inappropriate and could lead to discrimination on the basis of a particular disability.

The committee acknowledged that onasemnogene abeparvovec would only be delivered in a small number of highly specialised centres because there is a need to concentrate expertise. NHS England selected the centres to provide this service.

The committee heard that SMA can be grouped into 5 main types (types 0 to 4), based on the age of onset and the maximum motor function reached. These definitions are accepted clinically. The scope of the evaluation wasn't limited to a specific type, but the committee were only presented with evidence for the pre-symptomatic and type 1 populations.

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

The committee asked clinical experts about any potential equality issues and

asked if race or ethnicity affected SMA diagnosis. The clinical experts stated that the prevalence of SMA is consistent across regions, which suggests that race or ethnicity does not influence the diagnosis of SMA. However, diagnosis may be delayed in some disadvantaged groups. This was 1 of the factors that the committee considered when deciding to recommend treatment with onasemnogene abeparvovec in babies aged 7 to 12 months. The committee concluded that there were no other relevant equality issues related to onasemnogene abeparvovec treatment.

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

N/A

4. Do the 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 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 final evaluation document, and, if so, where?

Yes in section 4.41.

**Approved by Associate Director (name):** .....Nicole Elliott ...

**Date:** 22 June 2021

## Final evaluation determination

(when an ECD issued)

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed these?

None identified.

2. If the recommendations have changed after consultation, are there any recommendations that 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

3. If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

4. If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality?

No

5. Have the Committee's considerations of equality issues been described in the final evaluation determination, and, if so, where?

No

**Approved by Centre or Programme Director (name):** Nicole Elliott

**Date:** 11/01/21